

Update

## Reaching a consensus on research priorities in urinary incontinence

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Patients and clinicians worked together to indentify the most important gaps in the evidence base on managing urinary incontinence

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### Abstract

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Gaps in the evidence base in healthcare are common, and this is also the case for the [management](#) of urinary incontinence. The James Lind Alliance helped patients and clinicians to work together to identify and then prioritise gaps in the evidence base for managing this condition, producing a list of 10 research priorities. This article outlines the process involved in reaching this consensus.

**Keywords:** Continence, Urinary incontinence, Research priorities, Evidence base

### Introduction

Research often neglects important gaps in existing evidence. As a result, every day clinicians and patients must make decisions about treatments and management strategies without reliable evidence about their effectiveness. This is as true of urinary incontinence as it is of any other field.

With the aim of influencing the research agenda, the James Lind Alliance Priority Setting Partnership on Urinary Incontinence helped patients and clinicians to work together to identify and then prioritise gaps in the evidence base that affect decisions on treating and managing urinary incontinence (Buckley et al, 2009). Such gaps have variously been referred to as "unanswered research questions", "treatment uncertainties" or even "therapeutic ignorance" (Buckley et al, 2009; Chalmers, 2008; 2004).

The James Lind Alliance is an organisation which aims to help patients and clinicians to work together in healthcare research. It is named after an 18<sup>th</sup> century Scottish naval surgeon, who conducted what was perhaps the first fully reported clinical trial, in which he compared various supposed treatments for scurvy among sailors and established the value of citrus fruits (Lind, 1753).

One of the alliance's approaches is to facilitate partnerships of patient and clinician organisations in particular clinical areas to identify and prioritise research needs.

The partnership on urinary incontinence was proposed by representatives of Incontact (now the Bladder and Bowel Foundation) and the Cochrane Incontinence Group in 2007, and completed its work in 2009. Its findings have recently been published in *Neurourology and Urodynamics*, the journal of the International Continence Society (Buckley et al, 2009).

## The partnership

Very few projects of this type have been undertaken to date and so the partnership on urinary incontinence had to devise a methodology which would be systematic, transparent and inclusive, to ensure that all potential stakeholder organisations could become involved. In the first phase, UK clinician and patient organisations whose remit included urinary incontinence were identified and invited to participate. Thirty organisations were identified and eight patient and 13 clinician groups agreed to participate. These included both large organisations, such as royal college-related groups and national patient charities, and small ones, such as patient and clinician groups with specific clinical interests.

Participating organisations were required to ask their members to identify uncertainties which were of most concern to them. As a result of this, 417 submissions were received describing areas of uncertainty that regularly affected patients' and clinicians' ability to make decisions about treatment or management options in urinary incontinence. In addition, a further 131 unanswered research questions were identified in the recommendations of systematic reviews and clinical guidelines.

The examples of clinical uncertainty gathered in these ways were collated and refined: similar questions were combined while in some cases more than one were derived from a single submission; some were excluded because a systematic review which addressed them was identified; each was re-written in PICO format (population, intervention, comparator, outcome) (Akobeng, 2005; Sackett et al, 2000).

The final database contained 226 uncertainties: 79 came from patients; 37 from clinicians; six from both patients and clinicians; two from both patients and research recommendations; and 102 from research recommendations alone.

## Compiling the list

The resulting list was prioritised in two phases. First, each participating organisation identified a shortlist of 10 questions through consultation with their membership. These were then combined to produce a shortlist of 29. Second, at a workshop of patient and clinician organisation representatives, nominal group techniques were used to reach a consensus on a ranked "top 10" list of important clinical uncertainties. Prioritised uncertainties were verified by searching to ensure no up to date systematic reviews had been published which answered the questions. The final prioritised list of clinical uncertainties has been published and reported to funding agencies, with the dual aims of acting as a catalyst for research design and funding [applications](#) and of informing funding decisions (Buckley et al, 2009). Of the top 10, five were originally submitted by clinicians, four by patients and one came from research recommendations.

The wide range of evidence needs included in the final list reflects the breadth of urinary incontinence as a clinical area. Every prioritised uncertainty relates to treatment and management strategies that can have profound effects on quality of life and rehabilitation of those affected and yet about which little evidence exists. The 10 prioritised research questions are outlined in Box 1.

### Box 1. Final prioritised and ranked uncertainties

1. What are the optimal pelvic floor muscle training protocols (frequency and duration of therapy) for treating different patterns of urinary incontinence?
2. Can guidance or training for GPs on appropriate care pathways improve management of people with urinary incontinence?
3. What is best practice for treating combined stress urinary incontinence and detrusor overactivity?
4. Which catheter regimens are most effective in preventing urinary tract infections in people using intermittent self-catheterisation for the management of a neurogenic bladder?/What is the effectiveness and safety of prophylactic versus symptomatic antibiotic therapy in people with neurogenic bladder dysfunction using intermittent self-catheterisation?
5. Which treatment is most effective for reducing urinary frequency and urgency?
6. Is urodynamic testing before [surgery](#) for urinary incontinence associated with better continence rates and quality of life, than surgery indicated without such testing?
7. What is best practice for managing stress urinary incontinence following failed tension free vaginal tape surgery?
8. What are the most effective treatments of daytime urinary incontinence in children?

9. Are disposable catheters more or less acceptable than reusable catheters, in terms of effective bladder management, [patient experience](#) and urinary tract infections?

10. In women with prolapse and stress urinary incontinence, should suburethral tapes be inserted at the same time as repairing the prolapse?

## Gaps in the evidence

There are gaps in the evidence relating to interventions that are widely used yet not thoroughly understood. For example, pelvic floor muscle training is widely recommended as a treatment in many scenarios, yet uncertainty remains about which incontinence types it can treat best and which are the most effective exercise protocols in terms of outcomes, patient adherence and sustainability.

Urodynamic testing is commonly used in the care pathway for urinary incontinence, but it is not clear whether in all circumstances its effectiveness in informing treatment decisions justifies the expense, discomfort and small potential risk.

Intermittent catheterisation is the mainstay of management strategies in many situations where there are voiding problems, yet uncertainties still exist around many areas of its practice.

Two questions were combined on which regimens are most effective in preventing urinary tract infection, while the question of whether reusable catheters may be as acceptable and effective as disposable ones was also prioritised.

Other questions related to patterns of incontinence which, although commonly seen, have been inadequately addressed by research: optimal treatment and management strategies for "mixed" stress and urge incontinence, frequency and urgency in adults and daytime urinary incontinence in children.

Others relate to specific surgical uncertainties. For example, suburethral tapes are a common operation for urodynamic stress incontinence in women, yet for the 10% whose operation fails, there is no robust comparative data to guide decision making between medical or surgical treatment, and about whether an abdominal procedure such as colposuspension or repeat suburethral tape insertion is the correct intervention. And should suburethral tapes be inserted at the same time as repairing the prolapse in women with co-existing pelvic organ prolapse and stress urinary incontinence?

One area of uncertainty that was extremely highly placed by patients and clinicians alike related to access to care. Whether training for GPs in care pathways for urinary incontinence might improve referrals and, ultimately, outcomes probably reflects concerns that, while the majority of those affected who seek help do so from their family doctor, these clinicians may not be sufficiently trained to diagnose, treat and refer appropriately (Shaw et al, 2006; Grealish and O'Dowd, 1998).

## Conclusion

This partnership demonstrated that clinicians and patients can work together effectively and that unanswered research questions of everyday importance can be identified and prioritised through consultation and consensus. The results of this work have been published and reported to funding agencies such as the National Institute for Health Research and the Medical Research Council, who have signaled their intention to take into account the recommendations of James Lind Alliance Priority Setting Partnerships.

The 10 prioritised areas of clinical uncertainty reflect the heterogeneity of the patient group affected by incontinence and the wide range of treatment and management strategies available. They also reflect the uncertainty associated with commonly recommended treatment and management options. It is hoped the work will lead to the design and funding of research that seeks to answer questions on areas of clinical uncertainty regarded important by clinicians and patients alike.

## Dedication

We were very sorry to learn of the recent death of Jenny Henderson from the MS Trust, who gave a huge personal contribution to the project. This article is dedicated to her.

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