

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

Valuing Patient Engagement

Valuing Patient Engagement (PE) in Patient Reported Outcomes (PRO) research: an International PE Café
Kirstie L Haywood, Sam Salek, Anne Lyddiatt, Samantha Brace-McDonnell, Sophie Staniszewska.

In 2013, the International Society for Quality of Life Research (ISOQoL) hosted the first "Patient Engagement (PE) Café" which sought to explore the role of PE in PRO-research. Whilst communicating their enthusiasm for PE – and the potential to enhance the relevance of PRO measures and measurement science - delegates raised concerns over the lack of good practice guidance, limited evidence-base and the failure to include patients in the process! Two key challenges were defined: 1) Ensuring that patient research partners were present at the next conference; and 2) Developing a framework for PE in PRO-research.

In response, the PE special interest group, led by Dr Kirstie Haywood and Prof Sam Salek worked hard to embrace patient centricity for the 2014 conference, resulting in the awarding of the first ISOQOL PE Scholarships to Anne Lyddiatt (Canada) and Samantha Brace-McDonnell (Warwick Medical School, UK). Anne and Samantha worked collaboratively with the PE Special Interest Group to influence development of the second PE Café, held in Berlin during October 2014: the focus of which was to explore the values that should underpin PE in PRO-research and inform development of a good practice framework.

The event provided a fun and enjoyable opportunity to explore together the challenges for PE in PRO-research, drawing on and describing a wide array of international experiences. Eighty participants - 12 of whom were patient partners (another milestone for ISOQOL!) – communicated a diversity of views, values and opinions during the 90-minute event. The 'Wall of Engagement' made a welcome

return– with all participants encouraged to write their thoughts and suggestions on sticky labels that were subsequently attached to the 'wall'! (picture below). Participants clearly enjoyed the opportunity provided by the 'café' format to meet with other delegates – including the patient research partners - and to explore important issues of relevance to the community. The activity will result in a core set of values to underpin good PE which we hope will be endorsed by the ISOQOL community. The results will be presented to the community at next year's annual conference.

The 2014 Conference was a historic moment in the 21-year life of ISOQOL and will be remembered as the year that patients were positioned firmly at the heart of ISOQOL and PRO-research (<http://blogs.bmj.com/bmj/2014/11/07/paul-wicks-patients-at-the-heart-of-quality-of-life-research/>)

All our patient partners were absolutely brilliant with their active participation, enthusiasm and passion which radiated throughout the conference ensuring that this becomes a permanent feature at the future meetings of ISOQOL and of its strategy.

Kirstie Haywood



Sam Salek, Anne Lyddiatt, Caroline Burdett, Carolyn Morris, Samantha Brace-McDonnell, Kirstie Haywood

A view from patient engagement scholars

Patient Engagement and Patient-Reported Outcomes (PRO) research: the International Society for Quality of Life Research (ISOQOL) welcomes the first Patient Engagement (PE) Scholars Sami McDonnell and Anne Lyddiatt

The 21st ISOQOL conference in Berlin welcomed us as the first Patient Engagement Scholars to attend the scientific conference and share our perspectives as patient partners. Everyone from ISOQOL was very welcoming and inclusive from the moment we became PE Scholars, with the result that we didn't feel like strangers upon our arrival – thank you.

We experienced a fantastic level of engagement from many delegates at the conference and were able to share our experiences on individual and group levels. We thoroughly appreciated the opportunity to take part in some of the special interest group (SIGs) meetings and the second ISOQOL 'PE Café' which sought to explore the values associated with the

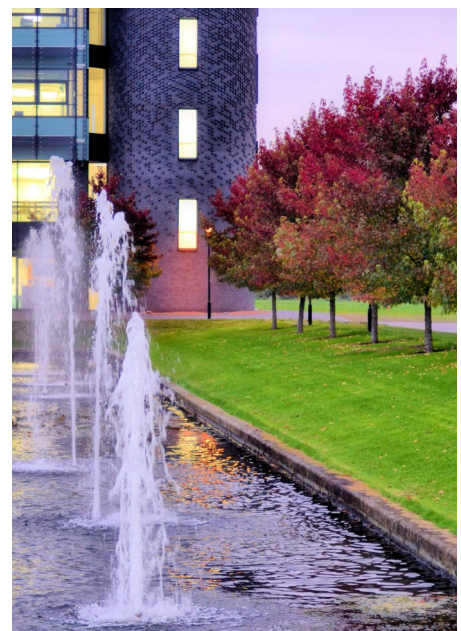
doing and impact of PE in PRO-research.

Sharing our experiences in healthcare and research was a positive encounter that renewed our vigour for continuing involvement as patients. Collaborating with delegates at the conference has given value to the patient perspective and can only continue to flourish within the ISOQOL community and beyond.

The conference program presented some very interesting symposia and sessions which we wished there had been more time to explore and learn from. The poster exhibition across the days of the conference provided the opportunity to engage with individual delegates and explore some of the more intricate issues around patient engagement and the accessibility of research outputs for the general public on a global level.

The overarching feeling at the end of the conference is excitement for the future of patient and public engagement in research and healthcare. As the first Patient

Engagement Scholars we are enthused by the ISOQOL community's response to our presence and the future involvement of patients within the scientific community. The importance of the patient agenda has been recognised as integral to the work of academics and clinicians and we look forward to taking this to Vancouver next year.



Recovery after Hip Fracture

Evaluating recovery following hip fracture: a qualitative interview study of what is important to patients

Patients who had sustained a hip fracture were invited to participate in semi-structured interviews up to 4-months post-hip repair to explore what was important to them when thinking about their recovery.

For those patients who were mobile pre-injury and able to communicate, stable mobility (without falls or the fear of falling) was the most important

factor. Many required assistive devices, extra support, or adapted to their new limitations. However, many patients were unable to disentangle fracture and problems from other health conditions.

Griffiths F, Mason V, Boardman F, Dennick K, Haywood K, Achten J, Parsons N, Griffin X, Costa M. Evaluating recovery following hip fracture: a qualitative interview study of what is important to patients.

BMJ Open. 2015 Jan 6;5 (1):e005406

Kirstie Haywood



Publications

Seers K (2014) Qualitative systematic reviews: their relevance of our understanding research relevant to pain. *British Journal of Pain*. Doi: 10.1177/2049463714549777 published online 22 September 2014

Toye, F., Seers, K., Barker, K. (2014). A meta-ethnography of patients' experiences of chronic pelvic pain: struggling to construct chronic pelvic pain as 'real'. *Journal of Advanced Nursing*. Early view online 1st August 2014 <http://onlinelibrary.wiley.com/doi/10.1111/jan.12485/abstract>

Lovatt, M. Nanton, V. Roberts, J. Ingleton, C. Noble, B. Pitt, E. Seers, K. Munday, D. (2015) The provision of emotional labour by health care assistants caring for dying cancer patients in the community: A qualitative study into the experiences of health care assistants and bereaved family carers. *International Journal of Nursing studies* 52 (1):271-279

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.

Core Outcomes Sets

Involving parents in developing a core outcome set on glue ear in cleft palate

Stephanie Tierney attended the Cleft Lip and Palate Association's annual conference in October. This event is a chance for people with experience of cleft lip/palate (e.g. patients and parents), clinicians and researchers to come together to discuss issues relevant to this condition.

As part of the day, Stephanie was involved in a session that gathered feedback from parents on important areas to measure in research on glue ear (which is a common problem for children with a cleft palate). This formed part of a bigger study to develop a core outcome set - an agreed recommendation of 'what' should be measured and reported in trials on a specific topic - on glue ear in cleft palate.

Stephanie had conducted some earlier qualitative work for this core outcome set development. At the

conference, parents were informed about key areas that might be included in the core outcome set on glue ear in cleft palate. They then could state, using a computer voting system, how far they thought each area should be included, on a scale of 1-10.

Feedback from parents at this session and earlier workshops will ensure that what is measured in future research on this topic is relevant to those affected by a cleft as well as to clinicians. The final project results will be published as a Health Technology Assessment report in 2015.

Stephanie Tierney



Workshop participants

Isobel Menzies Lyth

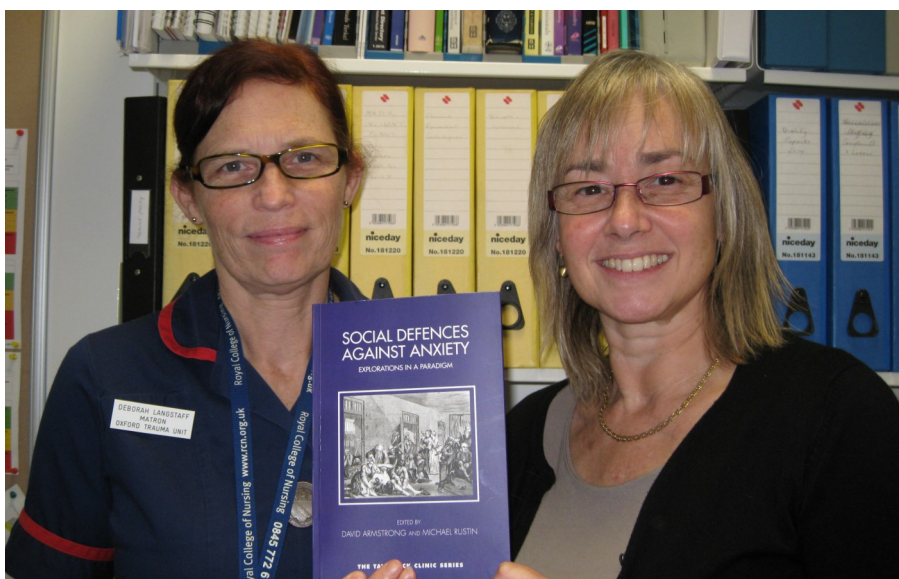
Liz Tutton and Debbie Langstaff have contributed a chapter to David Armstrong and Michael Rustin's book on *Social Defences against anxiety*, explorations in a paradigm published by Karnac books. The book provides a theoretical and practical exploration of social defences in a range of settings: health and nursing, the private sector, social welfare and education. The chapter reflects on Isabel Menzies Lyth's (1960) study of the way nursing was enacted at that time and examines some of the developments in nursing in light of current concerns.

Menzies Lyth identified the routinised and ritualistic nature of nursing work that mitigated against developing relationships, failed to use staff's skills and abilities and created a heightened sense of anxiety. Much work has occurred in nursing research and practice to develop improved ways of working and better care environments for people in need of health services. Developments in practice have occurred through a better understanding of the craft of nursing,

finding ways of organizing nursing that facilitate knowing the patient, and exploring the way emotional labour is enacted in practice. Current health care, societal and managerial changes require us to revisit the fundamental ways in which nursing is undertaken

whilst being attuned to our past. Re-examining how we experience and make sense of anxiety within the current context may be a fruitful way forward.

Liz Tutton



Debbie Langstaff, Liz Tutton

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