

Services After Hospital for People with Memory Loss

Services after Hospital: Action to develop REcommenDations (SHARED study)



Telford International Centre

people living with memory loss who leave an acute hospital and return to their homes.

Lay co-researchers, accompanied by the lead researcher, have conducted semi-structured interviews in two NHS Trusts. We interviewed 15 pairs of patients living with memory loss and their carers at hospital discharge, and again at 6 and 12 weeks post discharge. We also interviewed health and social care staff, devised a framework for analysis of the data, and facilitated focus groups with study participants to develop and finalise the recommendations.

The co-researchers are currently involved in writing papers, and presenting to a variety of audiences. The study is funded for two years by the NIHR: Research for Patient Benefit programme.

Mockford C. (2015) A review of family carers' experiences of hospital discharge for people with dementia and the rationale for involving service users in health research. Commissioned paper for the Journal of Healthcare Leadership June 2015: 7: 21-28.

Contact: Carole Mockford

Four lay co-researchers and a lay member of the Project Advisory Group of the SHARED study accompanied the lead researcher, Carole Mockford and study administrator, Claire New, to the UK Dementia UK Congress on 5th November at Telford International Centre. Our presentation was well received. Everyone enjoyed the other presentations and meeting the variety of people who were also attending the conference.

The SHARED study has had substantial lay input from the development of a research idea through to dissemination of the results. In 2011, carers helped to shape the project idea at a meeting held in London by the Alzheimer's Society Research Network and the National Institute for Health Research (NIHR). Further lay involvement has continued with the active involvement of lay co-applicants and lay members of the Project Advisory Group.

The aim of the SHARED study has been to develop service user led recommendations for



Uma Sharma, Sue Boex, Richard Grant,
Carole Mockford, Claire New,
Yvonne Diment, Andrew Entwistle

The Barbers' Company Scholarship

The Barbers' Company Clinical Nursing Scholarship 2016

The Barbers' Company Clinical Nursing Scholarship was set up to enable nurses/midwives making a career in clinical practice to undertake further education, research or a clinical project.

The Scholarship, of up to £7,500, is offered for the fees or subsistence of a nurse/midwife normally undertaking a taught Masters' programme or Doctorate relevant to nursing/midwifery or research in an academic

department in the United Kingdom, or at an approved academic department of nursing overseas. The Scholarship can be awarded to an individual or shared between individuals and is specifically intended for nurses/midwives in, or planning to return to, clinical practice.

The successful candidate will be expected to submit a report on their work at the end of the year in which the Scholarship is awarded, and may be asked to share some aspect of their work at a Scholarship Seminar. There is no formal

application form and applicants are asked to submit a 500 word supporting statement covering their motivation for undertaking their course/research and what they anticipate they will achieve, together with a short Curriculum Vitae and covering letter to:

Paul Kent
PA to the Director
RCNRI, Warwick Medical School
University of Warwick
Coventry
CV4 7AL

The closing date for applications is the **28 February 2016**.

Dr Louise Stayt

We were absolutely delighted to learn that one of our former PhD students Dr Louise Stayt has been awarded the first British Association of Critical Care Nurses (BACCN) National Institute of Health Research (NIHR) research grant. Very well done Louise.

Kate Seers and Liz Tutton supervised Louise's PhD which explored patients' experiences of technology in intensive care. The findings are available in

<http://wrap.warwick.ac.uk/53594/> and Stayt L, Seers K & Tutton L (2015) Patients' experiences of technology and care in adult intensive care: a Heideggerian phenomenological study. *Journal of Advanced Nursing*. 71 (9):2051-2061 DOI: 10.1111/jan.12664

Louise is taking forward her PhD research by focusing on patients and family members' experiences of utilising a patient diary to support psychological recovery whilst in

intensive care. This builds on her PhD findings that "families play an important role in helping patients make sense of their experiences by filling in gaps in memory and helping them to sort the real from unreal memories". Louise is a senior lecturer at Oxford Brookes University, and we wish her well with her study.

Contact: l.stayt@brookes.ac.uk

Patient and Public Involvement



The course participants pictured in Geneva

Sophie (3rd from left) was invited to a workshop at the Brocher Foundation in Geneva which focused on improving equitable access to health care through increasing patient and public involvement in prioritisation decisions. The workshop brought together global representatives of all the relevant disciplines to refine an emerging social values decision support tool that addresses content and processes values involved in prioritisation decisions. The plan is to test the tool with patients and the public in a range of countries. It was a fascinating meeting and collaborative papers from the event are now in progress.

Contact: Sophie Staniszewska

Publications

Churchill, N. Baranski, A and **Staniszewska, S.** (2015) Building national consensus on experiences of care. *Patient Experiences Journal* 2(1): article 17.

Achten, J, Parsons, NR, Bruce, J, Petrou, S, **Tutton, E**, Willett, K, Lamb, SE and Costa, ML (2015) Emergency medicine - Protocol for a randomised controlled trial of standard wound management versus negative pressure wound therapy in the treatment of adult patients with an open fracture of the lower limb: UK Wound management of Open Lower Limb Fractures (UK WOLFF). *BMJ Open* e009087 doi:10.1136/bmjopen-2015-009087

Tierney, S. O'Brien, K. Harman, NL. Madden, C. Sharma, RK and Callery, P. (2015) Otitis Media With Effusion: Experiences of Children with Cleft Palate and their Parents. *Cleft Palate-Craniofacial Journal* 52: 23-30.

Tierney, S. Blackhurst, M. Scahill, R and Callery, P. (2015) Loss and rebuilding: A qualitative study of late diagnosis of cleft palate. *Journal for Specialists in Pediatric Nursing* 20(4):280-9

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.

International Award: Patient Reported Outcomes in Maternity

International award for Quality of Life research for PhD student Dr Ayesha Mahmud. Outcome reporting in UK-based maternity trials – a systematic review of randomized controlled trials

Dr Ayesha Mahmud is currently developing a patient reported outcome measures (PROM) for maternity as part of her PhD at the University of Birmingham. She is jointly supervised by Professor Khaled Ismail and Dr Sara Kenyon (Birmingham) and Dr Kirstie Haywood.

Guidance for outcome reporting in maternity clinical trials does not currently exist. The first phase of Ayesha's PhD studies has involved a wide-ranging, systematic review of outcomes reported in UK Maternity clinical trials RCTs (2000-2014). Most outcomes (88%) were clinician-reported (CROs), with only 12% classified as patient-

reported (PROs). Over half identified PROMs were ad hoc, trial-specific measures without clear evidence of development or testing.

The impact of pregnancy and childbirth as understood from the perspective of the mother was poorly assessed. These findings underpin the importance of seeking to better understand the experience of mothers and the outcomes that they value in the pursuit of defining acceptable and relevant pregnancy-related outcome measures. A core outcome set for maternity clinical trials is urgently required.

Ayesha gave a superb oral presentation of her work, to an international panel of judges at the International Society for Quality of Life Research (ISOQOL) conference held in Vancouver, Canada in October. She was awarded the top prize and 'Student

Award for Excellence' in recognition of her superior achievement in quality of life research.

Contact: Kirstie Haywood



Kirstie Haywood, Ayesha Mahmud

Young Investigator Award: Core Outcomes for Cardiac Arrest

Laura Whitehead is a PhD student supervised by Gavin Perkins and Kirstie Haywood. She was awarded the prestigious Ian Jacobs Young Investigator Award at the European Resuscitation Council Congress held in Prague in October. The presentation provided an overview of the COSCA study (Core Outcomes for Cardiac Arrest effectiveness trials).

The COSCA study sought to define a core outcome set (COS) for cardiac arrest effectiveness trials. A COS is an agreed minimum number of outcomes to be reported across all trials to improve consistency in reporting.

A systematic review of RCTs (2002-2012) described significant heterogeneity in reporting and a lack of long-term and patient-reported assessment, further supporting the need for a COS. To further understand the outcomes important to survivors of cardiac arrest interviews were conducted with survivors and their partners. Interviews

highlighted; physical symptoms, emotional well-being, social well-being and participation, and the impact to others as important health outcomes.

Next an international two-stage Delphi survey sought consensus on the most important outcome domains identified from the review and interviews. After 2 rounds 27 outcomes across the patient trajectory and the core areas of pathophysiological manifestations, survival and life impact reached high consensus levels of critical importance.

The findings including economic impact, were discussed further during a lively and informative 2-day international consensus meeting held in advance of the COSCA meeting. Twenty-three voting participants (including 2 cardiac arrest survivors and 2 patient representatives) discussed which outcomes should be included as part of core outcome set and how and when these should be reported.

The meeting concluded: survival to hospital discharge/30days, neurological outcome at hospital discharge/30days and health related quality of life within 1 year should be reported as part of a COS.

Contact: Kirstie Haywood



Laura Whitehead, Professor Maaret Castrén (*Chair of the European Resuscitation Council*) and Professor Judith Finn (*wife of the late Professor Ian Jacobs*).

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