RCN RESEARCH INSTITUTE

DIRECTOR:

Prof Kate Seers

RCN Research Institute



I, ISSUE 2



OUR RESEARCH THEMES:

Patient Experiences and Involvement

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

Strategic Alliance: RCN and the University of Warwick

The RCNRI was formerly the Research Team at the Royal College of Nursing Institute from 1996-2007.

When the RCN wished to develop a Strategic Alliance with another Higher Education Institute to enhance its ability to deliver high quality research, the University of Warwick was successful in its bid to be the RCN's Strategic Alliance Partner for Research.

The RCNRI has been a Research Centre within the School of Health & Social Studies at the University of Warwick since 1st August 2007.

AIMS OF THE RCN RESEARCH INSTITUTE

The RCNRI is committed to staying at the leading edge of research in our specialist areas via national and international inter-disciplinary collaboration. Specifically we aim to:

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

Contact: Kate Seers

RCN Research Institute and the NHS Centre for Involvement

The NHS Centre for Involvement (NCI) supports and encourages the NHS and other organisations to involve patients and the public in health and social care decision-making.

The Evidence Practice Team,

led by Dr Sophie Staniszewska, has recently moved from the NCI to the RCNRI to ensure that its research can flourish.

The team is still part of the NCI but can now benefit from being part of an academic department. The work of the

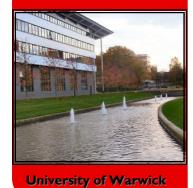
team complements research that the RCNRI already undertakes around patient and public involvement and patient experiences.

Contact: Sophie Staniszewska



"So far there has been limited public involvement"

"Patient and Public Involvement is integral to the commissioning process"



World Class Commissioning

Andy Gibson (NCI) is working on developments in World Class Commissioning. This means that the internal market in NHS services, first developed in the 1990s, will be opened up to much greater competition from the private and independent sector. Central to making commissioning world class is the strong emphasis placed by the Government

on the need to work closely with local patients and communities to develop services which meet local health needs.

This project will be examining how patient and public involvement will be embedded into World Class Commissioning.

The potential for local people to become involved in the development of new

services from the very beginning of the process is exciting. There has been limited patient involvement in commissioning to date, as it has tended to be viewed as a complex task requiring specialist expertise that service users do not possess.

Contact: Andy Gibson

The State of Patient Involvement in NHS Trusts Survey

This survey was conducted by the NHS Centre for Involvement (NCI) and published in November 2008. The Survey examines various aspects of the state of PPI (Patient and Public Involvement) highlighting areas of interest. The findings suggest:

Most Trusts were engaging well with PPI as a concept, had a strategy, and monitored activity but would benefit from further clarification of the definition of PPI, as well as guidance towards LINks.

- ▶There is a wide range of definitions of PPI, with PPI being considered more effective when the definition was tailored to a specific audience.
- Senior managers, along with PPI leads, play a key role in enabling and encouraging PPI activity throughout the Trust.
- Engaging in learning opportunities, such as conferences, was beneficial to maintaining awareness and exchanging best practice.

- Financial resources vary widely, from no additional financing to adequate amounts.
- LINks are developing well, but this has stalled some PPI activity.

Contact: Sandy Herron-Marx

Building an Evidence Base

The concept of involving patients, carers and the public in service design and development has been interpreted and reported in many different ways over several years.

In order to build on existing knowledge and experience, a firm evidence base needs to be developed over the next few years.

This evidence base will be informed by a review being undertaken to explore the impact of PPI on service planning and development. It will also examine how PPI has been interpreted and implemented into healthcare

services, what the gaps and limitations are according to existing literature, and how these can be addressed.

Contact: Carole Mockford

PhD Student: Dr Eileen Turner

We are delighted to announce that Eileen Turner has received her Doctorate from the RCN Research Institute and University of Manchester. Dr Turner is a Consultant Nurse in Diabetes Care at King College Hospital. Her work used an ethnographic approach to explore the socio-cultural meanings of insulin in the context of a diabetes clinic.

Diabetes is a common endocrine disorder but taking insulin is problematic for many people living with diabetes. Through observation, interviews and focus groups Eileen's work has unravelled the nuances around taking insulin. She identifies the concept of the 'insulinised body' and how this is constructed through many body types and matters.

An 'assumptive leap' is also noted where professionals jump to conclusions about diabetic management without exploring the full implications of treatments for people living with diabetes. Through exploring why people living with diabetes and professionals 'do what they do' in the context of a diabetic clinic the study provides clear guidance for future practice.

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 or full time, please contact:

Prof Kate Seers.

POPPY: Parents of Premature babies-Your needs

This study is a collaboration between the RCNRI and the National Childbirth Trust (NCT), BLISS (The premature baby charity), NPEU National Perinatal Epidemiology Unit, University of Oxford. The fund holders are the NCT and it is funded by the Big Lottery.

While medical advances mean that very young infants have a good chance of surviving when they are born, the impact of this experience on the infant and the parents cannot be underestimated. The birth of a pre-term infant can be an intensely stressful, confusing and a difficult time for parents and families. There are now around 80,000 pre-term infants born in the UK each year, 22,000 of these needing to be cared for in neonatal intensive care. The POPPY study has

provided a better understanding of the experiences of a range of parents with pre-term babies, particularly in relation to information, communication and support.

The findings support a family-centred model of care which embraces the mother and father or significant others in the medical care of their infant.

Contact: Jo Brett

"Mothers felt marginalised, often not seeing their baby for a long time, and not given sufficient support or information from the neonatal unit".

Patient choice in the treatment of diabetes

Dr Natasha Posner (RCNRI) in collaboration with Professor Vivien Coates (Institute of Nursing Research, University of Ulster) has received funding from The Insulin Dependent Diabetes Trust to conduct a pilot study assessing the extent to which adults with type I or type 2 diabetes experience desired choice in relation to their treatment, and the role

of information provision in relation to choice. Several focus groups will be held with a range of people with diabetes to explore participants' preferences for and experience of choice in relation to the treatment of their diabetes, their preferences for information relating to their treatments, and their experiences of

receiving or accessing such information. The evidence and insights gained from analysis of the focus group discussions will be used to design a questionnaire for possible use in a larger collaborative research study of the diabetic population. Dr Lydia Lewis who recently completed her ESRC post-doctoral fellowship is helping with this research.



Warwick Arts Centre

RCN Research Institute

School of Health and Social Studies
University of Warwick

Coventry CV4 7AL

Website Address:

www2.warwick.ac.uk/fac/soc/shss/rcn

RCNRI Administrator/Office Manager: Paul Kent

Phone: **024 761 50618**Fax: **024 761 50643**





RCNRI Staff — Contact Emails

j.brett@warwick.ac.uk

j.m.chandler-oatts@warwick.ac.uk

andrew.j.gibson@warwick.ac.uk

claire.hawkes@warwick.ac.uk

k.l.haywood@warwick.ac.uk

sandy.herron-marx@warwick.ac.uk

lydia.lewis@warwick.ac.uk

carole.mockford@warwick.ac.uk

natasha.posner@warwick.ac.uk

r.putz@warwick.ac.uk

kate.seers@warwick.ac.uk

tanya.smith@warwick.ac.uk

sophie.staniszewska@warwick.ac.uk

liz.tutton@warwick.ac.uk

Selected Recent Publications

Ara RM, Packham JC, **Haywood KL**. (2008) The direct health care costs associated with Ankylosing Spondylitis patients attending a UK secondary care rheumatology unit. *Rheumatology*. 47(1),68-71.

Evans R, Edwards AGK, Elwyn G, Watson, E, Grol R, **Brett J** & Austoker J (2008) It's a maybe test: men's experiences of prostate specific antigen testing in primary care. *British Journal General Practice* **57**, 303–310.

Wyke A Barby A Cowper A Lilleystone J **Staniszewska S** Williams S (2008) What is quality of life in patients? *British Journal of Healthcare Management* **14**, 280-287.

Pratt JP, **Chandler-Oatts J**, Nelstrop L, Branford D, Pereira S, Johnston S. (2008) Establishing gold standard approaches to rapid tranquillisation: A review and discussion of the evidence on the safety and efficacy of medications currently used. *Journal of Psychiatric Intensive Care*; 4(1-2):43-57.

Staniszewska S, Herron-Marx S, Mockford C (2008). Measuring the impact of patient and public involvement: The need for an evidence-base. International Journal of Quality in Healthcare, 20 (6): 373-374.

Taylor R (2008) Use of the internet to optimise collaborative healthcare research. *Nursing Standard*. **22** (38),35-38.



All photos by Paul Kent