

James Lind Alliance

Priority Setting Partnership on Urinary Incontinence

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BACKGROUND

There is a mismatch in many clinical areas between the questions that are being addressed by clinical and health services research and the questions for which practising clinicians and health care consumers need answers ^(1,2,3).

With the aim of influencing the research agenda, the James Lind Alliance (JLA) Priority Setting Partnership (PSP) on Urinary Incontinence (UI) has helped patients, carers and clinicians to work together to identify and prioritise questions about UI which are of practical, everyday importance but which cannot be answered by referring to existing systematic reviews of research evidence ^(4,5).



METHODS

The PSP on UI followed a protocol developed and predefined by the authors which consisted of five main stages: **initiation**, **consultation**, **collation**, **prioritisation** and **dissemination**.

INITIATION

30 organisations were identified which represented or could advocate for: people with UI; informal carers; clinicians treating UI. Following invitation, 8 patient-centred organisations and 12 health care organisations agreed to take part. Exploratory meeting held to plan the consultation process and arrange management and communication within the PSP.

CONSULTATION

Using a standard questionnaire, organisations "harvested" from their members uncertainties about treatments for UI. "Raw" uncertainties gathered: n417 (patient organisations, n291; clinician organisations, n126)

Existing sources of "clinical uncertainty" were also reviewed:
For example, Cochrane Reviews, NICE clinical guidelines, UK Clinical Trials Gateway

COLLATION

"Raw" uncertainties were entered in a working database and refined: ineligible submissions excluded (eg. uncertainties not relating to treatments); uncertainties re-written in standard language; duplicates combined; frequency of duplicates recorded.

Final JLA PSP UI database of treatment uncertainties relating to UI = n248 (from patient centred organisations = n76; clinician organisations = n 42; pat & clin org = n6; research recommendations = n124)

Examples

"Is urodynamic testing prior to surgery for urinary incontinence associated with better continence rates and quality of life than surgery indicated without such testing?"
"Can guidance or training for general practitioners on appropriate pathways of care improve the management of patients with urinary incontinence?"

PRIORITISATION

Phase 1: participating organisation consultation → n29 treatment uncertainties

- All the retained uncertainties were sent out to partnership organisations
- Each was asked to identify and rank ten that they considered most important
- Subsequently rankings were combined and a shortlist (n29) was identified

Phase 2: consensus meeting → n10 treatment uncertainties

- Emphasis on consensus between patients and clinicians
- Overlapping uncertainties combined into broader questions, so that more identified uncertainties can be included
- Emphasis on ensuring the "top ten" includes uncertainties which reflect the breadth of the clinical field and range of patients

DISSEMINATION

The methods and results of the JLA PSP UI presented at conferences (NICE, Cochrane) and published. All the unanswered treatment uncertainties published on the DUETS database ⁽⁶⁾.

CONCLUSION

An inclusive and transparent project whose methodology can inform future consensual prioritisation work. It is envisaged that quality applications for funding for research addressing questions identified by this MRC, DoH and Cochrane Collaboration backed project may be at a considerable advantage.