



News

from the NIHR Research Design
Service for the East Midlands

May 2011

A study into the prevalence of autistic spectrum conditions (ASC) in adults

Chief Investigator: Professor Terry Brugha
Department of Health Sciences,
University of Leicester

Funding stream: NHS Information Centre for Health and Social Care

Date of award: March 2010

Why are you doing this study?

In the 2010 National Autism Strategy, the Government highlighted the need to improve the lives of people with autistic spectrum conditions. To achieve this, we need to know the number of people who have autistic spectrum conditions in England.

Results from the Adult Psychiatric Morbidity Survey (APMS) of adults living in private households in England showed that 1 in 10 people had an autistic spectrum condition [1]. However, most people with learning disabilities could not have been included in the APMS survey because they either: (i) did not have sufficient verbal ability to take part in the interview or (ii) they were living in communal care establishments. Research indicates that people with learning disabilities are more likely to have autistic spectrum conditions than the general population, so it is important to capture information on this population.

The current study aims to look at adults with learning disabilities in private households and communal care establishments.

How are you doing this study?

We aim to recruit 500 adults with learning disabilities and their carers in this study. Our sample is drawn from three well-established learning disability case registers in Leicestershire, South London and Sheffield.

We are assessing all participants with a special tool called the Autism Diagnostic Observation Schedule (ADOS) Module 1, which is specifically designed for pre-verbal people. We are interviewing a random proportion (12%) of individuals' carers with an informant-rated interview called the Diagnostic Interview for Social and Communication Disorders (DISCO) as a validation of the ADOS.

What is your current progress?

We have recruited 226 adults from Leicestershire, 25 from Lambeth and are currently recruiting from Sheffield (mid-March).

Are there any things you have found particularly challenging?

Yes, ethics and R&D! Because we are dealing with a vulnerable population we have encountered a number of challenges on the way. For example, carers are understandably over-protective and an in-depth conversation is often required before consent can be obtained. Hopefully this is a learning experience, which will be valuable for future studies.

Did you receive any support from the Research Design Service (RDS)?

Yes, we received epidemiological and statistical support. Both Freya Tyrer (RDS Research Fellow in Epidemiology) and Nicky Spiers (RDS Research Fellow in Medical Statistics) were named on the bid and they are part of the research team.

Cited reference

[1] Brugha T, McManus S, Meltzer H at al. (2009). *Autism spectrum disorders in adults living in households throughout England. Report from the Adult Psychiatric Morbidity Survey 2007*. The NHS Information Centre for Health and Social Care, England.
http://www.ic.nhs.uk/webfiles/publications/mental%20health/mental%20health%20surveys/APMS_Autism_report_standard_20_OCT_09.pdf

Professor Terry Brugha



Patient and public involvement (PPI) in research, the journey: before, during and after

9.15am – 4.30pm on Wednesday 25th May 2011 at University of Leicester or 9.15am – 4.30pm on Wednesday 1st June 2011 at Centre for Health and Wellbeing Research University of Northampton

Details of the training event

PPI is an essential requirement in health research and funders now expect this aspect to be comprehensively addressed in research grant applications.

This educational event is targeted at NHS and academic health service researchers applying for national funding streams and will provide valuable guidance with illustrative examples of PPI at each stage of the research process:

- Developing the protocol
- Conducting the research
- Implementing the findings

There are only 70 places available, so please book early to avoid disappointment. Priority will be offered to researchers in Leicestershire, Northamptonshire and Rutland.

Learning outcomes – by the end of the day

1. Researchers will understand what *Leicestershire Northamptonshire and Rutland Research Engaging with Patients and Public (LNR REPP) is.
2. Researchers will understand more about free and paid local training and support available for PPI.
3. Researchers will understand what funders look for in bids in relation to PPI.
4. Researchers will see and hear of examples of good practice in PPI in different studies.
5. Researchers will learn how to disseminate and implement findings of research better.
6. Researchers will have an opportunity to network

To book, contact Lotus De Cort by email lfa1@le.ac.uk and ask for a booking form.

EU Register of clinical trials launched online

The European Medicines Agency has launched the online Clinical Trials register containing information about clinical trials authorised in the EU, whether they take place in one Member State or several. It includes clinical trials conducted by both industry and research institutions. The information is rendered public once the clinical trial has been authorised. The aim of this official public register is to make clinical research on pharmaceuticals more transparent for patients and others and to avoid unnecessary duplication of clinical trials.

Sponsors will provide and update the information in the register via the national competent authority (MHRA in the UK).

<https://www.clinicaltrialsregister.eu/>

*About LNR REPP

Leicestershire Northamptonshire and Rutland Research Engaging with Patients and Public (LNR REPP) is a newly established support structure that runs in the form of an alliance. LNR REPP is a partnership across many organisations in LNR. The partnership consists of around 45 organisations; some of which are funded by National Institute for Health Research (NIHR), the Universities and Hospitals as well as the voluntary sector.

The purpose of LNR REPP

To raise awareness of the importance and relevance and later the impact of PPI in research among the LNR research community and other stakeholders, including patients and carers.

To encourage LNR health care and academic groups, networks and organisations to embed meaningful and effective PPI in all aspects of their research.

To develop, promote and support increased PPI engagement across the LNR research community.

To work in partnership with research based PPI initiatives in LNR to enhance sharing of knowledge and experience.

To share examples of good practice in PPI in research with a view to learning in and beyond our locality, and applying this learning into research practice.

To work in partnership with research based PPI initiatives in LNR to enhance sharing of knowledge and experience.

First woman appointed as Chief Medical Officer for England

Professor Dame Sally Davies who was the Director-General for Research and Development was today named as the Chief Medical Officer (CMO) for England, the first woman to hold the post. The CMO is the Government's most senior medical advisor, responsible for providing expert advice on a wide range of issues relating to the health of the nation, including the handling of health related emergencies.

NIHR – Issue 3 of News from the Network published

News from the Network – the case study magazine of the National Institute for Health Research Clinical Research Network – is now available. In this issue you can find out why the Network remedy is the best prescription for a healthy study; read how the Medicines for Children Research Network has made a real difference to the routine vaccination programme for children in England and how the Clinical Research Network plans to improve the way that patients and the public are actively involved in research.

View interactive e-magazine with related video content (recommended) <http://digbig.com/5bdqtc> or view a PDF version (2Mb) <http://digbig.com/5bdqtg>



Guidance for researchers on how to obtain funding for excess treatment costs

In costing a research study researchers need to identify the category into which those costs fall. While the costs of the research itself will be the responsibility of the funding body, funding for all treatment costs associated with the project, including any excess element, comes from the NHS. Excess Treatment Costs (ETCs) are the difference between the cost of usual patient care and the cost of the treatment provided as part of the study. In some studies there may be treatment cost savings, but in others there will be extra costs. It is essential that ETCs are identified at an early stage in the planning of a study and that contact is made with the main recruitment site to check that costs are accurate and that ETCs can be funded.

The East Midlands and South Yorkshire Primary Care Research Leads Group (EMSY PCRLG) is a well established regional forum for the identification, development and promotion of best practice in primary care research development and management. Its members are Research and Development Managers from NHS primary care organisations across the East Midlands and South Yorkshire region; Senior Managers from the three associated Comprehensive Local Research Networks, the Primary Care Research Network for East Midlands & South Yorkshire, and the Mental Health Research Network East Midlands Hub with South Yorkshire; and representatives from the Strategic Health Authority and the NIHR Research Design Service for the East Midlands.

EMSY PCRLG has developed and agreed guidance for researchers on the process of obtaining funding for ETCs. This includes a process flow chart which shows the pathway from identification to funding of ETCs with links to further information including Department of Health guidance. The guidance also includes a checklist of information requirements for researchers making an application for ETCs for non-commercial studies in primary care and a list of top tips based on guidance from the Department of Health and local research management experts. This new resource can be found on the NIHR RDS for the East Midlands website <http://www.rds-eastmidlands.nihr.ac.uk/excess-treatment-costs.html>.

The ETCs guidance will be updated to reflect NHS changes in the future. EMSY PCRLG would welcome feedback from researchers on the usefulness of the guidance. Please send any comments or suggestions to Gill Sarre, gill.sarre@nottingham.ac.uk Partnerships/ Organisations Lead for NIHR RDS EM.

For more details see the website
<http://www.rds-eastmidlands.nihr.ac.uk>

For general enquiries contact:
enquiries-lnr@rds-eastmidlands.org.uk
Tel: 0116 252 3276 for Leicester (covering
Leicestershire, Northamptonshire and Rutland)

enquiries-ndl@rds-eastmidlands.org.uk
Tel: 0115 823 0500 for Nottingham (covering
Nottinghamshire, Derbyshire and Lincolnshire)

Designing applied health research: from idea to bid proposal

This popular course is designed to help in the preparation of bids for funds and will take place in Nottingham on 14th and 15th June 2011. The course will be especially helpful for researchers and clinicians who have some experience of research but have not previously been principal investigators in this type of study. Participants will be expected to submit a research idea prior to the course, and during the 2 days of the course they will work in small groups to build the sections of a proposal. These workshops will be interspersed with presentations and general discussion of all aspects of applied health research. A third day, on 14th July will provide an opportunity for participants to present the proposal they have been working on to an invited audience for feedback and further development.

This course will be free of charge to NHS, social care and voluntary sector researchers and their academic partners.

Further details and booking arrangements will be available on the RDS EM website: www.rds-eastmidlands.org.uk/ or contact Karen Taylor on 0115 846 6907 or email Karen.Taylor@nottingham.ac.uk

NIHR launches International Register for Health Research reviews

A major global initiative to establish an international register that will improve the transparency of health research has been launched by Health Minister Lord Howe.

The register, called PROSPERO, is the first online facility to register systematic reviews for research about health and social care from all around the world. It has been developed by the NIHR Centre for Reviews and Dissemination (CRD) and is completely free and open to the public. NETSCC is supporting this initiative as NETS programmes fund a large number of systematic reviews.

Systematic reviews are accepted as providing best quality evidence to support decision making in health and social care for policy and practice. They critically assess and collate the evidence from all the relevant studies on a research topic that have been previously undertaken. They are recognised and valued by decision-makers because they provide the best and most comprehensive information available. PROSPERO is designed to avoid the duplication of health research and will act as a guard against selective reporting of research.



NOTICEBOARD

– NIHR Portfolio Funding Opportunities

New NIHR Health Services and Delivery Research Programme announced

The new Health Services and Delivery Research Programme (HS&DR) is to be established by merging two existing programmes – Health Services Research (HSR) and Service Delivery and Organisation (SDO). The programme will still have the two main work streams of health services research and healthcare delivery research. The former will focus on research into the quality, appropriateness, effectiveness, equity and patient experience of health services. The latter will focus on evaluating models of service organisation, delivery, and interventions, which have the potential to improve service effectiveness, efficiency and productivity. In keeping with the existing programmes, the audiences for this research will be the public, service users, clinicians and managers. The budget of the new programme will be the total of the two existing programmes at £16m per year.

The first call for proposals will open in early 2012. In order to ensure that the commissioning of high quality research is sustained, the existing Health Services Research and Service Delivery and Organisation calls, programme boards and panels will continue to operate until December 2011. Further information about the HS&DR Programme will be available later in the year.

HTA Clinical Evaluation and Trials

The HTA Clinical Evaluation and Trials funding stream funds grants for evaluation studies and clinical trials supporting research that is immediately useful to clinical practice and decision makers in the NHS.

The programme is interested in receiving proposals addressing any health problem in areas not otherwise well covered in our portfolio. However, the programme is particularly interested in receiving proposals concerning people with Chronic Obstructive Pulmonary Disease. Please note that proposals should be written within the remit of the HTA programme.

Duration: unspecified

Closing date: 27 July 2011

<http://www.hta.ac.uk/funding/clinicaltrials/index.shtml>

Arthritis Research UK (formerly Arthritis Research Campaign), GB

Clinical PhD studentship

This studentship aims to provide training for medically qualified clinicians in a high quality research environment leading to a PhD and allows institutions to recruit candidates of the highest calibre.

Amount of funding available: unspecified

Duration: unspecified

Closing date: 10 August 2011

http://www.arthritisresearchuk.org/research/applying_for_a_grant/types_of_grant/clinical_phd_studentships.aspx

Arthritis Research UK Career Development Fellowships (Biomedical Sciences Panel)

Salaries will be according to age and experience on the appropriate scientific salary scale (see Essential information for applicants) and all career development fellows are eligible for an additional fixed salary supplement of £3,000 per annum. Application may also be made for reasonable running costs and small items of equipment.

Amount of funding available: > £100K

Duration: > 3 years

Closing date: 22 June 2011

<http://www.rdfunding.org.uk/queries/ListGrantDetails.asp?GrantID=12692>

Medical Research Council New investigator research grants – population and systems medicine

These provide support for clinical and non-clinical researchers while they are establishing themselves as independent principal investigators. Awards are worth up to £600,000 for a period of three years, but applications for a longer period of time are accepted. MRC will usually meet up to 80 per cent of the full economic cost.

Amount of funding available: £600,000 (MAXIMUM)

Closing date: 08 June 2011

<http://www.mrc.ac.uk/Fundingopportunities/Grants/NIRG/index.html>

Would you still like to receive this newsletter? Let us know!

We are currently updating our database and would appreciate it if you would take the time to enter just your name and email address into our website to indicate whether you wish to continue receiving the newsletter or would prefer to unsubscribe. So log on now at <http://www.rds-eastmidlands.nihr.ac.uk/> – you can enter your name and email address on the left hand side of the home page – it takes seconds and ensures that you will be kept up to date with research support and research activity in the region!

News from the Research Design Service for the East Midlands is edited by:

Christine Keen – ckeen@dmu.ac.uk

