Identifying uncertainties to prioritise research

Brian Buckley, PhD, MHSc, H Dip, BA, is research fellow, Department of General Practice, National University of Ireland, Galway.


Brian Buckley describes a project by the James Lind Alliance to identify treatment uncertainties in the care of people with urinary incontinence and prioritise these to influence and inform publicly funded research.

Much has been written and said about evidence-based practice in recent years and the concept is now universally accepted. According to its principles, decisions or recommendations made in clinical practice should be based on sound research evidence.

However, the reality is that very often the research evidence clinicians need to inform the decisions and recommendations they make does not exist.

The phrase ‘treatment uncertainty’ has been coined to describe a situation where no robust research evidence exists about the effectiveness of a treatment (Charmers, 2004).

One simple reason for the persistent abundance of treatment uncertainties is that, although an enormous amount of research is conducted each year around the world, there is a mismatch between the questions that are researched and the questions about the effectiveness of treatments that are of real day-to-day clinical importance to clinicians and patients alike (Tallon et al, 2000).

An appropriate and constructive response to such a situation must be to:
- Identify the uncertainties that are of most importance in everyday clinical situations;
- Prioritise commonplace treatment questions to which the identification of a robust evidence-based answer would most benefit patients.

The James Lind Alliance
The James Lind Alliance (JLA) was established in 2004 with the aim of encouraging patients and practising clinicians to work together to try to ensure that the most important uncertainties, which affect everyday clinical practice, are addressed by research.

The JLA tries to bring together patient and clinical organisations from within defined clinical areas to form working partnerships. The aim of these partnerships is to identify the treatment uncertainties that are of the greatest day-to-day clinical importance and to prioritise these to influence and inform publicly funded research.

The NHS health technology assessment programme has made a commitment to consider the recommendations for research emerging from the JLA’s work into its prioritisation process, and the Medical Research Council has also indicated that it will take account of priorities identified by JLA working partnerships.

The JLA and urinary incontinence
The JLA working partnership on urinary incontinence was proposed in 2006 as a way of identifying and prioritising treatment uncertainties relating to urinary incontinence that are of importance to patients, carers and clinicians. It began its work in 2007 with the participation and collaboration of patient and healthcare professional groups.

Process for identifying uncertainties
A transparent and inclusive process has been designed through which patients, carers and clinicians can work together to identify uncertainties about treatments for urinary incontinence, decide through consensus which of these are most important and then prioritise them in order to inform future research funding (Buckley et al, 2007).

The process can be described most simply in its five stages:
- Initiation – potential partnership organisations are identified, contacted and recruited where possible;
- Consultation – participating organisations gather from their membership or constituents treatment uncertainties of day-to-day clinical importance that have affected them or continue to affect them, and these are subjected to the following steps:
  - Selection of a group of key uncertainties to which the identification of a robust evidence-based answer would most benefit patients;
  - Prioritisation of the key uncertainties.

REFERENCES
affect them. Uncertainties identified by Cochrane reviews and other systematic reviews of evidence are also included:

- **Collation** – the working partnership gathers, categorises, refines and, where appropriate, combines reported uncertainties;
- **Prioritisation** – the most important treatment uncertainties are selected and then prioritised by consensus of the participating patient and clinician organisations;
- **Reporting** – the final prioritised list of treatment uncertainties relating to urinary incontinence will be reported to the NHS health technology assessment programme and the Medical Research Council and published in a leading peer-reviewed journal to encourage researchers to address them.

At present the JLA working party on urinary incontinence is at the consultation stage. Patient organisations and clinician organisations are asking their members to submit common questions about treatments for the condition to which they have been unable to find an evidence-based answer.

*Nursing Times* readers can also help by telling the partnership about treatment uncertainties that affect their practice. To enable them to do this, a short questionnaire (right) has been designed that should be accessible to patients and clinicians alike. An example of how the questionnaire may be completed is given in the box below.

Completed questionnaires can be returned directly to the JLA at the address on the questionnaire. Your help with this project is much appreciated. We hope that it will stimulate research into the areas of practice that have a real impact on incontinence and its treatment.

**EXAMPLE OF HOW TO COMPLETE THE QUESTIONNAIRE**

**What is the basic bladder problem?**  
Urinary incontinence in an adult male following prostate surgery.

**What information would have helped you to decide about treatment?**  
Do pelvic floor exercises help men with incontinence after prostate surgery?

**Where have you looked for the information you wanted to help you decide?**  
I have consulted the Cochrane Library and other resources but cannot find a clear answer about whether this treatment is effective.

---

**THE JLA WORKING PARTNERSHIP ON URINARY INCONTINENCE QUESTIONNAIRE**

**What is the basic bladder problem?**

**name of your organisation will NOT be published in association with the uncertainty.** Do we have your permission to do so?

- Yes
- No

**What information would have helped you to decide about treatment?**

**Where have you looked for the information you wanted to help you decide?**

**Are you (tick one):**

- A healthcare professional
- A patient
- A carer/parent

This form should be returned to the patient or professional organisation from which you received it. Alternatively, it can be posted to:

JLA WP on UI  
James Lind Alliance Secretariat  
James Lind Initiative  
Summertown Pavilion  
Middle Way  
Oxford  
OX2 7LG

**CONTACT DETAILS**

You do not have to supply your name and address. However, if you do so, we will be able to contact you if we want to ask you for more details about the information you send to us or if we feel we can help with the uncertainty you have identified.

**Name**  
___________________________

**Address**  
_________________________________

**Phone**  
___________________________

**Email**  
_________________________________

Thank you very much for your help with this important project.