Establishing a dedicated Research PPI Group in the NIHR CLAHRC LNR Rehabilitation Theme

Abstract: The NIHR CLAHRC for Leicestershire, Northamptonshire & Rutland Rehabilitation Theme is conducting a novel and ambitious programme of applied research in the field of rehabilitation for patients with chronic cardiopulmonary diseases. The benefits of pulmonary and cardiac rehabilitation are well established and embedded in national and international guidelines. Our research philosophy has been to design and test tailored rehabilitation interventions. We have embraced the need to integrate PPI in all our research and implementation programmes.

A presentation/poster session will identify the processes involved in establishing a dedicated research PPI group. Details of developing the group will be discussed along with how members defined and agreed their aims and objectives. Barriers and obstacles will be explored. Emerging member roles and responsibilities will be addressed.

An overview of the group's successes and future aspirations will be presented bymembers themselves. The development of the group's web-based portal for within-group communication will be described.

Our aim is to reflect on the group's journey enabling other research groups to learn from our experiences. A secondary aim is to inspire others to become involved in PPI activities.

What's the evidence for? A critical reflection on the evidence base for public involvement in research (invoNET sponsored session)

Abstract:

This workshop is organised by invoNET (www.invo.org.uk/invonet/) to debate:

- what do we mean by the 'evidence base' on nature, extent and impact of public involvement in research?
- who are we trying to influence with this evidence?
- what are the purposes of the evidence base on public involvement in research?
- What could and should the evidence be used for?
- what is lacking in the existing evidence base in order to fulfil the purposes identified? (For example, are we looking for evidence on impact on the research, evidence on what does and does not work, information in relation to particular groups and types of research including social care and health research).
- what are the next steps in building the evidence base?

Translating research into a patient friendly and cost effective health care tool: The role of PPI

Abstract:

The NIHR CLAHRC for Leicestershire, Northamptonshire & Rutland Rehabilitation Theme is conducting a novel and ambitious programme of applied research in the field of rehabilitation for patients with chronic cardiopulmonary diseases. One extremely important emphasis of CLARHC is around the implementation of research and how applied research is translated into the wider healthcare service.

Re-admission of patients with COPD are a national dilemma and at the University Hospitals of Leicester NHS Trust we have recently adopted a new process which has emerged from our London CLAHRC colleagues following a comprehensive review of the literature. The COPD Care Bundle comprises a comprehensive tool for optimising the patient pathway and will be offered to in-patients with COPD. This project also engages healthcare professionals in an educational programme to enhance delivery of the Care Bundle.

Our PPI members have been instrumental in the development of this improvement tool which will not only improve patient care but will also provide a cost saving strategy for our local NHS trust.

This presentation will focus on how PPI has been able to influence the translation of research and to facilitate the development of a strategic healthcare tool.

Developing and delivering accredited training on user-involvement

Abstract:

UNTRAP (University/User Teaching and Research Action Partnership) is a partnership between service users, carers and academics, based at the University of Warwick. The organisation works to strengthen the voice and role of service users and carers in teaching and research in Health and Social Care.

UNTRAP is delivering accredited training on User-involvement in Health and Social Care Teaching and Research through the University of Warwick Centre for Lifelong Learning. The course is devised and facilitated by academics and UNTRAP members. It uses inter-active teaching methods and assessment techniques. It provides an opportunity for those involved in partnership working to gain a qualification at level 3 or 4 of the National Framework in a supportive learning environment. It furthermore provides a way to formalize some of the skills that participants have acquired through involvement in teaching and research. The course is delivered over 6 sessions held on Saturdays.

This paper will present reflections and lessons learnt in developing and delivering this course. It will outline the content of the course, discuss the main teaching and assessment techniques, and consider issues of inclusiveness. Finally, it will present preliminary evaluations from participants on the course. This accredited training is an opportunity for either individuals or

organisations to formalise the experiential learning and
expertise of users professionals and academics involved in
teaching and research in health and social care.

How can researchers learn about PPI? The collaborative development of workshops to enhance the confidence of early career researchers to involve patients or the public in the design and conduct of their studies

Abstract:
A collaborative approach to developing awareness training for
NIHR doctoral award holders about patient and public
involvement.

We will give an account of how NETSCC, CCF and TCC worked
together to design a pilot workshop for targeted audiences
(with differing levels of experience in PPI) about the
importance of involving patients and the public in the design
and conduct of their studies.

We will show how involving a member of the public already
associated with NIHR and two award holders (members of the
workshop participant target population) helped us to design an

effective event.

We will examine:

- how we made use of the experience and contributions of different speakers
- how interactive exercises enabled participants to increase their understanding of approaches to PPI
- how it has changed practice among course delegates.

Our talk will be illustrated by photos and video and audio footage.

We will provide an opportunity to discuss:

- the best ways to change understanding about PPI in the researcher population and would welcome views on this, taking into account the needs of researchers
- how this work could be taken forward in the future.

The role of INVOLVE for developing the Framework for User Involvement in Research in Denmark

Abstract:
Denmark is on the top five list among nations for clinical research. It is documented that the Danish population has a very positive attitude towards participation in clinical research. In 2010 it was recognised that this attitude was just one aspect of an active user involvement in research.

This presentation will describe how and why the inspiration from INVOLVE has played a crucial role for the plans for implementation of a comprehensive user involvement in research in Denmark.

The Role of INVOLVE for developing the Framework for User Involvement in Research in Denmark

Performing an inquiry: An innovative model for involving people in the interpretation of research data

Abstract:
This workshop will explore how service users are being involved in the interpretation of qualitative research data, as part of a study looking at why people develop severe pressure ulcers (SPU). One of this study's challenges has been keeping the patient voice strong when data is interpreted by professionals. We are keen to see if service users interpret the data in the same way as a largely clinical research team.

To do this we will be holding a public engagement event with members of the Pressure Ulcer Research Service User Network UK, in May 2012. During this event participants will be asked

to interpret one of the case studies from the SPU project.

To make this event as engaging and accessible as possible, we will use a live simulation (a type of role play) and video clips to illustrate different perspectives within the data. Participants will then be asked to act as 'expert witnesses' and give their opinion on the case. The event will be evaluated using video.

During our interactive INVOLVE workshop we will take participants through part of the process described above and explore how performance-based approaches can facilitate involvement and create dialogue between service users and professionals.

Involving those detained in secure settings in research

Abstract:
What type of involvement do those detained in prison or secure mental health services have in shaping or conducting social research and evaluation? Putting aside philosophical and legal issues this might raise about their being 'members of the public' at that time, there is no doubt that people in receipt of services (the case for many of those in secure settings) have much to contribute to research. However, there are few opportunities to do so as a result of the restrictions and requirements of the institution. As part of evaluating services for women in secure settings, we explored ways of seeking their involvement in evaluation design which were meaningful to them and contributed to ownership of the findings by services as a whole. Using repertory grid

technique, we reflect on how this can be used to enable people to identify what matters most to them and what they think makes most difference to how they do or do not benefit from the service. The 'concepts' are tested with providers to help determine levels of shared understanding. These 'concepts' are also central to identifying indicators and in this way women contribute to the evaluation design.