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The James Lind Alliance

Introduction

Despite the vast amount of research on the effects of treatments in healthcare, many uncertainties remain. The James Lind Alliance (JLA; Fig. 1) aims to identify the most important gaps in knowledge about the effects of treatments, and has been established to bring patients and clinicians together in 'priority setting partnerships' to identify and prioritize the unanswered questions that they agree are the most important (JLA 2009a). This information will help to ensure that those who fund health research are aware of what matters to patients and clinicians.

The JLA is a non-profit-making initiative, which is being developed under the direction of a broadly based strategy and development group. Its secretariat is funded by the Medical Research Council and the Department of Health.

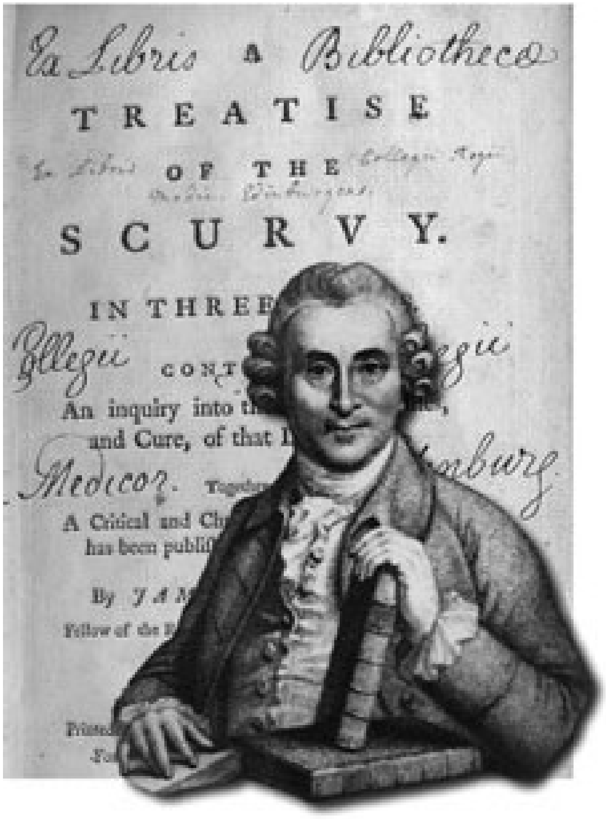

Figure 1. Portrait of the Scottish doctor James Lind (1716–1794), a pioneer of the clinical trial, superimposed on the title page of his book *A Treatise of the Scurvy* (1753).

The James Lind Alliance and urinary incontinence

The JLA working partnership on urinary incontinence was proposed in 2006 as a way of identifying and prioritizing treatment uncertainties relating to urinary incontinence that are of importance to patients, carers and clinicians (JLA 2009b). It began its work in 2007 with the participation and collaboration of patient and healthcare professional groups; ACPWH was one such group.

Process for identifying uncertainties

A transparent and inclusive process was designed through which patients, carers and clinicians could work together to identify uncertainties about treatments for urinary incontinence.

The process had five stages:

(1) *initiation* – potential partnership organizations were identified, contacted and recruited, where possible;
(2) *consultation* – participating organizations gathered from their membership treatment uncertainties of day-to-day clinical importance that affected their members (uncertainties identified by Cochrane reviews and other systematic reviews of evidence were also included);
(3) *collation* – the working partnership categorized, refined and, where appropriate, combined reported uncertainties;
(4) *prioritization* – the most important treatment uncertainties were selected and then prioritized by consensus of the participating patient and clinician organizations; and
(5) *reporting* – the final prioritized list of treatment uncertainties relating to urinary incontinence were reported to the National Institute for Health Research Health Technology Assessment Programme and the Medical Research Council, and published in a leading peer-reviewed journal (Buckley *et al.* 2009) to encourage researchers to address these issues.

A database of 226 uncertainties was initially formed: 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.

The prioritization was done in two phases. First, each participating organization identified a shortlist of 10 questions through consultation with their membership. These were then combined to produce a shortlist of 29. Secondly, at a workshop involving the representatives of patient and clinician organizations, nominal group techniques were used to reach a consensus on a ranked 'top 10' list of important clinical uncertainties. Prioritized uncertainties were verified by searching to ensure no up-to-date systematic reviews had been published that answered the questions.

The final prioritized 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 top 10 research questions

The top 10 research questions are:

(1) What are the optimal pelvic floor muscle training protocols (frequency and duration of therapy) for the treatment of different patterns of urinary incontinence?
(2) Can guidance or training for general practitioners on appropriate pathways of care improve the management of patients with urinary incontinence?
(3) What is best practice for the treatment of combined stress urinary incontinence and detrusor overactivity?
(4) What catheter regimens are most effective in preventing urinary tract infections in patients using intermittent self-catheterization for the management of a neurogenic bladder?/What is the effectiveness and safety of prophylactic versus symptomatic antibiotic therapy in patients with neurogenic bladder dysfunction using intermittent self-catheterization?
(5) Which treatment is most effective for the reduction of urinary frequency and urgency?
(6) Is urodynamic testing prior to surgery for urinary incontinence associated with better continence rates and quality of life, as opposed to surgery indicated without such testing?
(7) What is best practice for the management of 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?

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

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