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 Wilson1,12 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
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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.

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Plain English summary

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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.
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Editorial contact: nihredit@southampton.ac.uk

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