

Diabetes Research Network
Summer newsletter 2010

Encouraging patient involvement in research

**Making a Difference!
Research from a patients perspective**

ADDITION Recruitment is key

**Interview with Professor
David Matthews**

**NIHR DRN at the
Baishakhi Mela 2010**

Contact details and Who's Who



Making a Difference

Priorities for Diabetes Research from the Patient Perspective

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The second Diabetes Research Network (DRN) Patient and Public Involvement (PPI) conference was held on 4 December last year in central London.

The event was open to patient and public representatives working with either the DRN Coordinating Centre or Local Research Networks (LRNs) in England, as well as to representatives of DRN partner organisations and other interested parties. It was well attended by more than 70 delegates, including around 50 patient advocates.

The aim of this one day conference was to explore further the topics raised at last year's conference and to discuss priorities for diabetes research from the patient and carer perspective. The event comprised a mixture of presentations and workshops.

The morning session began with a presentation by Professor Des Johnston, DRN Director, who gave an overview of the progress made during DRN's first four years of operation. Dr Eleanor Kennedy, DRN Project Manager, then gave an update on the progress of DRN studies, showing the range of topics on the DRN Portfolio and emphasised the importance of the collaborative nature of the NIHR Clinical Research Networks. Martin Lodmore, DRN Patient and Public Liaison Officer, gave a presentation that stressed the need for more patient and public involvement in research. He gave a brief overview of the DRN's successful outreach and involvement programmes, showing how the DRN had benefited from including patient and carer perspectives, as well as how the research community in general is responding positively to an increase in patient and public involvement. This was followed by a joint presentation by two patient advocates, Diane Munday and Alex Mendoza, who discussed their work with the Public Involvement in Research Group at the Centre for Research in Primary and Community Care based at the University of Hertfordshire. They confirmed that the researchers who had engaged with the group had taken full consideration of the patient and carer views.

Following lunch, Professor Simon Heller, Chair of DRN's Clinical Studies Advisory Group, emphasised the importance of a robust method for priority setting and how it was vital to get patient and carer input into this process. He then explained the methods that would be used in the four parallel workshops, which would begin to bridge the gaps between clinicians, patients and researchers, and engender a greater understanding of the challenges of turning ideas into fundable research questions.

The workshops covered:

- Treatment and care for people with Type 1 diabetes
- Treatment and care for people with Type 2 diabetes
- Prevention and diagnosis of diabetes
- Education and support for people affected by diabetes

The workshops proved challenging because the wide variety of views on offer made it difficult to reach agreement about which topics should be given highest priority. Feedback from these workshops will inform the priority setting initiatives that will be conducted by the Clinical Studies Advisory Group during 2010.

Professor David Matthews, the DRN's Associate Director for Advocacy, closed the event with a passionate and sobering presentation about the worldwide challenge of diabetes, focusing on the Type 2 diabetes epidemic sweeping the globe.

Feedback from the delegates following the event has been very positive. It enabled researchers and patient advocates to discuss the DRN's progress and direction, as well as research priority areas.

A full report on the event is available from Martin Lodmore, DRN Patient and Public Liaison Officer (m.lodmore@imperial.ac.uk).





The Diabetes Research Network **NEEDS YOU!**

The School of Pharmacy at De Montfort University has a collaborative group working on a totally implantable closed loop insulin delivery pump.

The design is unusual because it is not electronic but depends on the behaviour of a glucose-sensitive polymer that controls the output from an insulin reservoir. The whole thing is contained in a refillable robust device that is intended for implantation in the peritoneal cavity, which is the fluid-filled gap between the wall of the abdomen and the organs contained within the abdomen. The idea is that it responds to peritoneal glucose and delivers close to the vessels in the peritoneum that feed into the liver.

Their NHS grant is mainly for the design and testing of the device but also to run a pair of surveys for people who use insulin either by injection or conventional pump. These surveys are about attitudes to diabetes and to its control by insulin and although we know that pumpers are mainly Type 1, the surveys are open to Type 2 as well, even if they also take tablets. They'd also like to hear from any unusual dose routes like Diaport. The purpose is to detect the real difficulties faced by people in controlling their glucose, including some that for various reasons perhaps, people never manage to actually convey to their professional carers. Both surveys are quite long, but if you have the time to tell the group, they have the time to listen and will find what you say useful.

This applies wherever you live, world-wide. So this is a chance to have your say, knowing it won't fall on deaf ears (even on the interactive version, you can add your own comments in free text if you like). They also want to hear about how people would view an implantable pump and there are questions in the surveys about this. Already people have pointed out some aspects we had not previously considered. It is totally anonymous but they will be able to build up a picture of the feedback and report their findings nationally and internationally, in the hopes that it may influence current policies and also have more accurate information about what might or might not be acceptable for future therapies.

*So this is a chance to have your say,
knowing it won't fall on deaf ears*

You can access the interactive links to one or both surveys on:
<http://www.dmu.ac.uk/diabetes>

Many of you have already responded to this. In 2009/10, the principal investigator had about 500 returns. When the DRN was asked to help, the returns more than doubled in a month!



A Very Civil Party

'The Mayor's Civic Award was presented to Mrs Sue Braeger on 28th April 2010 by Havering Mayor, Councillor Roger Ramsey at Langtons in Hornchurch, with a buffet afterwards.'

The certificate states For Services to the Community through Havering Family Diabetes Group and Sue received a lapel pin as well in recognition of her 15 years with the group.

The Mayor told of her commitment to the local diabetic community by giving talks about living with diabetes, although she does not have diabetes herself. He said that she goes to Primary Care Trust meetings to keep up to date and to fight for a better diabetes service in Havering.

She has also helped to look after her husband's diabetes for 39 years. Her husband says 'For the first 19 years I was very ill and constantly in and out of hospital until I was fitted with an insulin pump 20 years ago. Sue is totally committed to diabetes education and to insulin pumps and has fought tooth and nail to gain a pump service in Havering. And she'll keep an eye on it too to make sure it flourishes!'

Harry Sellars, who like Sue works closely with the North East London DRN, was given an award 'for services to diabetes' at the same ceremony.



ADDITION

Providing the missing piece of the jigsaw

Is earlier better? That's the question a five-year study looking at the effectiveness of large-scale screening and early treatment for Type 2 diabetes is asking – and the answers could inform national screening and treatment guidelines across the globe.

The Anglo-Danish-Dutch Study of Intensive Treatment in people with screen-detected diabetes in primary care (ADDITION) will provide evidence for the benefits of early detection and treatment – and the costs. The study has followed up a total of 3,000 people with Type 2 diabetes recruited in Denmark, the Netherlands and two centres in the UK; Cambridge and Leicester.

Dr Simon Griffin has been leading the trial in Cambridge. He says:

'Type 2 diabetes meets many of the criteria for suitability for screening. It is increasingly common and poses a major public health challenge.'

Dr Griffin continues: 'Population-screening and early treatment for Type 2 diabetes could reduce this growing burden. But we don't actually know if the benefits of early treatment for screen-detected patients outweigh the economic and psychological costs of screening the majority.'

'It's widely assumed that screening programmes are good, but they are a huge commitment of scarce resources and we need to know if they're effective. ADDITION will provide the missing piece of the jigsaw, helping us determine if finding and treating people earlier is better.'

Screening and treatment

The first stage of the study was a large-scale screening programme. Excluding those people who had already been diagnosed with Type 2 diabetes, the ADDITION-Cambridge study team worked with 60 practices in East Anglia to identify patients aged 40-69 who were at high risk of developing the condition.

Electronic checks of 151,464 patient records identified those at highest risk. These people were then invited to come for screening at their local GP,

starting with a finger-prick blood test, and if this was positive, a second fasting test and finally a glucose tolerance test. This was labour-intensive for the practice staff and the MRC Epidemiology team in Cambridge sent in extra teams for the finger-prick tests.

Following the step-wise screening programme, 867 individuals were diagnosed with Type 2 diabetes. They were then allocated by chance to either intensive management of risk factors or routine care, depending on which practice they were in. The 28 surgeries giving intensive care received three practice-based educational sessions for staff and educational materials for patients. 27 surgeries offered routine care according to NHS guidelines. This stage of the trial demonstrated that large-scale screening for Type 2 diabetes is feasible and acceptable to patients and practices; what it didn't demonstrate is whether the benefits outweighed the costs.

To help answer this question, after one year all the screen-detected diabetic patients were assessed for cardiovascular risk and the results showed clear differences between the routine and intensively-treated groups.

Both groups had started with similar comparable characteristics – with similar measures for their body mass index, cholesterol, blood pressure and blood glucose levels. But after one year, while both groups had reduced cardiovascular risk, the measurements for those who had received intensive treatment were significantly better: their blood glucose levels, body mass index, blood pressure and cholesterol were all lower than the measurements for the routine group.

Furthermore the intensively-treated group reported higher levels of well-being, more energy and a perceived change in their health for the better. They were also more satisfied with the treatment they had received, compared with the routine group.





Dr Griffin says: 'We know that half of all people with Type 2 diabetes are undiagnosed, and half of these will have damage to their tissues before they are even aware they have the condition. Given their increased cardiovascular risk, early intervention is advisable for people with Type 2 diabetes.'

The results for the whole ADDITION European trial will be reported at the European Association for the Study of Diabetes (EASD) annual conference taking place in Stockholm this September. Dr Griffin says: 'ADDITION is an extremely important study, and its conclusions will be relevant to national policy decisions made on screening for diabetes and subsequent management of people early in the course of the disease.'

'What ADDITION has shown is that intensive treatment of screen-detected patients is associated with significant and clinically important reductions in cardiovascular disease risk factors.'

The five-year follow-up study has received support from both the Primary Care Research Network and the Diabetes Research Network, as ADDITION Cambridge study co-ordinator Joanna Mitchell explains: 'At five years we wanted to remeasure the original participants and also assess cardiovascular events and mortality among them.'

Dr Griffin adds: 'Furthermore, we gained evidence to show that those individuals invited for diabetes screening did not have increased levels of anxiety or depression about diabetes or their health generally than those who weren't invited; this suggests that screening has limited psychological impact on patients. Nor did it offer false reassurance if people tested negative – if they intended to lose weight or get fit they didn't change their minds because of a negative result.'

'The Eastern Region Diabetes Local Research Network helped support the study, with some of their nurses remeasuring participants in testing centres in Cambridgeshire.'

'Eighty percent of those who were still alive after five years came back for measurement.'

'In addition the Eastern Region Diabetes LRN's information manager Garry King developed a search to see if those in the study had had heart attacks or strokes in the previous five years, which he then trained the nurses working for the Primary Care Research Network to use.'

'What we don't yet know is if treating people early makes a difference longer-term with fewer heart attacks and strokes – and this is what the ADDITION five-year follow-up is investigating.'

'These results will help us to see if early intervention actually leads to reduced heart attacks and strokes.'



Interview with Professor David Matthews, Co-Director NIHR Diabetes Research Network

David Matthews is a man with a mission. 'There are just three problems with clinical trials. Recruitment, recruitment and recruitment!' he says. True to his word, David has been striving to increase our levels of awareness about diabetes not just across the UK but across the globe.

As one of the leading trialists in the UK Prospective Diabetes Study (UKPDS), David is well aware of the issues facing researchers trying to run trials nowadays. UKPDS was a landmark randomised, multicentre trial of therapies in over 5000 patients with newly diagnosed Type 2 diabetes. It ran from 1977 to 1997 in 23 clinical centres in the UK and showed conclusively that the complications of Type 2 diabetes, previously often regarded as inevitable, could in fact be reduced by improving blood glucose and/or blood pressure control.

But running such a big study was no enviable task. 'Getting people into trials and keeping them there is a real art that relies heavily on a multidisciplinary motivated clinical team and informed, involved patients' he explains. 'The new network structure that encompasses everything from diabetes to dementia, and stroke to cancer is an incredibly forward-thinking initiative that is trying to embed such teams right the way across primary and secondary care to ensure that everyone can get involved in clinical research' David continues. But getting the message about trials out to potential study participants remains a challenge. For most people, getting involved in research remains a remote, almost esoteric opportunity that few are aware of. For some, it conjures up images of guinea pigs and Frankenstein science. However, nothing could be further from the truth. All trials and studies are carefully scrutinised by local ethics boards and then undergo a further round of checks and balances by the appropriate network before trial adoption can occur.

NIHR Diabetes Research Network

Within the NIHR Diabetes Research Network (NIHR DRN), well over 300 studies have run or are currently underway in England with dedicated research nurses recruiting patients across the length and breadth of the country.

'That's great' counters David 'but we still need more people getting actively involved in research. That can be getting involved in the research process and joining our patient and public initiatives or it can be simply putting your hand up at every opportunity to get recruited into a study. And that's where we still have work to do'

The NIHR DRN has launched a programme of awareness raising which has exploited peoples' increasing acknowledgment of technology and multimedia. In addition to the more conservative and well trodden paths of published printed media like leaflets and booklets, the NIHR DRN has launched a DVD in which patients who have participated in clinical trials speak passionately about their experiences. A website (www.diabetesresearchnetworking.org), packed with even more soundbites and informative video footage, has been built to accompany the DVD. Academic researchers and the pharmaceutical industry all striving to encourage people to participate in research can access copies of the DVD as it is made freely available to the former and only charged to cover duplication and mailing costs to the industry.



NIHR Clinical Research Network Coordinating Centre

The central NIHR Clinical Research Network Co-ordinating Centre has recently emulated the work of the NIHR DRN embracing the use of video to get the message across about clinical research. It too has produced a DVD, with the help of the NIHR DRN, which will, from June, be given to people who have been approached about taking part in a research study. The aim is to encourage them, following this initial approach, to watch the DVD, to understand a little more about clinical research and to sign up to participate

'I'm really delighted that our work is being recognised at this level' says David. 'I hope that the wider NIHR family which comprises not just the networks but the research centres, the biomedical research units and the experimental medicine facilities can all start to explore the possibilities that technology and, in particular, the web give us.'

The public love to hear about research and about the new results that might one day give us cures for the diseases that still blight our society. What better way to bring the excitement of medical and scientific research right into a person's living room or office than this!' he enthuses But, not content with his pioneering advocacy work, David is also involved in global initiatives that work on a larger scale.

Oxford Health Alliance

The Oxford Health Alliance (www.oxha.org) which he also

coordinates enables experts and activists from different backgrounds to collaborate in order to raise awareness and to change behaviours, policies and perspectives at every level of society. Alliance members from around the world include leading academics, activists and corporate executives, patients' rights advocates, doctors, nurses and others, all of whom share a sense of urgency about the worldwide epidemic of chronic disease. Their goal is to raise awareness among influencers and to educate critical decision-makers so that the pressing case for preventative measures can advance, and we can begin to combat chronic disease.

'We know that well over half the disease burden in the world is due to just four chronic non-communicable diseases: cardiovascular disease, diabetes, chronic lung diseases and some cancers. We also know that prevention of unhealthy behaviours - poor diet, physical activity and tobacco consumption - is critical in confronting the huge growth of these diseases' he says.

'In order to make a real difference, scientists and researchers need to be working together across borders to ensure that the work that is being done is relevant and applicable.'

What Now?

'Diabetes is now so common that it can be considered an epidemic. It affects around 4% of the population in Europe and 6% of those living in the USA. In developing countries, the problem is even greater with prevalences running, for example, at 10 to 15% in India and Sri Lanka. Rates of chronic disease like this – where patients need careful ongoing health provision for many years – have the potential to overwhelm already hard-pressed healthcare systems' David adds 'There is a crying need for robust communication, passionate advocacy and considered patient and public involvement that will allow us to continue to undertake big trials like UKPDS and small studies alike which will, in turn, change the way we treat diabetes for good'.





North East London DRN at the Baishakhi Mela 2010

On a hot Sunday in May, teams from the North East London DRN joined in the Bangladeshi New Year celebrations in the Brick Lane area of Tower Hamlets. As part of the DRN's engagement and involvement programme which aims to reach communities traditionally excluded from clinical research, the teams attended stalls at each of the main sites, Weavers Fields and Allen Gardens, where live music and funfairs entertained the record-breaking 110,000 strong crowd.

The Baishakhi Mela began with a procession through Banglatown, led by a magnificent and colourful mechanical elephant, followed by more than 350 local school children and community groups.

The DRN teams talked to festival goers, using a short questionnaire to explore awareness of diabetes, attitudes towards clinical research and methods of improving participation in studies. To complement this, information about diabetes and research was handed out and random blood glucose checks were performed. With the help of multilingual team members, the DRN was able to collect the opinions of many people

whose first language was not English, and who had a very limited knowledge of diabetes and the benefits of research.

As the day went on, temperatures soared and the crowds enjoyed a range of entertainment at both sites, from traditional Bengali music to modern dance, all broadcast on the BBC Asian Network.

A broad range of people from many backgrounds attended, creating a vibrant atmosphere and keeping the DRN staff busy throughout the day, performing over 150 blood glucose tests and completing nearly 500 questionnaires. With such fun to be had, and lots of positive feedback, the team are already making plans to return next year! who had received intensive treatment were significantly better: their blood glucose levels, body mass index, blood pressure and cholesterol were all lower than the measurements for the routine group.

Furthermore the intensively-treated group reported higher levels of well-being, more energy and a perceived change in their health for the better. They were also more satisfied with the treatment they had received, compared with the routine group.

Who's Who at the Coordinating Centre

Director:

Professor Desmond Johnston
(Imperial College London)

Assistant Director:

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(Imperial College London)

Co-Directors:

Professor David Matthews,
Consumer Advocacy (Oxford University)

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