James Lind Alliance – Urinary Incontinence

Tackling treatment uncertainties together

Report of the final priority setting workshop
Thursday 6 November 2008

Prepared by Katherine Cowan

Introduction and context

The James Lind Alliance (JLA) Urinary Incontinence Priority Setting Partnership (formerly known as the Working Partnership) was established in October 2006. The aim was to identify research uncertainties in the treatment of urinary incontinence, which were of importance to patients, carers and clinicians. Since then, a series of meetings, teleconferences and email consultations have taken place, which have resulted in the harvesting of 226 uncertainties about urinary incontinence treatment, and the short listing of 29 of those uncertainties.

A workshop took place on Thursday 6 November 2008 at Friends House in Euston, London, to turn the 29 treatment uncertainties into prioritised list of 10, shared by patients, carers and clinicians, to be taken into account in the commissioning of future research. This was the final priority setting workshop of the Urinary Incontinence partnership, and this report describes that process and the agreed next steps for the JLA and its partners.

Objectives for the day

1. *To brief the group on harvesting treatment uncertainties in urinary incontinence, interim priority setting and the final shortlist to be prioritised.*
2. *To reflect on and discuss participants' individual views of the short list.*
3. *In smaller and larger groups, to priority order the short list, noting areas of agreement and disagreement across groups, and finally agree a top ten.*
4. *Consider next steps, so that the top ten are taken forward for research funding.*

A list of the workshop participants and the organisations represented can be found at Appendix 1.

Session one: introductions and objectives (10:00am)

After registration and refreshments, the first session opened with housekeeping notices, objectives for the day and basic ground rules.

As an icebreaker, participants were divided into pairs and asked to draw a picture together quickly and without conferring. Each pair then took it in turns to introduce themselves, describe their role and interpret their drawing. The exercise was designed to help people relax and get to know each other, ahead of the day's intensive task.

Participants were then given an overview of the format of the day, and were introduced to the facilitators and the observers. The group was told that:

- Thirty wide-ranging groups/organisations were originally invited to participate in the JLA process, of which 21 expressed an interest in being kept informed.
- Ten groups submitted treatment uncertainties during the harvesting process.

- Eleven groups then each submitted a list of their top 10 treatment uncertainties out of 226, which were then short listed into a top 29.
- Fourteen groups were scheduled to attend this final priority setting process, of which seven had taken part in all stages of the process.
- Four last-minute cancellations were received (see Appendix 1). It was agreed that the completed pre-workshop prioritisation sheets for those organisations would be represented during the first round of small group sessions.

This reveals a high participation rate among organisations which have actively demonstrated an interest in the JLA process. Any gaps in interest groups (for example, stroke, Parkinson's disease, spinal cord injury or spina bifida) tend to reflect the relevant organisations not engaging during the early stages.

Session two: urinary incontinence treatment uncertainties – process and outcomes (10:40am)

Brian Buckley (Bladder and Bowel Foundation) then talked the group through the process of harvesting uncertainties and interim priority setting (see Appendix 2 for the slides). He noted that the JLA exists because of clinical research which does not address the concerns of patients, carers or clinicians. He described how the JLA process identifies unanswered clinical questions, prioritises them in order of importance to patients and clinicians and then turns them into research questions.

Brian Buckley's presentation provided a reminder of the JLA process with the Urinary Incontinence Priority Setting Partnership:

- Initiation
    - A wide range of 21 partner organisations were identified, of which 13 were clinical organisations and eight were patient-focused groups.
- Consultation
    - Harvesting uncertainties from members and existing sources such as guidelines, research, databases and research recommendations (e.g. Cochrane reviews).
- Collation
    - A total of 519 uncertainties were gathered, of which 102 came from existing sources and 417 were submitted by partner organisations.
    - These were refined to remove duplicates and non-uncertainties, leaving a total of 226 uncertainties to be entered into the JLA database.
    - It was noted that many discarded submissions described clinical dissatisfaction, rather than treatment uncertainties, meaning an additional body of evidence had therefore emerged as an interesting by-product of the harvesting process.
    - Of the 226 uncertainties, 79 came solely from patients and carers, 37 came solely from clinicians, six were submitted by patients and

clinicians simultaneously, two were from patients and research recommendations and 102 were derived from research recommendations.

- Prioritisation
    - An interim priority-setting process, conducted over email, saw 11 partner organisations choosing their top 10 uncertainties from the 226, and ranking them in priority order.
    - A range of techniques used by the participating organisations to reach their top 10s, including consulting members, pooling knowledge and combining the short lists of colleagues.
    - These priorities were then scored and a short list of 29 uncertainties, which proved to be a neat cut-off point, was developed. The scoring system saw the organisations' selections one to 10 allocated 10 to one points. Other factors which were taken into account were incidence of submission, and submission by multiple organisations, or by patients and clinicians.
    - Finally, organisations planning to attend the workshop were asked to choose and rank their top 10 from that short list as a precursor exercise for the shared priority setting workshop.
- Dissemination
    - The final stage will be to submit a list of prioritised research questions addressing the shared treatment uncertainties of patients and clinicians.
    - There is also an intention to publish a paper on the process and the priorities, which Brian Buckley is currently preparing, and to promote the work at various conferences, including the NICE and Cochrane conferences.

Brian Buckley acknowledged that this had been a learning process for all parties. A pragmatic approach had been taken, within a strict timescale and limited resources. This had been overseen by very experienced researchers, clinicians and patient advocates. He also emphasised how rare the JLA process still is, referencing recent JLA research which found that out of 640 relevant organisations, only nine worked with patients and clinicians to prioritise research questions. The workshop was therefore a very significant event. He added that a strength of the JLA process is that it is inclusive, wide-ranging and transparent.

The hard work and dedication of Brian Buckley, Adrian Grant (Cochrane Collaboration) and Mark Fenton (DUETs) was acknowledged. It was also noted that Ron Marsh had made a significant contribution to the early stages of the work, but had sadly had to withdraw due to unforeseen circumstances.

The workshop participants were given an opportunity to ask questions and make comments. It was noted that enabling diversity of assessment, by allowing organisations to compile their short lists in their own ways, was a strength of the process.

There was early interest in the results of the interim priority setting exercise, and the rankings within the short list of 29 uncertainties. However it was agreed that this would not be revealed until the final stage of the workshop. This would be to avoid influencing workshop discussions, and also to preserve its use for any potential final debates around the top priorities.

It was suggested by some participants that some of the 29 uncertainties were similar, and that some appeared to be less relevant than others to the urinary incontinence clinical field. It was noted that the potential to combine some uncertainties could be discussed within the group sessions of the workshop, and that the reduction of the 29 to 10 priorities would inevitably mean that questions considered to be less relevant to the group would be filtered out.

Session three: facilitated small group work (11:20am)

Due to the previous session slightly overrunning, and to compensate for the distance between the main room and two of the breakout rooms, it was decided that the first two small group work sessions would be merged into one. The morning coffee break was therefore taken prior to this.

The participants split into three small groups, which had been designed prior to the workshop to ensure diversity of expertise, and patient and clinician presence within each group (see Appendix 3). The aim of the facilitated small group work was to discuss the 29 uncertainties and to put them in order of importance (or at least to prioritise the first 10 to 15). Each group had 29 cards with the uncertainties printed on them, and an alphabetised code.

Each participant was asked to bring their pre-workshop task sheet, on which they had ranked all 29 treatment uncertainties in priority order. Participants started by sharing and discussing their respective prioritised uncertainties, explaining their rationale for inclusion, or exclusion.

The three groups' participants each listed their individually-ranked priorities on flip charts and worked to reach a consensus on up to all 29 uncertainties on cards laid out on the tables. Most started by separating all the cards which had appeared in all the participants' combined top 10s or top 15s. Participants in each group all seemed to be very open to hearing alternative rankings and different views of the importance of each uncertainty. Where an uncertainty which was originally deemed important by one participant was then demoted after discussion, it was agreed that a clear explanation for this would be required for groups whose memberships had contributed to the interim prioritisation exercise. While reaching a consensus on the most and the least important uncertainties was fairly straightforward, ranking those left in the middle was rather more challenging.

The dynamic of each group was slightly different, due to different interests, styles and personalities. The combined contribution of patient representatives and clinicians was particularly powerful, enabling sharing of different perspectives, experiences and information. Participants challenged each others assumptions about their interpretation of the questions.

A very neutral style of facilitation, adopting a non-prescriptive approach to small group prioritisation, ensured the groups developed their own way of working and made their decisions without being influenced by the JLA. Interestingly, each group took strong ownership of its new prioritised uncertainties, each expressing a competitive determination to see its priorities carried through to the final top 10. Despite this, the approach during that final stage was democratic, pragmatic and magnanimous.

The groups finalised their ranked uncertainties and the facilitators took them back to the main room to be entered into an Excel database by Mark Fenton.

Session four: plenary review and small group sessions (1:30pm)
Following lunch, the participants reconvened as one group. It was explained that the process of prioritising by taking everyone's opinions into account was also known as Nominal Group Technique (NGT). The interim prioritised 29 uncertainties were now shared with the group (see Appendix 4), alongside a ranked aggregated list from the morning's discussions.

However, this proved to be problematic, due to the merging of uncertainties by some groups. Mark Fenton described how he had combined the groups' different lists, giving equal prominence to merged uncertainties within each group by giving them a mid-ranked score. However, some participants expressed concerns that this misrepresented their intentions. There was also an issue where different groups had merged different uncertainties, or had wanted to reword the questions. Only one group had identified uncertainties they considered to be too similar and then took what they considered to be the overarching question, and relegated the remaining cards to the bottom of the pile.

After some debate, a consensus was reached: the groups which had merged uncertainties would revisit them and re-prioritise them as separate questions. It was decided that rather than try to do this in plenary, the same small groups would reconvene and re-rank the uncertainties to present Mark Fenton with a new top 10 of single questions.

It was suggested however that vignettes, or research questions, could potentially take suggested combinations into account. Indeed, after the Asthma Working Partnership process, the top 10 questions for research were underpinned by

vignettes comprising other unanswered questions which had not made it into the top 10.

There are several issues here for the JLA to consider in the context of future Priority Setting Partnerships:

- Consider developing clear guidelines on whether or not to attempt to merge uncertainties at the small group stage, or to reword the questions. Different groups generally combined the same ones, but there were some differences, creating new uncertainties. Instead, find a way to capture these suggestions and include them in the vignettes at a later stage, recognising the resources needed to do this.
- Think about establishing one method of data numbering across the small groups.
- Clearer instruction on scoring the uncertainties within the small groups may be required, including scoring of uncertainties considered to be duplicated or worth combining. There may be implications here for the pre-workshop scoring process.
- It is possible that a short list of 15 or 20 uncertainties may be more manageable than 29.

Session five: sharing the results (2:35pm)

After refreshments and a treasure hunt exercise designed to reinvigorate everyone, the results of the combined groups' prioritised uncertainties in the treatment of urinary incontinence were revealed, and printed cards with the uncertainties were laid out on the floor for clearer viewing. The first 18 were as follows:

Rank	Code	Uncertainty	Remarks
1	C2	What are the optimal pelvic floor muscle training protocols (frequency and duration of therapy) for the treatment of different patterns of urinary incontinence?	*Also in the interim top 10* *Similar to S, but more inclusive*
2	Y	Can guidance or training for general practitioners on appropriate pathways of care improve the management of patients with urinary incontinence?	*Also in the interim top 10*
3	J	What is best practice for the treatment of combined stress urinary incontinence and detrusor overactivity?	*Also in the interim top 10*
4	A2	What catheter regimens are most effective in preventing urinary tract infections in patients using intermittent self-catheterisation for the management of a neurogenic bladder?	*Also in the interim top 15*
5	B	Which treatment is most effective for the reduction of urinary frequency and urgency?	
6	E	Is urodynamic testing prior to surgery for urinary incontinence associated with better continence rates and quality of life than surgery indicated without such testing?	
7	Q	What is best practice for the management of stress urinary incontinence following failed tension free vaginal tape surgery?	*Also in the interim top 15*
8	X	What is the effectiveness and safety of prophylactic versus	

		symptomatic antibiotic therapy in patients with neurogenic bladder dysfunction using intermittent self-catheterisation?	
9	P	Does provision of accessible patient and carer information improve access to and uptake of appropriate care?	*Also in the interim top 10*
10	V	What are the most effective treatments of daytime urinary incontinence in children?	
11	I	Are disposable catheters more or less acceptable than reusable catheters in terms of effective bladder management, patient experience and urinary tract infections?	
12	K	Can peer support improve quality of life for people with incontinence?	
13	R	In women with prolapse (symptomatic or asymptomatic) and SUI, should suburethral tapes be inserted at the same time as repairing the prolapse?	
14	H	What clinical and patient characteristics determine the effectiveness and acceptability of treatment and management strategies for urinary incontinence following stroke?	
15	F	Can interventions aimed at improving patient-clinician communication improved patient experience and clinical outcomes?	*Also in the interim top 10*
16	N	What clinical and patient characteristics determine the effectiveness and acceptability of treatment and management strategies for neurogenic bladder dysfunction in multiple sclerosis?	
17	M	Does regular use of catheter valves maintain bladder tone and size?	*Also in the interim top 15*
18	B2	What is the effectiveness of Sacral nerve stimulation / Neuromodulation with implanted electrodes for urinary incontinence and voiding dysfunction in adults?	

These were then discussed by all participants. This was an opportunity for participants to voice any concerns, and for suggestions to be considered and changes to be agreed. Discussions included:

- P (*Does provision of accessible patient and carer information improve access to and uptake of appropriate care?)* was voted on and removed due to a perceived difficulty in researching the question. One participant had voted to retain it, suggesting patients are hampered by not knowing their options, and due to the lack of other questions concerning communication with patients in the top 10. However, it was noted that patient organisations should be gathering that information anyway.
- V (*What are the most effective treatments of daytime urinary incontinence in children?)* was debated. It was suggested that children generally do not suffer from their condition to the same extent as adults. However, it was also noted that no representative was present who could argue the case for children. Therefore, it was decided that V should remain in the top 10.
- N (*What clinical and patient characteristics determine the effectiveness and acceptability of treatment and management strategies for neurogenic bladder dysfunction in multiple sclerosis?*) was retained, as a condition-specific uncertainty. Meanwhile it was been confirmed that research relating specifically to urinary incontinence and stroke had recently been funded, meaning the related uncertainty (H) was relegated further down the list.

- A2 (*What catheter regimens are most effective in preventing urinary tract infections in patients using intermittent self-catheterisation for the management of a neurogenic bladder?*) would be underpinned by X (*What is the effectiveness and safety of prophylactic versus symptomatic antibiotic therapy in patients with neurogenic bladder dysfunction using intermittent self-catheterisation?*).
- Q (*What is best practice for the management of stress urinary incontinence following failed tension free vaginal tape surgery?*) and V (*What are the most effective treatments of daytime urinary incontinence in children?*) were then, as a result, ranked higher.
- I (*Are disposable catheters more or less acceptable than reusable catheters in terms of effective bladder management, patient experience and urinary tract infections?*) and K (*Can peer support improve quality of life for people with incontinence?*) then moved into the top 10. However, there was debate about the value of K. A vote decided that K would be removed from the top 10. Two participants who had voted to retain it noted that while peer support face to face may be less effective, patients have benefited from more anonymous forms of peer support, such as internet chat rooms.

It was noted that questions which do not appear in the top 10 are still important and may still merit investigation. It is simply for the purpose of promotion and attracting funders that a top 10 is developed, but organisations are still encouraged to make use of their own specific priorities.

The final top 10 research priorities for the treatment of urinary incontinence were agreed by the workshop participants as follows:

Rank	Code	Uncertainty
1	C2 (+ S)	What are the optimal pelvic floor muscle training protocols (frequency and duration of therapy) for the treatment of different patterns of urinary incontinence?
2	Y	Can guidance or training for general practitioners on appropriate pathways of care improve the management of patients with urinary incontinence?
3	J	What is best practice for the treatment of combined stress urinary incontinence and detrusor overactivity?
4	A2 (+ X)	What catheter regimens are most effective in preventing urinary tract infections in patients using intermittent self-catheterisation for the management of a neurogenic bladder?
5	B	Which treatment is most effective for the reduction of urinary frequency and urgency?
6	E	Is urodynamic testing prior to surgery for urinary incontinence associated with better continence rates and quality of life than surgery indicated without such testing?
7	Q	What is best practice for the management of stress urinary incontinence following failed tension free vaginal tape surgery?
8	V	What are the most effective treatments of daytime urinary incontinence in children?
9	I	Are disposable catheters more or less acceptable than reusable catheters in terms of effective bladder management, patient experience and urinary tract infections?
10	R	In women with prolapse (symptomatic or asymptomatic) and SUI, should suburethral tapes be inserted at the same time as repairing the prolapse?

Rankings 11 to 17 were also laid out as follows:

11	P	Does provision of accessible patient and carer information improve access to and uptake of appropriate care?
12	K	Can peer support improve quality of life for people with incontinence?
13	H	What clinical and patient characteristics determine the effectiveness and acceptability of treatment and management strategies for urinary incontinence following stroke?
14	F	Can interventions aimed at improving patient-clinician communication improved patient experience and clinical outcomes?
15	N	What clinical and patient characteristics determine the effectiveness and acceptability of treatment and management strategies for neurogenic bladder dysfunction in multiple sclerosis?
16	M	Does regular use of catheter valves maintain bladder tone and size?
17	B2	What is the effectiveness of Sacral nerve stimulation / Neuromodulation with implanted electrodes for urinary incontinence and voiding dysfunction in adults?

The JLA agreed to consider the following questions for the future:

- Should patient/clinician votes be weighted if either group is underrepresented as workshop participants?
- Should the ultimate aim be a top 10? Could it be a top five or 11, for example?

Session six – summing up (3:35pm)
Participants were thanked for their invaluable contribution to an important and enjoyable day.

It was agreed that the observational notes of the workshop would be shared with the participants before the document was finalised. The steering group will work to develop the basic uncertainties into detailed research questions, on which the partners will then be consulted.
Opportunities for promotion of the research priorities were discussed:

- It was reiterated that Brian Buckley is producing a paper for publication on the process and the agreed top 10 research priorities.
- In addition, Brian Buckley and Lester Firkins will be presenting the findings at the NICE conference in December.
- Information will be put on the MS Trust website and magazine and shared with the MS Society in due course.
- The questions will be circulated to professional bodies including the membership of the Royal College of Obstetricians and Gynaecologists.
- Potential funders can be developed from the NIHR. It was noted that the JLA process offers funders the justification they require to consider applications for research.

A policy for publishing the results of the exercise and sharing that information was discussed. Until Brian Buckley's paper has been published, it was agreed that participating organisations would keep the results of the priority-setting workshop confidential. Lester Firkins will inform partners when the results are in the public domain.

Feedback forms

All of the participants who returned their evaluation forms at the end of the workshop said they found the pre-workshop pack either helpful or very helpful. They all they were satisfied or very satisfied with the way the JLA facilitated the workshop, and the majority were satisfied or very satisfied that they were able to communicate their views in the workshop (one participant indicated that they were neither satisfied nor dissatisfied).

Almost all the returned feedback forms suggested those individuals were either satisfied or very satisfied that their views and preferences shaped the final list of urinary incontinence uncertainties (one person being neither satisfied nor dissatisfied), and they all indicated they were satisfied or very satisfied that the workshop achieved the objective of establishing a top ten urinary incontinence uncertainties for research.

An anonymous online evaluation survey examining the entire process was also set up, and a link was later sent to everyone who had been involved at some stage.

APPENDICES

Appendix 1 – workshop participants

Name	Organisation represented
Ms Patricia Atkinson	James Lind Alliance
Mrs Judy Birch	Pelvic Pain Support Network
Dr Brian Buckley	Bladder and Bowel Foundation
Ms Katherine Cowan	James Lind Alliance
Mrs Sally Crowe	James Lind Alliance
Mr Mark Fenton	DUETs (Database of Uncertainties about the Effects of Treatments)
Mr Lester Firkins	James Lind Alliance
Ms Jude Frankau	University of Aberdeen
Prof Adrian Grant	Cochrane Collaboration (Cochrane Incontinence Group, on behalf James N'Dow)
Dr Suzanne Hagen	Glasgow Caledonian University
Ms Jenny Henderson	MS Trust / Urostomy Association
Mr Paul Hilton	Royal College of Obstetricians and Gynaecologists
Ms Gaye Kyle	Association for Continence Advice
Ms Adele Long	BioMed HTC, Bristol Urological Institute
Dr Doreen McClurg	Association of Chartered Physiotherapists in Women's Health
Ms Maryrose Tarpey	James Lind Alliance/INVOLVE Support Unit
Mr Douglas Tincello	British Society of Urogynaecology
Dr Adrian Wagg	Continence Foundation / British Geriatrics Society
Apologies received	
Ms Liz Bonner	Royal College of Nursing Continence Forum
Ms Penny Dobson	ERIC (Education and Resources for Improving Childhood Continence)
Prof Marcus Drake	British Association of Urological Surgeons- Female and Reconstructive Urology
Mrs Caroline Sanders	Paediatric Urology Specialist Interest Group, Royal Liverpool Children's Hospital

Appendix 2 – presentation by Brian Buckley

James Lind Alliance
Priority Setting Partnership on Urinary Incontinence

Brian Buckley

James Lind Alliance Priority Setting Partnership on Urinary Incontinence

Initiation

Consultation

Collation

Prioritisation

Dissemination

James Lind Alliance Priority Setting Partnership on Urinary Incontinence

Initiation

Identification of potential partner organisations

Exploratory meeting

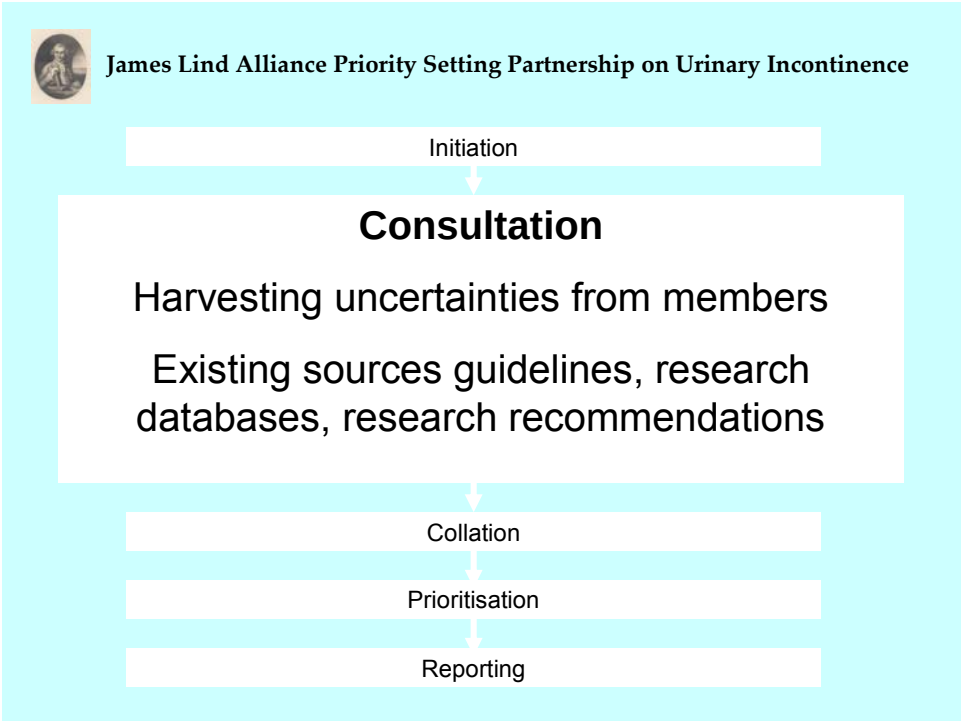
Consultation

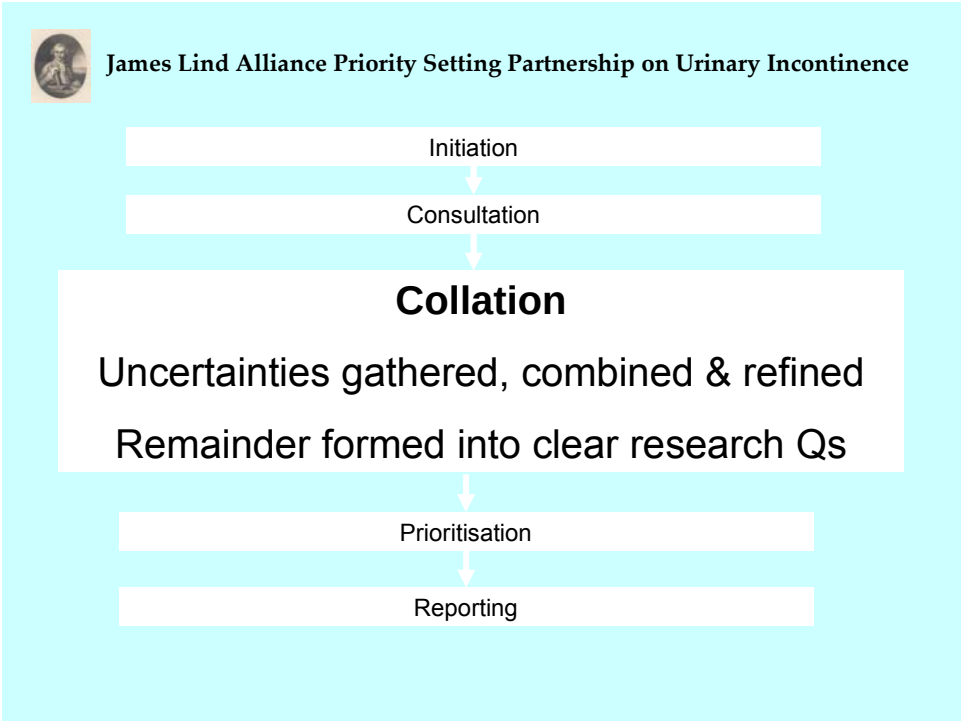
Collation

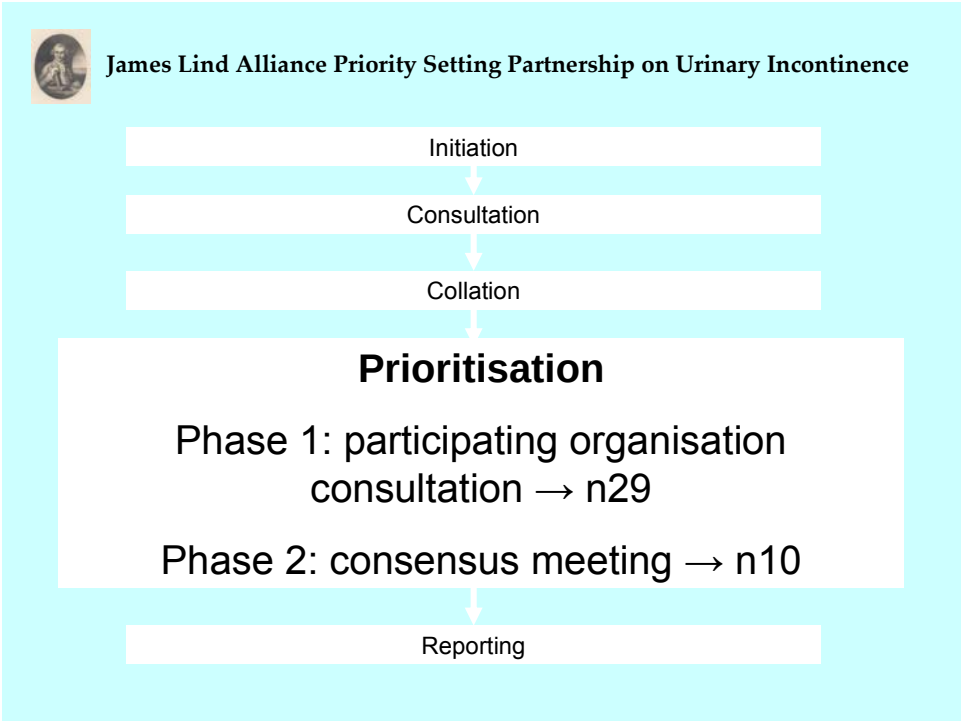
Prioritisation

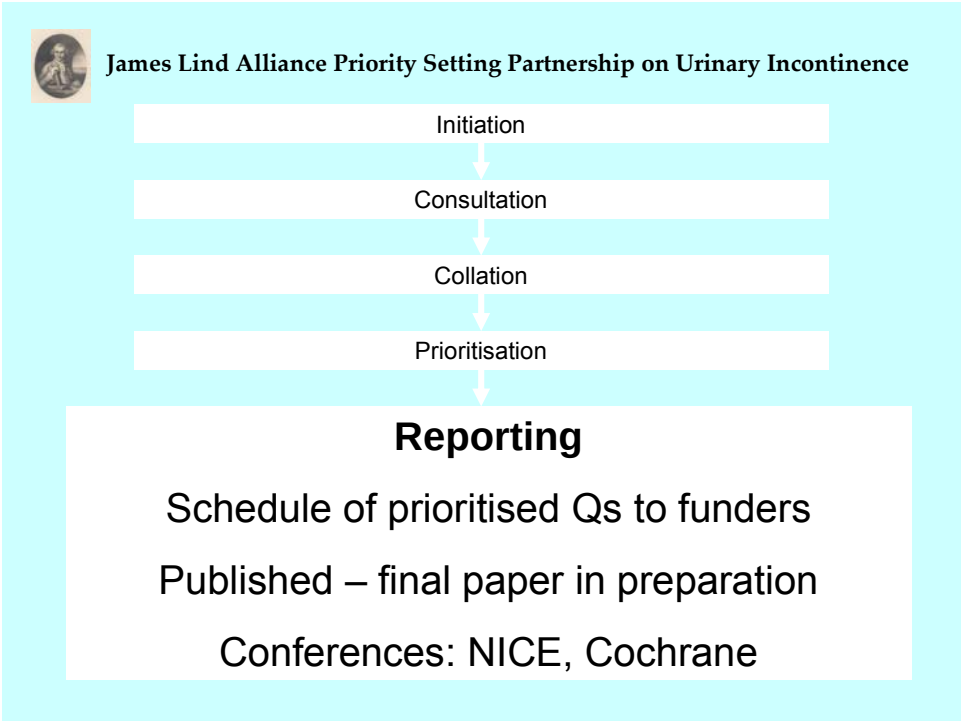
Reporting

1. **Association for Continence Advice**
2. **Association of Chartered Physiotherapists in Women's Health**
3. **BioMed HTC, Bristol Urological Institute**
4. British Association of Urological Nurses
5. British Association of Urological Surgeons- Female and Reconstructive Urology
6. **British Society of Urogynaecology**
7. **British Geriatrics Society**
8. **Cochrane Incontinence Group**
9. Continence UK
10. ERIC (Education and Resources for Improving Childhood Continence)
11. **Bladder & Bowel Foundation***
12. MS Society
13. **MS Trust**
14. Nursing Times
15. **Paediatric Urology Specialist Interest Group, Royal Liverpool Children's Hospital**
16. **Pelvic Pain Support Network**
17. Royal College of Nursing Continence Forum
18. **Royal College of Obstetricians and Gynaecologists**
19. Stroke Association
20. **Urostomy Association**
21. Women's Health Concerns


James Lind Alliance Priority Setting Partnership on Urinary Incontinence
Initiation
Consultation
Harvesting uncertainties from members
Existing sources guidelines, research databases, research recommendations
Collation
Prioritisation
Reporting

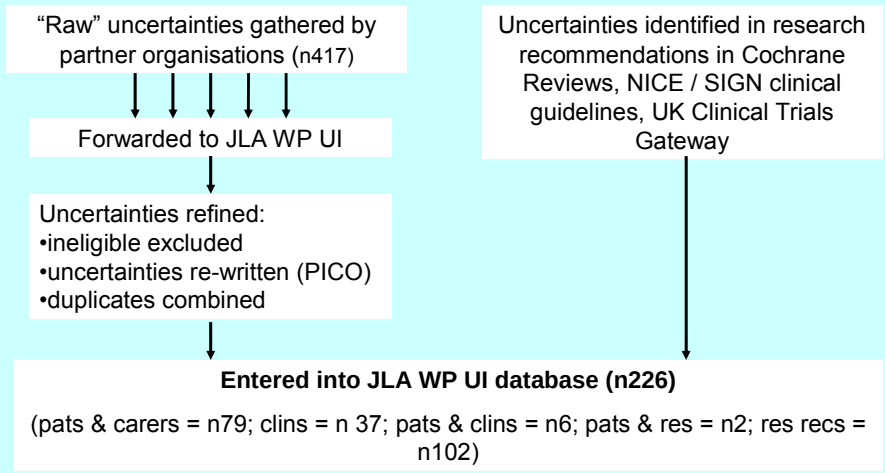

James Lind Alliance Priority Setting Partnership on Urinary Incontinence
Initiation
Consultation
Collation
Uncertainties gathered, combined & refined
Remainder formed into clear research Qs
Prioritisation
Reporting


James Lind Alliance Priority Setting Partnership on Urinary Incontinence
Initiation
Consultation
Collation
Prioritisation
Phase 1: participating organisation consultation → n29
Phase 2: consensus meeting → n10
Reporting


James Lind Alliance Priority Setting Partnership on Urinary Incontinence
Initiation
Consultation
Collation
Prioritisation
Reporting
Schedule of prioritised Qs to funders
Published – final paper in preparation
Conferences: NICE, Cochrane

James Lind Alliance Priority Setting Partnership on Urinary Incontinence

Consultation and collation of uncertainties



James Lind Alliance Priority Setting Partnership on Urinary Incontinence

Organisations returning prioritised "top tens"

- Association for Continence Advice
- Association of Chartered Physiotherapists in Women's Health
- BioMed HTC, Bristol Urological Institute
- British Society of Urogynaecology
- British Geriatrics Society
- Cochrane Incontinence Group
- Bladder & Bowel Foundation*
- MS Trust
- Paediatric Urology Specialist Interest Group, Royal Liverpool Children's Hospital
- Pelvic Pain Support Network
- Royal College of Obstetricians and Gynaecologists

James Lind Alliance Priority Setting Partnership on Urinary Incontinence

Scoring the prioritised uncertainties

Organisations' selections "1 to 10" selections allocated 10 to 1 points

Other factors:

- Incidence of submission: uncertainties which were submitted independently more than once were ranked accordingly and 10 to 1 points allocated to the top ten.
- Submission by multiple organisations or by patients and clinicians: uncertainties were ranked according to the number of organisations that identified the independently and weighted further if those included both patient and clinician organisations. 10 to 1 points were allocated accordingly.
- After processing, 29 uncertainties were shortlisted.

James Lind Alliance Priority Setting Partnership on Urinary Incontinence

- Process based on protocol devised & published at the outset
- The process also iterative
- Pragmatic –few resources and tight timescale
- But overseen by experienced researchers, clinicians and patient advocates & JLA
- Progress and developments published
- Novel project, inevitably flawed – but little previous work – JLA commissioned research
- But alternative?
- Will inform future work

James Lind Alliance Priority Setting Partnership on Urinary Incontinence

Issues in prioritising through consensus

- What importance should be given to ensuring the top ten includes uncertainties which reflect the breadth of the clinical field?
- Should the prevalence of UI type addressed by a question add weight to its importance?
- How do we take into account groups of patients / clinicians not represented here today?

Appendix 3 – small groups

Yellow	*Facilitator – Maryrose Tarpey*
Ms Jenny Henderson	MS Trust / Urostomy Association
Ms Gaye Kyle	Association for Continence Advice
Mr Douglas Tincello	British Society of Urogynaecology
Blue	*Facilitator – Sally Crowe*
Mrs Judy Birch	Pelvic Pain Support Network
Prof Adrian Grant	Cochrane Collaboration
Mr Paul Hilton	Royal College of Obstetricians and Gynaecologists
Ms Adele Long	BioMed HTC, Bristol Urological Institute
Green	*Facilitator – Suzanne Hagen*
Dr Brian Buckley	Bladder and Bowel Foundation
Mrs Doreen McClurg	Association of Chartered Physiotherapists in Women's Health
Dr Adrian Wagg	Continence Foundation / British Geriatrics Society

Appendix 4 – Interim priorities

Rank	ID	Urinary incontinence treatment uncertainties – in order of interim priority setting exercise, October, 2008
1	S	What is the optimum pelvic floor muscle training regimen for women with stress UI?
2	J	What is best practice for the treatment of combined stress urinary incontinence and detrusor overactivity?
3	P	Does provision of accessible patient and carer information improve access to and uptake of appropriate care?
4	W	Is urodynamic testing prior to surgery for stress urinary incontinence associated with better continence rates and quality of life than surgery indicated by history, examination, free uroflowmetry, stress test and bladder diary?
5	U	What are the long term effects of intermittent self catheterisation in terms of bladder health and function and adverse outcomes including carcinoma?
6	C	How effective are botulinum toxin injections for the treatment of overactive bladder and/or urge incontinence?
7	Y	Can guidance or training for general practitioners on appropriate pathways of care improve the management of patients with urinary incontinence?
8	F	Can interventions aimed at improving patient-clinician communication improved patient experience and clinical outcomes?
9	C2	What are the optimal pelvic floor muscle training protocols (frequency and duration of therapy) for the treatment of different patterns of urinary incontinence?
10	G	In the management of overactive bladder symptoms, is it more effective to start with anticholinerigic drugs, bladder training or the combination of the two?
11	M	Does regular use of catheter valves maintain bladder tone and size?
12	D	How should asymptomatic bacteriuria best be treated?
13	Q	What is best practice for the management of stress urinary incontinence following failed tension free vaginal tape surgery?
14	A2	What catheter regimens are most effective in preventing urinary tract infections in patients using intermittent self-catheterisation for the management of a neurogenic bladder?
15	N	What clinical and patient characteristics determine the effectiveness and acceptability of treatment and management strategies for neurogenic bladder dysfunction in multiple sclerosis?
16	R	In women with prolapse (symptomatic or asymptomatic) and SUI, should suburethral tapes be inserted at the same time as repairing the prolapse?
17	O	What clinical and patient characteristics determine which absorbent products are most effective in the management of urinary incontinence?
18	L	What clinical and patient characteristics determine which patients with mixed urinary incontinence will benefit most from surgery and which from conservative/medical therapy?
19	A	Are cranberry juice and other alternative or complimentary therapies effective in reducing urinary tract infections?
20	K	Can peer support improve quality of life for people with incontinence?
21	B2	What is the effectiveness of Sacral nerve stimulation / Neuromodulation with implanted electrodes for urinary incontinence and

		voiding dysfunction in adults?
22	Z	How effective are medical treatments for painful bladder syndrome (interstitial cystitis)?
23	T	What are the most effective surgical interventions for stress urinary incontinence in women over 70 years old?
24	B	Which treatment is most effective for the reduction of urinary frequency and urgency?
25	V	What are the most effective treatments of daytime urinary incontinence in children?
26	H	What clinical and patient characteristics determine the effectiveness and acceptability of treatment and management strategies for urinary incontinence following stroke?
27	I	Are disposable catheters more or less acceptable than reusable catheters in terms of effective bladder management, patient experience and urinary tract infections?
28	E	Is urodynamic testing prior to surgery for urinary incontinence associated with better continence rates and quality of life than surgery indicated without such testing?
29	X	What is the effectiveness and safety of prophylactic versus symptomatic antibiotic therapy in patients with neurogenic bladder dysfunction using intermittent self-catheterisation