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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/wrn](http://www2.warwick.ac.uk/fac/med/research/hscience/wrn)



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Review of Carers' Experience

This paper is published in Disability and Rehabilitation and highlights how carers' struggle to find the information they need. Saletti-Cuesta, L. Tutton, E. Langstaff, D. Willett, K. (2018) Understanding informal carers' experiences of caring for older people

with a hip fracture: a systematic review of qualitative studies. Disability and Rehabilitation. Apr;40(7):740-750
doi:10.1080/09638288.2016.1262467 Epub 2016 Dec 15 <http://www.tandfonline.com/doi/full/10.1080/09638288.2016.1262467>

Cardiac Arrest Research

Measuring What Matters in Cardiac Arrest Research: the COSCA-initiative

Recent recommendations for a multi-stakeholder, internationally endorsed core outcome set for cardiac arrest research (COSCA) have been well-received by delegates at international resuscitation conferences. In September 2017, Kirstie Haywood was invited to share the findings from the Warwick Medical School led COSCA-initiative during both the second Post-Resuscitation Rehabilitation Conference in Sweden and the European Resuscitation Congress (ERC) in Germany.

Working in collaboration with survivors of cardiac arrest and their advocates, the research involved participants from 13 countries, who contributed to an on-line modified Delphi survey and consensus meeting. The COSCA guidance includes the assessment of three core outcomes, as a minimum, in future cardiac arrest research: survival (at hospital discharge and/or xx days), neurological function (with the modified Rankin Scale (mRS) at hospital discharge and/or xx days) and health-related quality of life (HRQoL) (at xx as a minimum; and xx in the first year). A survivor-reported measure of HRQoL does not exist; current guidance

therefore recommends use of a generic measure (the Short-Form 36-item health survey (SF-36); Health Utility Index (HUI-3); EQ-5D-5L).

COSCA is endorsed by both the International Liaison Committee on Resuscitation (ILCOR) and the American Heart Association (AHA). Publications from the initiative are currently in press with Circulation and Resuscitation.



Kirstie Haywood presenting at the conference in Sweden

Contact: Kirstie Haywood

Cardio-Pulmonary Resuscitation



The First Round Table of Cardio-Pulmonary Resuscitation (CPR) – The Anancy Invitational

In October 2017 Kirstie Haywood was invited to participate in a senior scientific meeting that sought to explore the current challenges and advances in cardio-pulmonary resuscitation (CPR). International clinicians and scientists presented cutting edge research and engaged in debate that sought to advance CPR and highlight challenges for the future.

Whilst much of the meeting focused on the quality of CPR, Kirstie’s focus was the quality of survival: specifically,

the importance of engaging with survivors and their family members to better understand their unmet post-resuscitation care needs and experiences and how this should inform the provision of healthcare. The meeting was hosted at Le Meriyeux Foundation, on the shores of Lake Annecy, France.

<https://www.youtube.com/watch?v=Bc5CXGxU2YM>

Contact: Kirstie Haywood

Quality of Life Research



Patient Engagement and Health-related Quality of Life research: how to do it well

In October 2017, Kirstie Haywood led an international workshop which sought to engage participants in the exploring the ‘best’ approaches towards effective patient engagement

(patient and public involvement) in health-related quality of life research.

The workshop was part of the International Society for Quality of Life (ISOQOL) research annual conference held in Pennsylvania, USA. Kirstie co-hosted the workshop with patient research partners – Maarten de Wit, Jennifer Horonjeff, Jenifer Bostock (ISOQOL PE Scholar) and Philip Posner (ISOQOL PE Scholar) – and fellow academics – Sam Salek and Lori Frank (Patient Centred Outcomes Research Institute (PCORI)).

The workshop attracted media attention from US radio stations, resulting in Kirstie participating in a 30 minute interview with Adrienne Berg for Generation Bold Radio which sought to promote the importance of engaging with patients and members

of the public in health-related quality of life research. A great opportunity to promote the great work being undertaken at Warwick Medical School.



Kirstie Haywood and Sam Salek (Co-Chairs of the PE SIG) with Jennifer Bostock and Philip Posner (ISOQOL PE Scholars 2017)

Contact: Kirstie Haywood

PhD Students

Warwick Research in Nursing, 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.

Selected Publications

Bivins, Roberta E., **Tierney, Stephanie** and **Seers, Kate**. (2017) *Compassionate care: not easy, not free, not only nurses*. *BMJ Quality & Safety*, 26(12) <http://dx.doi.org/10.1136/bmjqs-2017-007005>

Ahmed, Imran., Chawla, Amit., Underwood, Martin., Price, Andrew J., Metcalfe, Andrew., Hutchinson, Charles E., Warwick, Jane., **Seers, Kate**., Parsons, Helen and Wall, Peter D. H. (2017) *Tourniquet use for knee replacement surgery*. *Cochrane Database of Systematic Reviews*, 11. CD012874. ISSN 1469-493X <https://doi.org/10.1002/14651858.cd012874>

Toye, Fran., **Seers, Kate**., **Tierney, Stephanie** and Barker, Karen Louise. (2017) *A qualitative evidence synthesis to explore healthcare professionals' experience of prescribing opioids to adults with chronic non-malignant pain*. *BMC Family Practice*, 18. 94. ISSN 1471-2296 <https://doi.org/10.1186/s12875-017-0663-8>

Sujan, Mark-Alexander., Howard-Franks, Hannah., Swann, Garry., Soanes, Kirsti., Pope, Catherine., Crouch, Robert., **Staniszewska, Sophie**., Maxwell, Elaine., Huang, Huayi and Cooke, Matthew. (2017) *Impact of advanced autonomous non-medical practitioners in emergency care: protocol for a scoping study*. *BMJ Open*, 7 (1). e014612. ISSN 2044-6055 <http://dx.doi.org/10.1136/bmjopen-2016-014612>

Haywood, KL., Pearson, N., Morrison, LJ., Castrén, M., Lilja, and G., Perkins, GD. (2018) *Assessing health-related quality of life (HRQoL) in survivors of out-of-hospital cardiac arrest: A systematic review of patient-reported outcome measures*. *Resuscitation*, 123: 22-37. [http://www.resuscitationjournal.com/article/S0300-9572\(17\)30756](http://www.resuscitationjournal.com/article/S0300-9572(17)30756)

Assessment of Fatigue

In October 2015 I started my PhD, supervised by Dr Kirstie Haywood, Dr Liz Tutton and Dr Jon Packham. My PhD aims to improve the assessment of fatigue in a specific rheumatic disease – Axial Spondyloarthritis (AxSpA). AxSpA patients frequently report physical symptoms of illness such as pain and reduced mobility, which are addressed with medication and physio/hydrotherapy. However, patients report fatigue as a significant part of the illness, yet there is no specific method to assess this and how it may impact on a patient's life.

AxSpA fatigue is a complex, multi-dimensional symptom which can complicate healthcare provision – how do we measure it? How do we know if treatments or interventions are working? The solution to this is the development of an AxSpA-fatigue specific

questionnaire that is both patient-derived, and patient self-completed. The use of a questionnaire enables specific aspects of fatigue, and how it may impact on the patient (physically, socially, emotionally), to be quantified. This quantification via a questionnaire allows the patient to communicate their experience of fatigue in a meaningful way to help the healthcare professional tailor healthcare provision to their needs.

My PhD project uses a mixed-methods approach to develop an AxSpA-fatigue specific questionnaire. I have also included patients as research partners to ensure the questionnaire is relevant and captures what is important to patients. To date, I have completed interviews with patients exploring their lived experiences of AxSpA-fatigue to create a 'picture' of what AxSpA-

fatigue is. I have also reviewed this in separate focus groups with patients and healthcare professionals and researchers to ensure it is relevant and acceptable to both the patient and the professional. I now have a draft long-form version of this questionnaire which will be finalised in anticipation of field-testing.

Contact: Nathan Pearson



Nathan Pearson

Public Involvement and Engagement

An international network for public involvement and engagement in health and social care research

Sophie Staniszewska is one of the founder members of a new international network for patient and public involvement and engagement in research in collaboration with Simon Denegri (NIHR), Richard Morley (Cochrane), Gary Hickey (INVOLVE) and Heather Bagley (COMET).

We launched the international network for public involvement and engagement in health and social care research in London in November 2017 when 33 people from ten countries came together in London, UK. Participants ranged from PPI 'practitioners' and

managers, involved members of the public, researchers, policy makers, and health professionals.

This is an exciting time for patient and public involvement (PPI) in health and social care research internationally. PPI is a rapidly growing, important global movement aspiring to produce better and more relevant research resulting in services and treatments that patients and the public need. Together we are creating an opportunity to change the face of research across the world, so that it better reflects the needs and priorities of patients, carers and the public.

We believe the time has come to join together and build a network, enabling the sharing of expertise and evidence-

base good practice. For organisations starting to develop public involvement in their own country, it would offer a powerful network of support to enable faster progress. This movement would have the power to influence international and regional health and research organisations.



Launch of the International Network

Patient Involvement in the HTA

Patient Involvement in Health Technology 2017 Eds Facey, K. Hansen, H, Single A. Springer Nature Singapore Pte Ltd

This is the first book to offer a comprehensive guide to involving patients in health technology assessment (HTA). Defining patient involvement as patient participation in the HTA process and research into

patient aspects, this book includes detailed explanations of approaches to participation and research, as well as case studies. Patient Involvement in HTA enables researchers, postgraduate students, HTA professionals and experts in the HTA community to study these complementary ways of taking account of patients' knowledge, experiences, needs and preferences. With cohesive contributions from

more than 80 authors from a variety of disciplines around the globe, it is hoped this book will serve as a catalyst for collaboration to further develop patient involvement to improve HTA.

<https://link.springer.com/book/10.1007/978-981-10-4068-9>

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