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Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
All Wales Perinatal Survey	AWPS	Perinatal, Neonatal, Children	Welsh Government Public Health Wales Cardiff University	Perinatal survey of deaths of babies in Wales from 20 weeks gestation to one year of age and includes: - fetal losses of 20 completed weeks of gestation or more (including therapeutic abortions) - still births - early and late neonatal deaths; and - post neonatal deaths	All Wales Perinatal Survey	Wales	Sailesh Kotecha	kotechas@cardiff.ac.uk	029 2074 4499
Alström Syndrome UK Clinical Research Database	ASUK	Long term conditions	Alström Syndrome UK Birmingham Children's Hospital NHS Foundation Trust Torbay District General Hospital (South Devon Healthcare NHS Foundation Trust)	Clinical and research test results for UK resident Alström Syndrome patients.	Alström Syndrome UK	Whole of UK Jersey / Guernsey / Isle of Man	Dr Mike Hales	mike.hales@alstrom.org.uk	01803 843 227
Association of Breast Surgery Breast Screening Audit Database	ABS	Cancer	West Midlands Cancer Intelligence Unit	An annual audit of screen detected breast cancer to monitor breast screening unit and individual surgical performance. It includes 100% of the cancers detected through the NHSBSP since 1996. Topics include diagnosis, treatment, clinical waiting times, adjuvant treatment information, survival and outcomes.	West Midlands Cancer Intelligence Unit	Whole of UK Isle of Man Republic of Ireland - partial. Some comparative data included in annual audit presentation at ABS annual meeting but data does not cover all the areas included in the audit and is not included in the published annual report.	Dr Gill Lawrence	Gill.Lawrence@wmciu.nhs.uk	0121 415 8129
BAUS Cancer Registry (BCR) Complex Operations Audit	BCR	Cancer		Cystectomy, prostatectomy and nephrectomy.	The British Association of Urological Surgeons	Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required).	Sarah Fowler	sarah@sarahfowler.org	01635 42487
Bawtry Computer Services System for Cochlear Implant Centres		OTHER	Cochlear Implant Programme at Great Ormond Street Hospital	Register and record of assessment and treatment of patients receiving cochlear implants.	Bawtry Computer Services	National	Ann Robbins	ann@bawtry.net	01302 710 969
Biliary Drainage and Stent Registry		Radiology	British Society of Interventional Radiology	Percutaneous radiologically guided biliary drainage and stenting for the relief of obstruction of the biliary system in patients with benign and malignant disease.	Dendrite Clinical Systems Ltd	Whole of UK Open to Jersey, Guernsey, Isle of Man (may not currently contain entries) Republic of Ireland Open to Australia, New Zealand - may not currently contain entries)	Moira Ritchie	moira.ritchie@bsir.org	0143 942 6744

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Biologics Register for Rheumatoid Arthritis	BSRBR	Long term conditions	British Society for Rheumatology ; Arthritis Research UK Epidemiology Unit (within the Musculoskeletal Research Group)	British Society for Rheumatology ; Rheumatoid Arthritis and Biologic therapies.	The British Society for Rheumatology	Whole of UK	Nia Taylor	ntaylor@rheumatology.org.uk	020 7842 0905
Bowel Screening Information Management System	BSIMS	Cancer	Public Health Wales Screening Division	Screening for Bowel cancer.	Public Health Wales	National - Wales Northern Ireland - separate database	Phil Walters	phil.walters@wales.nhs.uk	029 20 787815
Breast Cancer Clinical Outcome Measures Project	BCCOM	Cancer	West Midlands Cancer Intelligence Unit	Symptomatic primary breast cancers. Topics include diagnosis, treatment, clinical waiting times, adjuvant treatment information, survival and clinical outcomes.	West Midlands Cancer Intelligence Unit	Whole of UK	Dr Catherine Lagord Dr Gill Lawrence	gill.lawrence@wmcui.nhs.uk catherine.lagord@wmcui.nhs.uk	0121 415 8129 0121 414 7713
British Association of Blood and Marrow Transplantation Data Registry	BSBMT	Haematology			British Society of Blood and Marrow Transplantation - Stem Cell Transplantaton	Tba			
British Association of Paediatric Surgeons Congenital Anomalies Surveillance System	BAPS-CASS	Acute care			The British Association of Paediatric Surgeons Congenital Anomalies Surveillance System	Whole of UK Jersey, Guernsey, Isle of Man Republic of Ireland	Alex Bellenger	baps-cass@npeu.ox.ac.uk	
British Association of Urological Surgeons Cancer Registry	BCR	Cancer	British Association of Urological Surgeons	Newly presenting urological tumours 1999-2010.	The British Association of Urological Surgeons	Formal collection ceased March 2011 Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required).	Sarah Fowler	sarah@sarahfowler.org	01635 42487
British Paediatric Surveillance Unit (on behalf of its surveillance projects)	BPSU	Perinatal, Neonatal, Children	Royal College of Paediatrics and Child Health		British Paediatric Surveillance Unit	Tba	Richard Lynn (Scientific Coordinator) Helen Friend (Research Facilitator)	Richard.Lynn@rcpch.ac.uk Helen.Friend@rcpch.ac.uk	020 7092 6174
British Society of Interventional Radiology Iliac Artery Angioplasty-Stent Registry	BIAS	Radiology	British Society of Interventional Radiology	Procedures for the treatment of stenosis within the iliac arteries caused primarily by atherosclerosis. This is achieved either with an angioplasty balloon alone or necessitating the implantation of a permanent metallic stent.	Dendrite Clinical Systems Ltd	Whole of UK Open to Jersey, Guernsey, Isle of Man (may not currently contain entries) Republic of Ireland Australia, New Zealand	Moirá Ritchie	moira.ritchie@bsir.org	01429 426 744
British Society of Urogynaecology Surgical Audit Database	BSUG	Acute care	British Society of Urogynaecology	Surgical procedures for female urinary incontinence and / or Vaginal / Uterovaginal prolapse.		Whole of UK	Paul Moran	Paul.Moran@worcacute.nhs.uk	01905 760655
British Thoracic Society Difficult Asthma Registry		Long term conditions	Queens University Belfast	Difficult asthma (failure to respond to treatment at Step 4 of current British asthma management guidelines referred for specialist assessment.	Difficult Asthma Registry	Whole of UK	Liam Heaney Sally Welham	l.heaney@qub.ac.uk Sally.Welham@brit-thoracic.org.uk	02890 263821

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British Thoracic Society Interstitial Lung Disease Registry	BTS-ILD	OTHER	British Thoracic Society	Interstitial Lung disease: including idiopathic pulmonary fibrosis and sarcoidosis.		Whole of UK Jersey, Guernsey, Isle of Man	Sally Welham	sally.welham@brit-thoracic.org.uk	020 7831 8778
Cardiac Surgical Database		Cardiovascular disease	Liverpool Heart & Chest Hospital	The database is an in house system that collates clinical data on all Cardiac surgical procedures performed at LHCH.		Local	Andrew Ward	andrew.ward@lhch.nhs.uk	0151 600 1004
Cardiff Study of All Wales & North West of England Twins	CaSTANET	OTHER	Faculty of General Dental Practice (UK) British Association of Oral and Maxillofacial Surgeons		Cardiff University School of Medicine	Regional			
Child and Adolescent Psychiatry Surveillance System	CAPSS	Perinatal, Neonatal, Children	Royal College of Psychiatrists (RCPsych)	Rare childhood mental health conditions and events.	Child and Adolescent Psychiatry Surveillance System (CAPSS)	Whole of UK Republic of Ireland	Dr Alan Quirk	aquirk@cru.rcpsych.ac.uk	020 7977 6648
Chronic Heart Failure		Cardiovascular disease	Central Cardiac Audit Database	Chronic heart failure admissions.		Whole of UK	Dr A D Cunningham	david.cunningham@ucl.ac.uk	07753 682686

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Cleft-Net-East Database		Perinatal, Neonatal, Children	Cleft-Net-East Cambridge University Hospitals NHS Foundation Trust	Cleft lip and Palate.	Cleft Lip and Palate - East of England Cleft Network	East of England	Juan-Jose Blasco-Ramos	juanjose.blasco@addenbrookes.nhs.uk	01223 257249
Clinical and Laboratory Online Patient- and Research Database for Primary Immunodeficiencies	UKPID	Long term conditions	UK Primary Immunodeficiency Network	Primary Immunodeficiency Disorders.	UK Primary Immunodeficiency Network	National	Dr J David M Edgar	david.edgar@belfasttrust.hscni.net	02890 635396
Clinical Database for Cluster Headache		OTHER	British Association for the Study of Headache (BASH)	Cluster headache	British Association for the Study of Headache	Whole of UK	Stuart Weatherby	stuartweatherby@nhs.net	0845 155 8155
Collaborative HIV Paediatric Study	CHIPS	Perinatal, Neonatal, Children			Collaborative HIV Paediatric Study	Tba	Mike Sharland (Chair)	chips@ctu.mrc.ac.uk	020 7670 4784
Congenital Anomaly Register & Information Service for Wales	CARIS	Perinatal, Neonatal, Children	Public Health Wales NHS Trust Welsh Local Health Boards: Abertawe Bro Morgannwg University Health Board Aneurin Bevan Health Board Betsi Cadwaladr University Health Board Cardiff & Vale University Health Board Cwm Taf Health Board Hywel Dda Health Board Powys Teaching Health Board	Congenital anomalies, Birth defects, Metabolic diseases, Hereditary diseases, Antenatal detection, Down Screening, Pharmico-vigilance, Screening for Bowel cancer.	Congenital Anomaly Register & Information Service	National - Wales	David Tucker	david.tucker2@wales.nhs.uk	01792 285 241
Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire	CAROB	Perinatal, Neonatal, Children	National Perinatal Epidemiology Unit	Congenital anomalies.	Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire	Oxfordshire, Berkshire and Buckinghamshire	Cath Rounding	Catherine.rounding@npeu.ox.ac.uk	01865 289721
CRANE Database	CRANE	Perinatal, Neonatal, Children	Royal College of Surgeons	Cleft lip and Palate.	The Royal College of Surgeons of England CRANE Database	England Wales Northern Ireland Jersey, Guernsey, Isle of Man	Jackie Horrocks	crane@rcseng.ac.uk	020 7869 6610

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Database of Alkaptonuria Patients	AKU	Long term conditions	AKU Society	Records accepted from any AKU patient, regardless of country (mainly identified online and through contacts made at international medical conferences). Actively looking for patients in the UK (England, Scotland, Wales, Northern Ireland). Database of Alkaptonuria patients worldwide. Currently identified 650 patients, with 80 in the UK. Alkaptonuria is a genetic disease, presenting symptoms similar to osteoarthritis. The database records information on the name and location of patients, medical history, and social history. The aim of the database is to record information on AKU. As little is known on the natural history of the disease, questions are quite open, to allow us to record as much information as possible.	AKU Society	International	Oliver Timmis	oliver@akusociety.org	07799 037726
Databases in Histocompatibility and Immunogenetics		Blood transfusion	NHS Blood and Transplant	<ol style="list-style-type: none"> 1. Feto-maternal alloimmune thrombocytopenia. There is only one lab in England that performs diagnostic tests for this disease making it good ID data. 2. Inherited platelet glycoprotein disorders (Bernard – Soulier Syndrome and Glansmans Thrombasthenia) for a wide geography which could encompass the whole country as possibly only Sheffield performs thorough testing for these rare disorders. 3. Heparin induced thrombocytopenia for wide geographic areas. 4. Other drug induced immune mediated thrombocytopenias. 		National	Fiona Regan Cristina Navarrete	fiona.regan@nhsbt.nhs.uk cristina.navarrete@nhsbt.nhs.uk	020 8957 2834 020 2582 810
Databases in Red Cell Immunohematology	RCI	Blood transfusion	NHS Blood and Transplant	<ol style="list-style-type: none"> 1. haemolytic disease of the new born with significant antibodies in England (a few will be missed) 2. Immunoglobulin A deficiency 3. Certain Drug induced haemolytic anaemias 4. Haemolytic transfusion reactions. 		National	Fiona Regan Gordon Burgess	fiona.regan@nhsbt.nhs.uk gordon.burgess@nhsbt.nhs.uk	020 8957 2834
Diabetes Specialist Workforce Audits		Long term conditions	NHS Diabetes & Kidney Care Diabetes UK	Staff and their positions in three diabetes specialist workforces (Podiatrists, Dietitians and DSNs)		National	Adam Sweeney	adam.sweeney@diabetes.org.uk	020 7737 1073

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DiabetesE		Long term conditions	Innovate National Diabetes Information Service	The organisational structures and processes for delivering high quality diabetes services.	DiabetesE	England	Helen Seymour	Helen@innovate.info	0161 835 9494
Difficult Airway Society National Register of Airway Management Devices	DAS-ADEPT	Acute care	Difficult Airway Society (DAS)	Airway Management during Anaesthesia: There is concern that airway management devices are introduced into clinical practice with no prior evidence of their clinical efficacy or safety. DAS advises that anaesthetist should use or purchase only those devices for which there exists clinical trial evidence. The proposed registry will detail (a) which devices are purchased by Trusts; (b) which rejected; (c) the clinical trial evidence upon which those purchasing decisions were made.	St John's College Oxford - Fellows and Staff	Whole of UK Potential for registries to be linked with international device registries	Professor Jaideep J Pandit	jaideep.pandit@dpag.ox.ac.uk	07745 655885
Early Rheumatoid Arthritis Network		Orthopaedic	St Albans City Hospital	Rheumatoid Arthritis.		England: St Albans, Hereford, London, Basingstoke, Nottingham, Aylesbury, Stoke-on-Trent, Christchurch, Bristol, Yeovil, Weston-Super-Mare, Oxford, Lancaster. Wales: Haverfordwest Republic of Ireland: County Waterford	Dr Adam Young	marie.hunt@whht.nhs.uk	01727 897 362
Early Rheumatoid Arthritis Study	ERAS	Long term conditions	St Albans City Hospital	Rheumatoid Arthritis.		St Albans, Chelmsford, Grimsby, Gillingham, Sheffield, Winchester, Oswestry, Basingstoke	Dr Adam Young	Eras@whht.nhs.uk	01727 897 362
East Kent Carpal Tunnel Syndrome Database		Long term conditions	East Kent Hospitals University NHS Foundation Trust		East Kent Hospitals University Carpal-Tunnel.net	Regional	Jeremy Bland	Jeremy.Bland@nhs.net	01227 783 048
East Kent Movement Disorders Database		Long term conditions	East Kent Hospitals University NHS Foundation Trust		East Kent Hospitals University Carpal-Tunnel.net	Regional	Jeremy Bland	Jeremy.Bland@nhs.net	01227 783 048
Eastern Cancer Registration and Information Centre	ECRIC	Cancer	Eastern Cancer Registration and Information Centre	Cancer	The Eastern Cancer Registration and Information Centre	From the end of 2013 ECRIC will hold data (on the encore database) the whole of England.	Jane Richardson	jane.richardson@ecric.nhs.uk	01223 213 499
Einstein Secure Individual Patient Placements Database		OTHER	Tba	Tba	Tba	Tba	Tba		
Epidural Audit System	EAS	OTHER	Barnsley Hospital NHSFT	Elective and Emergency Obstetric Anaesthesia and Analgesia		Barnsley and bordering areas: Rotherham, Huddersfield, Doncaster, Wakefield, Sheffield	Deepa Kurup	deepa.kurup@nhs.net	01226 73000 Bleep 704
Family History of Bowel Cancer Clinic Database		Cancer	West Middlesex University Hospital NHS Trust	A clinic for people with a personal or family history suggestive of inherited of bowel cancer. This data is kept for surveillance, audit and research purposes.		West London	Dr Kevin Monahan	Kevin.monahan@wmuh.nhs.uk	020 8321 5752

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General Practice Research Database	GPRD	OTHER	Medicines and Healthcare products Regulatory Agency	<p>All coded and textual Data from 8% of UK wide primary care practices downloaded since 1987 to present, on a monthly "delta" basis. (600 practices, 5+ million, live, active patients)</p> <p>There are over 200 peer reviewed publications on data quality and the dataset undergoes extensive quality assurance prior to research use.</p> <p>The GP data is uniquely linked on a permanent basis to Hospital Episode Statistics; Central mortality data; Census data; Cancer registry data; The Myocardial Infarction Database; Air-pollution data.</p> <p>The database is also used for pragmatic point of care clinical trials and genetic sample collections. Over 150 research studies are undertaken using GPRD data every year. GPRD has contracts with most major global pharmas, many academic and regulatory groups.</p>	The General Practice Research Database	Whole of UK, Jersey, Guernsey, Isle of Man. Access to data from a range of European countries. Access to data from the USA.	Dr John Parkinson	john.parkinson@mhra.gsi.gov.uk	
Hepatology Database		Long term conditions	Royal Devon and Exeter Hospital NHS Foundation Trust	Patients with Liver Disease Data is captured on; diagnosis, blood results, investigations, treatment and success of this, medical history.		Local	Dr John Christie	John.Christie@rdefn.nhs.uk	01392 402 791
Hip Fracture Perioperative Network		Trauma		Hip fracture anaesthesia.	NHS Networks Hip Fracture Perioperative Network	Whole of UK Jersey, Guernsey, Isle of Man plus members from Australia and Canada	Dr Richard Griffiths	richard@wothorpe.com	
HIV and AIDS New Diagnoses Database		Long term conditions	Health Protection Agency	All new laboratory diagnoses of HIV infection, AIDS case reports, and reports of deaths in people with HIV.	Health Protection Agency New HIV Diagnoses	National	Dr Valerie Delpech	HARSQueries@hpa.org.uk	
Hospice Clinical Administration System	HCAS	Acute care	King's College Hospital NHS Foundation Trust	Palliative Care.		In or Out-Patients of King's College Hospital	Helen Rayner	H.rayner@nhs.net	020 3299 4060
IBD database (Infoflex)	IBD	Long term conditions	Barts and the London NHS Trust	Inflammatory bowel disease (Crohn's and ulcerative colitis) – register of all patients cared for here, with details of phenotype, treatment etc		Local database for patients at Barts and the London NHS Trust	Dr N M Croft Prof D S Rampton	n.m.croft@qmul.ac.uk d.rampton@qmul.ac.uk	020 7377 7442

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IBD Registry (Dendrite)	IBD	Long term conditions	Royal Devon and Exeter Hospital NHS Foundation Trust	Patients with Inflammatory Bowel Disease. Data: diagnosis, blood results, medication, investigations and results, basic medical history, surgical procedures performed.		England	Dr Tariq Ahmad	Tariq.Ahmad@rdefn.nhs.uk	01392 406 218
Inferior Vena Cava filter Registry	IVC	OTHER	British Society of Interventional Radiology		Dendrite Clinical Systems Ltd	Whole of UK Open to Jersey, Guernsey, Isle of Man (may not currently contain entries) Republic of Ireland Open to Australia, New Zealand - may not currently contain entries)	Moira Ritchie	moira.ritchie@bsir.org	0141 942 6744
Inflammatory Bowel Disease Database	IBD	Long term conditions	County Durham & Darlington NHS Foundation Trust	Gastroenterology – Inflammatory Bowel Disease.		County Durham	Dr Anjan Dhar	anjan.dhar@cddft.nhs.uk	01388 455 170
International Burn Injury Database	IBID	Trauma	National Network for Burn Care	The Database collects a comprehensive data-set on individual cases of burn injury severe enough to require treatment by specialised burn care services within the British Isles.	The International Burn Injury Database	England Wales Has capacity to cover the whole of the British Isles	Ken Dunn	ken.dunn@uhsm.nhs.uk	0161 291 6323
International Gastrointestinal Neuromuscular Disease Database		Gastro-intestinal	Barts and the London NHS Trust Great Ormond Street Hospital University College London Hospitals The Hope Hospital, Manchester St Mark's Hospital Huddinge Hospital & Karolinkska Institute, Stockholm, Sweden Bologna University Hospital, Italy	The database covers patients who suffer with gastrointestinal neuromuscular disorders. This includes gastrointestinal myopathies, neuropathies and mesenchymopathies. The database will include information on all aspects of these disorders from presenting symptoms, to radiological and histological appearances, and also including treatment and complications.	International Gastrointestinal Neuromuscular Disease Database	England Additionally covers centres in Sweden and Italy	Charles Knowles	c.h.knowles@qmul.ac.uk	020 7377 7184
Involve to Evolve		Acute care	Department of Health University of Birmingham	Children's Palliative Care in West Midlands.	Involve to Evolve	West Midlands	Dr Duncan Randall	d.c.randall@bham.ac.uk	0121 414 8377
KC65	KC65	Cancer	Barnsley Hospital NHS Foundation Trust	Colposcopy; cervical smears		Regional	Maxime Bowns		01226 432 258
Lipoprotein Apheresis Register		Cardiovascular disease	HEART UK Royal College of Physicians	Hyperlipoproteinaemia. Removal of LDL cholesterol, and lipoprotein[a] in refractory CAD, and triglyceride in pancreatitis by specific apheresis.		National	Dr Mary Seed	drmaryseed@hotmail.com	020 7221 4949
Liverpool Head and Neck Cancer		Cancer	Saving Faces	Head and neck cancer.		Local	Patrick Magennis	maxfac.uk@googlemail.com savingfaces@mail.com	
Liverpool Orthognathic Database		Acute care	Saving Faces	Orthognathic surgery.		Local	Patrick Magennis	maxfac.uk@googlemail.com	
National Bariatric Surgery Registry		Gastro-intestinal	The Association of Laparoscopic surgeons The Association of Upper GI Surgeons The British Obesity & Metabolic Surgery Society		National Bariatric Surgery Registry	Tba			

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National Botulinum Toxin Therapy Audit		Cancer		This study has finished. Data is available and consultants can access/analyse their own data.	The British Association of Urological Surgeons	Study has now finished Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required).	Sarah Fowler	sarah@sarahfowler.org	01635 42487
National Cancer Data Repository		Cancer	National Cancer Intelligence Network	Register of patients diagnosed with cancer including details of diagnosis, hospital treatment and death.		National		enquiries@ncin.org.uk	020 8282 6258
National Congenital Rubella Surveillance Programme	NCRSP	Long term conditions	UCL Institute of Child Health	Congenital rubella cases.		Whole of UK Republic of Ireland	Pat Tookey	p.tookey@ich.ucl.ac.uk	020 7905 2604
National Haemoglobinopathy Registry	NHR	Blood transfusion	National Screening Programme Department of Health UK Thalassaemia Society Sickle Cell Society	A database of patients with red cell disorders (mainly sickle cell disease and thalassaemia major) living in the UK. This new database collects data which is required by the Department of Health from haemoglobinopathy centres.	National Haemoglobinopathy Registry	National	Dr Rob Hollingsworth	rob.hollingsworth@nhs.net	
National Haemophilia Database	NHD	Long term conditions	United Kingdom Haemophilia Centre Doctors' Organisation	Register and clinical database of patients with bleeding disorders. Records from about 23000 patients. The database registers all pts diagnosed, records their treatment side-effects and mortality. We also conduct surveillance for HCV, HIV and vCJD in this group. We report to our membership, DH and commissioners and also monitor the national contract for clotting factor concentrates.		Whole of UK Crown Dependencies: Jersey / Guernsey / Isle of Man	Dr Charles R M Hay	charles.hay@cmft.nhs.uk	0161 276 4727
National Immunoglobulin Registry		Haematology	Department of Health		National Immunoglobulin Registry	Tba	Dr Denise O'Shaughnessy The National Demand Management Programme for Immunoglobulin e-Dendrite - Clinical Systems	denise.oshaughnessy@googlemail.com support@mdsas.com support@e-dendrite.com	0161 277 7917 (MDSAS)

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National Neuromodulation Database <i>(Pilot stage)</i>	NMD	Long term conditions	Neuromodulation Society of UK and Ireland (NSUKI)	Use of Neuromodulation in chronic conditions	Neuromodulation Society of the United Kingdom and Ireland	Currently 4 centres in pilot phase: 1. Basildon and Thurrock General Hospitals NHS Trust 2. Russells Hall Hospital Dudley, West Midlands 3. Leeds Teaching Hospitals NHS Trust 4. James Cook University Hospital Middlesborough Planned to expand to UK coverage	Dr G Baranidharan	G.baranidharan@nhs.net	07904 239397
National New Patient Registration of Patients with Bisphosphonate Related Osteonecrotic Jaw in England, Wales, Scotland & N Ireland	BRONJ	Long term conditions		Disease condition: potential side effect of treatment: bisphosphonate related osteonecrotic jaw. Registrations ended on 31 May 2011.		National	Prof Simon N Rogers Mrs Amrita Narain	snrogers@doctors.org.uk	020 7869 6750
National Ophthalmology Database	NOD	Ophthalmology	Royal College of Ophthalmologists	The whole of hospital clinical ophthalmology but concentrating initially on cataract, diabetic retinopathy, glaucoma, age-related macular degeneration and vitreoretinal surgery. Pseudoanonymised data are remotely extracted from electronic medical record systems (ECR) that collect nationally agreed datasets for different disease pathways within ophthalmology. As of July 2011, 31 NHS Trusts have contributed data.	https://nod.nhs.uk Note: only available from an N3 connected computer and in beta test version at present - July 2011	National	Rob Johnston	rob.johnston@glos.nhs.uk	08454 222529
National Registry of Childhood Tumours	NRCT	Cancer	Childhood Cancer Research Group	Malignant neoplasms and allied diseases (principally non-malignant CNS neoplasms and histiocytoses) diagnosed at age <15 years.	Childhood Cancer Research Group	Whole of UK Isle of Man	Charles Stiller	charles.stiller@ccrg.ox.ac.uk	01865 617 802
National Reporting and Learning System	NRLS	OTHER	National Patient Safety Agency	Patient safety incidents and near misses	National Patient Safety Agency	England Wales	Marcos Manhaes	Marcos.Manhaes@npsa.nhs.uk	020 7927 9199
National Spinal Cord Injury Database		Orthopaedic			The National Spinal Cord Injury Database	Tba			
National Study of HIV in Pregnancy and Childhood	NSHPC	Perinatal, Neonatal, Children	UCL Institute of Child Health	Register of diagnosed HIV infection in pregnant women, monitoring of health of infected children and children born to infected mothers.	National Study of HIV in Pregnancy and Childhood (NSHPC)	Whole of UK Jersey, Guernsey Republic of Ireland	Janet Masters	nshpc@ich.ucl.ac.uk	020 7905 2815

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National Suprapubic Catheter Insertion Audit		Urology and Kidney Care			The British Society of Urological Surgeons	Study finishes at end 2011 with all data due for return by end January 2012 Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required).	Sarah Fowler	sarah@sarahfowler.org	01635 42487
NHS Dental Epidemiology Programme - Wales		Perinatal, Neonatal, Children	Public Health Wales and Cardiff University	Dental caries as measured by the decayed, missing and filled index. For Primary School Year 1 children this index in the primary dentition is annotated as dmft. For Secondary School Year 7 children this index in the permanent dentition is annotated as DMFT. Collected via epidemiological survey examination, carried out every 4 years. Wales, Health Board and unitary authority level data is available.	Cardiff University School of Dentistry - Oral Health Childhood Epidemiology Programme	Wales level data and 22 unitary authorities. N.B. England, Scotland and Northern Ireland have their own local interpretations of British Association of the Study of Community Dentistry coordinated surveys.	Maria Morgan	morganmz@cardiff.ac.uk	029 2074 4612
North Devon Abdominal Aortic Aneurysm (AAA) Surveillance Register		Acute care	Northern Devon Healthcare NHS Trust	Tracking surveillance of small aortic aneurysms		Local	John Taylor	John.Taylor@ndevon.swest.nhs.uk	01271 322 424
North of England Collaborative Cerebral Palsy Survey	NECCPS	Perinatal, Neonatal, Children	Regional Maternity Survey Office North East Public Health Observatory	Children and young people with cerebral palsy	http://www.nepho.org.uk/rmsso/ http://www.ncl.ac.uk/ih/people/profile/m.p.ward-platt	North East England and North Cumbria	Mary Bythell	info@rmsso.org.uk	0191 233 1658
Northern Congenital Abnormality Survey	NorCAS	Perinatal, Neonatal, Children	Regional Maternity Survey Office North East Public Health Observatory	Database of all structural and chromosomal anomalies diagnosed antenatally or in children up to the age of twelve for mothers resident in the North East and North Cumbria at the time of pregnancy. Data collection since 1985.	www.rmsso.org.uk http://www.ncl.ac.uk/ih/people/profile/m.p.ward-platt	North East England and North Cumbria	Mary Bythell	info@rmsso.org.uk	0191 233 1658
Northern Region Young Persons' Malignant Disease Registry	NRYPMDR	Cancer	Newcastle University	Cancer in 0-24 year olds in the former Northern Region of England. Cases diagnosed 1968 onwards.	The Information Centre Clinical & health Outcomes Knowledge Base	Regional - North East and Cumbria	Dr Richard J Q McNally	Richard.McNally@ncl.ac.uk	0191 282 1356
Northern Survey of Diabetes in Pregnancy	NorDIP	Perinatal, Neonatal, Children	Regional Maternity Survey Office North East Public Health Observatory	Pregnancy outcomes for all women with pre-existing type 1 and 2 diabetes in the North East and North Cumbria. Data collection since 1994.	Regional Maternity Survey Office	North East England and North Cumbria	Mary Bythell	info@rmsso.org.uk	0191 233 1658
Northern Survey of Twins and Multiple Pregnancy	NorSTAMP	Perinatal, Neonatal, Children	Regional Maternity Survey Office North East Public Health Observatory	Pregnancy outcomes for all twin and higher multiple pregnancies in the North East and North Cumbria. Data collection since 1998.	http://www.nepho.org.uk/rmsso/ http://www.ncl.ac.uk/ih/people/profile/m.p.ward-platt	North East England and North Cumbria	Mary Bythell	info@rmsso.org.uk	0191 233 1658

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
Paediatric Intensive Care Audit Network	PICANet	Perinatal, Neonatal, Children	Universities of Leeds and Leicester		Paediatric Intensive Care Audit Network	Tba	Roger Parslow (Leeds) Liz Draper (Leicester) Generic email to whole team	r.c.parslow@leeds.ac.uk msn@leicester.ac.uk picanet@leeds.ac.uk	0113 343 4856 0116 252 3200
Pelvi-ureteric Junction (PUJ) Obstruction Audit		Urology and Kidney Care			The British Society of Urological Surgeons	Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required).	Sarah Fowler	sarah@sarahfowler.org	01635 42487
Penile Prosthesis Audit		Urology and Kidney Care			The British Society of Urological Surgeons	Formal collection for this study will cease at end 2011 Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required)	Sarah Fowler	sarah@sarahfowler.org	01635 42487
Percutaneous Nephrolithotomy Register	PCNL	Urology and Kidney Care			The British Society of Urological Surgeons	Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required)	Sarah Fowler	sarah@sarahfowler.org	01635 42487
Perinatal Mortality and Morbidity Survey	PMMS	Perinatal, Neonatal, Children	Regional Maternity Survey Office North East Public Health Observatory	Fetal losses from 20 weeks gestation, stillbirths, neonatal and infant deaths. Data collection since 1981.	Regional Maternity Survey Office	North East England and North Cumbria	Mary Bythell	info@rmso.org.uk	0191 233 1658
Podiatric Audit in Surgery and Clinical Outcome Measurement Tool	PASCOM-10	Acute care	College of Podiatrists	Podiatric medical diagnoses and treatment coding with patient outcomes.	PASCOM-10	National	Mr D R Tollafeld	dg@scpod.org	0845 450 3720
Poole Enhanced Recovery Database		Acute care	Poole Hospital NHS Foundation Trust	Outcomes following Laparoscopic and Colorectal surgery with Enhanced recovery.		Local	Tas Qureshi	taz.qureshi@poole.nhs.uk	01202 442 323

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
Practice-based Evidence in Nutrition Database	PEN	OTHER	British Dietetic Association	Currently covers 161 evidence based, dietetic specific 'knowledge pathways'. Most of these are disease states or stages of the lifecycle in which nutrition and dietetic interventions are common but also includes pathways for specific foods and nutrients and also professional practice. Around 1000 practice questions are answered using international guidelines and research. Links to evidence-based tools and resources are also available. The resource is continually reviewed, updated and enhanced.	PEN: Practice-based Evidence in Nutrition	Tba	Sylvia Turner	s.turner@bda.uk.com	01212 008 046
Pulmonary Hypertension Association	PHA UK	Cardiovascular disease			Pulmonary Hypertension Association	Tba	Caroline Drain (Office Manager)	office@phassociation.uk.com	01709 761450
RCoA National Audit Project 5 (NAP5): Accidental Awareness under General Anaesthesia (AAGA)	NAP5	Acute care	Royal College of Anaesthetists (RCoA) and Association of Anaesthetists of Great Britain and Ireland	Anaesthesia: Accidental awareness is of great importance to patients and anaesthetists alike. It is perhaps the second commonest adverse outcome for patients to discuss before surgery after postoperative nausea and vomiting, and both patients and anaesthetists rank it high in outcomes to avoid during anaesthesia. Despite this the incidence of AAGA remains controversial and causal factors have not been delineated. The purpose of this registry is to document the instances of AAGA over one year, and analyse the factors common to these incidents.	St John's College Oxford - Fellows and Staff	Whole of UK	Professor Jaideep J Pandit	jaideep.pandit@dpag.ox.ac.uk	07745 655885
Registry of diabetes in North East England and North Cumbria		Long term conditions	Newcastle University	Diabetes in 0-14 year olds in the former Northern Region of England. Cases diagnosed 1990 onwards.		Regional - North East and Cumbria	Dr Richard J Q McNally	Richard.McNally@ncl.ac.uk	0191 282 1356
Renal Database		Urology and Kidney Care	Queen Elizabeth Hospital Birmingham	This is a local clinical database covering most of the west midlands for renal biopsies, including native biopsies and grafts. The database covers primary diagnosis, adequacy of specimen, clinical data at the time of biopsy, classification of the lesions (for inclusions into trials and other data which are modified depending on treatment demands. It started 5 years ago but input has been intermittent and incomplete.		Regional - West Midlands, Herefordshire, Worcestershire Other countries outside Europe: Ghana	Kassiani Skordilis	Kassiani.skordilis@uhb.nhs.uk	0121 3713 354

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
Sarcoidosis Registry		Long term conditions	British Thoracic Society	Sarcoidosis		Whole of UK Jersey, Guernsey, Isle of Man	Dr Robina Coker	robina.coker@imperial.ac.uk Sally.welham@brit-thoracic.org.uk	020 7831 8778
Sarcoma Musculoskeletal Tumour Database		Cancer	Robert Jones and Agnes Hunt Orthopaedic & District Hospital NHS Trust	Sarcoma database and dataset	Paul Cool	Local	Paul Cool	paul@paulcool.com	01691 404 096
Simon Broome Register of Familial Hyperlipidaemia		Cardiovascular disease	HEART UK	Historic Data Only from 1980 to 2010 (i) Familial hypercholesteroleamia (ii) Severe hypertriglyceridaemia	Simon Broome FH Register Department of Primary Health Care	Historic Data Only from 1980 to 2010 England, Wales, Scotland	Professor H A W Neil	Andrew.neil@wolfson.ox.ac.uk	01865 274 107
Sloane Project		Cancer	West Midlands Cancer Intelligence Unit	UK prospective audit of screen detected non-invasive carcinomas and atypical hyperplasias of the breast, including diagnosis, treatment, follow up, survival, and clinical outcome data.	The Sloane Project	Whole of UK	Karen Clements Olive Kearins	karen.clements@wmcui.nhs.uk	01675 471907 0121 414 7713
Standardised Electronic Neonatal Database	SEND	Perinatal, Neonatal, Children	Development and Benchmarking: Neonatal Data Analysis Unit (an independent academic unit based at the Chelsea & Westminster campus of Imperial College London) Local Management by: Medway Maritime Hospital NHS Foundation Trust	Neonatal admissions	NHS Standardised Electronic Neonatal Database	Whole of UK, Jersey, Guernsey, Isle of Man	Dr Ghada Ramadan	Ghada.Ramadan@medway.nhs.uk	01634 825 146
Sudden Arrhythmic Death Syndrome Database	SADS	Cardiovascular disease	UK Cardiac Pathology Network	Collates all cases of sudden cardiac death	Sudden Arrhythmic Death Syndrome Database	National	Perry Elliott	perry.elliott@ucl.ac.uk	020 7573 8888
Survey of Prevalent HIV Infections Diagnosed		Long term conditions	Health Protection Agency	Patients with HIV aged over 15 seen for care (data collected twice yearly).	Health Protection Agency SOPHID	National	Dr Valerie Delpech	HARSQueries@hpa.org.uk	
System for Evaluating Play and Creative Arts Therapy Outcomes	SEFACTO	OTHER	Play Therapy UK	The national UK database of play therapy practice based evidence using measured outcomes. It has data based on nearly 8000 cases of children with emotional, behaviour, social and mental health difficulties.	Play Therapy United Kingdom	Whole of UK, Guernsey, Isle of Man, Republic of Ireland, Hong Kong, Australia, New Zealand, Malaysia, Ethiopia	Jeff Thomas	jefferyht@yahoo.co.uk	01825 761 143
Temporomandibular joint prosthesis national registration		Orthopaedic	British Association of Oral and Maxillofacial Surgeons	Temporomandibular joint prosthesis (partial/complete)		Whole of UK	Professor Simon N Rogers	snrogers@doctors.org.uk	07721 459840
Thames Cancer Registry	TCR	Cancer	Thames Cancer Registry	The TCR collects information about all occurrences of cancer in the 12 million residential populations of London and the South East Coast Strategic Health Authority areas (London, Kent, Surrey, Sussex).	www.tcr.org.uk www.ncin.org.uk	London and the South East Coast SHAs (London, Kent, Surrey, Sussex). TCR is part of the national cancer registration system for England supplying data to ONS and the National Cancer Data Repository.	Dr Maggie Barker (maternity cover for Dr Elizabeth Davies to 10th February 2012)	maggie.barker@kcl.ac.uk	020 7378 7688

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
The East Midlands and South Yorkshire Congenital Anomalies Register	EMSYCAR	Perinatal, Neonatal, Children	University of Leicester	Congenital Anomalies – structural, genetic, chromosome, endocrine, metabolic – diagnosed antenatally and postnatally up to the age of 16 yrs. Collects details of congenital anomalies in pregnancies and births to mothers resident within the East Midlands and South Yorkshire regions of England at the time of delivery/end of pregnancy. The geographical area covered is currently defined by 14 PCTs and 1 CTP. These are Barnsley, Rotherham, Doncaster,	East Midlands & South Yorkshire Congenital Anomalies Register	East Midlands South Yorkshire	Dr Judith Budd	jlsb1@le.ac.uk	0116 252 3210
The Neonatal Survey	THS	Perinatal, Neonatal, Children		For the year June 2011-May 2012 The Neonatal Survey is part of the EU FP7 funded EPICE study which covers regions in: Belgium, France, Denmark, Poland, Portugal, Netherlands, Germany, Italy, Sweden and UK For further details please see http://www.epiceproject.eu/	TNS The Neonatal Survey	Regional - East Midlands and Yorkshire For the year June 2011-May 2012 The Neonatal Survey is part of the EU FP7 funded EPICE study which covers regions in: Belgium, France, Denmark, Poland, Portugal, Netherlands, Germany, Italy, Sweden and UK	Prof E S Draper Prof D J Field	msn@le.ac.uk df63@le.ac.uk	0116 252 3200
Thoracic Surgical Database		Acute care	Liverpool Heart and Chest Hospital NHS Foundation Trust	The database is an in house system that collates clinical data on allThoracic surgical procedures performed at LHCH.		Whole of UK Isle of Man Holland, Monaco, Malta	Ian Whittle	ian.whittle@lhch.nhs.uk	0151 600 1030
Trauma Audit and Research Network	TARN	Trauma			Trauma Audit & Research Network	Tba		support@tarn.ac.uk	0161 206 4397
UK Collaborative HIV Cohort Study	UK CHIC	Long term conditions	University College London	People with HIV who have attended a collaborating clinic for care. Currently includes 14 HIV clinical centres across London and Scotland.	The UK Collaborative HIV Cohort	Regional - as at October 2011 the database includes 14 HIV clinics across England and Scotland. Other centres, or any from Wales, Northern Ireland or the Republic of Ireland are welcome subject to appropriate databases.	Prof Caroline Sabin	c.sabin@ucl.ac.uk	
UK Cystic Fibrosis Registry		Long term conditions	The Cystic Fibrosis Trust	The subject area of the UKCF Registry are patients in the UK with Cystic Fibrosis (CF). Clinical data is collected annually by the centres and clinics themselves. This anonymous data is then collated to produce a national report. The hypothesis underpinning the design of the UK CF Registry is that robust software design could standardize patient care while the resulting multicentre data set would facilitate local, regional and national audit as well as cross-sectional and longitudinal research	Cystic Fibrosis Trust	National	Joanne Osmond	josmond@cftrust.org.uk	020 7464 7211

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
UK Fatal Anaphylaxis Register		Acute care		For every death in UK attributed to anaphylaxis (either as the certified cause of death or determined retrospectively to have this cause), it records full PID, cause of death, autopsy findings, previous medical history, allergic history and investigations, circumstances of the fatal reaction, putative cause of the reaction, treatment given and how it failed, timing of progression of the reaction and other relevant details.		England Scotland (incomplete coverage due to different coronarial system) Wales Northern Ireland - incomplete coverage	Dr Richard Pumphrey	Richard.pumphrey@nhs.net	
UK HIV Drug Resistance Database	HIVDRD	Long term conditions	Medical Research Council Clinical Trials Unit Laboratories performing resistance tests, links with clinical sites	Tests for resistance to HIV drugs.	UK HIV Drug Resistance Database	Whole of UK	Jonathan Crofts	hivrd@ctu.mrc.ac.uk	020 7670 4748
UK National HALO Patient Registry		Acute care	University College London Hospitals NHS Foundation Trust	Registry of all patients in the UK undergoing HALO Radiofrequency ablation for Barrett's oesophagus with or without dysplasia and for patients undergoing HALO Radiofrequency ablation for squamous dysplasia of the oesophagus.		National	Sarah Green	s.green@ucl.ac.uk	020 7679 9087
UK National Neuromuscular Database	NaND	Long term conditions	MRC Centre for Neuromuscular Diseases	Children and adults with neuromuscular disease. Currently hosts longitudinal clinical information for Duchenne muscular dystrophy and spinal muscular atrophy. Modules for inclusion body myositis and congenital muscular dystrophies and congenital myopathies currently in development.	https secure site accessible to participating clinical centres	National	Elaine Scott	elaines@muscular-dystrophy.org	07795 227 170
UK Register of HIV Seroconverters		Long term conditions	Medical Research Council HIV clinics across UK	Individuals with HIV whose date of infection is (approximately) known (consented, so may be considered research).	MRC Clinical Trials Unit UK Register of HIV Seroconverters	National	Dr Kholoud Porter	ukregister@ctu.mrc.ac.uk	

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
UK Rehabilitation Outcomes Collaborative Database.	UKROC	Acute care	Northwick Park Hospital (North West London Hospitals NHS Trust) British Society of rehabilitation medicine All specialist level 1 and 2 neurorehabilitation units in England	In-patient rehabilitation for neurological conditions. The Database collates the information in the 'inpatient rehabilitation' section of the DoH Dataset for Long Term neurological Conditions for all case episodes admission to level1 and 2 units, and provides information on complexity of needs, inputs and outcomes. It will be used to inform tariff development for specialised neurorehabilitation under PbR.		England Will accept data for whole of UK	Prof Lynne Turner-Stokes	lynne.turner-stokes@dial.pipex.com	020 8869 5161
UK Renal Registry		Urology and Kidney Care	The Renal Association		UK Renal Registry	Tba	Ron Cullen	ron.cullen@renalregistry.nhs.uk renalreg@renalreg.com	0117 323 5665
UK Shunt Registry		Acute care				National	Dr Hugh Richards	Hkr10@medschl.cam.ac.uk	01223 336 946
UK Thoracic Surgical Register		Acute care				Whole of UK Jersey, Guernsey, Isle of Man Republic of Ireland	Richard Page	richard.page@lhch.nhs.uk	
UK Thrombotic Thrombocytopenic Purpura Registry		Haematology				Tba			
UK TOBY Cooling Register		Perinatal, Neonatal, Children	National Perinatal Epidemiology Unit	Moderate hypothermia for the treatment of perinatal ischaemic encephalopathy in term babies.	UK TOBY Cooling Register	Whole of UK Crown Dependencies: Jersey / Guernsey / Isle of Man Republic of Ireland	Prof Denis Azzopardi Brenda Strohm	tobyregister@npeu.ox.ac.uk	01865 289735
UK Transplant Registry	UKTR	Haematology	NHS Blood & Transplant	Organ Donation and Transplants. The registry records details of all patients waiting for an organ transplant in the UK, details about all transplants and details about the patient receiving the transplant at three months post transplant and thereafter annually either until the patient dies or the graft fails. The registry also records details of all organ donors.	NHS Blood and Transplant - Organ Donation	Whole of UK Jersey / Guernsey / Isle of Man Republic of Ireland - partial data Other European countries - details of donor organs imported from Europe and patients who have received a transplant and are receiving post transplant care who are resident in the UK whether their transplant was performed in the UK or abroad.	David Shute	david.shute@nhsbt.nhs.uk	0117 975 7520
UK Vasculitis Register	UKVas	Long term conditions	Ipswich Hospital NHS Trust University College Hospital	Vasculitis - inflammation of the blood vessels.		Whole of UK	Dr Richard Watts	richard.watts@ipswichhospital.nhs.uk	01473 702131
Ulcerative Colitis Surveillance	UCoS	Gastro-intestinal	North West London Hospitals NHS Trust	Identification of cancerous or pre-cancerous lesions in Ulcerative Colitis. Inflammatory Bowel Disease - Ulcerative Colitis. It covers starting time for colitis surveillance and risk stratification for future colonoscopies to pick up early cancers/dysplasia.		Tba	Dr Naila Arebi	naila.arebi@imperial.ac.uk	020 8235 4084
Unique Database		Long term conditions	Unique (The Rare Chromosome Disorder Support Group)	Rare chromosome disorders/pathogenic copy number variants.	Unique Rare Chromosome Disorder Support Group	National	Beverly Searle PhD	info@rarechromo.org	01883 330 766

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Unisoft Gastrointestinal (GI) Reporting Tool		Gastro-intestinal	Royal Devon and Exeter NHS Foundation Trust Tiverton and District Hospital (Northern Devon Healthcare Trust) Axminster Hospital	The Gastro-intestinal Endoscopy is a database that functions as an electronic patient record and reporting mechanism which holds procedural details of patients that have GI endoscopy (Colonoscopy, Flexible Sigmoidoscopy, Gastroscopy, EUS, ERCP, PEG Procedures). Data is captured on; proc type, indications, drugs administered, success of endoscopy/complications, therapeutic interventions diagnosis, follow up.		Local - Royal Devon and Exeter Foundation Trust. The Reporting tool is used locally by the hospital and only contains details of patients that have had a procedure at the hospital and 2 community hospitals that use the same computer network and GI reporting tool.	Abigail Forbes	Abigail.Forbes@rdeft.nhs.uk	01392 406 110
Upper Urinary Tract Transitional Cell Carcinoma Audit	UTTCC Audit	Cancer			The British Association of Urological Surgeons	Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required)	Sarah Fowler	sarah@sarahfowler.org	01635 42487
Urethreroplasty Audit		Urology and Kidney Care			The British Association of Urological Surgeons	Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required)	Sarah Fowler	sarah@sarahfowler.org	01635 42487
Ventricular Assist Devices Database	VADS	Blood transfusion	NHS Blood and Transplant Royal College of Surgeons	Treatment of heart failure.		Republic of Ireland (data received in the past but not recently. This can/will change as required)	Kerri Barber	kerri.barber@nhsbt.nhs.uk	0117 975 7556
Welsh Cancer Intelligence and Surveillance Unit	WCISU	Cancer	Public Health Wales NHS Trust The Welsh Cancer Intelligence & Surveillance Unit	Cancer	Welsh Cancer Intelligence and Surveillance Unit	National - Wales	Shelagh Reynolds	shelagh.reynolds@wales.nhs.uk	02920 373 500
Wessex Antenatally Detected Anomalies Register	WANDA	Perinatal, Neonatal, Children	Wessex Clinical Genetics Service	Congenital anomalies.		Some of England Jersey, Guernsey	Dr Diana Wellesley	dgw@soton.ac.uk	02380 796167
West Midlands Regional Children's Tumour Registry	WMRCTR	Cancer				Regional	Sheila Parkes	sheila.parkes@bch.nhs.uk	0121 333 8672
Yorkshire and Humber Congenital Anomalies Register		Perinatal, Neonatal, Children	University of Leeds	All congenital anomalies detected antenatally and postnatally in Yorkshire and Humber SHA.	Yorkshire and Humber Congenital Anomalies Register	Regional - Yorkshire and Humber SHA	Dr Roger Parslow Dr Catherine Whibley	r.c.parslow@leeds.ac.uk c.whibley@leeds.ac.uk	0113 3434856 0113 3439160
Yorkshire Register of Diabetes in Children and Young People	YRDCYP	Long term conditions	University of Leeds		The Yorkshire Specialist Register of Cancer in Children and Young People University of Leeds	Regional - Yorkshire and Humber SHA	Dr Roger Parslow Carolyn Stephenson	r.c.parslow@leeds.ac.uk c.r.stephenson@leeds.ac.uk	0113 3434856 0113 3434957

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British Association of Paediatric Surgeons Congenital Anomalies Surveillance System	BAPS-CASS	Acute care			The British Association of Paediatric Surgeons Congenital Anomalies Surveillance System	Whole of UK Jersey, Guernsey, Isle of Man Republic of Ireland	Alex Bellenger	baps-cass@npeu.ox.ac.uk	
British Society of Urogynaecology Surgical Audit Database	BSUG	Acute care	British Society of Urogynaecology	Surgical procedures for female urinary incontinence and / or Vaginal / Uterovaginal prolapse.		Whole of UK	Paul Moran	Paul.Moran@worcsacute.nhs.uk	01905 760655
Hospice Clinical Administration System	HCAS	Acute care	King's College Hospital NHS Foundation Trust	Palliative Care.		In or Out-Patients of King's College Hospital	Helen Rayner	H.rayner@nhs.net	020 3299 4060
Involve to Evolve		Acute care	Department of Health University of Birmingham	Children's Palliative Care in West Midlands.	Involve to Evolve	West Midlands	Dr Duncan Randall	d.c.randall@bham.ac.uk	0121 414 8377
Liverpool Orthognathic Database		Acute care	Saving Faces	Orthognathic surgery.		Local	Patrick Magennis	maxfac.uk@googlemail.com	
North Devon Abdominal Aortic Aneurysm (AAA) Surveillance Register		Acute care	Northern Devon Healthcare NHS Trust	Tracking surveillance of small aortic aneurysms		Local	John Taylor	John.Taylor@ndevon.swest.nhs.uk	01271 322 424
Podiatric Audit in Surgery and Clinical Outcome Measurement Tool	PASCOM-10	Acute care	College of Podiatrists	Podiatric medical diagnoses and treatment coding with patient outcomes.	PASCOM-10	National	Mr D R Tollafeld	dg@scpod.org	0845 450 3720
Poole Enhanced Recovery Database		Acute care	Poole Hospital NHS Foundation Trust	Outcomes following Laparoscopic and Colorectal surgery with Enhanced recovery.		Local	Tas Qureshi	taz.qureshi@poole.nhs.uk	01202 442 323
Thoracic Surgical Database		Acute care	Liverpool Heart and Chest Hospital NHS Foundation Trust	The database is an in house system that collates clinical data on allThoracic surgical procedures performed at LHCH.		Whole of UK Isle of Man Holland, Monaco, Malta	Ian Whittle	ian.whittle@lhch.nhs.uk	0151 600 1030
UK Fatal Anaphylaxis Register		Acute care		For every death in UK attributed to anaphylaxis (either as the certified cause of death or determined retrospectively to have this cause), it records full PID, cause of death, autopsy findings, previous medical history, allergic history and investigations, circumstances of the fatal reaction, putative cause of the reaction, treatment given and how it failed, timing of progression of the reaction and other relevant details.		England Scotland (incomplete coverage due to different coronarial system) Wales Northern Ireland - incomplete coverage	Dr Richard Pumphrey	Richard.pumphrey@nhs.net	
UK National HALO Patient Registry		Acute care	University College London Hospitals NHS Foundation Trust	Registry of all patients in the UK undergoing HALO Radiofrequency ablation for Barrett's oesophagus with or without dysplasia and for patients undergoing HALO Radiofrequency ablation for squamous dysplasia of the oesophagus.		National	Sarah Green	s.green@ucl.ac.uk	020 7679 9087

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UK Rehabilitation Outcomes Collaborative Database.	UKROC	Acute care	Northwick Park Hospital (North West London Hospitals NHS Trust) British Society of rehabilitation medicine All specialist level 1 and 2 neurorehabilitation units in England	In-patient rehabilitation for neurological conditions. The Database collates the information in the 'inpatient rehabilitation' section of the DoH Dataset for Long Term neurological Conditions for all case episodes admission to level1 and 2 units, and provides information on complexity of needs, inputs and outcomes. It will be used to inform tariff development for specialised neurorehabilitation under PbR.		England Will accept data for whole of UK	Prof Lynne Turner-Stokes	lynne.turner-stokes@dial.pipex.com	020 8869 5161
UK Shunt Registry		Acute care				National	Dr Hugh Richards	Hkr10@medschl.cam.ac.uk	01223 336 946
UK Thoracic Surgical Register		Acute care				Whole of UK Jersey, Guernsey, Isle of Man Republic of Ireland	Richard Page	richard.page@lhch.nhs.uk	

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Databases in Histocompatibility and Immunogenetics		Blood transfusion	NHS Blood and Transplant	<p>1. Feto-maternal alloimmune thrombocytopenia. There is only one lab in England that performs diagnostic tests for for this disease making it good ID data.</p> <p>2. Inherited platelet glycoprotein disorders (Bernard – Soulier Syndrome and Glansmans Thrombasthenia) for a wide geography which could encompass the whole country as possibly only Sheffield performs thorough testing for these rare disorders.</p> <p>3. Heparin induced thrombocytopenia for wide geographic areas.</p> <p>4. Other drug induced immune mediated thrombocytopenias.</p>		National	Fiona Regan Cristina Navarrete	fiona.regan@nhsbt.nhs.uk cristina.navarrete@nhsbt.nhs.uk	020 8957 2834 020 2582 810
Databases in Red Cell Immunohematology	RCI	Blood transfusion	NHS Blood and Transplant	<p>1. haemolytic disease of the new born with significant antibodies in England (a few will be missed)</p> <p>2. Immunoglobulin A deficiency</p> <p>3. Certain Drug induced haemolytic anaemias</p> <p>4. Haemolytic transfusion reactions.</p>		National	Fiona Regan Gordon Burgess	fiona.regan@nhsbt.nhs.uk gordon.burgess@nhsbt.nhs.uk	020 8957 2834
National Haemoglobinopathy Registry	NHR	Blood transfusion	National Screening Programme Department of Health UK Thalassaemia Society Sickle Cell Society	A database of patients with red cell disorders (mainly sickle cell disease and thalassaemia major) living in the UK. This new database collects data which is required by the Department of Health from haemoglobinopathy centres.	National Haemoglobinopathy Registry	National	Dr Rob Hollingsworth	rob.hollingsworth@nhs.net	
Ventricular Assist Devices Database	VADS	Blood transfusion	NHS Blood and Transplant Royal College of Surgeons	Treatment of heart failure.		Republic of Ireland (data received in the past but not recently. This can/will change as required)	Kerri Barber	kerri.barber@nhsbt.nhs.uk	0117 975 7556

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Association of Breast Surgery Breast Screening Audit Database	ABS	Cancer	West Midlands Cancer Intelligence Unit	An annual audit of screen detected breast cancer to monitor breast screening unit and individual surgical performance. It includes 100% of the cancers detected through the NHSBSP since 1996. Topics include diagnosis, treatment, clinical waiting times, adjuvant treatment information, survival and outcomes.	West Midlands Cancer Intelligence Unit	Whole of UK Jersey, Guernsey, Isle of Man Republic of Ireland - partial. Some comparative data included in annual audit presentation at ABS annual meeting but data does not cover all the areas included in the audit and is not included in the published annual report.	Dr Gill Lawrence	Gill.Lawrence@wmciu.nhs.uk	0121 415 8129
BAUS Cancer Registry (BCR) Complex Operations Audit	BCR	Cancer		Cystectomy, prostatectomy and nephrectomy.	The British Association of Urological Surgeons	Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required).	Sarah Fowler	sarah@sarahfowler.org	01635 42487
Bowel Screening Information Management System	BSIMS	Cancer	Public Health Wales Screening Division	Screening for Bowel cancer.	Public Health Wales	National - Wales Northern Ireland - separate database	Phil Walters	phil.walters@wales.nhs.uk	029 20 787815
Breast Cancer Clinical Outcome Measures Project	BCCOM	Cancer	West Midlands Cancer Intelligence Unit	Symptomatic primary breast cancers. Topics include diagnosis, treatment, clinical waiting times, adjuvant treatment information, survival and clinical outcomes.	West Midlands Cancer Intelligence Unit	Whole of UK	Dr Catherine Lagord Dr Gill Lawrence	gill.lawrence@wmciu.nhs.uk catherine.lagord@wmciu.nhs.uk	0121 415 8129 0121 414 7713
British Association of Urological Surgeons Cancer Registry	BCR	Cancer	British Association of Urological Surgeons	Newly presenting urological tumours 1999 - 2010.	The British Association of Urological Surgeons	Formal collection ceased March 2011 Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required).	Sarah Fowler	sarah@sarahfowler.org	01635 42487
Eastern Cancer Registration and Information Centre	ECRIC	Cancer	Eastern Cancer Registration and Information Centre	Cancer	The Eastern Cancer Registration and Information Centre	From the end of 2013 ECRIC will hold data (on the encore database) the whole of England.	Jane Richardson	jane.richardson@ecric.nhs.uk	01223 213 499
Family History of Bowel Cancer Clinic Database		Cancer	West Middlesex University Hospital NHS Trust	A clinic for people with a personal or family history suggestive of inherited of bowel cancer. This data is kept for surveillance, audit and research purposes.		West London	Dr Kevin Monahan	Kevin.monahan@wmuh.nhs.uk	020 8321 5752
KC65	KC65	Cancer	Barnsley Hospital NHS Foundation Trust	Colposcopy; cervical smears		Regional	Maxime Bowns		01226 432 258
Liverpool Head and Neck Cancer		Cancer	Saving Faces	Head and neck cancer.		Local	Patrick Magennis	maxfac.uk@googlemail.com savingfaces@mail.com	
National Botulinum Toxin Therapy Audit		Cancer		This study has finished. Data is available and consultants can access/analyse their own data.	The British Association of Urological Surgeons	Study has now finished Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required).	Sarah Fowler	sarah@sarahfowler.org	01635 42487

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
National Cancer Data Repository		Cancer	National Cancer Intelligence Network	Register of patients diagnosed with cancer including details of diagnosis, hospital treatment and death.		National		enquiries@ncin.org.uk	020 8282 6258
National Registry of Childhood Tumours	NRCT	Cancer	Childhood Cancer Research Group	Malignant neoplasms and allied diseases (principally non-malignant CNS neoplasms and histiocytoses) diagnosed at age <15 years.	Childhood Cancer Research Group	Whole of UK Isle of Man	Charles Stiller	charles.stiller@ccrg.ox.ac.uk	01865 617 802
Northern Region Young Persons' Malignant Disease Registry	NRYPMDR	Cancer	Newcastle University	Cancer in 0-24 year olds in the former Northern Region of England. Cases diagnosed 1968 onwards.	The Information Centre Clinical & health Outcomes Knowledge Base	Regional - North East and Cumbria	Dr Richard J Q McNally	Richard.McNally@ncl.ac.uk	0191 282 1356
Sarcoma Musculoskeletal Tumour Database		Cancer	Robert Jones and Agnes Hunt Orthopaedic & District Hospital NHS Trust	Sarcoma database and dataset	Paul Cool	Local	Paul Cool	paul@paulcool.com	01691 404 096
Sloane Project		Cancer	West Midlands Cancer Intelligence Unit	UK prospective audit of screen detected non-invasive carcinomas and atypical hyperplasias of the breast, including diagnosis, treatment, follow up, survival, and clinical outcome data.	The Sloane Project	Whole of UK	Karen Clements Olive Kearns	karen.clements@wmciu.nhs.uk	01675 471907 0121 414 7713
Thames Cancer Registry	TCR	Cancer	Thames Cancer Registry	The TCR collects information about all occurrences of cancer in the 12 million residential populations of London and the South East Coast Strategic Health Authority areas (London, Kent, Surrey, Sussex).	www.tcr.org.uk www.ncin.org.uk	London and the South East Coast SHAs (London, Kent, Surrey, Sussex). TCR is part of the national cancer registration system for England supplying data to ONS and the National Cancer Data Repository.	Dr Maggie Barker <i>(maternity cover for Dr Elizabeth Davies to 10th February 2012)</i>	maggie.barker@kcl.ac.uk	020 7378 7688
Upper Urinary Tract Transitional Cell Carcinoma Audit	UTTCC Audit	Cancer			The British Association of Urological Surgeons	Whole of UK Jersey, Guernsey, Isle of Man (data received but not consistently) Republic of Ireland (data received in the past but not recently. This can/will change as required)	Sarah Fowler	sarah@sarahfowler.org	01635 42487
Welsh Cancer Intelligence and Surveillance Unit	WCISU	Cancer	Public Health Wales NHS Trust The Welsh Cancer Intelligence & Surveillance Unit	Cancer	Welsh Cancer Intelligence and Surveillance Unit	National - Wales	Shelagh Reynolds	shelagh.reynolds@wales.nhs.uk	02920 373 500
West Midlands Regional Children's Tumour Registry	WMRCTR	Cancer				Regional	Sheila Parkes	sheila.parkes@bch.nhs.uk	0121 333 8672
Yorkshire Specialist Register of Cancer in Children and Young People		Cancer		All children and young people (up to 29 years) diagnosed with any type of diabetes.	The Yorkshire Register of Diabetes in Children and Young People University of Leeds	England	Dr Richard Feltbower	r.g.feltbower@leeds.ac.uk	0113 343 4841

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Cardiac Surgical Database		Cardiovascular disease	Liverpool Heart & Chest Hospital	The database is an in house system that collates clinical data on all Cardiac surgical procedures performed at LHCH.		Local	Andrew Ward	andrew.ward@lhch.nhs.uk	0151 600 1004
Chronic Heart Failure		Cardiovascular disease	Central Cardiac Audit Database	Chronic heart failure admissions.		Whole of UK	Dr A D Cunningham	david.cunningham@ucl.ac.uk	07753 682686
Lipoprotein Apheresis Register		Cardiovascular disease	HEART UK Royal College of Physicians	Hyperlipoproteinaemia. Removal of LDL cholesterol, and lipoprotein[a] in refractory CAD, and triglyceride in pancreatitis by specific apheresis.		National	Dr Mary Seed	drmaryseed@hotmail.com	020 7221 4949
Pulmonary Hypertension Association	PHA UK	Cardiovascular disease			Pulmonary Hypertension Association	Tba	Caroline Drain (Office Manager)	office@phassociation.uk.com	01709 761450
Simon Broome Register of Familial Hyperlipidaemia		Cardiovascular disease	HEART UK	Historic Data Only from 1980 to 2010 (i) Familial hypercholesteroleamia (ii) Severe hypertriglyceridaemia	Simon Broome FH Register Department of Primary Health Care	Historic Data Only from 1980 to 2010 England, Wales, Scotland	Professor H A W Neil	Andrew.neil@wolfson.ox.ac.uk	01865 274 107
Sudden Arrhythmic Death Syndrome Database	SADS	Cardiovascular disease	UK Cardiac Pathology Network	Collates all cases of sudden cardiac death	Sudden Arrhythmic Death Syndrome Database	National	Perry Elliott	perry.elliott@ucl.ac.uk	020 7573 8888

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Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
International Gastrointestinal Neuromuscular Disease Database		Gastro-intestinal	Barts and the London NHS Trust Great Ormond Street Hospital University College London Hospitals The Hope Hospital, Manchester St Mark's Hospital Huddinge Hospital & Karolinksa Institute, Stockholm, Sweden Bologna University Hospital, Italy	The database covers patients who suffer with gastrointestinal neuromuscular disorders. This includes gastrointestinal myopathies, neuropathies and mesenchymopathies. The database will include information on all aspects of these disorders from presenting symptoms, to radiological and histological appearances, and also including treatment and complications.	International Gastrointestinal Neuromuscular Disease Database	England Additionally covers centres in Sweden and Italy	Charles Knowles	c.h.knowles@qmul.ac.uk	020 7377 7184

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Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
British Association of Blood and Marrow Transplantation Data Registry	BSBMT	Haematology			British Society of Blood and Marrow Transplantation - Stem Cell Transplantation	Tba			
National Immunoglobulin Registry		Haematology	Department of Health		National Immunoglobulin Registry	Tba	Dr Denise O'Shaughnessy The National Demand Management Programme for Immunoglobulin e-Dendrite - Clinical Systems	denise.oshaughnessy@googlemail.com support@mdsas.com support@e-dendrite.com	0161 277 7917 (MDSAS)
UK Thrombotic Thrombocytopenic Purpura Registry		Haematology				Tba			

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Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone	Subject
Alström Syndrome UK Clinical Research Database	ASUK	Long term conditions	Alström Syndrome UK Birmingham Children's Hospital NHS Foundation Trust Torbay District General Hospital (South Devon Healthcare NHS Foundation Trust)	Clinical and research test results for UK resident Alström Syndrome patients.	Alström Syndrome UK	Whole of UK Jersey / Guernsey / Isle of Man	Dr Mike Hales	mike.hales@alstrom.org.uk	01803 843 227	Clinical and research test results for UK resident Alström Syndrome patients.
Biologics Register for Rheumatoid Arthritis	BSRBR	Long term conditions	British Society for Rheumatology Arthritis Research UK Epidemiology Unit (within the Musculoskeletal Research Group)	British Society for Rheumatology ; Rheumatoid Arthritis and Biologic therapies.	The British Society for Rheumatology	Whole of UK	Nia Taylor	ntaylor@rheumatology.org.uk	020 7842 0905	British Society for Rheumatology ; Rheumatoid Arthritis and Biologic therapies.
British Thoracic Society Difficult Asthma Registry		Long term conditions	Queens University Belfast	Difficult asthma (failure to respond to treatment at Step 4 of current British asthma management guidelines referred for specialist assessment).	Difficult Asthma Registry	Whole of UK	Liam Heaney Sally Welham	l.heaney@qub.ac.uk Sally.Welham@brit-thoracic.org.uk	02890 263821	Difficult asthma (failure to respond to treatment at Step 4 of current British asthma management guidelines referred for specialist assessment).
Clinical and Laboratory Online Patient- and Research Database for Primary Immunodeficiencies	UKPID	Long term conditions	UK Primary Immunodeficiency Network	Primary Immunodeficiency Disorders.	UK Primary Immunodeficiency Network	National	Dr J David M Edgar	david.edgar@belfasttrust.hscni.net	02890 635396	Primary Immunodeficiency Disorders.
Database of Alkaptonuria Patients	AKU	Long term conditions	AKU Society	Records accepted from any AKU patient, regardless of country (mainly identified online and through contacts made at international medical conferences). Actively looking for patients in the UK (England, Scotland, Wales, Northern Ireland). Database of Alkaptonuria patients worldwide. Currently identified 650 patients, with 80 in the UK. Alkaptonuria is a genetic disease, presenting symptoms similar to osteoarthritis. The database records information on the name and location of patients, medical history, and social history. The aim of the database is to record information on AKU. As little is known on the natural history of the disease, questions are quite open, to allow us to record as much information as possible.	AKU Society	International	Oliver Timmis	oliver@akusociety.org	07799 037726	Records accepted from any AKU patient, regardless of country (mainly identified online and through contacts made at international medical conferences). Actively looking for patients in the UK (England, Scotland, Wales, Northern Ireland). Database of Alkaptonuria patients worldwide. Currently identified 650 patients, with 80 in the UK. Alkaptonuria is a genetic disease, presenting symptoms similar to osteoarthritis. The database records information on the name and location of patients, medical history, and social history. The aim of the database is to record information on AKU. As little is known on the natural history of the disease, questions are quite open, to allow us to record as much information as possible.
Diabetes Specialist Workforce Audits		Long term conditions	NHS Diabetes & Kidney Care Diabetes UK	Staff and their positions in three diabetes specialist workforces (Podiatrists, Dietitians and DSNs)		National	Adam Sweeney	adam.sweeney@diabetes.org.uk	020 7737 1073	Staff and their positions in three diabetes specialist workforces (Podiatrists, Dietitians and DSNs)
DiabetesE		Long term conditions	Innovate National Diabetes Information Service	The organisational structures and processes for delivering high quality diabetes services.	DiabetesE	England	Helen Seymour	Helen@innove.info	0161 835 9494	The organisational structures and processes for delivering high quality diabetes services.
Early Rheumatoid Arthritis Study	ERAS	Long term conditions	St Albans City Hospital	Rheumatoid Arthritis.		St Albans, Chelmsford, Grimbsy, Gillingham, Sheffield, Winchester, Oswestry, Basingstoke	Dr Adam Young	Eras@whht.nhs.uk	01727 897 362	Rheumatoid Arthritis.
East Kent Carpal Tunnel Syndrome Database		Long term conditions	East Kent Hospitals University NHS Foundation Trust		East Kent Hospitals University Carpel-Tunnel.net	Regional	Jeremy Bland	Jeremy.Bland@nhs.net	01227 783 048	
East Kent Movement Disorders Database		Long term conditions	East Kent Hospitals University NHS Foundation Trust		East Kent Hospitals University Carpel-Tunnel.net	Regional	Jeremy Bland	Jeremy.Bland@nhs.net	01227 783 048	

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone	Subject
Hepatology Database		Long term conditions	Royal Devon and Exeter Hospital NHS Foundation Trust	Patients with Liver Disease Data is captured on; diagnosis, blood results, investigations, treatment and success of this, medical history.		Local	Dr John Christie	John.Christie@rdefn.nhs.uk	01392 402 791	Patients with Liver Disease Data is captured on; diagnosis, blood results, investigations, treatment and success of this, medical history.
HIV and AIDS New Diagnoses Database		Long term conditions	Health Protection Agency	All new laboratory diagnoses of HIV infection, AIDS case reports, and reports of deaths in people with HIV.	Health Protection Agency New HIV Diagnoses	National	Dr Valerie Delpech	HARSQueries@hpa.org.uk		All new laboratory diagnoses of HIV infection, AIDS case reports, and reports of deaths in people with HIV.
IBD database (Infloflex)	IBD	Long term conditions	Barts and the London NHS Trust	Inflammatory bowel disease (Crohn's and ulcerative colitis) – register of all patients cared for here, with details of phenotype, treatment etc		Local database for patients at Barts and the London NHS Trust	Dr N M Croft Prof D S Rampton	n.m.croft@qmul.ac.uk d.rampton@qmul.ac.uk	020 7377 7442	Inflammatory bowel disease (Crohn's and ulcerative colitis) – register of all patients cared for here, with details of phenotype, treatment etc
IBD Registry (Dendrite)	IBD	Long term conditions	Royal Devon and Exeter Hospital NHS Foundation Trust	Patients with Inflammatory Bowel Disease. Data: diagnosis, blood results, medication, investigations and results, basic medical history, surgical procedures performed.		England	Dr Tariq Ahmad	Tariq.Ahmad@rdefn.nhs.uk	01392 406 218	Patients with Inflammatory Bowel Disease. Data: diagnosis, blood results, medication, investigations and results, basic medical history, surgical procedures performed.
Inflammatory Bowel Disease Database	IBD	Long term conditions	County Durham & Darlington NHS Foundation Trust	Gastroenterology – Inflammatory Bowel Disease.		County Durham	Dr Anjan Dhar	anjan.dhar@cddft.nhs.uk	01388 455 170	Gastroenterology – Inflammatory Bowel Disease.
National Congenital Rubella Surveillance Programme	NCRSP	Long term conditions	UCL Institute of Child Health	Congenital rubella cases.		Whole of UK Republic of Ireland	Pat Tookey	p.tookey@ich.ucl.ac.uk	020 7905 2604	Congenital rubella cases.
National Haemophilia Database	NHD	Long term conditions	United Kingdom Haemophilia Centre Doctors' Organisation	Register and clinical database of patients with bleeding disorders. Records from about 23000 patients. The database registers all pts diagnosed, records their treatment side-effects and mortality. We also conduct surveillance for HCV, HIV and vCJD in this group. We report to our membership, DH and commissioners and also monitor the national contract for clotting factor concentrates.		Whole of UK Crown Dependencies: Jersey / Guernsey / Isle of Man	Dr Charles R M Hay	charles.hay@cmft.nhs.uk	0161 276 4727	Register and clinical database of patients with bleeding disorders. Records from about 23000 patients. The database registers all pts diagnosed, records their treatment side-effects and mortality. We also conduct surveillance for HCV, HIV and vCJD in this group. We report to our membership, DH and commissioners and also monitor the national contract for clotting factor concentrates.
National Neuromodulation Database (Pilot stage)	NMD	Long term conditions	Neuromodulation Society of UK and Ireland (NSUKI)	Use of Neuromodulation in chronic conditions	Neuromodulation Society of the United Kingdom and Ireland	Currently 4 centres in pilot phase: 1. Basildon and Thurrock General Hospitals NHS Trust 2. Russells Hall Hospital Dudley, West Midlands 3. Leeds Teaching Hospitals NHS Trust 4. James Cook University Hospital Middlesborough Planned to expand to UK coverage	Dr G Baranidharan	G.baranidharan@nhs.net	07904 239397	Use of Neuromodulation in chronic conditions
National New Patient Registration of Patients with Bisphosphonate Related Osteonecrotic Jaw in England, Wales, Scotland & N Ireland	BRONJ	Long term conditions		Disease condition: potential side effect of treatment: bisphosphonate related osteonecrotic jaw. Registrations ended on 31 May 2011.		National	Prof Simon N Rogers Mrs Amrita Narain	snrogers@doctors.org.uk	020 7869 6750	Disease condition: potential side effect of treatment: bisphosphonate related osteonecrotic jaw. Registrations ended on 31 May 2011.
Registry of diabetes in North East England and North Cumbria		Long term conditions	Newcastle University	Diabetes in 0-14 year olds in the former Northern Region of England. Cases diagnosed 1990 onwards.		Regional - North East and Cumbria	Dr Richard J Q McNally	Richard.McNally@ncl.ac.uk	0191 282 1356	Diabetes in 0-14 year olds in the former Northern Region of England. Cases diagnosed 1990 onwards.
Sarcoidosis Registry		Long term conditions	British Thoracic Society	Sarcoidosis		Whole of UK Jersey, Guernsey, Isle of Man	Dr Robina Coker	robina.coker@imperial.ac.uk Sally.welham@brit-thoracic.org.uk	020 7831 8778	Sarcoidosis
Survey of Prevalent HIV Infections Diagnosed		Long term conditions	Health Protection Agency	Patients with HIV aged over 15 seen for care (data collected twice yearly).	Health Protection Agency SOPHID	National	Dr Valerie Delpech	HARSQueries@hpa.org.uk		Patients with HIV aged over 15 seen for care (data collected twice yearly).
UK Collaborative HIV Cohort Study	UK CHIC	Long term conditions	University College London	People with HIV who have attended a collaborating clinic for care. Currently includes 14 HIV clinical centres across London and Scotland.	The UK Collaborative HIV Cohort	Regional - as at October 2011 the database includes 14 HIV clinics across England and Scotland. Other centres, or any from Wales, Northern Ireland or the Republic of Ireland are welcome subject to appropriate databases.	Prof Caroline Sabin	c.sabin@ucl.ac.uk		People with HIV who have attended a collaborating clinic for care. Currently includes 14 HIV clinical centres across London and Scotland.

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone	Subject
UK Cystic Fibrosis Registry		Long term conditions	The Cystic Fibrosis Trust	The subject area of the UKCF Registry are patients in the UK with Cystic Fibrosis (CF). Clinical data is collected annually by the centres and clinics themselves. This anonymous data is then collated to produce a national report. The hypothesis underpinning the design of the UK CF Registry is that robust software design could standardize patient care while the resulting multicentre data set would facilitate local, regional and national audit as well as cross-sectional and longitudinal research	Cystic Fibrosis Trust	National	Joanne Osmond	josmond@cftrust.org.uk	020 7464 7211	The subject area of the UKCF Registry are patients in the UK with Cystic Fibrosis (CF). Clinical data is collected annually by the centres and clinics themselves. This anonymous data is then collated to produce a national report. The hypothesis underpinning the design of the UK CF Registry is that robust software design could standardize patient care while the resulting multicentre data set would facilitate local, regional and national audit as well as cross-sectional and longitudinal research
UK HIV Drug Resistance Database	HIVDRD	Long term conditions	Medical Research Council Clinical Trials Unit Laboratories performing resistance tests, links with clinical sites	Tests for resistance to HIV drugs.	UK HIV Drug Resistance Database	Whole of UK	Jonathan Crofts	hivrd@ctu.mrc.ac.uk	020 7670 4748	Tests for resistance to HIV drugs.
UK National Neuromuscular Database	NaND	Long term conditions	MRC Centre for Neuromuscular Diseases	Children and adults with neuromuscular disease. Currently hosts longitudinal clinical information for Duchenne muscular dystrophy and spinal muscular atrophy. Modules for inclusion body myositis and congenital muscular dystrophies and congenital myopathies currently in development.	https secure site, accessible to participating clinical centres	National	Elaine Scott	elaines@muscular-dystrophy.org	07795 227 170	Children and adults with neuromuscular disease. Currently hosts longitudinal clinical information for Duchenne muscular dystrophy and spinal muscular atrophy. Modules for inclusion body myositis and congenital muscular dystrophies and congenital myopathies currently in development.
UK Register of HIV Seroconverters		Long term conditions	Medical Research Council HIV clinics across UK	Individuals with HIV whose date of infection is (approximately) known (consented, so may be considered research).	MRC Clinical Trials Unit UK Register of HIV Seroconverters	National	Dr Kholoud Porter	ukregister@ctu.mrc.ac.uk		Individuals with HIV whose date of infection is (approximately) known (consented, so may be considered research).
Unique Database		Long term conditions	Unique (The Rare Chromosome Disorder Support Group)	Rare chromosome disorders/pathogenic copy number variants.	Unique Rare Chromosome Disorder Support Group	National	Beverly Searle PhD	info@rarechromo.org	01883 330 766	Rare chromosome disorders/pathogenic copy number variants.
Yorkshire Register of Diabetes in Children and Young People	YRDCYP	Long term conditions	University of Leeds		The Yorkshire Specialist Register of Cancer in Children and Young People University of Leeds	Regional - Yorkshire and Humber SHA	Dr Roger Parslow Carolyn Stephenson	r.c.parslow@leeds.ac.uk c.r.stephenson@leeds.ac.uk	0113 3434856 0113 3434957	

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National Ophthalmology Database	NOD	Ophthalmology	Royal College of Ophthalmologists	The whole of hospital clinical ophthalmology but concentrating initially on cataract, diabetic retinopathy, glaucoma, age-related macular degeneration and vitreoretinal surgery. Pseudoanonymised data are remotely extracted from electronic medical record systems (ECR) that collect nationally agreed datasets for different disease pathways within ophthalmology. As of July 2011, 31 NHS Trusts have contributed data.	https://nod.nhs.uk Note: only available from an N3 connected computer and in beta test version at present - July 2011	National	Rob Johnston	rob.johnston@glos.nhs.uk	08454 222529

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Early Rheumatoid Arthritis Network		Orthopaedic	St Albans City Hospital	Rheumatoid Arthritis.		England: St Albans, Hereford, London, Basingstoke, Nottingham, Aylesbury, Stoke-on-Trent, Christchurch, Bristol, Yeovil, Weston-Super-Mare, Oxford, Lancaster. Wales: Haverfordwest Republic of Ireland: County Waterford	Dr Adam Young	marie.hunt@whht.nhs.uk	01727 897 362
National Spinal Cord Injury Database		Orthopaedic			The National Spinal Cord Injury Database	Tba			
Temporomandibular joint prosthesis national registration		Orthopaedic	British Association of Oral and Maxillofacial Surgeons	Temporomandibular joint prosthesis (partial/complete)		Whole of UK	Professor Simon N Rogers	snrogers@doctors.org.uk	07721 459840

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All Wales Perinatal Survey	AWPS	Perinatal, Neonatal, Children	Welsh Government Public Health Wales Cardiff University	Perinatal survey of deaths of babies in Wales from 20 weeks gestation to one year of age and includes: - fetal losses of 20 completed weeks of gestation or more (including therapeutic abortions) - still births - early and late neonatal deaths; and - post naeonatal deaths	All Wales Perinatal Survey	Wales	Sailesh Kotecha	kotechas@cardiff.ac.uk	029 2074 4499
British Paediatric Surveillance Unit (on behalf of its surveillance projects)	BPSU	Perinatal, Neonatal, Children	Royal College of Paediatrics and Child Health		British Paediatric Surveillance Unit	Tba	Richard Lynn (Scientific Coordinator) Helen Friend (Research Facilitator)	Richard.Lynn@rcpch.ac.uk Helen.Friend@rcpch.ac.uk	020 7092 6174
Child and Adolescent Psychiatry Surveillance System	CAPSS	Perinatal, Neonatal, Children	Royal College of Psychiatrists (RCPsych)			Tba	Alan Quirk	aquirk@cru.rcpsych.ac.uk	020 7977 6648
Collaborative HIV Paediatric Study	CHIPS	Perinatal, Neonatal, Children			The Collaborative HIV Paediatric Study	Tba	Mike Sharland (Chair)	chips@ctu.mrc.ac.uk	020 7670 4784
Congenital Anomaly Register & Information Service for Wales	CARIS	Perinatal, Neonatal, Children	Public Health Wales NHS Trust Welsh Local Health Boards: Abertawe Bro Morgannwg University Health Board Aneurin Bevan Health Board Betsi Cadwaladr University Health Board Cardiff & Vale University Health Board Cwm Taf Health Board Hywel Dda Health Board Powys Teaching Health Board	Congenital anomalies, Birth defects, Metabolic diseases, Hereditary diseases, Antenatal detection, Down Screening, Pharmico-vigilance, Screening for Bowel cancer.	Congenital Anomaly Register & Information Service	National - Wales	David Tucker	david.tucker2@wales.nhs.uk	01792 285 241
Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire	CAROB	Perinatal, Neonatal, Children	National Perinatal Epidemiology Unit	Congenital anomalies.	Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire	Oxfordshire, Berkshire and Buckinghamshire	Cath Rounding	Catherine.rounding@npeu.ox.ac.uk	01865 289721
CRANE Database	CRANE	Perinatal, Neonatal, Children	Royal College of Surgeons	Cleft lip and Palate.	The Royal College of Surgeons of England CRANE Database	England Wales Northern Ireland Jersey, Guernsey, Isle of Man	Jackie Horrocks	crane@rcseng.ac.uk	020 7869 6610
National Study of HIV in Pregnancy and Childhood	NSHPC	Perinatal, Neonatal, Children	UCL Institute of Child Health	Register of diagnosed HIV infection in pregnant women, monitoring of health of infected children and children born to infected mothers.	National Study of HIV in Pregnancy and Childhood (NSHPC)	Whole of UK Jersey, Guernsey Republic of Ireland	Janet Masters	nshpc@ich.ucl.ac.uk	020 7905 2815

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
North of England Collaborative Cerebral Palsy Survey	NECCPS	Perinatal, Neonatal, Children	Regional Maternity Survey Office North East Public Health Observatory	Children and young people with cerebral palsy	http://www.nepho.org.uk/rmso/ http://www.ncl.ac.uk/ihs/people/profile/m.p.ward-platt	North East England and North Cumbria	Mary Bythell	info@rmso.org.uk	0191 233 1658
Northern Congenital Abnormality Survey	NorCAS	Perinatal, Neonatal, Children	Regional Maternity Survey Office North East Public Health Observatory	Database of all structural and chromosomal anomalies diagnosed antenatally or in children up to the age of twelve for mothers resident in the North East and North Cumbria at the time of pregnancy. Data collection since 1985.	www.rmso.org.uk http://www.ncl.ac.uk/ihs/people/profile/m.p.ward-platt	North East England and North Cumbria	Mary Bythell	info@rmso.org.uk	0191 233 1658
Northern Survey of Diabetes in Pregnancy	NorDIP	Perinatal, Neonatal, Children	Regional Maternity Survey Office North East Public Health Observatory	Pregnancy outcomes for all women with pre-existing type 1 and 2 diabetes in the North East and North Cumbria. Data collection since 1994.	Regional Maternity Survey Office	North East England and North Cumbria	Mary Bythell	info@rmso.org.uk	0191 233 1658
Northern Survey of Twins and Multiple Pregnancy	NorSTAMP	Perinatal, Neonatal, Children	Regional Maternity Survey Office North East Public Health Observatory	Pregnancy outcomes for all twin and higher multiple pregnancies in the North East and North Cumbria. Data collection since 1998.	http://www.nepho.org.uk/rmso/ http://www.ncl.ac.uk/ihs/people/profile/m.p.ward-platt	North East England and North Cumbria	Mary Bythell	info@rmso.org.uk	0191 233 1658
Paediatric Intensive Care Audit Network	PICANet	Perinatal, Neonatal, Children	Universities of Leeds and Leicester		Paediatric Intensive Care Audit Network		Roger Parslow (Leeds) Liz Draper (Leicester) Generic email to whole team	r.c.parslow@leeds.ac.uk msn@leicester.ac.uk picanet@leeds.ac.uk	0113 343 4856 0116 252 3200
Perinatal Mortality and Morbidity Survey	PMMS	Perinatal, Neonatal, Children	Regional Maternity Survey Office North East Public Health Observatory	Fetal losses from 20 weeks gestation, stillbirths, neonatal and infant deaths. Data collection since 1981.	Regional Maternity Survey Office	North East England and North Cumbria	Mary Bythell	info@rmso.org.uk	0191 233 1658
Standardised Electronic Neonatal Database	SEND	Perinatal, Neonatal, Children	Development and Benchmarking: Neonatal Data Analysis Unit (an independent academic unit based at the Chelsea & Westminster campus of Imperial College London) Local Management by: Medway Maritime Hospital NHS Foundation Trust	Neonatal admissions	NHS Standardised Electronic	Whole of UK, Jersey, Guernsey, Isle of Man	Dr Ghada Ramadan	Ghada.Ramadan@medway.nhs.uk	01634 825 146
The East Midlands and South Yorkshire Congenital Anomalies Register	EMSYCAR	Perinatal, Neonatal, Children	University of Leicester	Congenital Anomalies – structural, genetic, chromosome, endocrine, metabolic – diagnosed antenatally and postnatally up to the age of 16 yrs.	East Midlands & South Yorkshire Congenital Anomalies Register	East Midlands South Yorkshire	Dr Judith Budd	jlsb1@le.ac.uk	0116 252 3210

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
The Neonatal Survey	TNS	Perinatal, Neonatal, Children		For the year June 2011-May 2012 The Neonatal Survey is part of the EU FP7 funded EPICE study which covers regions in: Belgium, France, Denmark, Poland, Portugal, Netherlands, Germany, Italy, Sweden and UK For further details please see http://www.epiceproject.eu/	TNS The Neonatal Survey	Regional - East Midlands and Yorkshire For the year June 2011-May 2012 The Neonatal Survey is part of the EU FP7 funded EPICE study which covers regions in: Belgium, France, Denmark, Poland, Portugal, Netherlands, Germany, Italy, Sweden and UK	Prof E S Draper Prof D J Field	msn@le.ac.uk df63@le.ac.uk	0116 252 3200
UK TOBY Cooling Register		Perinatal, Neonatal, Children	National Perinatal Epidemiology Unit	Moderate hypothermia for the treatment of perinatal ischaemic encephalopathy in term babies.	UK TOBY Cooling Register	Whole of UK Crown Dependencies: Jersey / Guernsey / Isle of Man Republic of Ireland	Prof Denis Azzopardi Brenda Strohm	tobyregister@npeu.ox.ac.uk	01865 289735
Wessex Antenatally Detected Anomalies Register	WANDA	Perinatal, Neonatal, Children	Wessex Clinical Genetics Service	Congenital anomalies.		Some of England Jersey, Guernsey	Dr Diana Wellesley	dgw@soton.ac.uk	02380 796167
Yorkshire and Humber Congenital Anomalies Register		Perinatal, Neonatal, Children	University of Leeds	All congenital anomalies detected antenatally and postnatally in Yorkshire and Humber SHA.	Yorkshire and Humber Congenital Anomalies Register	Regional - Yorkshire and Humber SHA	Dr Roger Parslow Dr Catherine Whibley	r.c.parslow@leeds.ac.uk c.whibley@leeds.ac.uk	0113 3434856 0113 3439160

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Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
Hip Fracture Perioperative Network		Trauma		Hip fracture anaesthesia.	NHS Networks Hip Fracture Perioperative Network	Whole of UK Jersey, Guernsey, Isle of Man plus members from Australia and Canada	Dr Richard Griffiths	richard@wothorpe.com	
International Burn Injury Database	IBID	Trauma	National Network for Burn Care	The Database collects a comprehensive dataset on individual cases of burn injury severe enough to require treatment by specialised burn care services within the British Isles.	The International Burn Injury Database	England Wales Has capacity to cover the whole of the British Isles	Ken Dunn	ken.dunn@uhsm.nhs.uk	0161 291 6323
Trauma Audit and Research Network	TARN	Trauma			Trauma Audit & Research Network	Tba		support@tarn.ac.uk	0161 206 4397

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Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
Bawtry Computer Services System for Cochlear Implant Centres		OTHER	Cochlear Implant Programme at Great Ormond Street Hospital	Register and record of assessment and treatment of patients receiving cochlear implants.	Bawtry Computer Services	National	Ann Robbins	ann@bawtry.net	01302 710 969
British Thoracic Society Interstitial Lung Disease Registry	BTS-ILD	OTHER	British Thoracic Society	Interstitial Lung disease: including idiopathic pulmonary fibrosis and sarcoidosis.		Whole of UK Jersey, Guernsey, Isle of Man	Sally Welham	sally.welham@brit-thoracic.org.uk	020 7831 8778
Cardiff Study of All Wales & North West of England Twins	CaStANET	OTHER	Faculty of General Dental Practice (UK) British Association of Oral and Maxillofacial Surgeons		Cardiff University School of Medicine	Regional			
Clinical Database for Cluster Headache		OTHER	British Association for the Study of Headache (BASH)	Cluster headache	British Association for the Study of Headache	Whole of UK	Stuart Weatherby	stuartweatherby@nhs.net	0845 155 8155
Einstein Secure Individual Patient Placements Database		OTHER	Tba	Tba	Tba	Tba	Tba		
Epidural Audit System	EAS	OTHER	Barnsley Hospital NHSFT	Elective and Emergency Obstetric Anaesthesia and Analgesia		Barnsley and bordering areas: Rotherham, Huddersfield, Doncaster, Wakefield, Sheffield	Deepa Kurup	deepa.kurup@nhs.net	01226 73000 Bleep 704
General Practice Research Database	GPRD	OTHER	Medicines and Healthcare products Regulatory Agency	All coded and textual Data from 8% of UK wide primary care practices downloaded since 1987 to present, on a monthly "delta" basis. (600 practices, 5+ million, live, active patients) There are over 200 peer reviewed publications on data quality and the dataset undergoes extensive quality assurance prior to research use. The GP data is uniquely linked on a permanent basis to Hospital Episode Statistics; Central mortality data; Census data; Cancer registry data; The Myocardial Infarction Database; Air-pollution data. The database is also used for pragmatic point of care clinical trials and genetic sample collections. Over 150 research studies are undertaken using GPRD data every year. GPRD has contracts with most major global pharma, many academic and regulatory groups.	The General Practice Research Database	Whole of UK, Jersey, Guernsey, Isle of Man. Access to data from a range of European countries. Access to data from the USA.	Dr John Parkinson	john.parkinson@mhra.gsi.gov.uk	
Inferior Vena Cava filter Registry	IVC	OTHER	British Society of Interventional Radiology		Dendrite Clinical Systems Ltd	Whole of UK Open to Jersey, Guernsey, Isle of Man (may not currently contain entries) Republic of Ireland Open to Australia, New Zealand - may not currently contain entries)	Maira Ritchie	moira.ritchie@bsir.org	0141 942 6744

Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
National Reporting and Learning System	NRLS	OTHER	National Patient Safety Agency	Patient safety incidents and near misses	National Patient Safety Agency	England Wales	Marcos Manhaes	Marcos.Manhaes@npsa.nhs.uk	020 7927 9199

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Current funded audit	Register Name	Acronym	Category	Lead Organisation	Subject	Website	Geographical Coverage	Contact	Email	Telephone
Audit	Adult Coronary Intervention Database		Cardiovascular disease	Society for Cardiothoracic Surgery in Great Britain & Ireland	All patients receiving non-surgical coronary interventions.	British Cardiovascular Intervention Society	Whole of UK	Dr A D Cunningham	david.cunningham@ucl.ac.uk	07753 682686
Audit	Adult Cardiac Surgery Database		Cardiovascular disease	NICOR, University College London			Whole of UK	Dr A D Cunningham	david.cunningham@ucl.ac.uk	07753 682686
Audit	Congenital Cardiac Surgery Database		Cardiovascular disease	NHS Information Centre - Central Cardiac Audit Database (CCAD)	All patients with congenital heart disease who receive surgical or interventional procedures.		Whole of UK	Dr A D Cunningham	david.cunningham@ucl.ac.uk	07753 682686
Audit	Congenital Central Cardiac Audit Database	CCAD	Cardiovascular disease	British Congenital Cardiac Association Society of Cardiothoracic Surgery in Great Britain & Ireland National Institute of Cardiovascular Outcomes Research	Outcomes of surgery and therapeutic catheterisation in children and adults with congenital heart disease.	The Information Centre CCAD Congenital Heart Disease Website	Tba	Dr John Gibbs	jljgibbs@mac.com	0113 3925757
Audit	Cardiac Rhythm Management - National Pacemaker and Implantable Cardioverter-Defibrillator (ICD) Database - National Cardiac Ablation Database		Cardiovascular disease	Central Cardiac Audit Database	- Patients receiving cardiac rhythm management devices for cardiac rhythm disorders. - Patients receiving definitive curative interventions for cardiac rhythm disorders.		Whole of UK Jersey, Guernsey, Isle of Man	Dr A D Cunningham	david.cunningham@ucl.ac.uk	07753 682686
Audit	National Neonatal Audit Programme Dataset vs National Neonatal Data Analysis Unit Database	NDAU	Children	Imperial College London Royal College of Paediatrics & Child Health (NNAP)		http://www1.imperial.ac.uk/departmentofmedicine/divisions/infectiousdiseases/paediatrics/neonatalmedicine/ndau/	Tba	Richard Colquhoun, NDAU first point of contact Kim Davis, NNAP Project Co-ordinator Dr Mike Watkinson, Project Clinical Lead Eugene Statnikov, NDAU Data Manager	rachel.thompson@imperial.ac.uk	020 8746 5841 020 7092 6168