RCN RESEARCH INSTITUTE

DIRECTOR:

Prof Kate Seers





RCN Research Institute Newsletter

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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.

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Website address:

http://www2.warwick. ac.uk/fac/med/ research/hscience/rcn

New International Journal

RESEARCH INVOLVEMENT AND ENGAGEMENT

New international journal for patient and public involvement in research

In collaboration with Biomed Central, the open access publisher, we have established a new journal, Research Involvement and Engagement, an interdisciplinary, health and social care journal focussing on patient and wider involvement and engagement in research, at all stages. Developing the evidence base to underpin patient and public involvement in health and social care research is one of the RCN RI core areas of research.

The journal is co-produced by all key stakeholders, including patients, academics,

policy makers and service users. Sophie Staniszewska is Co-editor in Chief, with a patient Co-editor in Chief, Richard Stephens, reflecting a new model of academic publishing which recognises the value of the patient contribution in co-producing knowledge. We encourage submissions from patients and researchers and have a pool of academic and patient peer reviewers who read each paper or commentary. We are busy reviewing papers and commentaries submitted to date, with a formal launch of Research Involvement and Engagement in June 2015.

http://www.researchinvolvement.com/

Contact: Sophie Staniszewska

Patient and Public Involvement

Patient and public involvement in health technology assessment in Sweden

Sophie Staniszewska was invited to the Swedish Health Technology Agency, SBU, in Stockholm, in December 2015, to present on the state of the current international evidence base in patient and public involvement.

SBU carries out comprehensive assessments of healthcare technology from medical, economic, ethical, and social standpoints, on behalf of the Swedish Government. SBU reports are used by the National Board of Health and Welfare, the Medical Products Agency and the Dental and Pharmaceutical Benefits Agency. Professional associations of health care personnel, such as doctors, nurses and dentists, can use SBU reports as a basis in preparing their own guidelines.

Sophie provided an overview of key issues that SBU needs to consider as it develops their

patient and public involvement work. The visit also provided the opportunity to develop a paper focused on the nature of evidence, with Sophie Werko who leads on PPI for SBU. Sophie Werko is co-chair, alongside Sophie Staniszewska, of the Methods and Impact Subgroup of Health Technology Assessment International Patient and Citizen Involvement in HTA Interest Sub-Group (PCISG).



Contact: Sophie Staniszewska

Emotional Aspects of Eating Disorders

Division of Clinical Psychology Annual Conference: Standing up and speaking out: Clinical Psychology and social context – Glasgow

In December 2014, Stephanie Tierney was part of a symposium entitled: 'There's more to it than weight and food: The emotional aspects of eating disorders.' Her presentation focused on a qualitative study exploring the 'anorexic voice' that patients depict as driving their weight-controlling behaviours.

Data consisted of written accounts from 21 women with anorexia nervosa. They described developing a strong bond with their 'anorexic voice'. However, overtime this relationship appeared to shift from being one based on comfort that

made them feel safe and supported, to a harsh and volatile encounter that damaged their physical and psychological well-being.

In the presentation, Stephanie related words of the women involved in her study to findings from others' research on domestic abuse.

Similarities within the two sets of data included:

- a) the effect of the relationship on individuals' self-esteem;
- b) feeling trapped within the relationship, and
- c) struggling to leave the relationship.

Of note, the conference also ran several sessions on the topic of compassionate care, which psychologists, like nurses, are seeking to address within their work. Sessions at the conference suggested this could be a difficult task due to current resource pressures and changes in the NHS. In a workshop on compassionate leadership, delegates deliberated the difficulty of being compassionate when there were significant levels of stress in an organisation, without an outlet for verbalising any anxieties.

The group suggested that a safe space for compassion-focused discussion was necessary, with protected time for reflection. The point was raised that lapses of compassion are often blamed on an individual but this overlooks the need to think about systems and how they become toxic, leading to critical incidents, such as those that occurred at Mid-Staffordshire and Winterbourne View.

Contact: Stephaney Tierney

Breaking Boundaries Review



Breaking Boundaries Review Launched

We have been part of a strategic review of public involvement in the National Institute for Health Research (NIHR). Sophie Staniszewska was Vice Chair for the Review, working closely with Simon Denegri, the National Director for Patients and the Public in Research and Chair of INVOLVE, who led the Review.

Patients, carers, researchers and international, third sector and industry representatives contributed to the review by submitting documents, audio and video evidence, completing questionnaires and online surveys, and through taking part in workshops, meetings and social media, all of which informed the final report and recommendations.

The review of public involvement in the NIHR, commissioned by the Director General Research and Development/Chief Medical Officer in March 2014, provided an opportunity for an independent review panel to assess how far the NIHR has been successful in achieving public involvement across its activities to date and to recommend a direction for the NIHR for the future that builds on these achievements.

"Going the extra mile," is now published on the NIHR website.

http://www.nihr.ac.uk/newsroom/get-involved-news/going-the-extra-mile-a-strategic-review-of-public-involvement-in-the-national-institute-for-health-research/2739

Contact: Sophie Staniszewska



Publications

Tierney, S. Kislov, R. Deaton, C. (2014) A qualitative study of a primary care based intervention to improve the management of patients with heart failure: the dynamic relationship between facilitation and context. *BMC Family Practice*, 15(1):153

Whitehead, L; Perkins, GD; Clarey, A; Haywood KL. (2015) A systematic review of the outcomes reported in cardiac arrest clinical trials: the need for a core outcome set. *Resuscitation*. Mar;88:150-7. doi: 10.1016/j.resuscitation.2014.11.013. Epub 2014 Dec 9.





The RCN Research Institute, within the Division of Health Sciences, Warwick Medical School 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.

Improving experiences of care

Launch of "Improving experiences of care: Our shared understanding and ambition"

Sophie Staniszewska has acted as academic advisor to the National Quality Board (NQB), which with the support from other partners, has published *Improving* experiences of care: Our shared understanding and ambition, which sets out a common way for the national health and care organisations on the NQB to talk about people's experiences of care and their roles in improving them.

This new vision is based on the Warwick Framework, an evidence -based account of what matters most to people about their experiences of care, which informed the development of the NICE <u>Guideline</u> and <u>Quality Standard</u> for patient experience (Staniszewska et al 2014).

The document includes our shared ambition for improving

people's experiences of care, and also includes examples of good practice and resources, to support organisations and individuals in improving experiences of care.

This approach puts a strong emphasis on what are sometimes called the relational aspects of care; in other words the human interactions between staff, patients and carers which underpin personalised, responsive and compassionate care (Baranski et al 2015).

Improving experiences of care: Our shared understanding and ambition is for all individuals and organisations within, or with an interest in, the health system. It also aims to provide people who use services with an understanding of what they can expect from their experiences of care.

Staniszewska S, Boardman F, Gunn L, Roberts J, Clay D, Seers K, Brett J, Avital L, Bullock I, O'Flynn N (2014). The Warwick Patient Experiences Framework:

patient-based evidence in clinical guidelines. International Journal of Quality in Health Care, 26 (2):151-7.

Baranski, A, Churchill N, Staniszewska S (2015). Building national consensus on experiences of care. Patient Experiences Journal (in press).

http://www.england.nhs.uk/wp-content/uploads/2015/01/improving-experiences-of-care.pdf

Contact: Sophie Staniszewska



Retrospective: Professional Culture

Tutton, E. Seers, K. Langstaff, D. (2008) Professional nursing culture on a trauma unit: experiences of patients and staff. Journal of Advanced Nursing 61(2); 145-153. doi: 10.1111/j.1365-2648.2007.04471.x

This paper identified patient centred care within three themes: closeness to suffering and death; therapeutic care as an active dynamic approach to care, and; working as a team to tailor the system to patients' needs. The study used ethnography with in-depth interviews and observations of daily ward life.

Closeness identified the way both patients and staff engaged in emotional work to process the impact of suffering and nearness to death. Patient's relived their experience of the injury event, were shocked at how little they could do and how much energy it took to undertake daily activities. For them life was an emotional rollercoaster of waiting for surgery and processing the uncertainty of recovery. Their journey

was shared by other patients in their bay who were a source of support but sometimes a source of worry or concern.

The staff had positive experiences of their work and loved the range of activities that included people with minor and major injuries, long term disabilities and care of the dying. They identified the high level of emotional work required. Strategies such as 'letting go' were used to process emotions and maintain momentum. They were aware that they feel overwhelmed and would sometimes become detached as a means of enduring until they felt they had the energy to re-engage with their emotions.

Therapeutic care was facilitated by a friendly open social environment that enabled patients to voice their needs and concerns. However the fundamental aspect was the proactive dynamic approach to care. This focused on being concerned for the patient,

knowing the patient, making decisions with patients, actively following through on those decisions and providing continuity of care. This element was fundamental to ensuring good quality care and actively focused on making life easier for patients. Working a team was crucial to the running of the trauma unit. There was a focus on knowing through doing. So all staff including senior staff were involved in the daily work with patients. This was a way of keeping nursing expertise within frontline care. Working together to share knowledge and skills helped develop the expertise of all staff. Active decision making was facilitated through nursing staff taking a lead in activities such as doctors rounds. Team energy was directed towards making things happen for individual patients whilst being aware of the needs of the whole group. This paper forms part of the body of knowledge informing our current work on compassionate care.

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