



19 February 2008

## **James Lind Alliance – helping shape the future of research**

The James Lind Alliance Working Partnership on Urinary Incontinence is a project which will help patients, carers and clinicians to work together to ensure that future research will help people come to a decision about the best course of treatment for bladder problems.

The aim is to identify and then prioritise areas where there is not currently enough research-based information about treatments for bladder problems.

The evidence that comes from clinical research helps patients, carers and clinicians make a choice between different treatments or methods of management for health problems. Where research has not been done then decisions can only be based on incomplete information, leading to uncertainty and concern for all.

Professor Marcus Drake of the Bristol Urological Institute says: “Every day patients and clinicians have to make choices about treatments and sometimes not enough research has been done to help them make the right choice. We are calling these situations ‘clinical uncertainties’. We want to identify the ‘clinical uncertainties’ that affect patients and clinicians most often. This information will be used to guide future research in this area, helping us focus on what patients feel to be their greatest priorities.”

The project is being supported by over twenty leading patient and professional organisations. Incontact, the leading UK charity for people with bladder and bowel problems is one of the organisations supporting this important work. A simple questionnaire has been posted to its members and is also available on line at <http://www.incontact.org/news-telling-researchers-what-to-research.html>

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Dr Brian Buckley, health services researchers says: "Whether you are a patient, a carer or a clinician, you can help to ensure future research addresses important areas of uncertainty by using this questionnaire to tell us about uncertainties that have affected you. It is vitally important that people fill in these questionnaires. We cannot help influence future research without any evidence to show where the gaps are".

The information collected from all the returned questionnaires will be collated at the end of June 2008. A list of the most important uncertainties will then be published and will ensure future research addresses these issues.

Dr Buckley emphasises: "The choices made between different treatments or methods of management for bladder problems can have a huge impact on the quality of life of the person involved. These cannot be properly informed choices if sufficient research has not been carried out. If that is the case then research is not supporting patients and clinicians in the way it should".

## **Ends.**

### **Notes to Editors**

For further information please contact Gill Turton at Incontact on 01536 533255 or 07766 077242.

1. The James Lind Alliance Working Partnership on Urinary Incontinence 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 of "clinical uncertainty";
- assemble and publish these in the Database of Uncertainties about the Effects of Treatments (DUETS);
- decide which of these uncertainties are most important.

A list of the most important uncertainties will then be published and provided to organisations that fund research, to promote the search for the evidence needed to make sure that it will become easier to make well informed decisions about treatment.

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The James Lind Alliance is supported by the Medical Research Council and the Department of Health. More information about the James Lind Alliance, DUETS and this project is available at [www.lindalliance.org](http://www.lindalliance.org) and **[www.duets.nhs.uk](http://www.duets.nhs.uk)**

2. *In*contact is the leading UK advocacy charity which campaigns for people living with bladder & bowel control problems. Dedicated to raising awareness and improving the understanding of continence issues, they provide user-friendly booklets and fact sheets, offer an on-line support forum and a magazine three times a year. Call confidentially on 01536 533255, email [info@incontact.org](mailto:info@incontact.org) or visit [www.incontact.org](http://www.incontact.org). Registered charity number 1085095.