

RCN RESEARCH INSTITUTE

DIRECTOR:

Prof Kate Seers

OUR RESEARCH THEMES:

Patient & Public
Involvement

Experience of Health
Care

Person Reported
Outcomes

Translating Knowledge
into Practice

*This newsletter presents
selected highlights of our
research. For details of the full
programme please see our
website.*

INSIDE THIS ISSUE:

Hip Fracture 2

Fire Study 2

**Women in
Leadership** 3

The Study of Pain 3

**Health Technology
Assessment
International** 4

Contacts 4

Website address:

<http://www2.warwick.ac.uk/fac/soc/shss/rcn>

RCN Research Institute



Newsletter

THE UNIVERSITY OF
WARWICK

VOLUME 4, ISSUE 4

JULY/AUG/SEP 2012

Impact of User Involvement

Brett J, Staniszewska S, Mockford C, Sandra Herron-Marx S, Hughes J, Tysall C, Suleman R. Mapping the Impact of Patient and Public Involvement (PPI) on Health and Social Care Research: A systematic review. Health Expectations. 19 July 2012 Doi:1111/J1369-7625.2012.00803

This paper aimed to identify the impact of patient and public involvement on health and social care research. Active involvement of service users in research can lead to research of greater quality and relevance owing to the unique perspective that users can bring to a research project. Interest in involvement has expanded internationally with many countries now actively involving users in research. However, involvement in health research has rarely been systematically evaluated.

A systematic review method was adopted for the study, utilizing the principles and methods provided by the NHS Centre for Reviews and Dissemination guidelines. A total of 66 studies reporting the impact of PPI on health and social care research were included. Impacts were reported for all stages of research.

During the initial stages of developing and setting up a research programme, users helped to identify user-relevant topics for the research agenda, helped prioritise topics for the research agenda, and offered pragmatic criticism and commented on the extent to which they perceived existing research proposals to be relevant or appropriate to users.

Studies reported that user involvement helped in assessing the appropriateness of research instruments, assisted in the development of questionnaires and interview schedules by identifying lines of inquiry not previously considered, suggested better timing of interventions, and assisted in recruitment

through greater access to the research community.

The review showed that the involvement of users during data analysis helped to ensure that emerging themes and trends were interpreted from the different lay perspectives as well as from the academic and clinical perspectives, and assisted in identifying research gaps. In addition, users became advocates for implementation and dissemination of results.

However, more challenging impacts of PPI were also identified including the time and cost of planning, collaborating with users and managing user involvement in the research. Furthermore, the lack of knowledge about the benefits of user involvement lead to tokenistic use of PPI, and researchers were concerned that incorporating user views into the research agenda may lead to divergence from scientific methods and cause ethical dilemmas during the protocol design. Users found PPI time consuming, and often felt left out of discussions or their views not taken seriously, leading to a loss of motivation to continue being involved.

The paper discusses the importance of having the right contextual factors in place for user involvement to succeed, such as funding and time to involve users, training for users, clear definition of roles of different parties involved, the right attitude, and having PPI policy in place. Consideration for the level of user involvement, the stages of the research study that users are involved in, and the design of involvement are also important. Further discussion highlights the need for future reporting of impact to include detailed description of how, where and when the user involvement was conducted and to consider PPI as a complex intervention that requires appropriate evaluation.

Contact: Jo Brett

Hip Fracture - PRO-Hip Study

PRO-Hip Patient Reported Outcomes following Hip Fracture. This study is a collaboration between the University of Warwick and the Trauma Unit at the John Radcliffe in Oxford.

For many patients, a hip fracture brings loss of mobility or loss of independence at home, and mortality is high. The aim of the PRO-Hip study is to find out how well we are measuring patient outcomes through a systematic literature review of the quality and acceptability of Patient reported

outcome measures (PROMs) used in the assessment of patients with traumatic hip fracture. This review has highlighted the poor quality and limited acceptability of all reviewed PROMs.

Further research is required which focuses on both the methodological quality of PROMs development and evaluation, and seeks to incorporate the patient perspective more actively.

The current phase of the study therefore aims to identify

important outcomes of relevance to traumatic hip fracture and its treatment, through interviews with patients 3 months after their surgery, and through focus groups with other stakeholders. The study is currently recruiting patients into the study.

Contact: Jo Brett, Kirstie Haywood

FIRE Study

A day (or two) trip to Bangor!

The FIRE (Facilitating Implementation of Research Evidence) study* is an EU FP7 funded study which began in 2009 and will be completed by June 2013. It is a pragmatic randomised controlled trial with an embedded process evaluation.

In 2010, evidence-based recommendations on continence



Menai Straits, Anglesey

care were given to three randomly assigned groups of 24 nursing homes in England, the Netherlands, Republic of Ireland and Sweden. Two groups have received different types of support, over either one or two years, to implement these recommendations into daily practice and one group just received the recommendations.

With the final data collections now complete in England both quantitative and qualitative analyses are currently taking place.

Both Bangor University and the University of Warwick are working with the England homes. Part of the qualitative analysis uses realistic evaluation methods to explore the context, mechanisms and outcomes of the implementation of the recommendations. The purpose of this approach is to see what works, for whom and in what circumstances.

In August, the researchers from both universities met up in Bangor to discuss the analysis so far in the different homes. The combined analysis for England will be discussed with the analyses from other countries this September when all researchers meet together in London.

*Seers K, Cox K, Crichton N, Tudor Edwards R, Eldh A, Estabrooks CA, Harvey G, Hawkes C, Kitson A, Linck P, McCarthy G, McCormack B, Mockford C, Rycroft-Malone J, Titchen A and Wallin L (2012). FIRE (Facilitating Implementation of Research Evidence): a study protocol. *Implementation Science* 2012, 7:25.

Contact: Carole Mockford, Kate Seers

Women in Leadership

Women in Leadership – Tackling Progression

Kate Seers participated in this course run by the Windsor Leadership Trust. It was held at Cumberland Lodge in Windsor and attracted a diverse range of participants from a wide variety of backgrounds. This led to some very interesting discussions

and insights, and a surprising number of shared issues. Two plenary speakers gave participants many issues to think about and debate. It was very valuable to discuss a range of leadership issues with other people in senior leadership positions.

Contact: Kate Seers



Cumberland Lodge, Windsor

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 International Association for the Study of Pain

The International Association for the Study of Pain (IASP) - 14th World Congress on Pain was held in Milan at the end of August 2012.

IASP is a truly multidisciplinary association, and basic scientists, a range of healthcare professionals and researchers meet to learn about new developments in pain and its management and discuss a range of topics.

Kate was on the Scientific Programme Committee and had thus been working with the Committee for some time on the scientific content of the meeting. The meeting attracted a record 7,500 delegates from all over the world. We were treated to excellent plenary speakers, over 70 topical workshops, and hundreds of informative posters, which changed every day. There were many discussions about research into pain management, and plenty of opportunity to network with key people in the area. It was a brilliant opportunity to

keep up to date with the latest pain research across a wide range of areas.

Contact: Kate Seers



Milan Conference Centre

Health Technology Assessment International

The Health Technology Assessment International (HTAi) Conference took place in Bilbao, Spain in June 2012. HTAi is the global scientific society for all those who produce, use, or encounter health technology assessment. The title of the conference was 'HTA in Integrated Care for a Patient Centred System.'

Sophie Staniszewska, in collaboration with the team from the National Clinical Guidelines Centre at the Royal College of Physicians presented the development of the Warwick Patient Experiences Framework (WaPEF). The WaPEF was developed within a scoping study commissioned by the National Clinical Guidelines Centre, which reviewed patient experiences in three main areas, cardiac care, diabetes and cancer.

The WaPEF provided the architecture for the development of the NICE Guidance on Patient Experiences, by helping the Guideline Development Group focus on areas of relevance and

importance to patients. Sophie Staniszewska was also part of the presentation at the same conference led by Liz Avital from the National Clinical Guidelines Centre at the Royal College of Physicians, on the development of the NICE Guidance.

This Guideline and Quality Standard represent a landmark in the development of guidance which synthesises a range of evidence sources through a process of consensus and provides guidance for the NHS on enabling a good patient experience. There has been international interest in this work, including the ways in which patients were integrally involved in its development. Papers from this work have been published. <http://guidance.nice.org.uk/CG138/Guidance/pdf/English>

Staniszewska S, Bullock I (2012). Can we help patients have a better experience? Implementing NICE guidance on patient experience. *Evidence Based Nursing*, 15(4):99 doi:10.1136/eb-2012-100988

O' Flynn N, Staniszewska S (2012). Improving the experience of care for people using NHS services: Summary of NICE Guidance. *British Medical Journal*, 344:d6422 doi:10.1136/bmj.d6422 (16 March 2012)

Contact: Sophie Staniszewska

The work of the RCNRI aims to:

- ▶ Produce high quality research that improves patient care and impacts on policy
- ▶ Increase research capacity within nursing by providing high quality research training
- ▶ Contribute towards the RCN delivering on its strategic objectives

Contact: Kate Seers

RCN Research Institute

School of Health and Social Studies
University of Warwick
COVENTRY
CV4 7AL

Website Address:

www2.warwick.ac.uk/fac/soc/shss/rcn

RCNRI Research Team Administrator:

Paul Kent

Phone: 024 761 50618

Fax: 024 761 50643

email: p.d.kent@warwick.ac.uk

RCNRI Staff and Email Contacts:

Jo Brett j.brett@warwick.ac.uk

Dr Kirstie Haywood k.l.haywood@warwick.ac.uk

Deirdre Kennedy d.r.kennedy@warwick.ac.uk

Dr Carole Mockford carole.mockford@warwick.ac.uk

Claire New c.e.new@warwick.ac.uk

Prof Kate Seers kate.seers@warwick.ac.uk

Dr Sophie Staniszewska sophie.staniszewska@warwick.ac.uk

Dr Liz Tutton liz.tutton@warwick.ac.uk



THE UNIVERSITY OF
WARWICK