Patient Research Cohorts Initiative

The Patient Research Cohorts Initiative is a joint initiative, funded by the MRC, the National Institute for Health Research (NIHR) in England, the Wales Office of Research and Development and the Chief Scientist Office of the Scottish Government Health Directorates. More than seven million pounds in funding has been awarded to researchers to create small, extensively defined groups of patients to help detect, treat or prevent disease.

This page provides an overview of each funded cohort linked to full details. This is intended to allow researchers to perform a preliminary assessment of whether a particular cohort would meet their needs.

Summary of the Cohorts (click on link for full details)

**Title:** A Population-based Ankylosing Spondylitis [PAS] cohort  
**Contact/website:** PAS administrator Liz Irvine e.m.irvine@abertawe.ac.uk  
Study website http://www.ashealth.co.uk/  
HIRU website: Information about HIRU  
**Principal investigator:** Dr Stefan Siebert, Swansea University  
**Disease:** Ankylosing Spondylitis  
**Patients available:** Yes

**Title:** Bipolar II Disorder  
**Contact/website:** Professor I N Ferrier, i.n.ferrier@newcastle.ac.uk  
Website: http://research.ncl.ac.uk/theabcstudy  
**Principal investigator:** Professor Ian Ferrier, Newcastle University  
**Disease:** Bipolar II disorder  
**Inclusion/exclusion criteria:** Bipolar-II Disorder phenotype as defined by the Diagnostic and Statistical Manual-IV  
**Patients available:** Yes

**Title:** Characterisation of the United Kingdom thrombotic thrombocytopenic purpura (TTP) patient cohort  
**Contact/website:** Dr Marie Sculley, m.scully@ucl.ac.uk  
**Principal investigator:** Dr Marie Scully, UCLH NHS Trust  
**Disease:** Thrombotic thrombocytopenic purpura  
**Inclusion/exclusion criteria:** To be confirmed  
**Patients available:** Yes
Title: **The London COPD exacerbation cohort (The EXCEL Cohort)**

**Contact/website:** Professor Wisia Wedzicha, j.a.wedzicha@medsch.ucl.ac.uk
0207 3177517

**Principal investigator:** Professor Jadwiga Wedzicha, University College London

**Disease:** Chronic obstructive pulmonary disease

**Inclusion/exclusion criteria:** FEV1<80% predicted for a period of 3 years

**Patients available:** Yes

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Title: **The MRC Centre for Translational Research in Neuromuscular Disease Mitochondrial Disease Patient Cohort (UK)**

**Contact/website:** Professor Doug Turnbull, d.m.turnbull@ncl.ac.uk, 0191 222 8565
Dr Robert McFarland, robert.mcfarland@ncl.ac.uk 0191 222 8233

**Principal investigator:** Professor Douglass Turnbull, Newcastle University

**Disease:** Mitochondrial disease

**Inclusion/exclusion criteria:** mitochondrial disease based on phenotype and/or genotype with equal numbers of males and females. Symptomatic patients with a clinical diagnosis of mitochondrial disease, based on history, examination, muscle histochemistry and/or biochemistry and/or genetic diagnosis and asymptomatic relatives of index cases who wish to be tested. The cohort will be subdivided into specific genotypes and/or phenotypes.

**Patients available:** Yes

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Title: **The Paediatric-Onset Inflammatory Bowel Disease Cohort and Treatment Study (PICTS)**

**Contact/website:** Dr D Wilson, D.C.Wilson@ed.ac.uk

**Principal investigator:** Dr David Wilson, University of Edinburgh

**Disease:** Inflammatory Bowel disease

**Inclusion/exclusion criteria:** Age 0 to 18

**Patients available:** Yes

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Title: **Pathobiology of Early Arthritis Cohort (PEAC)**

**Contact/website:** Professor Costantino Pitzalis, c.pitzalis@qmul.ac.uk
Website: [http://www.peac-mrc.mds.qmul.ac.uk](http://www.peac-mrc.mds.qmul.ac.uk)

**Principal investigator:** Professor Costantino Pitzalis, William Harvey Research Institute

**Disease:** Arthritis

**Inclusion/exclusion criteria:** Early symptomatic inflammatory arthritis: Adults over 18, with at least one swollen joint, with evidence of active arthritis shown by Disease Activity Scores for 28 joints (DAS-28) over 2.6, and who are able and willing to give informed consent. Patients in whom biopsy is contra-indicated
(e.g. taking anticoagulants), or who have a serious underlying medical disorder (e.g. end stage renal disease) will be excluded.

**Patients available:** Yes

**Title:** Rapidly evolving multiple sclerosis: opening the window of therapeutic opportunity

**Contact/website:** Dr Paolo Muraro, p.muraro@imperial.ac.uk, 020 7594 6670
Research Nurse: Mr Julius Labao, j.labao@imperial.ac.uk, Telephone: 075 319 40601

Web site (aimed at candidate patients):
http://www1.imperial.ac.uk/departmentofmedicine/divisions/experimentalmedicine/neurosciences/mosaic/clinical_trials/

**Principal investigator:** Dr Paolo A Muraro, Imperial College London

**Disease:** Multiple sclerosis

**Inclusion/exclusion criteria:** Age 18-60; Diagnosis of MS according to McDonald’s criteria; Relapsing-remitting or secondary progressive MS; Disease duration ≤10 years; Expanded disability status scale (EDSS) score 2.0 to 6.0 at screening evaluation; Two clinical exacerbations in the previous year; OR: one clinical exacerbation AND sustained increase in EDSS of at least 1 point in the past year while on immunomodulatory treatment (IFN-β or GA) for at least 6 months; or not tolerating immunomodulatory treatment and meeting all other criteria.

**Patients available:** Yes

**Title:** Type 2 diabetes in childhood: building a platform to support novel intervention strategies

**Contact/website:** Prof Timothy Barrett t.g.barrett@bham.ac.uk
Website www.jump.bham.ac.uk

Applications to use the cohort are made through The Diabetes, Endocrinology and Metabolism Clinical Studies Group (CSG) of The Medicines for Children Research Network, www.mcrn.org.uk or email Professor David Dunger dbd25@cam.ac.uk as head of the Diabetes CSG for academic studies or industry@mcrn.org.uk for industry studies.

**Principal investigator:** Professor Timothy Barrett, University of Birmingham

**Disease:** Type 2 diabetes

**Inclusion/exclusion criteria:** Childhood type 2 diabetes. Exclusion Criteria: Diabetic Ketoacidosis at any time after diagnosis; Use of inhaled glucocorticoids at a dose above 1000 micrograms fluticasone or equivalent; or use of oral glucocorticoids; Genetic syndrome or disorder known to affect glucose; Haemoglobinopathy affecting HbA1c value; Pregnancy; Maturity Onset Diabetes of the Young confirmed by identification of genetic mutation; Other significant organ system illness e.g. psychiatric.

**Patients available:** Yes

**Title:** United Kingdom Primary Sjogren’s Syndrome Registry (UKPSSR)

**Contact/website:** Dr. Wan-Fai Ng, chief investigator Wan-Fai.Ng@ncl.ac.uk
Website www.sjogrensregistry.org

**Principal investigator:** Dr Wan Fai Ng, Newcastle University  
**Disease:** Sjögren’s Syndrome  
**Inclusion/exclusion criteria:** Adult  
**Patients available:** Yes  

**Title:** Wessex severe asthma cohort  
**Contact/website:** Dr P Howarth, University of Southampton  
(P.H.Howarth@soton.ac.uk)  
**Principal investigator:** Dr Peter Hugo Howarth, University of Southampton  
**Disease:** Asthma  
**Inclusion/exclusion criteria:** Age 18-70, severe asthma  
**Patients available:** Yes  

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**Full Cohort Details**

**The Population-based Ankylosing Spondylitis (PAS) cohort**  
Chief Investigator: Dr Stefan Siebert, s.siebert@swansea.ac.uk  
Swansea University has recruited a cohort of people with Ankylosing Spondylitis (AS) throughout Wales who are tracked longitudinally through a combination of patient-completed questionnaires and linkage of routine NHS data. The cohort consists of a traditional, consented cohort, who complete regular online or paper-based questionnaires regarding their health, embedded within a larger, population-based, anonymised e-cohort of patients with AS in Wales (for information about methods see: Atkinson, *BMC Musculoskelet Disord* 2010;11). This approach will help ensure the cohort is representative of people with this condition and can be used to evaluate issues that are difficult to assess using traditional means, including long-term follow-up of natural history, outcomes and NHS resource utilisation. Completed questionnaires to date have included fatigue, flares, health economics, work, information needs and exercise, in addition to regularly completed questions about disease activity. Future aims include characterising this cohort further using radiology and biomarkers, as well as setting up similar cohorts for other chronic conditions.  
Enquiries about research collaboration in PAS are welcomed from industry and academic institutions. The Health Informatics Research Unit (HIRU), Swansea University utilises on-site High Performance Computing infrastructure overlaid with innovative data extraction and transportation technologies. Access to data is available through the existing governance arrangements for the SAIL databank in the Health Informatics Research Unit (HIRU), Swansea University.  

**Key contacts:**  
PAS administrator: Liz Irvine e.m.irvine@abertawe.ac.uk  
Study website (aimed at AS patients): http://www.ashealth.co.uk/  
HIRU website: Information about HIRU
ABC Study - A Bipolar Cohort
Chief Investigator: Professor I N Ferrier, University of Newcastle (i.n.ferrier@newcastle.ac.uk)

With MRC funding, researchers at Newcastle University have established a clinical cohort of 180 patients with a DSM IV diagnosis of Bipolar II. About 20% of cases are newly diagnosed through screening in Primary care. The cohort is very well characterised, including 3-months prospective daily mood monitoring and regular systematic follow-ups incorporating the Longitudinal Interview Follow-up Evaluation (LIFE-II) plus social and functional measures.

A Cohort Advisory Group (CAG), which includes academics, service users and representatives of Bipolar advocacy groups and industry approves access to the cohort for research purposes. The CAG scrutinises and prioritises applications for ethically-approved projects: these include multi-centre studies such as the MRC funded CEQUEL Study and Cardiff University’s BDRN Study of genome wide association screening in Bipolar Disorder, as well as projects by local research groups including user-led studies and the sharing of data with some European bipolar research networks. Clients in the Cohort are informed by letter about studies that are approved by the CAG and are invited to choose up to two projects that they would like to participate in at any one time. Upon completion of currently approved projects, the CAG will invite a further round of research applications. In the first instance those interested in accessing the Cohort should contact Professor I N Ferrier, Chief Investigator (i.n.ferrier@newcastle.ac.uk), but may also contact one of the other Principal Investigators if appropriate, Professor Jan Scott (jan.scott@newcastle.ac.uk), Professor Heinz Grunze (heinz.grunze@newcastle.ac.uk) or Dr Thomas Meyer (thomas.meyer@newcastle.ac.uk).

Further information can also be obtained at our website: http://research.ncl.ac.uk/theabcstudy

The UK (Thrombotic Thrombocytopenic Purpura) TTP Registry
Chief Investigator: Dr Marie Sculley, m.scully@ucl.ac.uk

Thrombotic Thrombocytopenic Purpura is an acute life threatening disorder, reportedly affecting 4-6 per million of the population and a mortality of 20%. The UK TTP registry is a national database of patients and a central site to undertake assays (ADAMTS 13 activity and antibody titres). It provides a UK wide service to correctly identify the patient subtype, the true incidence and prevalence of TTP and important epidemiological and scientific information, furthering the understanding of the pathophysiology of this disease and other thrombotic microangiopathies. The registry has collected a DNA bank of all consented cases. The benefit of treatments used in patients can be reviewed and newer treatments can be trialled in a multicentre approach. Secondary precipitating causes of TTP are less common. Larger patient numbers, available from the registry will provide a greater insight into reasons these patients develop TTP and response to treatments. The large number of samples generated from the registry can be used in conjunction with and aid in the understanding of other thrombotic/multisystem disorders.

The registry, funded by the MRC, started 1ST January 2009, at the Haemostasis Research Unit, UCL, London, UK. Over one hundred new acute TTP episodes have been documented per year.

Contacts:
Chief Investigator: Dr Marie Scully (m.scully@ucl.ac.uk) Tel: 0207 025 7970)
THE LONDON COPD EXACERBATION COHORT (EXECL COHORT)
Chief Investigator: Professor Wisia Wedzicha (j.a.wedzicha@medsch.ucl.ac.uk)

This cohort is specifically designed for the study of exacerbations of chronic obstructive pulmonary disease (COPD) that are a major cause of morbidity, mortality and hospital admission. Utilisation of the cohort will allow study of the actual exacerbation and also interventions for prevention of exacerbations. The cohort has been the subject of many publications since 1998 on topics relating to COPD exacerbations.

The cohort is based in UCL Medical School at the Royal Free Campus. We currently have 200 COPD patients included and the target is around 250 patients to be reached end of 2011. Patients are well phenotyped for lung function, healthstatus, exacerbation frequency, airway infection, CT scans and co-morbidity. Patients are trained to report exacerbations to the study team and complete daily diary cards for symptom changes to carefully monitor events. Thus we have both frequent and infrequent exacerbators included in the cohort and representative of the population. We are also performing some novel exacerbation questionnaires. We also have long term follow up on many of the patients (over 5 years) and can respond to specific questions about for example onset or recovery of exacerbations. We have excellent laboratory support in our department and an adjacent clinical trials are specific for the cohort.

The key staff are:
Professor Wisia Wedzicha
Dr Gavin Donaldson
Dr John Hurst

For enquiries about the cohort, please contact Professor Wisia Wedzicha on j.a.wedzicha@medsch.ucl.ac.uk and phone 0207 3177517

The MRC Centre for Translational Research in Neuromuscular Disease - Mitochondrial Disease Patient Cohort (UK)

Chief investigator: Professor Douglas Turnbull, University of Newcastle

The mitochondrial disease cohort comprises symptomatic adults and children in whom a mitochondrial disease phenotype and where possible genotype, have been confirmed and characterized. Asymptomatic individuals who have requested genotyping (and proved positive) are also included. There are several aims driving the development of this cohort:

1. To assess the acceptability and efficacy of potential disease-modifying drugs and novel interventional therapies.
2. To assess the impact of pharmacological and physiological interventions on long-term mitochondrial disease progression.
3. To evaluate and optimize current management strategies and provide evidence-based clinical guidelines.
4. To perform a detailed analysis of genotype-phenotype correlations and the role of physiological, environmental and genetic factors in mitochondrial disease expression and progression.

The mitochondrial disease cohort offers an opportunity, currently not available anywhere else in the world, to assess the clinical benefit of pharmaceutical and physiological interventions in a fully characterized group of mitochondrial disease patients. Applications for access to the cohort are welcomed and should be directed to Dr Robert McFarland, Chair of the Mitochondrial Disease Patient Cohort Oversight Committee. Further information on mitochondrial diseases is available at www.mitochondrialncg.nhs.uk.

Contacts:

<table>
<thead>
<tr>
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<td>4th Floor Cookson Building</td>
<td>Tel: 0191 222 8565</td>
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<tr>
<td>The Medical School</td>
<td>Dr Robert McFarland (<a href="mailto:robert.mcfarland@ncl.ac.uk">robert.mcfarland@ncl.ac.uk</a>)</td>
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<td>Newcastle University</td>
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| London                         | Professor Michael Hanna ([mhanna@ion.ucl.ac.uk](mailto:mhanna@ion.ucl.ac.uk)) |
| MRC Centre for Neuromuscular    | Tel: 0207 837 3611 ext 3014                                                    |
| Diseases                       | Dr Rob Pitceathly ([rpitceat@ion.ucl.ac.uk](mailto:rpitceat@ion.ucl.ac.uk))   |
| National Hospital for Neurology| Tel: 0845 155 5000 ext. 3028                                                   |
| and Neurosurgery               | Dr Shamima Rahman ([s.rahman@ich.ucl.ac.uk](mailto:s.rahman@ich.ucl.ac.uk))   |
| 8-11 Queen Square              | Tel: 0207 4059200 ext 8519                                                    |
| London, WC1N 3BG               |                                                                                  |

| Oxford                         | Professor Joanna Poulton ([joanna.poulton@obsgyn.ox.ac.uk](mailto:joanna.poulton@obsgyn.ox.ac.uk)) |
| Nuffield Dept Obstetrics and   | Tel: 01865 221007 (221067 direct)                                             |
| Gynaecology                    | Ms Julie Phipps ([Julie.Phipps@orh.nhs.uk](mailto:Julie.Phipps@orh.nhs.uk))    |
| John Radcliffe Hospital        | Tel: 01865 226015                                                               |
| Headington                     |                                                                                  |
| Oxford, OX3 9DU                |                                                                                  |

**The Paediatric-Onset Inflammatory Bowel Disease Cohort and Treatment Study (PICTS)**

Chief Investigator: Dr D Wilson, University of Edinburgh ([D.C.Wilson@ed.ac.uk](mailto:D.C.Wilson@ed.ac.uk))
This project will focus on the consolidation and expansion of a proven, scientifically important cohort of Scottish patients with childhood-onset inflammatory bowel disease (IBD). Scottish families with IBD strongly support this research, with over 450 cases in the cohort to date, all with comprehensive phenotypic description and extensive genetic analysis. Expansion will allow a near-complete ascertainment of cases of IBD diagnosed 16 years of age in Scotland, provide a complete geographical spread throughout Scotland, and expand numbers in the rarer subtypes of IBD. Follow-up will allow characterisation of disease progression, natural history, responsiveness to therapy, and of pathogenetic factors.

SUCCESS OF COHORT TO DATE:

- Enrollment of over 450 cases of childhood-onset IBD in Scotland
  - Built on epidemiological study of this population for more than 4 decades and genetic studies for the last 8 years
- Very high acceptance by children and families (99% recruitment in SE Scotland)
- Rigorous and extensive phenotypic characterisation of cohort
- Demonstration of extensive disease at childhood diagnosis and rapid progression in extent and disease behaviour
  - Demonstration of geographical and socio-economic variance in disease prevalence within Scotland
- High impact publications on paediatric phenotype and genotype-phenotype relationships
- Research group at international forefront of phenotypic and genotypic analysis of childhood-onset IBD
  - Close links with international groups with similar childhood-onset IBD cohorts, and also more widely in adult Gastroenterology
  - Development of paediatric clinician scientists with skills in translation medicine
- 500,000 SNP genetic profiling of 410 Scottish children with IBD available shortly

Pathobiology of Early Arthritis Cohort (PEAC)

Chief Investigator: Professor Costantino Pitzalis (c.pitzalis@qmul.ac.uk)

The Pathobiology of Early Arthritis Cohort (PEAC) is being established through the effort of a nationwide consortium with international support (details available: http://www.peac-mrc.mds.qmul.ac.uk). The main aim is to create an extensively phenotyped early inflammatory arthritis cohort of patients: target population 300- currently recruited 185.

This project will generate a unique bio-medical resource with high-density data including pathobiological blood and tissue characterization linked to state-of-the-art ultrasound imaging, and detailed clinical phenotyping. This resource will facilitate testing and generating hypotheses on the role of a spectrum of molecular and cellular pathways that may be involved in disease susceptibility, heterogeneity and treatment response.

The novel concept of PEAC is to match the synovial “pathotype” to clinical outcomes and response to therapy. It is hoped that this resource will represent a valuable tool in the identification and characterization of early biomarkers and, similarly to renal or cancer medicine, through tissue histopathology inform patient stratification into specific management algorithms.
Additionally, PEAC will constitute an ideal platform for innovative clinical trials of novel therapeutics in early proof of concept studies as well as in therapeutic strategies aimed at induction of remission both through academia and industry including:

- Arthritis Research UK Clinical Studies Groups
- OSCHR/ABPI Therapeutic Capability Cluster Initiative
- MRC/ABPI Inflammation & Immunology Initiative

Additionally, high level contacts are taking place directly between the PEAC Consortium and Industry including: Roche/Genentech, Pfizer, UCB and GSK.

Contacts
Professor Costantino Pitzalis (c.pitzalis@qmul.ac.uk)
William Harvey Research Institute
Barts and the London School of Medicine and Dentistry
Queen Mary University of London
Charterhouse Square
London EC1M 6BQ

Co-Investigators:
Prof C Buckley (University of Birmingham, c.d.buckley@bham.ac.uk)
Prof IB McInnes (University of Glasgow, IBM@clinmed.gla.ac.uk)
Prof PC Taylor (Imperial College, London, peter.c.taylor@imperial.ac.uk)
Dr E Choy (King’s College, London, ernest.choy@kcl.ac.uk)

Rapidly Evolving Multiple Sclerosis: Opening the Window of Therapeutic Opportunity

Chief Investigator: Dr Paulo Muraro

**Summary:** The overall goal of this observational study is to establish and utilise a research cohort of patients with rapidly evolving multiple sclerosis (MS). Patients with highly active relapsing-remitting or secondary progressive MS as defined per inclusion criteria are being recruited with target n = 200.

**Aims:** (1) To facilitate patient access to clinical trials or appropriate management for rapidly evolving MS (2) Access and utilization of cohort data (3) Development of bio-markers (4) Development of clinical prognostic markers.

**Progress:**
As of 15/01/2011, 81 patients were recruited and completed the screening visit; of them 59 (73%) have completed both study visits. Clinical phenotype data already available in the study database include Demographics, Age at Onset, Disease Duration, EDSS, MSFC, PASAT, Progression Index, Relapses in previous year, CSF Oligoclonal bands, and treatment history. Clinical laboratory data include full blood counts, serum chemistry, and systemic autoantibodies titres. All patients had a high-resolution 3T MRI of brain and c-spine without and with gadolinium, including MTR and DWI. An analysis of Immune biomarkers in blood cells was carried out by 4-colour FACS analysis in 24 tubes that allowed characterizing 58 immune cell subpopulations in each patient. Genetic studies of immune function genes polymorphisms have started on 44 patients’ DNA samples.

**Perspective:**
The Cohort is ideally suited to exploit the availability of well defined as well as more innovative phenotypic metrics and provides the opportunity to explore
relevant aspects of the disease process for the development of therapeutic targets and biomarkers.

Key contacts:
Principal Investigator: Dr Paolo Muraro
Email: p.muraro@imperial.ac.uk
Telephone: 020 7594 6670
Research Nurse: Mr Julius Labao
Email: j.labao@imperial.ac.uk
Telephone: 075 319 40601

Web site (aimed at candidate patients):
http://www1.imperial.ac.uk/departmentofmedicine/divisions/experimentalmedicine/neurosciences/mosaic/clinical_trials/

Type 2 diabetes in childhood
Chief investigator: Professor T Barrett, University of Birmingham (t.g.barrett@bham.ac.uk)

This is a UK national, prospective, cohort study of children and young people with type 2 diabetes (T2D) characterised by anthropometry, biomarkers, and co-morbidities; and in whom other diagnoses (such as type 1 diabetes, maturity onset diabetes of the young (MODY)) have been excluded. The tight clinical characterisation will allow inclusion of patients into studies of novel interventions in this group, including evaluation of both glycemic control and risk factors for cardiovascular disease; targeted interventions in small scale open label studies; and enrolment into multi-national clinical trials. The cohort is designed to encourage academic and industry collaboration for patient benefit.

The overall objective of this study is to characterise a cohort of children and young people with T2D. This will include baseline and repeat assessments over time of the anthropometric, cardiovascular, metabolic and psychological status of individuals with T2D in order to describe the natural history of T2D and related co-morbidities in a multiethnic cohort of UK children with the disease.

Progress: As of March 2011 there are 85 children in the cohort, from 36 NHS hospital sites across the UK. The cohort is currently being used for one commercial Phase II intervention study and one academic observational study.

Applications to use the cohort are made through The Diabetes, Endocrinology and Metabolism Clinical Studies Group (CSG) of The Medicines for Children Research Network www.mcrn.org.uk or email Professor David Dunger dbd25@cam.ac.uk as head of the Diabetes CSG for academic studies or industry@mcrn.org.uk for industry studies. Alternatively contact the Chief Investigator for the cohort, Prof Timothy Barrett on t.g.barrett@bham.ac.uk or visit our website at www.jump.bham.ac.uk

United Kingdom primary Sjögren’s syndrome Registry (UKPSSR)
Chief Investigator: Dr. Wan-Fai Ng (Wan-Fai.Ng@ncl.ac.uk)

UKPSSR is a patient cohort and research biobank of 500 patients with primary Sjögren’s syndrome (PSS) patients funded by the MRC. 500 age-, gender- and ethnicity-matched healthy controls are also being recruited.
Clinical data include demographics, disease activity and damage, patient-reported outcome measures, co-morbidity, treatment and quality of life using standardized instruments. Biological samples include DNA, RNA, serum and peripheral blood mononuclear cells.

The aims of the UKPSSR are to facilitate PSS research, foster research collaboration, raise the profile and improve public awareness of PSS.

As of Jan 2011, over 430 PSS patients from 21 UK hospitals have been included. Interim data analysis of the cohort is expected to be available in summer 2011. The cohort data and biological samples are available for research immediately. At present, there are seven scientific and clinical studies utilizing the cohort.

Research proposals for using the data and biological samples of the UKPSSR are welcome from academic institutions and industry in the UK and abroad. Generic research ethics approval has been granted for using the UKPSSR data and biological samples for research directly relevant to PSS. All proposals will be reviewed by the steering committee of the UKPSSR and decisions will be based on scientific merits and relevance to PSS. Informal discussion of the research or collaborative proposals is encouraged prior to submission.

For further information and application for utilizing the UKPSSR data and biological samples for research, please contact Dr. Wan-Fai Ng, chief investigator, at Wan-Fai.Ng@ncl.ac.uk or visit our website at www.sjogrensregistry.org

**Wessex severe asthma cohort**

Chief Investigator: Dr P Howarth, University of Southampton

(P.H.Howarth@soton.ac.uk)

This cohort of patients with persistent and severe asthma specifically responds to a significant unmet clinical need and is not duplicated within National Service Framework strategies or any Topic Specific Clinical Research Networks, as none exist for asthma. This will provide well characterised subjects that facilitate the proof of principle investigation of novel therapies with a sound rationale in this group of patients. The collection and characterisation of these patients reflects a strong partnership between NHS and academic respiratory physicians in Wessex and the close geographic localisation makes possible the potential conduct of sophisticated, mechanistic, translational, pharmacological studies that would not be possible in a widely disseminated cohort and for which Southampton has a proven track record.

Three hundred patients with asthma who, despite regular maintenance therapy at level 4 or level 5 of the British Thoracic Society asthma management guidelines, remain symptomatic and have unstable disease, in that they have a history of severe exacerbation necessitating a course of oral steroids or an increased in maintenance oral steroid dose, will be recruited. Characterisation, in addition to a detailed history which will include details of smoking habit and medication use, will consist of 1) patient centered questionnaires and diary card recording of upper and lower airway symptoms, to evaluate the impact of the disease on the individual, 2) physiological measures of lung function at home and in the laboratory before and after bronchodilator therapy, to assess lung function in relationship to the norm (predicted values), the natural diurnal variation and the short term pharmacological reversibility of any impairment, 3) biological sample collection to evaluate airway inflammation within the upper and lower airways and to store samples from induced sputum, nasal lavage, peripheral blood (serum
and plasma) and urine for subsequent biomarker evaluation, for which separate funding would need to be applied for. Additional assessments include documentation of atopic status, measurement of BMI and measurement of urinary cotinine to verify tobacco smoking history.

Dr Des Walsh

Desmond.walsh@headoffice.mrc.ac.uk

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