

## RCN RESEARCH INSTITUTE

### DIRECTOR:

Prof Kate Seers

### OUR RESEARCH THEMES:

Patient and Public Involvement & Patient Experiences

Patient 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/soc/shss/rcn>

# RCN Research Institute



## Newsletter

THE UNIVERSITY OF  
**WARWICK**

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## Patient Reported Outcomes

### Quality and Acceptability of Patient Reported Outcome Measures (PROMs) used in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME): a systematic review.

This systematic review sought to identify and evaluate all PROMs used in published studies of patients with CFS/ME for quality and acceptability against an appraisal framework which captured evidence of both the thoroughness and results of evaluations: evidence of measurement (reliability, validity, responsiveness, interpretability, data quality/precision) and practical properties (feasibility, acceptability), and the extent of active patient involvement (consultation, collaboration, user-led) was sought. Systematic literature searches were made to identify clearly defined and reproducible PROMs and published evidence of development/subsequent evaluation (years 1980-2011). Completion of a PROM, where patients are sources of data, was not considered a form of active involvement.

137 articles relating to 77 clearly defined PROMs (CFS/ME-specific n=11; domain-specific n=55; generic n=11)

were reviewed. With the exception of the generic SF-36, all measures had mostly limited evidence of essential measurement and practical properties. Sample sizes were often small and study design poorly reported. Only eight measures (10%) had evidence of test-retest reliability. Assessment of PROM relevance and comprehensiveness by adults with CFS/ME was largely unavailable. Evidence of construct validity was limited by the failure of authors to explicitly evaluate hypothesised associations between variables. Evidence of responsiveness was limited, and statistical evaluations of score interpretation were not identified. Most PROMs did not have published evidence of acceptability or feasibility. Active patient involvement was largely cursory and poorly reported.

In conclusion, the quality and acceptability of reviewed PROMs is limited, and recommendations for patient-reported assessments are difficult. Significant methodological and quality issues in PROM development / evaluation were identified by the appraisal framework, which must be addressed in future research. Moreover, clear discrepancies exist between what is measured in research and how patients define their

experience of CFS/ME. Future PROM development / evaluation must seek to involve patients in an active collaboration to measure outcomes of importance using relevant and credible methods of assessment.

This research was funded by GUS Charitable Trust and was part of the PRIME initiative (Partnership for Research in ME/CFS <http://prime-cfs.org/>).

Haywood KL, Staniszewska S, Chapman S. (2011) Quality and Acceptability of Patient Reported Outcome Measures (PROMs) used in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME): a systematic review. *Quality of Life Research. in press April 2011*

**Contact: Kirstie Haywood**

The work of the RCNRI aims to:

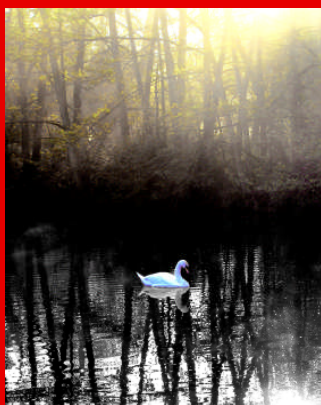
- ▶ Produce high quality research that improves patient care and impacts on policy
- ▶ Increase research capacity within nursing by providing high quality research training
- ▶ Contribute towards the RCN delivering on its strategic objectives

**Contact: Kate Seers**

Digital Posters: a way of displaying complex information in an eye catching way.



Sophie and Hugh Grant at the Museum of London



Warwick Swan

## Health at Warwick Poster Day

A wide range of research institutes, centres and departments gave a presentation of their work at the University of Warwick, Institute of Health Poster Day. It was a great opportunity for researchers to share their work with the public, a range of stakeholders, practitioners and academics. A new development this year were

the digital posters, many of which were beautifully crafted with music and moving images. Professor Seers presented the work of the RCNRI and a range of posters were displayed to present ongoing research studies. Posters presented were: *RCNRI Research Themes*; *Evaluating Ankylosing Spondylitis Quality of Life (EASI-QoL)*; *Facilitating Implementation of Research*

*Evidence (FIRE Study)*; *Patient Important Outcomes following Traumatic Hip Fracture*; *Hope in Trauma and Stroke Care*; and *Conceptualising, Measurement, Impact and Outcomes of Patient and Public Involvement in Health and Social Care Research*.

Full list of posters available at: [http://www2.warwick.ac.uk/fac/cross\\_fac/healthatwarwick/events/posters2011/posters](http://www2.warwick.ac.uk/fac/cross_fac/healthatwarwick/events/posters2011/posters)

Contact: Liz Tutton

## Patient and Public Involvement

### Nursing & Patient and Public Involvement - Why it matters for nurses and how to do it effectively

Sophie Staniszewska in collaboration with Mark Platt from the RCN Policy Unit, who leads in patient and public involvement, ran a fringe event at RCN Congress April 2011 focusing on patient and

public involvement and the role of nursing. The event was well attended and participants discussed a range of issues in relation to patient and public involvement in health and social care.

### DIPEX (healthtalkonline)

On 15<sup>th</sup> March 2011, Sophie Staniszewska attended the DIPEX (healthtalkonline) celebration of its 10<sup>th</sup>

anniversary at the Museum of London at an event chaired by broadcaster Jenni Murray. Speakers included Hugh Grant, patron of DIPEX, Andrew Lansley, Secretary of State for Health, Clare Gerada, Chair of the Royal College of GPs and Mike Richards, National Cancer Director.

[www.healthtalkonline.org](http://www.healthtalkonline.org)

Contact: Sophie Staniszewska

## RCN International Nursing Research Conference

The 2011, International Nursing Research Conference, RCN was held in Harrogate this year. A team from the RCNRI attended the conference and took part in churning sessions and the lively debates that took place after each presentation. Many important research issues were raised and discussed and there were plenty of opportunities for networking. The following papers were presented by the RCNRI team:

*What are the impacts of patient and public involvement (PPI) in health and social care research?* A systematic review of the evidence by Jo Brett;  
*Challenges in Researching Patient Experience* by Liz Tutton & Sophie Staniszewska;  
*Peri-operative Implementation Study Evaluation: Implementing evidence into practice* by Kate Seers;  
*Pathways to urgent and emergency care for people with diabetes* by Kate Seers;

*The impact of user involvement in service development and planning: Where is the evidence base?* Results from a systematic review by Carole Mockford and;  
*Strengthening the evidence base of involvement: Guidance for reporting the impact of patient and public involvement* by Sophie Staniszewska.

Contact: Liz Tutton

## PhD Student: Jo Brett

Jo Brett is a PhD student in her first year at the RCN Research Institute, having gained 1+3 funding from the Economical and Social Research Council (ESRC). Her study aims to explore the experiences of patients who have had a traumatic hip fracture after they have been discharged from hospital. More specifically, she wants to explore the support needs and care needs of this patient group to facilitate the development of a patient-focussed care pathway for hip fracture patients after being discharged from hospital.

The study has a strong user-involvement element to it, involving patient partners, support groups and support group website forums in the study. Jo aims to evaluate the impact this has on the different stages of the research.

A literature review of patient experiences of having a hip fracture is being carried out, and Jo plans to conduct interviews with patients 3-4 months after hip fracture surgery in her second year.

**Contact: Jo Brett**

The RCN Research Institute, within the School of Health and Social Studies, 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.**

## Trauma Outcomes

Professor Keith Willett, National Clinical Director of Trauma Care, ran a workshop to explore the utility of a range of outcome measures for major trauma. Key stakeholders were present and nursing was represented by Debbie Langstaff Matron of the John Radcliffe Trauma Unit in Oxford and Liz Tutton.

The key agenda for the day was to consider which outcome measures could be used to measure the impact of care on patient recovery in people with major trauma. There is a strong government agenda to measure outcomes across the NHS. It is proposed to build on the existing work of the Trauma and Audit Research networks (TARN) that already collects valuable data regarding the process of care for those who experience major trauma. TARN collects data such as: time of chest drain insertion, time and seniority of medical review

within each speciality; time from arrival to head CT scan; and time to theatre for abdominal injuries. A review of the literature and relevant outcome tools prepared for the meeting by TARN and the Cochrane Injuries Group suggest a practical way forward may be to use the Glasgow Outcome Score extended version (GOSE) developed for traumatic brain injury and the EQ5D that identifies five factors: mobility; self-care; usual activities; pain/discomfort; anxiety/depression in addition to an overall rating of general health. Both these measures could be administered 6 months after injury and would provide useful data regarding the progress of patient recovery.

The workshop provided ample opportunity for discussion of these proposals and a diverse range of issues in relation to the use of outcomes measures were covered.

One of the areas covered was the utility of existing outcome tools. Many people had a preference for a variety of outcomes measures and issues were identified in relation to: their validity (if they measure what they intend to measure) and their reliability (if they measure the same thing over time); whether they were suitable for this population of trauma patients; the lack of a pre injury status; whether the same result was achieved if a family member or carer filled them in; how they were useful for clinical decision making and whether they would provide the basis for improving practice; how the tools were derived and if patients had been involved in the development of the tools, and; whether the tools were sensitive enough to measure the effect of different approaches to rehabilitation.

**Contact: Liz Tutton**



# Barbers' Company Clinical Nursing Scholarship

On 25 May 2011, the awards panel for the Barbers' Company Clinical Nursing Scholarship met at the Barbers' Hall in London to consider the short-listed candidates for this year's award. Six applicants were short-listed for interview from a total of 86 applications. The Worshipful Company of Barbers, one of the City of London's ancient livery companies, give £7,500 every year to enable nurses making a career in clinical nursing to undertake further education, research or a clinical project.

The successful applicants for 2011 are all nursing in different areas and studying a wide variety of subjects, from an Advanced Nurse Practitioner undertaking a PhD at City University to a Senior Sister studying an MSc in Children's Nursing; and 2 specialist nurses registered for doctorates in Clinical

Practice and a Post Graduate Certificate in Osteoporosis and Falls Management.

This was the final awards panel for Mr John Bootes from the Barbers' Company after 23 years, in which he has interviewed 138 candidates and

awarded over £100,000 to nurses in clinical practice. Joining Prof Kate Seers and Prof Claire Hale on future awards panels, as the representative of the Barbers' Company, will be Dr Jeremy Bolton.



2011 Awards Panel (left to right)  
Mr Bootes, Prof Hale, Prof Seers, Dr Bolton

Painting of Henry VIII by Hans Holbein the Younger. Commemorates the Act of Parliament of 1540 by which the Company of Barbers and Surgeons of London was set up. This picture, on wood panels, shows the King handing a document to his Serjeant-Surgeon, Thomas Vicary, Master in 1541, in the presence of other important medical men and barbers.

## RCN Research Institute

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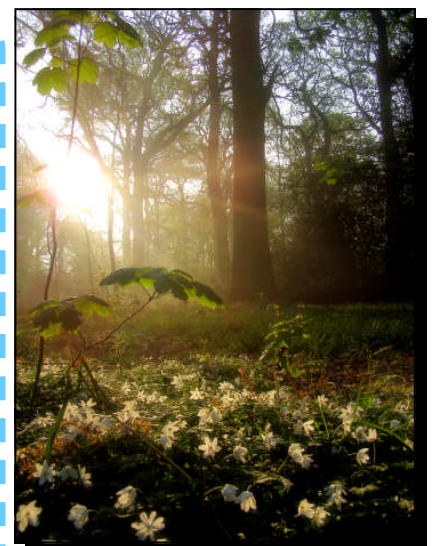
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Early dawn at Warwick