

# The Spark

**NHS**

**National Institute for  
Health Research**

**NIHR CLAHRC**  
Leicestershire, Northamptonshire and Rutland (LNR)



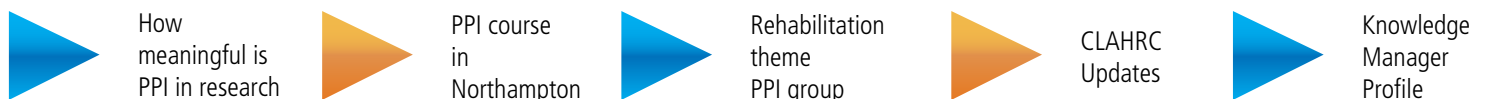
"Working together to conduct and implement high quality research to improve the health of the population of Leicestershire, Northamptonshire and Rutland"

Dear Colleagues,

The role of Patient and Public Involvement (PPI) in healthcare delivery and research is now widely recognised. However that involvement can take many forms and, in some cases, can be seen as paying lip service to the concept. In this edition of SPARK there are three pieces on PPI which cover training for PPI representatives, a practical approach to engaging with patients and members of the public and a personal view on the challenges that PPI still faces. Together they provide useful insights into how we can deliver effective PPI within CLAHRC for LNR and make though provoking reading.

Bill O' Leary  
Editor

## In this issue



## How meaningful is most Patient and Public Involvement (PPI) in Research?

- Raksha Pandya-Wood, Regional Patient and Public Involvement in Research Lead and Leicestershire Northampton and Rutland Research Engaging with Patients and Public (LNR-REPP) Forum Co-ordinator

PPI is, and has been for some time, Department of Health policy and is reflected in the drive by the NIHR to ensure effective PPI is demonstrated in all the research it funds. The result is that in today's research climate we are faced with the inherently positive concept that patient and public involvement research is "thought to be a 'good thing'". Whilst I agree with this I think that we need to encourage a healthy research culture that asks three questions:

- *Who are the public the research affects?*
- *What do you want to achieve by PPI?*
- *What are the best modes of involvement?*

Firstly, who does this research most affect? Health research does affect a larger group of people than you might first imagine. It might affect different charities, it will definitely affect staff in different hospital departments, of course it will affect the patients, maybe even partners, siblings, parents and

*continued overleaf*

carers. A recent survey from INVOLVE highlighted that a new priority might be to challenge the assumption that PPI in health research only involves patients and public. In reality anyone affected by the research, including the receptionists and porters, in hospitals and GP surgeries that might be affected and their views should be sought.

Secondly working out what you want can be very difficult, but it is essential it is done. Seek opinions from different members of the research team about how much involvement might be meaningful and how much appropriate from the people the research affects. Remember every study is very different, but consider:

- What is meaningful patient involvement in this research?
- Who is this research for?
- What is this research hoping to achieve and who will it benefit?
- Is patient involvement aimed at framing the research?
- Is the involvement important so that a larger group of affected people are plugged into the research?
- Is it just to involve someone who is interested in health research?

The third set of issues to consider is how much involvement is appropriate. Sometimes consultation is the most appropriate and meaningful thing to do and it seems to be a popular vehicle for involvement in a lot of research I hear about. Sometimes I have noticed that active involvement could have worked but because of the pressures of time in research and the restraints in resources, researchers pick consultation as a means to an end. I like the quote "being in favour of better public consultation . . . is rather like being against sin; at a rhetorical level, it is hard to find disagreement."

Doing consultation properly requires researchers to listen to patient's views and sometimes changing the focus of research. However if researchers don't listen to the views of the people consulted they are just practicing tokenism. Consultation might be appropriate sometimes but there are alternative ways of having effective PPI, I would encourage researchers to think about collaborating with users in developing undertaking and implementing research. Full involvement will eliminate tokenism, produce more relevant research and generate a culture where PPI is as integral a part of the research process as ethics.



Raksha Pandya-Wood

## PPI Research Course @ University of Northampton

- Dr Paula Wray, Community Research and Networking Officer

▶ CLAHRC for LNR supported by Northampton LINK has funded a Public Engagement in Research Course at the University of Northampton. It was a fully accredited, eight week, course run by Dr Jackie Parkes designed for service users and carers. The aim was to equip participants with the skills and confidence to enable effective involvement in research, service development, delivery and evaluation.

*'I was motivated to register for the pilot PER Course by a desire to be a potential partner in the type of research that influences policy, provision, and delivery of services particularly in the area of Mental Health.'*

The course covered all aspects of the research process from initial proposal through to the dissemination of results, including production of reports and publications.

*'The ethics of research project management was illuminating – addressing issues such as confidentiality and impartiality which have to be agreed and fully understood. As both a service user and prospective project team member this knowledge is invaluable.'*

The course has now been completed and 10 empowered and willing participants are looking for the right opportunity to be involved. The plan is to support this and other similar groups to provide a resource for researchers. An additional result of the course was increased confidence and analytical skills of all members throughout all areas of their lives.

*'The course has resulted in me feeling confident that I can be of potential value to a research team. I have always considered the service user perspective as a unique one. This course has enabled an opportunity for the service user voice to be heard collaboratively. Thank you.'*

## CLAHRC-LNR Rehabilitation Theme Patient & Public Involvement (PPI) Group

### - Theresa Harvey-Dunstan, PPI Lead, CLAHRC for LNR Rehabilitation Theme

On 7 July 2011, the Rehabilitation Theme held a meeting for patients, carers and members of the public to gauge interest in forming a PPI group. This group would be involved in the Theme's research and clinical activities in pulmonary and cardiac rehabilitation. Ten people attended this meeting and all expressed a keen interest to become involved.

An event was held on 13<sup>th</sup> September to mark the formal launch of the Rehabilitation Theme PPI group. Eleven people came together to discuss how they could contribute to our research programme and clinical service development. The meeting was facilitated by Theresa Harvey-Dunstan, a senior research physiotherapist, and the group heard of number of presentations from researchers and clinicians. Alison Reynolds, the Voluntary Services Coordinator for UHL, was on hand to help with any administrative queries. The meeting got off to a successful start by agreeing the aims and objectives of the group and identifying projects people would like to become involved in. It was agreed that deputy group leads and other roles would be elected at the next meeting with people being encouraged to nominate themselves.

Everyone said they would like to become permanent members of the group, feeding into the clinical and research activities of the departments. It was agreed that monthly meetings would be appropriate in the first instance.

At the next meeting in October Dr Ruth Green will give a brief overview of rehabilitation in difficult asthma. Feedback from the group will inform the PPI component of her research funding application. The training needs of the group will be addressed at this

meeting. Alison Reynolds will once again be available to deal with any administrative queries.

Much of the good work happening in the group is also occurring in the Cardiovascular Biomedical Research Unit (BRU) at UHL. It seems sensible to consider merging these two groups to achieve greater effectiveness particularly as they could also support PPI in the newly announced Respiratory BRU. This would result in one large multi-funded forum with over 30 members linking into all cardiovascular & respiratory research and clinical activities within UHL. Discussions about this are ongoing.

The Theme's PPI group, together with lead researchers and clinicians from Cardiac and Pulmonary Rehabilitation, have been invited to speak at the UHL Medicine for Members Meeting on 17<sup>th</sup> November 2011. This will provide an excellent opportunity to promote the Theme's PPI activities and to encourage new members to join this thriving group.

We are already benefiting from PPI members' expertise and knowledge. For example, one member, Glyn, has been instrumental in developing a new research proposal. He highlighted a gap in the market for a technological application that would embrace the ethos of rehabilitation and translate it across into the community setting – making rehabilitation more sustainable. This idea has already led to a research proposal being submitted as part of a larger project for research funding approval. Glyn will be key to the entire research process, from the technical development and piloting of the application through to dissemination and implementation of the findings. A perfect example of PPI in practice!

Their experience is their expertise and a valuable resource for researchers. Patient and Public Involvement is fundamental to making research relevant and courses like this facilitate this process by empowering individuals with their unique perspective to work as partners in research.

As one of the course participants said

*'Thanks to CLAHRC for giving me the opportunity to attend'*



Northampton PPI course attendees

## New team members

We welcome Aaron Boland who is an Intern working within the Implementation Theme and Helena Ferrao-Read who is supporting Michelle as an Administrative Assistant.

## Award Success

Two CLAHRC: LNR projects won awards at the recent Quality in Care: Diabetes ceremony.

The Leicester Self-Assessment Diabetes Risk Score won first prize in the screening category whilst Walking Away from Diabetes won second prize in the prevention category.



Anna Morton, Bernie Stribling

For more information see [http://www.qualityincare.org/awards/diabetes/qic\\_diabetes\\_results](http://www.qualityincare.org/awards/diabetes/qic_diabetes_results)

## Website Updates

- Using Evidence Based Research
- Acute Admissions Evaluation Report
- New GP cancer tools mark a 'defining moment' in diagnosis
- Making it Happen; CLAHRC for LNR Knowledge Translation theory
- A foot in the door: a guide to engaging housing and health
- What Does Efficiency Mean?
- NHS hospitals will struggle to deliver productivity improvements
- Public Want More Choice in NHS care
- New GP Triage Model Reduces A&E Attendance
- NIHR Annual Report
- GP referral cuts a 'catastrophe' for hospital finances
- Following NICE guidelines for diabetes treatment 'could save NHS £625m'
- How PCTs set their priorities

For more on these and other stories go to <http://www.clahrc-lnr.nihr.ac.uk/news-a-events>

## Profile: Adele Horobin, Knowledge Manager

I started the new role as Knowledge Manager of CLAHRC for LNR at the end of June 2011. With a background in academic research and managerial roles within Technology Transfer at the University of Nottingham, I have experience in communicating with academics and the pharmaceutical industry. At the heart of Technology Transfer lies the ability to identify technologies of potential commercial interest, and, through market research and technology appraisal, present these technologies in such a way as to gain commercial interest. This experience in transforming academic knowledge into something suitable for a non-academic audience, and liaising with people with differing interests and perspectives is proving useful in my CLAHRC role.

As Knowledge Manager my role is primarily facilitating the joining together of knowledge producers and users, in the CLAHRC for LNR scenario researchers and NHS staff, to discuss ideas, the latest research and potential solutions to improve healthcare services. This should help introduce research evidence into debates and, hopefully, provide feedback for developing future research projects. An additional aim is to improve and strengthen network links between researchers and NHS staff, and also between NHS staff in different disciplines or places of work,

facilitating the development and implementation of future projects. Here, I will be establishing knowledge exchange events and online as well as face-to-face communities of practice. I am currently building links with the new Clinical Commissioning Groups to ensure they are aware of the contribution CLAHRC for LNR can provide to their research activities.

I also support making resources on finding and using research evidence, and in carrying out research, more readily available for people within the NHS. This involves signposting to existing services and databases through enhancing the resource hub of the CLAHRC for LNR website. My work also supports the activities of the Training and Education work stream through helping to promote courses.

A fundamental principle of my approach is to try and ensure sustainability of the resources and activities that CLAHRC for LNR have developed when it winds down. Embedding them within NHS organisations across the region, so that they continue to support bringing together research and implementation activities within the NHS, will be a true achievement.



Adele Horobin