

Press Release

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Partnership gives a voice to pressure ulcer patients

A new survey aims to give patients and carers a voice in the search to find the most effective prevention and treatment for pressure ulcers.

Pressure ulcers – pressure sores or bed sores - are hard-to-heal wounds that are painful for patients and distressing for both them and their carers. A wide range of interventions are available for their treatment and management, but evidence of their effectiveness remains limited.

The James Lind Alliance Pressure Ulcer Priority Setting Partnership (JLAPUP), which includes health scientists from the Universities of York and Manchester, is conducting the survey. It is part of a project to identify and prioritise the questions about prevention and treatment that matter most and to encourage research in these priorities.

JLAPUP needs as many patients, carers and clinicians as possible to take part in its survey.

The partnership is funded by a National Institute for Health Research (NIHR) Programme Grant, as part of the Wounds Research for Patient Benefit Programme (WRPB) at Leeds Community Healthcare NHS Trust in collaboration with the Department of Health Sciences at York and the University of Manchester's School of Nursing, Midwifery and Social Work.

The survey can be completed on-line or on paper, with all responses being included in a process to find the top ten priorities.

Sally Crowe, of the James Lind Alliance and Chair of the Partnership, said: "Pressure ulcers are distressing and disabling for many people in the UK and also pose significant treatment challenges and costs to the NHS. So this is an area that needs new perspectives and solutions, especially from people that live with, or are at risk of, pressure ulcers, and those who treat and care for them. The James Lind Alliance looks forward to working with a wide variety of people and groups on this important project."

Dr Mary Madden, from the University of York's Department of Health Sciences, said: "Though there are no patient-led groups specifically representing the interests of people with or at risk of pressure ulcers, many other groups include people affected by them. We are inviting these and allied clinician and carer groups to join JLAPUP to help with 'uncertainty gathering' – highlighting gaps in knowledge - and prioritisation. Current members include the Multiple Sclerosis Society, Spinal Injuries Association and Action on Elder Abuse."

Professor Nicky Cullum, from the University of Manchester's School of Nursing, Midwifery and Social Work, who leads the Wounds Research for Patient Benefit research programme, said: "Research funds are precious so it is essential that we use them wisely to address the uncertainties that matter most to patients, carers and the clinicians who deliver care. This James Lind partnership is focused on ensuring we get these priorities right."

For further information or to take part in the survey visit www.jlapressureulcerpartnership.co.uk or contact Richard Morley on 01904 321105.

Ends

Notes to Editors

- The Wounds for Patient Benefit programme presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0407-10428).
- The National Institute for Health Research provides the framework through which the research staff and research infrastructure of the NHS in England is positioned, maintained and managed as a national research facility. The NIHR provides the NHS with the support and infrastructure it needs to conduct first-class research funded by the Government and its partners alongside high quality patient care, education and training. Its aim is to support outstanding individuals (both leaders and collaborators), working in world-class facilities (both NHS and university), conducting leading edge research focused on the needs of patients. www.nihr.ac.uk
- Programme Grants for Applied Research are awards made by the National Institute for Health Research (NIHR) to fund high quality research that addresses areas of priority or need for the NHS. Programme Grants award up to £2 million over three to five years to the best applied research teams from the NHS and academia working together to provide evidence to improve health outcomes in England through the promotion of health, the prevention of ill health and optimal disease management (including safety and quality). Programme Grants typically fund programmes of interrelated, high-quality research projects and associated infrastructure that are designed to deliver findings that can be directly and practically applied in the relatively near future, for the benefit of patients and the NHS. www.pgfar.nihr.ac.uk
- The James Lind Alliance Pressure Ulcer Partnership (JLAPUP) is a partnership of organisations representing patients, carers and clinicians. Its aim is for patients, carers and clinicians to work together to:
 - identify important areas where further research is needed to improve care;
 - assemble and publish these in the Database of Uncertainties about the Effects of Treatments (UK DUETs) which publishes treatment uncertainties from patients, carers, clinicians, and from research recommendations, covering a wide variety of health problems www.duets.nhs.uk;
 - decide which of these research questions are most important.

A list of the most important research questions will then be published and provided to organisations that fund research about pressure ulcer treatment and prevention.

More information is available at: www.jlapressureulcerpartnership.co.uk or follow the JLAPUP on Twitter at www.twitter.com/JLAPUP

- The James Lind Alliance is funded and supported by the Medical Research Council and the National Institute of Health Research. More information about the James Lind Alliance is available at www.lindalliance.org.
- The Department of Health Sciences at the University of York is large and multidisciplinary, offering a broad range of taught and research programmes in the health and social care field, including nurse education (for which it was ranked the top department in the country for nursing education, by the 2011 Times Good University Guide). It aims to develop the role of scientific evidence in health and healthcare through high quality research, teaching and other forms of dissemination. In the recent national assessment of research quality, the University was rated equal first for its Health Services Research and fourth for its Nursing and Midwifery research. Visit www.york.ac.uk/healthsciences