



Involving Service Users, Carers and the General Public in Mental Health Research

News and Updates

INVOLVE 2014: Changing Landscapes

inspire has been accepted to present a poster at the INVOLVE 2014 Conference in Birmingham. The conference takes place on 26 and 27 November and will be attended by public, patient involvement groups, representatives and members from throughout the country.

Launch of new NSFT Research webpages

The new NSFT Research webpages will go live on

1st November 2014. Visit the webpages to find out more about how to get involved in research at NSFT and more about what we can offer as a mental health research centre. www.nsft.nhs.uk/research

inspire Research Register

You can now sign up for the register, we will be writing more about this in the next issue of *inspire you* but in the mean time please visit the website or email us for information.

Current Study Updates

DNA Polymorphisms in Mental Illness (DPIM): The study is still recruiting well across Norfolk and Suffolk, and due to finish in 2017, when results will be available. Many thanks to everyone who has taken part so far.

PATTERN: Recruitment has now finished on the study, and participants are in Follow-up. The study is due to finish in December 2014.

Health Improvement Profile (HIP) study: Final analysis is just being completed, and results are due for publication shortly. In total, 148 people across Norfolk and Suffolk took part in this study.

PRODIGY has successfully recruited sufficient participants for its initial pilot phase and is not currently taking new referrals into the study. More information about the study will be available in the next edition of the newsletter.

PPIP: PPIP is still recruiting well across Norfolk and Suffolk, and we have had a lot of interest and enthusiasm from participants. The study is due to finish in 2015.

Research Study Opportunities



The IDEAL project is a five-year study of 1,500 people with dementia and their family carers throughout the UK. Researchers, led by Professor Linda Clare, will investigate how social and psychological factors affect the way in which people adapt to the effects of dementia and the challenges it presents, and how this changes over time as dementia progresses. The aim is to better identify at what stage individuals, communities, health and social care practitioners, care providers and policy-makers can intervene to improve the likelihood of living well with dementia.

See: www.idealproject.org.uk



The aim of this project is to design, develop and evaluate an online focused resource for siblings of people affected by psychosis.

The E Sibling Project provides an online resource for brothers and sisters of people who are affected by psychosis. Our dedicated website <http://siblingpsychosis.org/> provides peer support and information on psychosis, coping and management strategies for common symptoms and ways for you to look after yourself.

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Jo Williams, Clinical Study Office for the Clinical Research Network (Mental Health).

For more information about the Clinical Research Network (CRN) see: <http://www.crn.nihr.ac.uk/>

A day in the life of a Clinical Study Officer (CSO)

Jo Williams is a Clinical Studies Officer (CSO) for the Clinical Research Network (CRN) and has been working in this post for nearly 1 year, here she tells us about a typical working day for her.

"As a CSO my days can be vary varied. I usually spend the first hour checking emails, liaising with my colleagues within NSFT and the Clinical Research Network and organising my diary.

After this, I could go and attend a clinical team meeting to present a research study I am working on. As part of my role I promote research within the trust - I go into different clinical teams or services in order to talk to them about research relevant to their team and outline how they can help identify and refer relevant potential participants to different research studies. I try and do so by focusing on telling teams what the benefits might be for participants and what it would involve, taking part.

Around lunch time I typically pop back to the office and check emails again. I will spend time reading the materials available to me that relate to the studies I support. I might re-read the study protocol and email the study team if I have any questions about how I can support the research. I often spend some time emailing and ringing relevant clinicians who might be able to help identify contacts, or looking at local support groups so I can attend and present

about research.

After lunch I often have visits booked in. When I visit people who have expressed an interest in taking part in research, I book an appointment to meet them either in their own home or at a local NHS base. When we first meet I introduce myself and explain very briefly my role within the trust. I will then talk to them about the rationale behind the study and what it involves. This is called an informed consent process: I make sure the person understands everything involved in participating and has a chance to ask any questions. This process culminates in the participant signing a consent form. After this I then follow the steps outlined in the relevant research protocol in order to take the data from the participant for the research. This is called *Assessment*. So for example, if the study involves taking a blood sample, I will try and do this first. After which I will then complete some of the assessment paperwork with the participant, at their own pace. Usually visits last between 1 hour and 3.

Once an assessment has been completed I will come back to the office and read over the paperwork, ensuring it is accurate and locked away safe, and then its home time!"



Focus on... The PRODIGY Study

PRODIGY (Prevention of Long-Term Social Disability in Young People with Emerging Psychological Difficulties) is a pilot randomised controlled trial of social recovery cognitive behaviour therapy.

Study aim: Recent reports have highlighted the lack of appropriate services for young people with severe and complex mental health problems: particularly those at risk of social disability.

This study will evaluate a new psychological intervention specifically tailored to the needs of this group: Social Recovery Cognitive Behavioural Therapy (SRCBT). SRCBT is a novel form of CBT designed to target social disability. The intervention combines outreach case management approaches with well-established cognitive behavioural techniques.

Participants: 100 young people aged 16 to 25 years with emerging severe and complex mental health problems and associated social disability.

Study design: Participants will be randomised to receive SRCBT plus standard care or standard care alone. For participants randomised to receive SRCBT the intervention will last nine months. Both groups will receive detailed assessment and monitoring.

Referring to the trial: PRODIGY has successfully recruited sufficient participants for its initial pilot phase and is not currently taking new referrals into the study. Referrers will be updated on any progress to extend the trial and will be notified when / if PRODIGY will be recruiting again.

Study Team: This is a multi-site

study, with research conducted by Norfolk and Suffolk NHS Foundation Trust, University of East Anglia, Greater Manchester West NHS Trust and the University of Manchester.

The Norfolk study team consists of David Fowler (Chief Investigator), Jo Hodgekins (Norfolk Principal Investigator), Tim Clarke (Trial Manager & Therapist), Rebecca Lower (Therapist), Brioney Gee (Research Assistant) and Alice Rose (Research Assistant).

For any enquiries please contact Tim Clarke on 01603 201486 or timothy.clarke@nsft.nhs.uk

This project is funded by the National Institute for Health Research HTA programme (10/104/51). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HTA programme, NIHR, NHS or the Department of Health. (www.nihr.ac.uk)

inspire update

Following our successful launch in May inspire has been very busy! The launch itself was a great day, the inspire team met lots of new people and attendees were given the opportunity to listen to three excellent talks by researchers about the impact that patient, public and carer representatives can have on research and the importance of this input for the research itself.



Attendees at the May inspire launch event in Norwich



One of the researcher talk at the inspire launch

Attendees were given the chance to register their interest in inspire and we are pleased to say that we collected contact details for over 40 people on the day. The event also provided people with a chance to learn more about mental health research taking place locally with representatives from NSFT, The Clinical Research Network (Mental Health and Dementia) as well as from local Clinical Commissioning Groups.

Following a busy time registering a great range of people with inspire, In August we held our first panel meetings for all current members of inspire. There was a panel meeting for each of our three panel areas (Youth, Adult and Older Age). At the meetings members were introduced to just some of the opportunities they could take part in through inspire (such as being named on research grant applications and developing their own research ideas). Training was given on critically reviewing research and attendees were given actual pieces of research, sent to us by local researchers to go away review and feedback on.



The inspire team in May 2014

Feedback from the panel meetings and also from the researchers who submitted research to the panels was extremely positive. Researchers commented on the quality of all the inspire reviews in particular. This is a fantastic start for inspire as we become more and more recognised locally.

Finally, we are pleased to announce that inspire has been accepted to present a poster at the national INVOLVE 2014 Conference in November 2014 <http://www.invo.org.uk/involve2014/> this is a great opportunity for us to promote inspire and also to network with other similar organisations—we will report back on this in the next issue of *inspire you!*



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To subscribe to *inspire you* please contact us via any of the means above and we will add you to our database!

In the next *inspire you* we will report back on the INVOLVE 2014 Conference and update you of other inspire developments, launch our exciting series of Research Podcasts and update you on all the latest study opportunities going on at NSFT. **Look out for this exciting new edition at the end of February 2015!**