

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.

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Website address:

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



RCN Research Institute Newsletter

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International Association for the Study of Pain World Congress

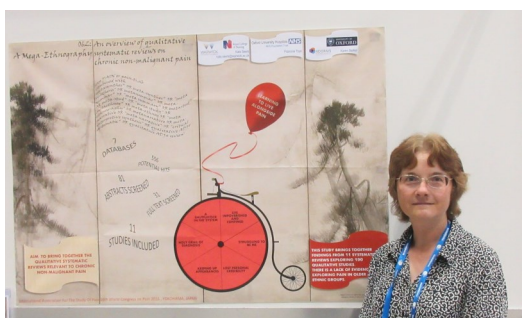
Professor Kate Seers presented a poster at the International Association for the Study of Pain World Congress in Japan on 27th September.

The poster reported on research that combined all the qualitative systematic reviews on chronic non-malignant pain. Dr Fran Toye and Professor Karen Barker at the Nuffield Orthopaedic Centre in Oxford were co-authors. We found common themes of people feeling like a shuttlecock in the system, struggling to be themselves, and driven by a search for a diagnosis.

The poster session went very well, with a lot of interest from delegates, and many interesting discussions took place. Many people commented on the quality of the poster and how it helped you get the key messages very quickly. With hundreds of posters in each session, that was very important!

We are currently writing this up as a paper so watch this space.

Contact: Kate Seers



Professor Kate Seers



National Convention Hall, Japan

RCN International Centenary Conference



Liz Tutton, Carole Mockford, Stephanie Tierney, Kate Seers, Sophie Staniszewska, Kirstie Haywood

The RCNRI team presented a symposium at the RCN International centenary conference in London in November. The title was 'Developing partnership through involving and

engaging others' with the following papers: Knowing: staff and patient experience by Dr Liz Tutton and Dr Stephanie Tierney; Involving: how we involve patients and users by Dr Carole Mockford; Influencing: how we use evidence to influence policy by Sophie Staniszewska; Engaging: how we make sure what matters to patients is measured by Dr Kirstie Haywood; Changing: how we use the evidence we need to examine and change our practice by Professor Kate Seers. The conference was very enjoyable and with lots of interactions with international colleagues.

Contact: Liz Tutton

Health Technology Assessment International

Sophie Staniszewska recently attended the annual meeting of the Health Technology Assessment International (HTAi) Patient and Citizen Involvement Special Interest Group in Manchester, hosted at the offices of NICE. This group includes researchers, academics, practitioners, patients and advocates from all over the world who bring a wide range of experience and perspectives.

The group met for three days and discussed a wide range of topics. It provided an opportunity to hear about examples of patient and public involvement in health technology assessment from around the world.

Sophie Staniszewska co-chairs the Methods and Impact sub-group with Sophie Werko, from the Swedish Agency for Health Technology Assessment. The annual meeting

provides invaluable time for the group to review strategy and the projects they are collaborating on as a network. A key output the group are preparing is a paper that reports an evaluation of patient and public involvement initiatives in health technology assessment, following an environmental scan of international agencies.

Contact: Sophie Staniszewska



ATOCP Annual Conference

Liz Tutton attended the Association of Trauma and Orthopaedic Chartered Physiotherapists (ATOCP) Annual Conference at Wolfson College Oxford on Saturday 26th November. She presented on 'Improving recovery and rehabilitation: learning through patient experience'. Liz used the interviews as part of the ankle injury

management trial published by Health Technology Assessment in October to illustrate the broader challenges patients face when recovering from injury. The discussion focussed on the impact of injury on emotions and how patient perspectives may change over time. Further research is required to review the utility of interventions aimed at promoting

recovery from injury. The conference was very lively with lots of discussion focussed on change to improve practice led by Professor Keith Willett and Professor Sallie Lamb. A great forum for looking to the future that I would thoroughly recommend.

Contact: Liz Tutton

The Compassionate Mind Foundation

On 21st October, Dr Stephanie Tierney (RCNRI) attended the Compassionate Mind Foundation's Conference in Manchester.

Several presentations highlighted the potential role that compassion-focused therapy may play in a range of

conditions, including cases of trauma, obesity, chronic stress, and as a public health initiative. The afternoon included a talk about compassion and organisational culture by Angela Kennedy (Tees, Esk and Wear Valleys NHS Trust). She emphasised the notion of 'common humanity' as

important for developing a compassionate culture, in which staff care for one another as well as for patients.

Contact: Stephanie Tierney

Publications

Haywood, KL; Wilson, R; **Staniszewska, S** and Salek, S (2016) Using PROMs in healthcare. Who should be in the driving seat - Policy makers, health professionals, methodologist or patients? *The Patient: Patient-Centred Outcomes Research*. 9(6): 495-498

Haywood, KL; Brett, J; **Tutton, E** and **Staniszewska, S** (2016) Patient reported outcome measures in older people with hip fracture: a systematic review of quality and acceptability. *Quality of Life Research*. (EPub ahead of print). doi: 10.1007/s11136-016-1424-1

Haywood, KL; Brett, J; Salek, S; Marlett, N; Penman, C; Shklarov, S; Norris, C; Santana, MJ and **Staniszewska, S** (2015) Patient and public engagement in health-related quality of life and patient-reported outcomes research: what is important and why should we care? Findings from the first ISOQOL patient engagement symposium. *Quality of Life Research*. 24(5):1069-76. doi: 10.1007/s11136-014-0796-3

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:

Professor Kate Seers.

American Heart Association

In November 2016 the city of New Orleans, Louisiana, hosted the American Heart Association's Scientific Sessions and Resuscitation Science Symposium (ReSS). Dr Kirstie Haywood was invited to be part of an inspirational Main Event Session entitled – 'Long-term Outcomes: What matters to patients?'

During this presentation she shared the results from the international, multi-stakeholder COSCA initiative – developing a Core Outcome Set for Cardiac Arrest effectiveness clinical trials – with a particular focus on the research that sought to better understand the outcomes that really matter to cardiac arrest survivors and their partners.

The research highlighted the real problems experienced by survivors as they struggled to respond to new symptoms and limitations, whilst striving to return to 'normality' or to define a new normal. However, these problems are not currently captured in

research or routine practice. The COSCA recommendation includes three core outcome domains which should be included in future clinical trials for out of hospital cardiac arrest - including survival at 30-days/hospital discharge, neurological function at hospital discharge and health-related quality of life within the first 12-months.

The session also included powerful presentations from Dr Kelly Sawyer and Dr Bryan McVerry – both emergency care doctors and survivors of cardiac arrest and traumatic injury respectively – both of whom highlighted the importance of engaging with survivors to better understand the outcomes that really matter and individual care needs.

Haywood, KL; Whitehead, L and Perkins, GD (2014) The psychosocial outcomes of cardiac arrest: Relevant and robust patient-centred assessment is essential. *Resuscitation*. 85(6):718-9.

doi: 10.1016/j.resuscitation.2014.03.305

Whitehead, L; Perkins, GD; Clarey, A and **Haywood, KL** (2015) A systematic review of the outcomes reported in cardiac arrest clinical trials: The need for a core outcome set. *Resuscitation*. 88:1 50-7. doi: 10.1016/j.resuscitation.2014.11.013

Contact: Kirstie Haywood



Dr Kelly Sawyer, Dr Kirstie Haywood, Dr Maureen McCunn, Dr Bryan McVerry.

Quality of Life Research

The International Society for Quality of Life Research (ISOQOL) held its 23rd Annual Conference in Copenhagen, Denmark during October 2016.

An ISOQOL Patient Engagement Taskforce has recently endorsed the concept of widening patient engagement within health-related quality of life (HRQOL) and measurement science research, fully supporting the full engagement of patients as research partners during ISOQOL conferences and in HRQOL research.

www.isoqol.org/about-isoqol

As co-chairs and founders of the Patient Engagement Special Interest Group (PE SIG), Dr Kirstie Haywood and Professor Sam Salek were instrumental in facilitating a fantastic plenary session entitled 'Increasing Patient Involvement in PRO Research' which celebrated this recent endorsement by ISOQOL. The session saw patient research partners, health professionals and health service researchers from both Europe and the

USA sharing the stage. Invited presenters included Dr Sophie Staniszewska from the RCNRI who shared the findings from GRIPP2, the new guidance on reporting of patient and public involvement in research.

The researcher's perspective was also illustrated by the experiences of Dr Danilella Lavalley from the University of Washington, Seattle, USA who leads CERTAIN Patient Voices, an initiative to incorporate the patient perspective into both quality and research activities. Dr Suzanne Dietz – a patient research partner - and Dr Anna Thit Johnsen then shared their experiences of working collaboratively on a project entitled 'Patient empowerment in cancer follow-up'.

Finally, Amye Leong, an internationally recognised patient advocate leader, health communications and policy strategist shared her experiences and journey of becoming a patient advocate.

The speakers were joined by the 2016 ISOQOL Patient Engagement Scholars - Cynthia Chauhan and Dr Jane Perlmutter.

Contact: Sophie Staniszewska and Kirstie Haywood



Dr Sophie Staniszewska, Dr Daniella Lavalley, Cynthia Chan, Prof Sam Salek (seated), Dr Susanne Dietz, Dr Kirstie Haywood, Amye Leong (seated), Dr Jane Perlmutter, Dr Anne Thit Johnsen.

RCN Research Institute

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