

Diabetes Research Network
Autumn newsletter 2009

Encouraging patients' involvement in research

The NIHR DRN 'Clinical Research in Diabetes: A patient perspective' DVD

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DRN Patient and Public Involvement Training

The NIHR Diabetes Research Network has forged ahead with plans to develop and to deliver training events designed for patients and for the public.

The aim of this training is to de-mystify the research process and, following discussions on the training needs of three Local Research Network (LRN) lay panels, we delivered this training in the Thames Valley where 25 people attended and London with 30 delegates.

As the research process proved to be the most popular topic, and a one-day training session the preferred option in both regions, the programme was designed to incorporate a mix of presentations, workshops and interactive sessions delivered by a combination of LRN and coordinating centre staff.

The two events covered similar topics including:

- Research from concept to design
- Research funding
- Understand regulatory agencies and the ethics process
- What makes a successful study?
- Study protocols – what should they contain?
- Research terminology and lay summaries
- Creating patient information sheets

Each training event concluded with an update from the local team on the research studies currently supported in their region, and an open question and answer session. The London event also included a talk on the work of the James Lind Alliance and DUETS (The Database of Uncertainties about the Effects of Treatments) in setting research priorities.

Both the events were well received and have led to both panels assessing and commenting on a series of study protocols and patient information sheets developed by local researchers. Feedback from these first two events was particularly good with comments like 'well-run and well-timed', 'comprehensive' and 'informative' being given.

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As a result of this success, there are now plans to roll these training days out to other LRNs, as well as to the patient advocates working with the coordinating centre. Follow-up training sessions to develop individuals' committee skills, presentation skills and critical analysis skills are currently in development, as areas highlighted as priorities in the feedback from each event.



The NIHR DRN 'Clinical Research in Diabetes: A patient perspective' DVD

Following the launch of the network's DVD and sister website, www.diabetesresearchnetworking.org, in May last year, we have been busy monitoring its impact and adding new content to the site.

This year, the number of unique visitors to the site has remained fairly constant at around 500-600 per month. The number of hits i.e. the number of times people both new to the site and those returning to it enter it, is currently around 10-12,000.

With this information, we have been able to dig down a bit into who is looking at the site and what their favourite pages are.

Most of the visitors to our site in 2008 were from the USA, the UK and other European countries. This year, however, has seen a huge increase in the number of people logging on in the Russian Federation and China. Given the statistics of growth in the numbers of people with diabetes in these two countries, it's good to see that some of them at least are interested in taking part in a clinical trial!

The most popular pages are:

Diabetes

- What is diabetes?
- Type1 diabetes
- Transplant
- Cardiovascular
- Pumps
- Children
- Lifestyle
- Genetics
- Complications
- Diagnosis

General

- Diabetes and Research
- How to get involved
- Primary care
- What is research
- Clinical research
- Clinical trials
- UK Diabetes Research Network
- History

With this in mind, we are currently creating more content for children and adolescents. We are inviting patients with Type 1 diabetes to work with us to design the web pages and to carry out some of the interviews that will feature on the site.

We're also delighted to report that the DVD was shortlisted for the Good Clinical Practice Journal Awards in 2008 and was a finalist in this year's BUPA Foundation Communications Awards 2009.



Portfolio Update

The NIHR Diabetes Research Network has, over the past four years, created a thriving portfolio which, as of summer 2009, has around 270 studies in it.

These range from single-centre studies which are carried out in just one site to those that are multi-centre and are being carried out in a number of different places. Additionally, some of our studies are being done just in the UK and, in others, we are part of much larger, international studies with people participating in the studies in many different countries.

The total number of people accrued or recruited into trials and studies from 2006 to present are shown in [Table 1](#) below:

Year	Number of Accruals
2006 – 2007	10, 043
2007 – 2008	17, 565
2008 - 2009	37, 096
2009 – 2010 (first half)	20, 282

There is now more and more evidence that, by putting the study through the network, trials can recruit quicker than if a study is not placed with the network and works through traditional recruitment methods that do not have the opportunity to exploit the network's infrastructure.

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One such success study is a non-commercial multi-centre study which is still open for recruitment. Two research nurses (pictured above) working with the NIHR Diabetes Research Network in Ealing in west London helped the study to outstrip national recruitment trends at this site.

The diabetes inpatient treatment satisfaction among British and South Asian populations within the UK (DIPSat) study aims to investigate the relationship between diabetes treatment satisfaction questionnaires for inpatients and various aspects of inpatient diabetes care for 2,800 participants from different ethnic backgrounds in the UK. This population was selected in order to study whether language and ethnicity influence the scores and to evaluate the economic cost associated with poor questionnaire scores and the length of stay in hospital. The study is funded by Diabetes UK and is open at over sixty sites across the UK.

The questionnaires were offered in seven different versions:

- a Standard English version for all English speakers who can read and write in English and who are not of South Asian origin
- an English for South Asians for those of South Asian origin but who use English as their first language and
- the five main South Asian languages.

The North West London Local Diabetes Research Network has been supporting the study at Ealing Hospital NHS Trust since March 2009. Two research nurses, Anna Widdowson (above, left) and Una Fraser (above, right) together with a Diabetes Specialist Nurse from Ealing Hospital NHS Trust have been responsible for identifying and recruiting suitable patients into the study. Recruiting to the South Asian languages arm of the study has been a challenge as there is a common tendency for British South Asians to opt for the English language even if they are not fluent in the language. The required target of forty standard English recruited was achieved over the summer and the nurses have almost finished recruiting for the South Asian arm. The Ealing team has been awarded 'Best Recruitment Team' for this quarter and are due to receive Marks and Spencers' vouchers for their efforts.



Interview with Derek Stewart

Derek Stewart is keen to learn from the clinical networks. As the new Associate Director for Patient and Public Involvement (PPI) at the NIHR Clinical Research Network Co-ordinating Centre (NIHR CRN CC) he has the not insubstantial task of ensuring that PPI activities are coordinated across the identified priority topics which include diabetes. In addition, Derek and his team have plans to support the involvement of patients and members of the public in the work of NIHR CRN CC across an even wider platform of other disease areas

But how did he first get involved in the research pathway? 'I got involved in 1999 when I was asked to take part in a local health service forum' says Derek. 'The group was made up of patients and professionals and it was right at the very beginning of the process when there was just this slow, dawning realisation about the possibilities that PPI could have for healthcare professionals and their work'. 'In 1999 there were only a handful of patients involved at this level' he adds 'Now there are hundreds'

His passion for involvement has led him to a role where he feels he can make a real difference. 'When I started on this PPI path, patients were largely excluded from the whole business of diagnosis and care. By that I mean that we were excluded by the language that was being used, from the meetings and from giving ideas. It seemed very like a 'them' and 'us' situation. But things have improved. Several areas have showcased what active PPI can do particularly if you think about areas like mental health, the HIV/AIDS communities, and breast cancer awareness. All of these have profited from having very vocal lobbies with current patients taking on the mantle of discussing their experiences and getting involved at all levels to make the care more relevant and more patient-focussed for future generations'

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PPI is now seen more frequently as a vehicle for improving research by working in effective partnerships and less about people sitting on endless committees where their input and even their presence historically may have been merely tokenistic.

With his experience of cancer, Derek knows first hand the various PPI roles. These are as an active presence, a vigilant watcher, a contributor to the dialogue, a challenging partner and a participant in a shared decision making.

- As an active presence there is an expectation of being asked to participate, sitting at the table and acting as a physical reminder of the purpose
- As a vigilant watcher we are able to witness that the patients' interests are being considered but we must make sure that people continue working together and make maximum use of resources.
- As a contributor to the dialogue it is about having a right to add our voice to the dialogue with a responsibility to gain an understanding of the wider issues.
- As a challenging partner we should all be encouraged to ask awkward questions. We, as patients, need to spend time listening to different patient communities to gather their views. We might as a by-product become ambassadors for research in general and some may want to be involved in our own research
- As participants in a shared decision-making where our experiences, values and preferences are equated with the treatment options, potential benefits, harms, outcomes of clinical trials and the organisation of research for patient gain.

In turn each of these shifts the role into advocacy - speaking up and out on issues which are central to our experience.

Derek says 'My cancer led me to national participation and involvement becoming a member of a national board, the chair of a Primary Care Trust, and a journey travelling through Education and Health to the Home Office and to local authority. I have moved beyond cancer patient and taken on new roles but each stems as a direct result of having had the cancer and the change made to my life through the disease and its treatment. It has become more about the patient experience in change management taking on roles in leadership and identifying what makes the voice of patient experience so effective'

But where do we go from here? Much progress has been made over the past few years since the clinical research networks started. Hundreds of people are contacting the networks eager to find out more, wanting to get involved and impatient for progress.

'We are all agents for improvement when you think about it' Derek muses. 'Change is constant and we need to continue to work hard to drive policy and to identify and overcome any obstacles'. Despite the inherent difficulties in implementing meaningful PPI across such a diverse and constantly changing landscape, Derek firmly believes that we are making progress. 'Oddly enough, I have this strange and persistent notion that it could be the grit in the oyster' he laughs. 'Difficult at first but something that can indeed, given the right conditions of course, grow into something of worth and appreciation!'



Dr Colin Dayan



Professor Debbie Sharp



Dr Rob Thomas

Early ACTID

With the network now over four year's old, some of the trials adopted into the portfolio at the very start are now coming towards completion. One such trial is the Early ACTID study run by Dr Rob Andrews at the University of Bristol. Along with his colleagues, Dr Colin Dayan and Professor Debbie Sharp, Rob's study wanted to recruit almost 600 people with newly-diagnosed diabetes making this one of the biggest exercise and diet intervention study in newly-diagnosed patients ever conducted. Faced with this enormous challenge, how did the team find the people to join the trial?

The main problem with running clinical trials is often recruitment. The formation of the clinical research networks including the Diabetes Research Network and the Primary Care Research Network hopes to remedy this by putting in place a wide ranging infrastructure that will facilitate recruitment. But what about trials that were set up before the networks began?

Rob says 'The team pounded the pavements cajoling GP practices into finding suitable people on their databases who could be approached about participation and we did an initial media launch in an effort to raise awareness about the study but we targeted the wrong audience. We wanted people between five and eight months post-diagnosis with Type 2 diabetes because that first year after diagnosis is so important. However, a lot of people who had had the condition for much longer than this ended up contacting us about participation'

Happily, though, over the three years on from November 2005 when the study started, Early ACTID has managed to recruit 593 people with diabetes randomised into one of the following:

- a control ('usual care') arm
- an intensified diet arm and
- an intensified diet and exercise arm with a goal of at least 30 minutes of moderate intensity physical activity like walking five days each week

The patients in the study have loved being a part of it. One participant said 'You can never have too much information so I was really motivated to get involved' Randomised to the diet and exercise arm, he believes that there were two main benefits. 'First, it gives you a real focus. You have milestones to reach and the learning is progressive so you build up a huge fund of knowledge. Second, it helped me to lose weight. Knowing that someone else was watching your progress was great. It does wonders for your conscience!'

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For the time being we don't know the outcome of the study. The last person to be randomised into the trial reached the 12 month point in late summer this year. It's possible that, in the short term, if increasing physical activity is found to show an improvement in well-being, glucose control, a decreased requirement for diabetes medication and maybe fewer visits to their GP, there could be major implications for improving the management of the condition. More importantly though, Early ACTID may show what benefits can be achieved through joint decision-making with the healthcare team both with regards to diet and exercise.

Who's Who at the Coordinating Centre

Director:

Professor Desmond Johnston
(Imperial College London)

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(Imperial College London)

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Professor David Matthews,
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