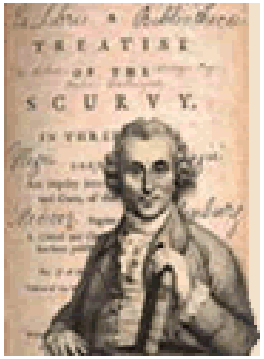


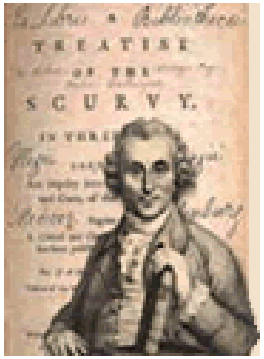
James Lind Alliance

Priority setting treatment uncertainties in Prostate Cancer - together

Sally Crowe

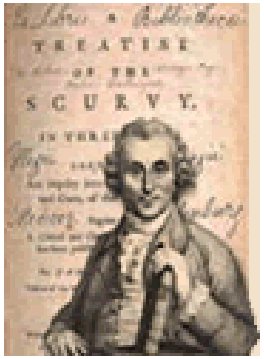
James Lind Alliance

The James Lind Alliance is funded by the Department of Health and Medical Research Council



Our starting point…….

Do treatment uncertainties considered important by patients and clinicians, influence the clinical research agenda?



Our finishing point…….

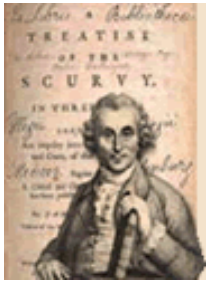
Shared priorities in treatment uncertainties from clinical and patient perspectives, that leads to potentially useful research.

START

The total number of treatment uncertainties in prostate cancer gathered – for example 300

A ‘top ten’ prostate cancer treatment uncertainties, that are considered the most important by all involved in the process

FINISH



Uncertainties from patients, carers, professionals, research literature

Consultation and collation of uncertainties

Uncertainties refined: *e.g. ineligible excluded, uncertainties re-written (PICO), duplicates combined*

Entered into DUETs

Share Prostate Cancer treatment uncertainties (DUETs) with partner organisations (JLA affiliated etc)

Each asked to choose their top ten uncertainties – share with they achieved their top ten

Each submission scored
1 to 10 selections allocated 10 to 1 points

Other factors that could be taken into account

Uncertainties which are:
submitted independently more than once - freqency
submission by multiple organisations – shared
and/or submitted by both patients and clinicians

Final priority setting

Final short list circulated to priority setting workshop participants for individual selection of top ten prior to workshop.

Workshop consists of **four rounds** of discussion in mixed groups

*Considering and sharing their own choices **(Round 1)** in small groups*

*Agreeing a short list of ten and rank order the rest **(Round 2)** in small groups*

Aggregating results from all small groups = 'first top ten' + ranked list

*New groups consider aggregate top ten **(Round 3)** aggregate results again*

*Final whole group discussion of aggregate top ten – **final chance** for changes **(Round 4)***

End result = ten prioritised areas of treatment uncertainties worthy of further research

Prioritised uncertainties	**Likely research needs**
What are the optimal **pelvic floor** muscle training protocols (frequency and duration of therapy) for the treatment of different patterns of urinary incontinence?	• Development of system for classifying 'intensity' of pelvic floor muscle training programmes • Systematic review to assess the effectiveness of programmes of increasing intensity • Modelling with economic evaluation of cost-effectiveness of programmes of increasing intensity • [Subsequent primary studies may be needed]
Can guidance or **training for general practitioners** on appropriate pathways of care improve the management of patients with urinary incontinence?	• Systematic review of GP-based interventions (such as guidelines, and continuing professional development) aimed at increasing the quality of care of patients with urinary incontinence • [Subsequent primary data collection studies likely to be needed.]
What is best practice for the treatment of combined stress urinary incontinence and detrusor over activity?	• Systematic review of interventions for incontinence where the patient group have a combination of stress and urgency incontinence. • [Subsequent primary data collection studies likely to be needed.]

What **catheter regimens** are most effective in preventing urinary tract infections in patients using intermittent self-catheterisation 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-catheterisation	• [Updated systematic reviews] • Randomised trials in patient with neurogenic bladder dysfunction using intermittent self-catheterisation to evaluate: alternative catheter regimens; and antibiotic prophylaxis vs. no antibiotic prophylaxis.
Which treatment is most effective for the **reduction of urinary frequency** and urgency?	• New systematic review
Is **urodynamic testing** prior to surgery for urinary incontinence associated with better continence rates and quality of life, than surgery indicated without such testing?	• Pre-trial economic modelling • Pragmatic randomised controlled trial

What is best practice for the **management of stress urinary incontinence** following failed tension free vaginal tape surgery?	• New systematic review • [[Subsequent primary data collection studies likely to be needed.]
What are the most effective treatments of daytime urinary incontinence in children?	• Updated systematic review • [Subsequent primary data collection studies likely to be needed.]
Are **disposable catheters** more or less acceptable than reusable catheters, in terms of effective bladder management, patient experience and urinary tract infections?	• [Updated systematic review] • Pragmatic randomised controlled trial comparing disposable (single use) catheters with reusable catheters
In women with prolapse (symptomatic or asymptomatic) and stress urinary incontinence, should suburethral tapes be inserted at the same time as repairing the prolapse?	• Pragmatic randomised controlled trial

Learning from previous priority setting partnerships, and from the literature

Data used for priority setting purposes must be checked for true uncertainty first

Experience tells us that it is vital that groups stick to rules, e.g. no clumping of uncertainties

People/groups will feel strongly about ‘their uncertainties’ – however the process will make people talk and compromise if needed

Uncertainties identified will probably range from very specific clinical or surgical issues to broad service delivery issues, this presents challenges for priority setting

The balance of patients and clinicians participating in the process is likely to have an important bearing on the outcome of the process, especially the final prioritisation meeting, so plan for attrition of participants!