Pressure ulcer partnership chooses top 12 pressure ulcer prevention and treatment questions.

On the 28th March 2013 patients, carers and health professionals came together at Leeds, Shine to choose its top research questions. Read below to find out how the top 12 were chosen, what will happen next and the big reveal – what were the final questions?

Forming the partnership
On 22nd March 2011, people from across the UK attended a meeting organised by Wounds Research for Patient Benefit team including the University of York and Leeds Community Healthcare NHS Trust in collaboration with James Lind Alliance to launch the James Lind Alliance Priority Setting Pressure Ulcer Partnership (JLAPUP). At this meeting, people with experience of pressure ulcers (either providing care and treatment or receiving it) came together with representatives of groups and charities with an interest in the management and treatment of pressure ulcers to discuss treatment and prevention uncertainties associated with pressure ulcers.

The objective of JLAPUP was clarified (to discover the research questions that matter most to patients, carers and clinicians) and a steering group was appointed from attendees.
Launch of the James Lind Alliance Pressure Ulcer Priority Setting Partnership, University of York, 22nd March 2011

The story so far
Earlier this year we asked patients, carers and healthcare professionals where they would like to see further research or where they thought there was uncertainty about the best medical and nursing care. We gathered nearly 1,000 questions about pressure ulcer prevention and treatment.

A quarter of these were non-intervention questions (for example the biology of pressure ulcers, how they are distributed through the population, environmental factors and so on) and we will report on these questions separately.

Three quarters were about what works in pressure ulcers treatment and prevention. We sorted, categorised and combined duplicate to produce 284 distinct questions.

Significant finding!
We checked to see where existing research already provides a reliable and complete answer to these questions and could find full positive evidence for only one question – the effectiveness of medical sheepskins in the prevention of pressure ulcers.

All intervention questions without a reliable or complete answer and where further research is called for, are being published on NHS Evidence in the UK Database of Uncertainties about the Effects of Treatments (DUETs) http://www.library.nhs.uk/duets/

Prioritisation
Online and paper surveys were launched on 1st October 2012 and ran until 5th November 2012. Participants were asked to rate questions according to importance using a 10-point scale.

141 people took part in the prioritisation survey. There was a lot of agreement between patients, carers and health professionals about a core of topics that they felt should be researched but a lack of agreement outside that.
Integration

During the integration phase we looked at the differences and similarities between patients’, carers’ and health professionals’ views in order to build a picture of the types of questions that all groups see as a priority for research. Events were held in Leeds at Shine and St James Hospital on Worldwide STOP Pressure Ulcer Day, 16th November 2012. A focus group was run with members of PURSUN UK on 10th December 2012.

The views of those who are older and in care homes have been under-represented so far so we took shortlisted questions out to people in care homes for discussion.

Final Priority Setting Meeting

On Thursday 28th March 2013 27 patients, carers and health professionals came together at Shine, in Leeds to choose their top pressure ulcer prevention and treatment research questions from a shortlist of the 30 most highly rated questions submitted and rated by over five hundred stakeholders in all.

A full day of debate, discussion and hard choices in workshop groups and a final plenary session led to the selection of the top 12 (see later in the newsletter)

A big thank you!
The JLAPUP would like to thank all the participants who took part in our final day for their time and contributions to making it such a successful day. Thanks!

Read on to find out the top 12…
James Lind Alliance Pressure Ulcer Priority Setting Partnership

Top 12

1. How effective is repositioning in the prevention of pressure ulcers?

Particular questions were raised about three affected groups: those in bed, those seated and those with contracted limbs. Key areas of uncertainty for those in bed were the most effective means of turning yourself, being turned (or having your position changed) by others and whether the impact on health and well-being of sleep disruption was taken into account. For those seated, the key area of uncertainty was the most effective means of repositioning yourself or being repositioned (by others) in a chair.

2. How effective at preventing pressure ulcers is involving patients, family and lay carers in patient care?

This question includes uncertainties about the best means of informing, educating and motivating people.

3. Does the education of health and social care staff on prevention lead to a reduction in the incidence of pressure ulcers and, if so, which are the most effective education programmes (at organisational and Health/Social Care level)?

4. What is the relative effectiveness of the different types of pressure relieving beds, mattresses, overlays, heel protectors and cushions (including cushions for electric and self-propelling wheelchairs) in preventing pressure ulcers?

There were uncertainties about whether devices were meeting the needs of the full range of patients at risk and how devices in use compared with conventional and other specialist surfaces. The needs of three affected groups were raised in particular: those who share a mattress with a partner, people with Multiple Sclerosis and those with contracted limbs.

5. What impact do different service models have on the incidence of pressure ulcers including staffing levels, continuity of care [an on-going relationship with same staff members] and the current organisation of nursing care in hospitals?

There were particular uncertainties about whether, for example, for people with Multiple Sclerosis or Spinal Cord Injury, working with specialist clinicians was more effective for prevention than working with generalists. Also, whether access to a specialist wound prevention service improved pressure ulcer prevention.

6. What are the best service models (and are they sufficiently accessible) to ensure that patients with pressure ulcers receive the best treatment outcomes (including whether getting people with pressure ulcers and their carers more involved in their own pressure ulcer management improves ulcer healing and if so, the most effective models of engagement)?

There were particular uncertainties about whether awareness of and access to Tissue Viability nurses improved outcomes and whether people with specialist conditions (e.g. Spinal Cord Injury) received the best pressure ulcer treatment at specialist centres compared to generalist services. There were also particular uncertainties about the most effective way for family carers to be involved and the effectiveness of education strategies aimed at lay
carers to ensure understanding and concordance to recommendations from health care professionals (like turning regimes, diet and fluids).

7. For wheelchair users sitting on a pressure ulcer, how effective is bed rest in promoting pressure ulcer healing?

There were concerns about whether bed rest was detrimental to mental health, whether it was safe for those with Multiple Sclerosis who have been advised to keep moving, how its effectiveness compared with sitting on a pressure relieving cushion and whether sitting for a small time (for example to eat a meal) was likely to substantially increase pressure ulcer healing time.

8. How effective are wound dressings in the promotion of pressure ulcer healing?

There were particular uncertainties relating to honey dressings and the optimal number of times that dressings should be changed.

9. Does regular turning of patients in bed promote healing of pressure ulcers?

There were particular uncertainties about how often it is best to turn people, the most effective means of repositioning for people who require a carer to help them move, and whether a “prompt of routine” tool which reminds people to reposition themselves would be helpful for people with limited memory as well as limited mobility.

10. Does improving diet (eating) and hydration (drinking) promote pressure ulcer healing?

10. How effective are surgical operations to close pressure ulcers?

This included uncertainty about the most appropriate surgical referral for people with MS and ulcers that won’t heal.

12. How effective are topical skin care products and skin care regimes at preventing pressure ulcers?

There were particular uncertainties about for example, the application of barrier creams or sprays (Sudocrem and Cavilon), methylated spirits and moisturisers. Also whether the use of skin care regimes diminishes the likelihood of pressure ulcer occurrence. For example, for patients confined to bed, whether treating with washing, surgical spirit and/or talcum powder at all pressure areas would prevent the occurrence of pressure ulcers.

What next... and we need your help!
The key task in the immediate future will be to write up and disseminate the results from the process and to promote research to the questions in its top 12. Already we have:

- Met with Dr. Tom Kenny at the NIHR Evaluation, Trials and Studies Coordinating Centre about commissioning research. He will attend the Steering Group meeting on 18th June 2013
- Presented the top 12 at the Tissue Viability Society Conference, on 17th and 18th April 2013
We are preparing a press release and will circulate this as soon as it is agreed by the Steering Group.

We now **really** need your help. You may have ideas of your own about how you can contribute to getting the word out, but here are a few:

- Promote the top 12 in your network for example by issuing a press release, putting an item in your organisation’s newsletter, website, or social media (a draft “core” text will be in the official press release and we can help with adaptations)
- Invite us to present the top 12 to your organisation, your conference or other gatherings
- Consider identifying research funding to answer the questions in the top 12
- Put us in touch with other people who might be interested in our work and who might be influential in disseminating our work or commissioning research
- Blog, tweet to your followers on social media
- Write to your MP!

Also, if you might be interested in becoming involved in writing papers for academic or clinical journals please let us know.

**Further wounds research**

Partners from the JLAPUP are hoping to build on this work in a number of ways, subject to funding, including:

- Doing further work in pressure ulcer priority setting that combining participative, deliberative processes with value of information approaches
- Developing a leg ulcer priority setting partnership.
- Having more members of the public with direct experience of chronic wounds involved in developing and helping run new research projects.

To be kept informed of developments and ways of becoming involved, or for any other information contact [richard.morley@york.ac.uk](mailto:richard.morley@york.ac.uk), ring 01904 321105 or write to Project Support Officer, Wounds Group, Room A/TB/130, Area 2, Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, YO10 5DD.

Follow us on Twitter @JLAPUP