Dr Kirstie Haywood, Senior Research Fellow (Patient Reported Outcomes) was invited to speak at an afternoon seminar hosted by the RCN Policy Unit at the RCN HQ on Thursday 19th November, 2009. The event highlighted the role of patient reported outcome measures (PROMs) in healthcare and the relevance for patients and nursing.

Dr Andrew Vallance-Owen, Group Medical Director, BUPA, gave an interesting presentation about PROMs in a commercial setting, with a particular focus on the relevance to current DH thinking and the potential future for PROMs in the healthcare arena. Professor Nancy Devlin, Director of Research, Office of Health Economics, talked about the value of PROMs to healthcare. Kirstie presented the results of a recent survey conducted by the RCN RI at Warwick of Continence Specialists. The survey explored the use of PROMs within a routine practice setting and highlighted the real-life challenges and barriers that currently exist with regards to the knowledge-base of health professionals, and the identification and application of PROMs within routine practice settings of relevance to nursing.

The take-home message was that significant support is required at both undergraduate and postgraduate levels to enable nurses and other health professionals to fully embrace the PROMs agenda.

Contact: Kate Seers
“We need a consensus on the most important topics for research”.

We need to understand the process of user involvement and the impact this has on health services. We need a consensus on the most important topics for research. As a result of the on-going programme of work undertaken by Dr Kirstie Haywood and Dr Sophie Staniszewska in relation to CFS/ME (Partnership for Research in CFS and ME: PRIME www.prime-cfs.org/) and their contribution to the UK National ME Observatory, Kirstie was invited to participate in a research priority setting exercise hosted by the Medical Research Council. The MRC have, for several years, identified CFS/ME as an important area for future research. The event was held over two days in November 2009 and was attended by more than 30 invited delegates, representing patients, patient groups and a range of health professionals with specific expertise in CFS/ME. Day one consisted of several presentations covering key topics of current interest. Day two consisted of group discussions with the aim of identifying key priorities for future research that should be supported by the MRC. The aim was to move towards a consensus on the most important topics. Professor Stephen Holgate chaired the event on behalf of the MRC and aims to present a synthesis of the results in the New Year.

Contact: Sophie Staniszewska

United Kingdom Clinical Research Collaboration (UKCRC) Jo Brett and Sophie Staniszewska have been undertaking a systematic review of the impact of patient and public involvement on health and social care research. This review has been funded by the United Kingdom Clinical Research Collaboration (UKCRC). We hope to substantially develop our understanding of the evidence base underpinning patient and public involvement and draw together recommendations for its future development in order to strengthen our understanding of what difference PPI makes.

One key area we have identified in the UKCRC review is the poor understanding of what impact means in relation to patient and public involvement. We are just about to start a follow-on study funded by Warwick University to explore how researchers and users think about impact, to help us understand what we should be capturing or measuring in the future.

Research Development Fund (RDF) The Warwick RDF Study is a small qualitative study that will involve interviews with up to 15 users and 15 researchers to develop our understanding of user involvement impact. The study is led by Sophie Staniszewska and Jo Brett. We hope to develop a clearer insight into the nature of user involvement impact, its dimensions and what influences impact. In addition we want to better understand how the context of involvement and the process or method used to undertake user involvement, might affect impact.

This study is an important step in creating the clarity around user involvement impact required for the next step in our programme: Developing an instrument to measure impact.

We are trying to secure funding for this next phase of our work. We are working collaboratively with Jackie Sturt and Dan Munday at the Warwick Medical School. If you are interested and would like to find out more please contact Jo Brett.

Contact: Sophie Staniszewska, Jo Brett
Michele Platt is a PhD student in her third year at the RCN Research Institute having successful passed her upgrade panel. Her work as Nurse Consultant for the Critical Care Outreach team and Lecturer at Nottingham University has led her to question the quality of care provided for acutely ill patients in ward settings. The focus of Michele’s work is therefore to explore what happens in practice when patients become ill, what communications and actions take place and how staff make sense of what they say and do.

A literature review has highlighted the extent of suboptimal care in this group, the limitations of tools to alert staff such as Track and Trigger scores and the challenges in relation to communication and subsequent action within multidisciplinary teams.

Despite research in some areas there is little understanding of the processes that help or hinder staff within ward environments. The intention of this study is to bridge this gap and provide a framework that will be useful for improving practice in this area.

A grounded theory methodology will be used combining observations of daily practice and in-depth qualitative interviews. Data will be analysed to develop core concepts that can be used to direct practice.

This is very valuable work and clearly links to the patients safety agenda. www.patientsafetyfirst.nhs.uk

We are delighted to be working with Michele who has a great deal to offer this area.

Contact: Liz Tutton

Sophie Staniszewska is part of a successful collaboration led by Dr Chris Burton at Bangor University that has secured a small grant from UKSRN (United Kingdom Stroke Research Network) for a research development group. The aim is to develop a fundable proposal that tests a generalist model of end of life care for adoption in stroke services to be submitted as a NIHR Programme Grant application.

The model is built on earlier, exploratory research, and will address practical challenges in delivering generalist end of life care in stroke services. These include timing the commencement of end of life care in non-cancer services; and addressing organisational and workforce factors that limit opportunities for implementing end of life care. Rigorous evaluation of the impact of this model on care processes and patient, family and staff outcomes has the potential to address a significant gap in both the stroke and end of life literatures, and generate evidence for service design and delivery across the United Kingdom.

Contact: Sophie Staniszewska

Dr Lorna Henderson received her doctorate from the University of Warwick in January. (Pictured above with Dr Liz Tutton, Senior Research Fellow, RCNRI). Lorna’s work has explored the role of disclosure in the management of long term conditions.

Quotation from a participant in Lorna Henderson’s study of disclosure.....

“...something like epilepsy or diabetes.....you have to disclose it. You have to make your employers aware cos they need to know if you have a hypo or a fit, what to do and sometimes you do feel you’re baring your soul to people and (they) know things that are quite private and personal”.

The RCN Research Institute, within the School of Health and Social Studies, at the University of Warwick, provides a vibrant student research community. If you are interested in undertaking a PhD, part time or full time, please contact: Prof Kate Seers.
the research process from concept design to actively undertaking research. The evidence suggests that real benefits can be gained from involvement although there are also limitations.

More work is required to understand which approaches work best and the meanings ascribed to underlying concepts and terminology. As the area is complex it is difficult to make comparisons across studies and hence further clarity is required.

Future challenges are to develop a conceptual model to help identify the impact of involvement and examine further methods for implementing successful models of involvement in practice.

This paper highlights the importance of patient and public involvement in health services at both local and National levels. This is now a legal requirement within the United Kingdom (UK) and reflects an international movement to increase patient and public involvement in the governance of health care systems.

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