

Pressure UlceR Programme Of reSEarch (PURPOSE): using mixed methods (systematic reviews, prospective cohort, case study, consensus and psychometrics) to identify patient and organisational risk, develop a risk assessment tool and patient-reported outcome Quality of Life and Health Utility measures

Jane Nixon,^{1*} E Andrea Nelson,² Claudia Rutherford,¹
Susanne Coleman,¹ Delia Muir,¹ Justin Keen,³
Christopher McCabe,⁴ Carol Dealey,^{5,6} Michelle Briggs,⁷
Sarah Brown,¹ Michelle Collinson,¹ Claire T Hulme,⁸
David M Meads,⁸ Elizabeth McGinnis,⁹
Malcolm Patterson,¹⁰ Carolyn Czoski-Murray,⁸
Lisa Pinkney,³ Isabelle L Smith,¹ Rebecca Stevenson,¹
Nikki Stubbs,¹¹ Lyn Wilson^{1,12} and Julia M Brown¹

¹Clinical Trials Research Unit, School of Medicine, University of Leeds, Leeds, UK

²School of Healthcare, University of Leeds, Leeds, UK

³Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

⁴Department of Emergency Medicine, University of Alberta Hospital, Edmonton, AB, Canada

⁵Research and Development Team, University Hospitals Birmingham NHS Foundation Trust, Birmingham, UK

⁶Department of Nursing, School of Health and Population Sciences, University of Birmingham, Birmingham, UK

⁷School of Health and Community Studies, Leeds Beckett University, Leeds, UK

⁸Academic Unit of Health Economics, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

⁹Department of Tissue Viability, Leeds Teaching Hospitals NHS Trust, Leeds, UK

¹⁰Sheffield University Management School, University of Sheffield, Sheffield, UK

¹¹Wound Prevention and Management Service, Leeds Community Healthcare NHS Trust, Leeds, UK

¹²Research and Development Department, The Mid Yorkshire Hospitals NHS Trust, Wakefield, UK

*Corresponding author

Declared competing interests of authors: Jane Nixon has received post-doctoral fellowship grant funding from the Smith & Nephew Foundation; Jane Nixon, E Andrea Nelson, Claudia Rutherford, Susanne Coleman and Julia Brown have received grant funding from the Worldwide Universities Network Leeds Fund for International Research Collaborations; Delia Muir has received consultancy funding from Smith & Nephew PLC on behalf of the Pressure Ulcer Research Service User Network for the UK (PURSUN UK) for patient and public involvement input into educational materials; and Jane Nixon, Claudia Rutherford and Carol Dealey have received grant funding from Mölnlycke Health Care. Carol Dealey is a member of an expert advisory board which advises Mölnlycke on the use of dressings for pressure ulcer prevention. We confirm that the report content is acceptable to the other funding bodies (Smith & Nephew Foundation and the Worldwide Universities Network Leeds Fund for International Research Collaborations) and that there are no competing proprietary interests in respect of the tools and methods set out in the monograph.

Dedication to Professor Donna Lamping: It was with great sadness that the team learned of Donna's illness in 2010 and her passing in 2011 at age 58. Donna was an international expert in the field of health psychology, health status and quality of life assessment. Educated and trained in centres of excellence in Canada and the USA, she moved to the London School of Hygiene and Tropical Medicine in 1992 where she established her position as an international leader in the field. Donna was an inspiration to the team, making a major contribution to the conception, design and gold standard evaluation of the Pressure Ulcer Quality of Life (PU-QOL) studies in her role as a grant co-applicant and through PhD supervision of Claudia Rutherford (née Gorecki). We feel privileged to have worked with her and dedicate this monograph to her memory.

Published September 2015

DOI: 10.3310/pgfar03060

Plain English summary

Pressure UlceR Programme Of reSEarch

Programme Grants for Applied Research 2015; Vol. 3: No. 6

DOI: 10.3310/pgfar03060

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Plain English summary

Background

Pressure ulcers (sometimes called bedsores or pressure sores) are areas of damaged skin and tissue. They are usually caused by limited mobility and often occur as a complication of another illness or injury. They can lead to extended hospital stays, reduced quality of life and, rarely, death.

Pressure ulcer programme of research

The Pressure Ulcer Programme Of reSEarch (PURPOSE) comprises two themes: risk assessment and quality of life. Each theme was split into work packages.

Theme 1: risk assessment

Work package 1: pain

We found that many patients reported pressure ulcer and pressure area pain and that pressure area pain is a pressure ulcer early warning sign. We demonstrated the importance of assessing and reacting to pressure ulcer and pressure area pain.

Work package 2: severe pressure ulcers

We investigated the development of particularly severe pressure ulcers and found that they are more likely to occur in environments where:

- clinicians fail to listen to patients and carers
- clinicians fail to recognise and react to signs that patients are at risk of, or already have, pressure ulcers
- services are not organised effectively.

Work package 3: risk assessment

Risk assessment tools are used to identify people at risk of pressure ulcers. We have developed and tested an up-to-date risk assessment tool.

Theme 2: quality of life

Work package 4: Pressure Ulcer Quality of Life

General health questionnaires may not capture what is important to people with a specific health problem. We have developed and tested a pressure ulcer questionnaire to assess issues that are important to patients.

Work package 5: pressure ulcer cost–utility

To determine whether or not new treatments are good value for money, we have developed a pressure ulcer-specific economic measure to evaluate the cost-effectiveness of pressure ulcer treatments more accurately.

Patient and public involvement

The Pressure Ulcer Research Service User Network (PURSUN UK) was established as part of PURPOSE. PURSUN UK is made up of service users with personal experience of pressure ulcers or pressure ulcer risk. Members have contributed throughout the programme and continue to be involved in research.

Programme Grants for Applied Research

ISSN 2050-4322 (Print)

ISSN 2050-4330 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: nihredit@southampton.ac.uk

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This report

The research reported in this issue of the journal was funded by PGfAR as project number RP-PG-0407-10056. The contractual start date was in September 2008. The final report began editorial review in December 2013 and was accepted for publication in November 2014. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, CCF, NETSCC, PGfAR or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PGfAR programme or the Department of Health.

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