

Case study: A patient–clinician collaboration that identified and prioritized evidence gaps and stimulated research development

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Abstract

Objective: To assess the effect of a research prioritization partnership that aimed to influence the research agenda relating to urinary incontinence (UI).

Study Design and Setting: Research often neglects important gaps in existing evidence so that decisions must be made about treatments without reliable evidence of their effectiveness. In 2007–2009, a United Kingdom partnership of eight patient and 13 clinician organizations identified and prioritized gaps in the evidence that affect everyday decisions about treatment of UI. The top 10 prioritized research questions were published and reported to research funders in 2009. A year later, new research or funding applications relating to the prioritized topics were identified through reviews of research databases and consultation with funding organizations, elements of the research community, and organizations that participated in the partnership.

Results: Since dissemination of the prioritized topics, five studies are known to have been funded, three in development; five new systematic reviews are under way, one is being updated; five questions are under consideration by a national research commissioning body.

Conclusion: The partnership successfully developed and used a methodology for identification and prioritization of research needs through patient–clinician consensus. Prioritization through consensus can be effective in informing the development of clinically useful research. © 2013 Elsevier Inc. All rights reserved.

Keywords: Patient and public involvement; Research prioritization; Urinary incontinence; Lower urinary tract symptoms; Pelvic floor muscle training; Urethral catheter

1. Background

Despite its huge volume and scope, much of health care research is not targeted well, so that important gaps in the existing evidence base are neglected. In every clinical area, there are commonly asked questions that remain unanswered by research. As a result, clinicians and patients must make decisions about treatments without reliable evidence about their effectiveness. The James Lind Alliance (JLA) is an initiative that encourages patients and clinicians to work

together in health research. One approach used is partnerships of patient and clinician organizations that work together to identify and prioritize the most pressing research needs in a particular clinical area.

The JLA Priority Setting Partnership (PSP) on urinary incontinence (UI) was a partnership of 21 UK patient and clinician organizations that identified and then prioritized gaps in the evidence that affect everyday clinical decisions relating to the treatment of UI. The partnership was

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What is new?

- Methods for the identification of research priorities through consensus of patients and clinicians working together are being developed. However, whether they have any effect upon research activity is unclear.
- The James Lind Alliance Priority Setting Partnership on Urinary Incontinence successfully developed and employed a methodology for identification and prioritization of research needs by patient-clinician consensus.
- It would appear from this assessment of its impact that prioritization through patient-clinician consensus can be effective in informing the development of clinically useful research.

originally proposed in 2007 by representatives of a UK charity, the Bladder and Bowel Foundation, and the Cochrane Incontinence Review Group. It completed its work in 2009.

When the JLA PSP on UI began, few projects of its kind had been completed. Mapping studies that have examined research prioritization exercises internationally found that only a handful of projects had featured clinicians and patients working together to identify specific research questions [1,2]. Thus, a methodology had to be developed that would be systematic and transparent and at the same time flexible and inclusive, so that all the potential stakeholder organizations with an interest in the area could become involved. The methods devised have been widely reported elsewhere and hence are described only in brief below [3–9].

The principal output of the JLA PSP on UI was a list of 10 research questions that were identified as priority issues by clinicians and patients working together (Table 1). This report considers the impact that the work of the JLA PSP on UI and the dissemination of that list of 10 prioritized research questions have had on research activities.

2. Methods

2.1. The methods of the JLA PSP on UI

In brief, the process involved five phases. In the first phase, 30 UK clinician and patient organizations whose area of interest included UI were identified through web searches and peer consultation and invited to participate. Eight patient and 13 clinician groups participated, including both large organizations, such as royal colleges and national patient charities, and small organizations with specific clinical interests.

In the second phase, participating organizations asked their members to identify questions about the treatment of UI for which no evidence base was available, regularly affecting their ability to make treatment decisions. An issue was considered “uncertain” if no up to date systematic review of research evidence provided reliable guidance as to the best treatment. Subsequently 417 individual submissions were received. In addition, a further 131 unanswered research questions were identified from the recommendations of systematic reviews and clinical guidelines.

The third phase involved collating and refining these questions: similar questions were combined, whereas in some cases, multiple questions were derived from a single submission; some were excluded because a systematic review that addressed them was identified; each was rewritten in PICO format (population, intervention, comparator, outcome) [10]. The final database contained 226 uncertainties: 79 came from patients, 37 from clinicians, 6 from both patients and clinicians, 2 from both patients and research recommendations, and 102 from research recommendations alone.

In the fourth phase a two-stage strategy was used to identify and prioritize, through consensus of clinician and patients representatives, a “top 10” unanswered research questions relating to UI. First, each participating organization shortlisted 10 questions from the database through consultation with their membership. These shortlists were then combined to produce a combined penultimate shortlist of 29. Second, at a workshop of patient and clinician organization representatives, nominal group techniques were used to reach a consensus on a ranked list of 10 important clinical uncertainties. Prioritized uncertainties were verified by

Table 1. Identified research activity associated with the James Lind Alliance Priority Setting Partnership on Urinary Incontinence

Prioritized topic	Research in development	Research funded	New or updated review	In HTA process
1. Pelvic floor training	Yes		Updated	Yes
2. GP training or guidance				
3. Mixed stress and urge UI	Yes	Yes	New	Yes
4. Neurogenic bladder management		Yes		Yes
5. Mixed frequency and urgency				Yes
6. Effectiveness of urodynamics		Yes		
7. Failed tape surgery			New	
8. Daytime UI in children		Yes (×2)	New	
9. Disposable/reusable catheters	Yes			Yes
10. Concomitant SUI and prolapse surgery			New (×2)	

Abbreviations: HTA, Health Technology Assessment; GP, general practitioner; UI, urinary incontinence; SUI, stress urinary incontinence.

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