Dear Active Member or Supporter

We are pleased to bring you up to date with developments in the James Lind Alliance Pressure Ulcer Partnership (JLAPUP).

As you may remember, the JLAPUP is working to answer the following questions: What do we need to know in order to improve prevention and treatment of pressure ulcers? What are the questions about pressure ulcer prevention and treatment that matter most to patients, carers and clinicians?

Our revised plan (taking into account some slippage) is set out below:
Uncertainty Gathering

Our new website went live in the New Year as did our online survey. We tweeted from our Twitter account (@JLAPUP) to generate visits to the survey and our Facebook page generated some interest too.

Paper surveys were distributed through three sites in the NHS: Leeds Hospital and Leeds Community NHS and the Spinal Injuries Unit at James Cook University Hospital in Middlesbrough. Our surveys closed on 18th May 2012.

We also attended a number of events including the MS conference, Manchester and the Tissue Viability conference, Kettering and the Carers’ Forum in York and this gave us an opportunity to talk directly to patients, carers and clinicians.

We would like to record our thanks those who have helped with uncertainty gathering including survey distribution. Thanks too to all those Members and Supporters who helped in spreading the word about the survey and distributing questionnaires.

Analysis

We have now completed our Gathering process and we are now in our Analysis phase.

We received a total of 359 submissions. The online survey generated 180 submissions. 85 paper surveys were received and the remainder were from meetings, telephone, Twitter, a webinar and email.

Submissions were made by clinicians (42%), patients (36%) and carers (12%) and mixed groups (10%). A majority of the questions submitted by clinicians (57%) were from tissue viability nurses.
Analysis of the submissions has identified nearly a thousand questions. One quarter of the submissions concerned the epidemiology and the biology of pressure ulcers, or were questions that would require qualitative research to answer. Three quarters of the submission related to interventions.

Of these the most frequently submitted questions related to Organisation of care (32%) and Pressure and shear reduction and relief (28%).
Where outcomes had been given or could be inferred, prevention was identified in 62% of the questions and healing in 31%.

**Outcomes - all submissions**

- Ability to undertake normal activities
- Other
- Patient safety
- Prevention
- Quality of life
- Reduction in number of dressing changes an ulcer requires
- Secondary prevention
- Speed of ulcer healing
- Ulcer healing
- Ulcer related infection
- Ulcer related leakage
- Ulcer related odour
- Ulcer related pain

**NB Interim results**

**Next Steps**

We are presently completing our analysis and this involves checking whether the questions we have received are genuine uncertainties and we will be looking at a range of evidence in the form of systematic reviews and trials.

All genuine uncertainties will be submitted to UK DUETs, a database of treatment uncertainties. However the JLAPUP Partnership will be prioritising the uncertainties. An online and paper survey, home-based interviews, and deliberation groups will help produce short lists of patient, carer and clinician uncertainties. Mixed dialogue groups will bring these together, culminating in March with our final partnership meeting to produce two top 10 lists – one of prevention uncertainties and a second of treatment uncertainties.

**How you can help**

Over the next few months there will be opportunities to help.

- Help prioritise our two top 10s
- Take part in our online or paper survey
- Join a clinician only or a mixed deliberation group
- Offer a venue for venue for a deliberation meeting
- Spread the word - tweet...blog...Facebook
And finally

If you have any questions or suggestions please do contact us:

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