

**James Lind Alliance – Urinary Incontinence
Tackling treatment uncertainties together**

**Report of the Working Partnership meeting
Tuesday 18 March 2008**

Prepared by Katherine Cowan

Introduction and context

The James Lind Alliance Working Partnership on Urinary Incontinence was established in October 2006 and has had a programme of teleconferences and face-to-face meetings since then. This project is helping patients, carers and clinicians to work together to identify and then to prioritise important areas of uncertainty about the effectiveness of treatments for urinary incontinence (UI). It is hoped that the recommendations of the Working Partnership (WP) will be taken into account in the commissioning of future research.

This WP meeting took place on Tuesday 18th March 2008 at Friends House in Euston, London. This report describes the meeting and examines the progress of the UI WP in harvesting treatment uncertainties for prioritisation, and sets out actions for the future.

Objectives for the day

- 1. To understand where participants are in the Harvesting Process*
- 2. To share issues / problems / opportunities / concerns*
- 3. To debate and agree the best way forward*
- 4. To agree a firm way forward with accountabilities and time lines*
- 5. To start thinking about the Priority setting stages*

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

Session one: introductions and context (10:30am)

The first session started with an overview of the day's objectives and a recap of the purpose of the project and the JLA process: to be able to present to funders an agreed list of UI research priorities in order of importance, with a view to getting them researched.

An icebreaker was then facilitated, where each participant was invited to introduce themselves, to explain their interest in UI and to describe a personal quality, interest or passion. This exercise worked well, generating a lot of laughter and participation, and raising awareness of each participant's different perspective equally among the group.

The JLA is about partnership, and the group was asked to reflect on each others' views, despite the inevitable differences. It was pointed out that it was important to allow each other time to talk, and to avoid jargon wherever possible.

Following introductions, the participants were encouraged to share any concerns they had with regards to the meeting, the working group or indeed the JLA process. A number of issues were raised, and captured on a flip chart. These mostly concerned the wider issues of UI in Primary Care and in provision of services:

- *A perceived lack of impact of research and expertise on the care of people with incontinence – this has contributed to a poor rate of improvement in these services*
- *Lack of basic and clinical research generally – Cinderella condition and “it can’t kill you” approach means that it is poorly ranked in importance*
- *Poor interface between specialist and general nurses and the medical specialists and clinical practice*
- *Lack of interest in incontinence from the centre despite its burden and impact of people’s quality of life – do we have accurate and accessible measures of these?*
- *Cycle of low expectations from service users and carers – and low expectations of professionals*
- *Too many patients putting up with their status quo in terms of treatment and solutions*
- *Need to break this cycle and embrace the ignorance out in the general NHS!*
- *Even if we develop a top ten – are there the researchers to do the research? UI is not an attractive area for research*
- *Some of the academic research does not address the what health professionals need to get on with their job well*
- *Although it is hard to see the advantages of basic research it is crucial in the development of new products etc*
- *Too many people with UI are wasting their money on ineffective treatments and devices that are advertised in popular magazines and journals – it is a sign of how desperate they can get*
- *People can hide incontinence for a long time before they seek treatment – the whole area suffers from ignorance and shame – this may impact on the success of JLA work – does the JLA model fit the challenges?*
- *There are particular barriers for women from minority ethnic communities that are not being addressed either in research or in practice.*

The JLA objectives around tackling treatment uncertainties together will not directly address these wider, fundamental problems. However, a great deal of the research conducted each year does not address many of the questions and uncertainties which patients, carers and clinicians face. This situation was described as a mismatch between what is researched and the information needed to inform everyday decisions about care.

The JLA working partnership therefore aims to bring together patients, carers and clinicians to identify the questions which are not answered by research, then prioritise those unanswered questions and report them to research commissioning bodies. It is hoped that the JLA work may provide an exemplar in research priority setting and help politically to raise the profile of UI, therefore tackling indirectly the lack of awareness and understanding of the condition. It will be important not to lose sight of these issues throughout the process.

Session two – collecting uncertainties (11.15am)

Next Brian Buckley guided the group through a presentation on the harvesting, collation and processing of uncertainties. Brian's slides can be found at Appendix 2.

The process of harvesting and prioritising happens in five stages:

- Initiation
 - The identification and invitation of potential partner organisations.
- Consultation
 - Harvesting questions from members and interrogating existing sources of unanswered questions.
- Collation
 - The gathered questions are rationalised, checked by the Cochrane Incontinence Group and formed into clear research questions.
- Prioritisation
 - This stage will be done through consensus of clinicians and patients.
- Reporting
 - The final product will be a list of questions of everyday clinical importance unanswered by current up-to-date systematic reviews of research evidence which will be reported to the MRC and the NHS R&D programme.

Currently the process is at the consultation stage. Originally, each organisation in the WP was to develop its own way of collecting uncertainties. However, this was not well received. So for consistency a standard harvesting instrument was devised with guidelines about how to use it and distribute it to all parties. This was essentially a questionnaire designed to glean the right information while being understandable to patients, carers and clinicians. This was sent to all partners for dissemination via email, internet and post.

Incontact's approach was used as an example of the type of harvesting activity undertaken. So far, the questionnaire has been distributed in the following ways:

- Posted on the website
- Signposted on the homepage
- Posted in the online Forum
- Posted on Cystitis & Overactive Bladder website
- Web links in Incontact and COB magazines
- Bulletin in Coloplast patient magazine
- Distributed by post to 1000 members

To date, 250 responses have been received. The distribution by post to the last 1000 people to have contacted Incontact was thought to be the most fruitful approach.

Clinical uncertainties identified in the research recommendations of the existing body of Cochrane reviews on UI treatment, NICE guidelines, SIGN clinical guidelines and the UK Clinical Trials Gateway, can go straight on to the DUETs

database, because their inclusion in these research recommendations indicates that their status as confirmed uncertainties has been established.

'Raw' uncertainties identified by patients, carers and clinicians will be forwarded to the working partnership. They will then be put through the following process:

- Ineligible submissions can be discarded (see below).
- Submissions can be re-written into a standardised language in PICO terms (see below).
- Duplicates can be combined, but their frequency recorded, as this may influence prioritisation.
- Uncertainties can be checked against existing systematic reviews.
- Arbitration of the final stage would ensure agreement that the uncertainties are unanswered.
- These will then be entered into the DUETs database, which will facilitate the later stages of the process.

Examples of ineligible submissions were given. These contained no defined treatment, and therefore no clearly defined treatment uncertainty. While ineligible submissions can be recorded as submitted in the working database, they cannot be taken any further within the JLA working partnership process.

Eligible submissions will then need to be rewritten, or re-phrased, into PICO format, to further clarify the precise research question being submitted and to ensure consistency in language and expression across the board.

PICO format was explained as follows:

- P = patient or problem
- I = intervention of interest
- C = comparator
- O = outcome

See Appendix 2 for an example.

Uncertainties will then be fed into a JLA WP UI Working Database and then verified by the Cochrane Incontinence Group by checking against the Cochrane Reviews and other systematic reviews. A pragmatic approach will be taken whereby if a question is clearly answered by a review it will be rejected, but if there is any doubt, it can be retained as an uncertainty.

The final stage is prioritisation, the methodology for which is yet to be determined.

While the approach was well received, the group also raised some specific concerns:

- *It will be important to draw out the difference between valid uncertainties and uncertainties which are simply due to poor advice or management of an individual's condition.*

- *Sometimes answers are known, but they are not known widely.*
- *The lack of expertise in the UI field has created uncertainties for many individuals.*
- *The questions will need to be challenged to eradicate personal bias.*
- *The lack of published information on UI may make it hard to access the required data.*
- *UI faces a barrier in terms of profile: dissemination of information is low and people are shy about raising the issue, which means dissemination remains low.*

The JLA is just concerned with uncertainties, but will pass back any questions to which there are answers, or other concerns to the partner organisations – this approach worked well with the Asthma WP. In this way, an important added benefit of the prioritisation exercise will provide information on other areas.

It was suggested that a mechanism for identifying where people with UI are let down by the health care system should perhaps be an outcome of the JLA process. For some areas of ignorance, it may be an opportunity to turn them into uncertainties which can then be addressed through research.

The WP also agreed to discuss how the process between DUETs and prioritisation is done

Mark Fenton then gave the group a demonstration of the DUETs database (www.duets.nhs.uk) which will be the final repository of the uncertainties which the WP identifies. The system draws on three main sources to identify uncertainties about the effects of treatments:

- patients', carers' and clinicians' questions about the effects of treatments
- research recommendations in reports of systematic reviews and clinical guidelines
- ongoing research, both systematic reviews in preparation and new 'primary' studies

There is currently one example of a treatment uncertainty for UI in the database, which concerns the effectiveness of pelvic floor exercise for UI in men after prostate surgery. It was clarified that UI questions being tackled by research which is currently underway will be accessible to the UK Clinical Trials Gateway. The inclusion of children's issues in the harvesting was queried. It was agreed that children should not be excluded, as there is a significant minority with a lifetime of issues ahead of them.

WP members were invited to report back on their harvesting activity to date. Executed and planned actions included:

- Putting the questionnaire online
- Including information in conference packs
- Direct mailing to members with UI interest

- Information in newsletters
- Picking up questions directly from families using continence services

Some members reported that they had received information about the questionnaire from other sources, which confirmed that it was circulating. In addition to the aforementioned responses to Incontact's campaign, the Urostomy Association had received between 25 and 30 responses, while 20 had been submitted directly to the JLA. Primary care, including GPs, and the UKCRN primary care research network were also suggested as potential harvesting sources.

Treatment guidelines were then discussed as a source of nationally identified uncertainties. Mark and Ron agreed to collate a list of all the key guidelines and extract the uncertainties, while Liz Bonner will invite ERIC to contribute to the work.

The JLA needs to identify some learning points regarding why this has taken so long, in terms of communications and engagement. One suggestion was that the lack of funding meant the work wasn't a priority. It was agreed that the JLA would email the template out to the WP again for distribution, and that the deadline for submissions will be the end of June.

Session three – planning for priority setting (1:30pm)

After lunch a session on priority setting took place. Sally Crowe presented this – please see Appendix 3 for the slides. Generally priority setting is not at the forefront of research funders' minds. Researchers therefore tend to adjust proposals to meet the funding criteria. The JLA process steps back from this and asks what should be researched, rather than what can be funded to be researched. Involving service users at this stage is unusual, but is worthwhile, as long as it is meaningful and not tokenistic.

The JLA goal is to gather all possible treatment uncertainties for UI (*in the case of the Asthma WP this came to over 300*), and distil this down to a top ten of UI treatment uncertainties that are considered the most important by all involved in the process. The following milestones in this process were highlighted:

- End of June deadline for harvesting uncertainties
- Collation activity (validating and combining – as described above)
- Agreement of realistic and pragmatic priority setting methods
- Communicate these clearly to stakeholder groups, together with a timeline
- Receive prioritised submissions from stakeholders
- Final priority setting workshop(s) – probably October 2008

The factors which could influence which 30 treatment uncertainties go forward to the priority setting workshop were described and could include the following:

- Frequency – how often the uncertainty has been expressed

- Perceptions of each uncertainty, and strength of feeling based on personal experience
- Burden on carers or health services, including cost of treatments
- Quality of evidence

The JLA Asthma WP used frequency as the most important influencing factor.

With this in mind, the meeting participants were then divided into smaller groups to discuss priority setting in more detail. Each group was facilitated by a member of the JLA team.

The first task was to rank the factors that could be used in prioritising treatment uncertainties (see Appendix 4). The groups approached this in different ways, ranking the factors individually, then discussing and modifying their choices as a group, or by discussing them together and then agreeing a consensus from that. Despite being small, the multi-disciplinary nature of the groups generated good debate, and an opportunity to explore each other's perspectives.

There were however concerns that clarity about the overall process was still lacking, and that it was hard to do the rankings when they did not still fully understand what each factor meant in practice. Where certain factors had been questioned or combined, this impacted on the consistency of the ranking system between individuals and groups. Some groups did not agree with some factors and so did not rank these at all. One group added 'prevalence of the condition' as a factor, and another added 'is there a comparator?' The factors which caused most debate were:

- *Burden of treatment – cost effectiveness for the NHS and ease of care for patient are two very different things*
- *How to measure the burden*
- *The importance of symptoms should be reworded as the burden of symptoms*
- *The concept of importance of symptoms/outcome is 'woolly'*
- *Frequency needs to avoid bias*

There were concerns from some about heterogeneity and competing uncertainties from different client groups. It was therefore suggested a 'Crufts approach' could be taken, whereby people are put into different categories (e.g. by age), their treatment uncertainties are considered separately, and then the 'winners' from each category are brought together to be prioritised.

Each group's rankings were then entered into an Excel spreadsheet and the following emerged:

FACTOR	Rank GRP 1	Rank GRP 2	Rank GRP 3	Total Rank	Overall Rank
The number of times the uncertainty has been expressed by patients carers (frequency)	2	1	1	4	1
The importance of symptoms/outcome that the treatment uncertainty is associated with	1	3		4	1
The quality of published evidence that suggests the uncertainty - e.g. Cochrane Review	2	2		4	1
The risks associated with the treatment uncertainty	5	4		9	4
What others think about the uncertainty, based on their experiences	7	6		13	5
The burden of the treatment uncertainty for example: Is it very expensive for the NHS or does it represent good value for money? Does it potentially make caring for the patient much easier?	6	5	2	13	6
The strength of feeling about a treatment uncertainty	9	7		16	7
If sub-categories of incontinence are used, are they treated as equal or do we assign some priority to these as well (Children & YP; Women; and elderly. Stratified by 65+ & 85+).	8	8	3	19	8
Is there a comparator?			4	4	
Prevalence	2			2	

This exercise helped participants to appreciate the complexity of priority setting, and helped the JLA and the UI working group see and hear which priority setting factors were most popular.

The three groups then went on to discuss the methods that could be used in prioritising treatment uncertainties (see Appendix 5). A number of concerns quickly emerged:

- Capacity to implement the methods due to constraints on time and resources.
- Any questionnaire requires a lot of explanation and cannot simply be distributed without explanation.
- If patients are involved they need face to face contact and comprehensive explanations.
- Members might not understand the voting system.
- Whether or not a formal meeting is an appropriate setting for the exercise.
- Some people with UI cannot travel very far.
- The expense of getting people to meetings to vote.
- The questions being voted on need to be worded so that bias is completely eradicated.
- The bias which could come from different sized organisations.
- People do not want to talk about this issue – could therefore miss the needs of what could be a silent minority or majority.

It was agreed that by the voting stage, the questions will be completely clear and valid. The clarification stage is in many ways the most important and the main one to get right.

The following remarks were made about the methods discussed:

Methods	Pros	Cons
Specially convened meetings: whereby uncertainties are discussed and suggestions for priorities made: <ul style="list-style-type: none"> • Of patient and clinician reps • Of just clinicians • Of just patients/carers 	<ul style="list-style-type: none"> • Best option • Refine ideas better 	<ul style="list-style-type: none"> • Time • Expense • Travel issues for patients • Need support and back up info for patients • Power relationships • Conflict between clinicians and patients
Meetings that are tacked on to existing meetings or opportunities where people are gathered already	<ul style="list-style-type: none"> • Cheap • Use support group meetings 	<ul style="list-style-type: none"> • Time • Too much work to take on • Lack of opportunity • Lose the voice of patients who are not in support groups
Electronic voting – using existing partner websites	<ul style="list-style-type: none"> • Possible • Cheap • Could use ERIC 	<ul style="list-style-type: none"> • Not accessible to all – esp older people • How to explain • Bias from orgs depending on size • Confusion • How to interpret
Postal voting	<ul style="list-style-type: none"> • Better than electronic • Needs to go to reps for all 21 partner orgs 	<ul style="list-style-type: none"> • Cost • How to explain • Who to send it to • Poor returns
Externally facilitated focus groups – whereby uncertainties are discussed and suggestions for priorities made		<ul style="list-style-type: none"> • Cost • Time • Travel issues

The JLA team emphasised that part of their role is to bring people together from different backgrounds, whether patients or clinicians, and ensure they are able to contribute confidently to the debate on an equal and secure footing – with all elements of bias carefully managed.

It was also re-emphasised that even the questions which are not prioritised will be valid and will be able to be found on the DUETs database, should anyone want to look for them and research them. However, politically, in order to move the UI agenda forward, realistically priorities are needed. This was a challenging session, which was well received and served to illustrate in a very practical way how difficult the whole area of consensus priority setting can be

Next steps

Next steps, actions and responsibilities were summed up.

Task	Lead	Deadline
Production of a full report of the meeting	Katherine Cowan	04/04/08
Circulation of harvesting template among WG	Patricia Atkinson	04/04/08
ERIC invited to participate in the WG	Liz Bonner	04/04/08
Collation of key guidelines and extraction of research recommendations	Mark Fenton and Ron Marsh	30/06/08
Raw uncertainties collected	Brian Buckley	30/06/08
Uncertainties refined into PICO and entered in DUETs	Brian Buckley and Adrian Grant	29/08/08
Schedule preliminary priority setting stages	JLA (Sally Crowe/Katherine Cowan/Lester Firkins)	30/09/08
Schedule final priority setting meeting	JLA (Sally Crowe/Katherine Cowan/Lester Firkins)	31/10/08

Any further suggestions or comments are invited via email.

APPENDICES

Appendix 1 – Participants

Name	Title	Organisation Represented
Ms Patricia Atkinson	Administrator	James Lind Alliance
Mrs Alison Bardsley	Clinical Editor	Continence UK
Ms Liz Bonner	Nurse Consultant Bladder/Bowel Dysfunction	Bedfordshire Continence Service
Mr Brian Buckley	Chairman	Incontact
Ms Katherine Cowan	Independent Consultant	James Lind Alliance
Mrs Sally Crowe	Chair, Monitoring & Implementation Group	James Lind Alliance
Prof Marcus Drake	Urologist	Bristol Urological Institute
Mr Mark Fenton	Editor	DUETs
Mr Lester Firkins	Chair, Strategy and Development Group	James Lind Alliance
Ms Jude Frankau	PhD Student (Observer)	University of Aberdeen
Prof Adrian Grant	Professor of Health Services Research	University of Aberdeen
Ms Gaye Kyle	Executive Member	Association for Continence Advice
Ms Adele Long	Director, BioMed HTC	Bristol Urological Institute
Mr Ron Marsh	Patient representative	
Mrs Hazel Pixley	National Secretary	Urostomy Association
Mrs Caroline Sanders	Nurse Consultant Paediatric Urology	Royal Liverpool Children's Hospital
Ms Maryrose Tarpey	Public Involvement Adviser	James Lind Alliance/INVOLVE

Appendix 2 – *Collecting Uncertainties* presentation

**James Lind Alliance
Working Partnership on Urinary Incontinence**

Harvesting, collation & processing of uncertainties



Brian Buckley 18th March 2008



James Lind Alliance Working Partnership on Urinary Incontinence





James Lind Alliance Working Partnership on Urinary Incontinence

Initiation

Identification of potential partner organisations

Exploratory meeting

↓
Consultation

↓
Collation

↓
Prioritisation

↓
Reporting



James Lind Alliance Working Partnership on Urinary Incontinence

Initiation

Consultation

Harvesting questions from members

Existing sources: question-answering resources, research recommendations

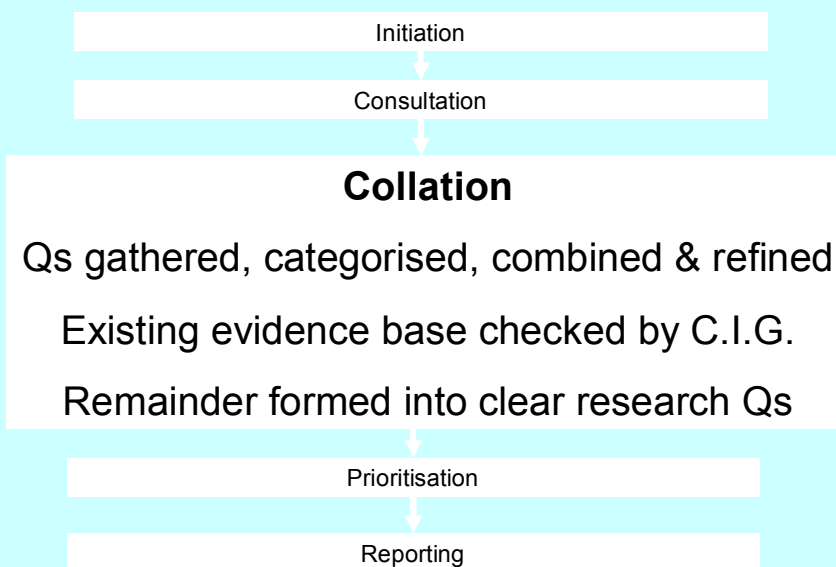
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Collation

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Prioritisation

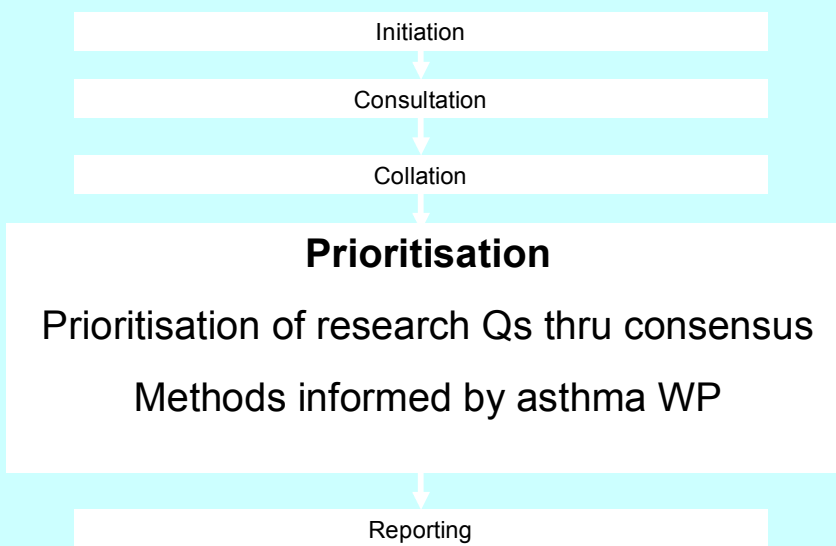
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Reporting



James Lind Alliance Working Partnership on Urinary Incontinence

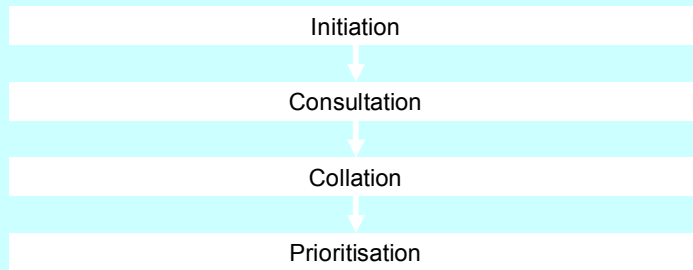


James Lind Alliance Working Partnership on Urinary Incontinence





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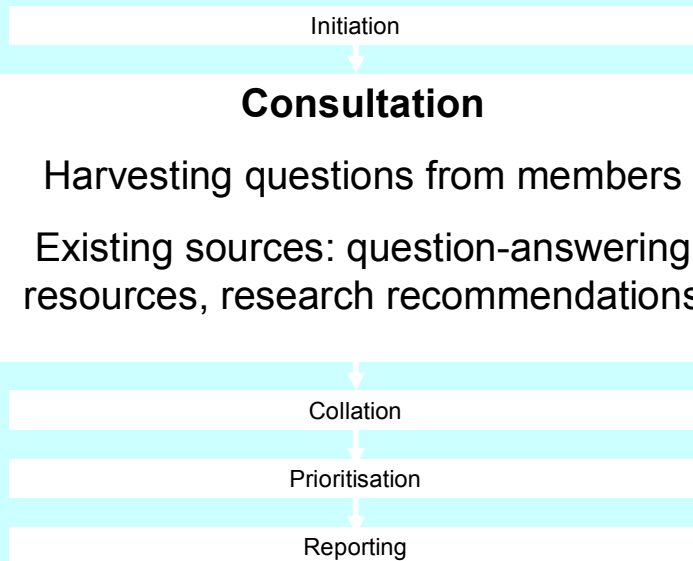


Reporting

Schedule of prioritised Qs to MRC & NHS
HTA programme and published
Resulting funding applications at advantage?

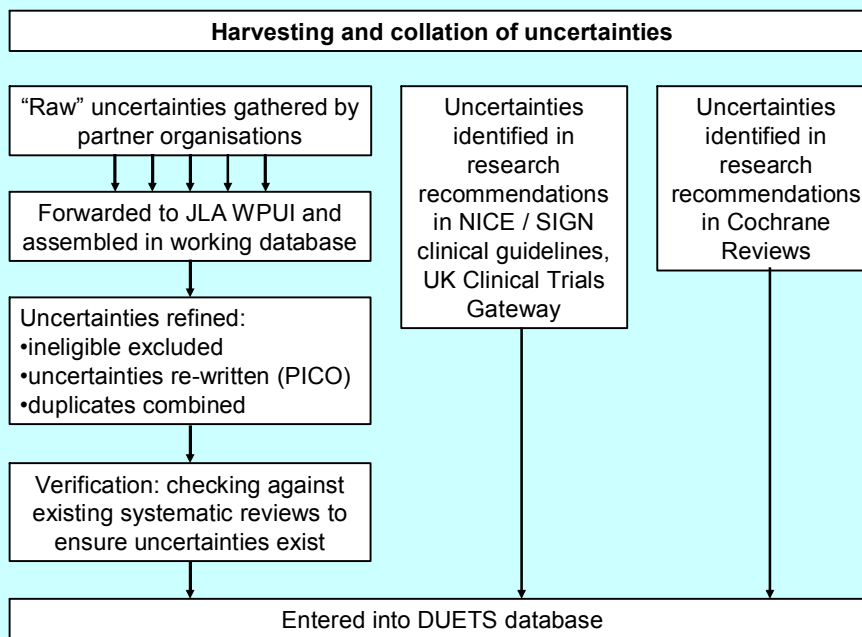


James Lind Alliance Working Partnership on Urinary Incontinence



Incontact's approach

- Questionnaire posted on website
- “Signposted” on home page
- Drawn to attention of Forum users by posting of notices
- Posted on Cystitis & Overactive Bladder website
- Weblinks in Incontact & COB magazines
- Announced in Coloplast patient magazine
- Distributed by post to 1,000 members
- c.250 responses to date



Ineligible submissions

Questionnaire	Submitted
What is the basic bladder problem?	Heavy urine loss day and night
What information would have helped you to decide about treatment?	Leaflets, newsletter (none at hospital or health centre).
Where have you looked for the information you wanted to help you decide?	Health clinic, hospitals and asked nurses and the specialist who I was seeing

no defined treatment, no clear uncertainty

Re-writing submitted uncertainties

- The uncertainty harvesting questionnaire used a form of words intended to be accessible to all and which prompts respondents to provide the information we need
- Re-writing involves rephrasing the submitted uncertainties in P.I.C.O. format:
 - "P" = patient or problem
 - "I" = the intervention of interest
 - "C" = comparator
 - "O" = outcome

Questionnaire	Submitted
What is the basic bladder problem?	Frequent passing urine during night
What information would have helped you to decide about treatment?	Information on BOTOX
Where have you looked for the information you wanted to help you decide?	Consulted my GP & consultant. No treatment or advice other than pills (Oxybutynin) given. This proved to be ineffective.

Possible P.I.C.O. interpretations

P	Nocturia & enuresis
I	Botox injections
C	No treatment
O	Reduction in nocturia & enuresis

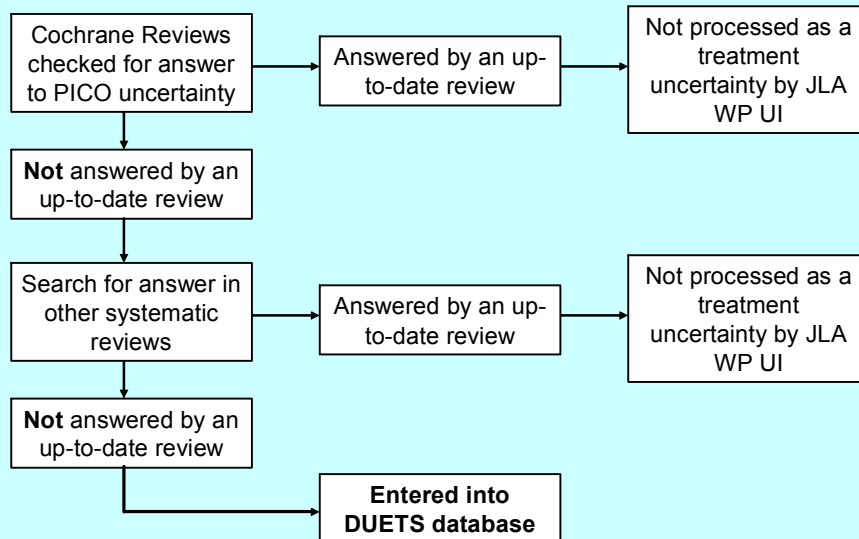
P	Nocturia & enuresis
I	Oxybutynin
C	No treatment
O	Reduction in nocturia & enuresis

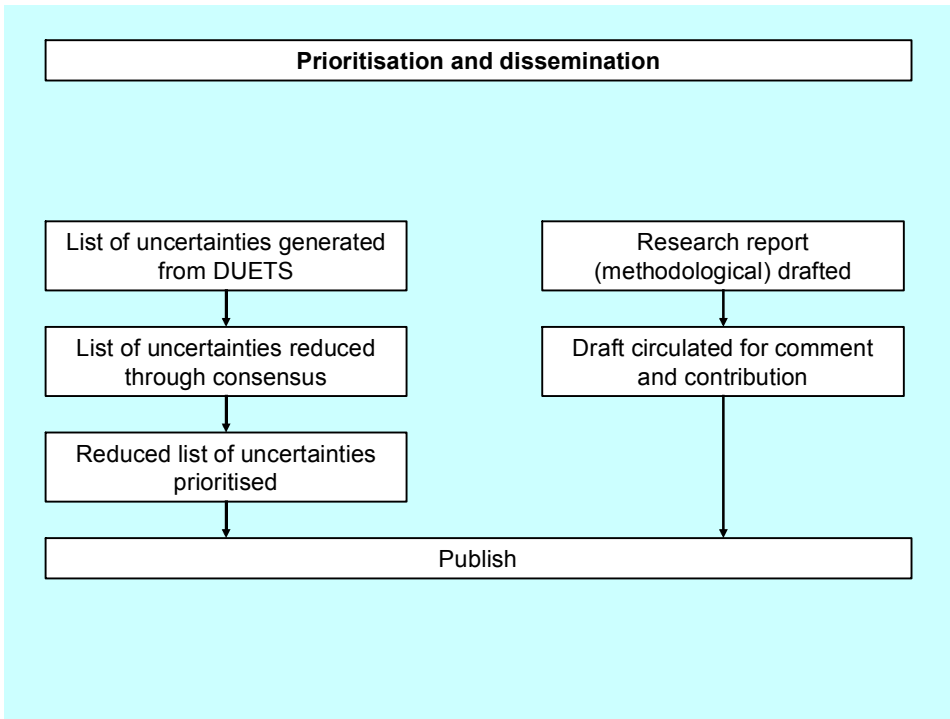
P	Nocturia & enuresis
I	Botox injections
C	Oxybutynin
O	Reduction in nocturia & enuresis

JLA WP UI Working Database

No	Basic bladder problem	What information needed?	Where sought?	P	I	C	O	Uncertainty Confirmed?
1	Frequent passing urine during night	Information on BOTOX	Consulted my GP & consultant. No treatment other than pills (Oxybutynin) given. This proved to be ineffective.	Nocturia & enuresis	Botox injections	No treatment	Reduction in nocturia & enuresis	
2	Frequent passing urine during night	Information on BOTOX	Consulted my GP & consultant. No treatment other than pills (Oxybutynin) given. This proved to be ineffective.	Nocturia & enuresis	Oxybutynin	No treatment	Reduction in nocturia & enuresis	
3	Frequent passing urine during night	Information on BOTOX	Consulted my GP & consultant. No treatment other than pills (Oxybutynin) given. This proved to be ineffective.	Nocturia & enuresis	Botox injections	Oxybutynin	Reduction in nocturia & enuresis	

Verification – when is an uncertainty an uncertainty?





Appendix 3 – *Planning for priorities presentation*



James Lind Alliance

James Lind Alliance

tackling treatment uncertainties together

Priority Setting

*urinary incontinence
treatment uncertainties*



Piece of cake?

Culture change – ongoing JLA research shows that priority setting is not at the forefront of research funders minds

It is hard to know which are the important priorities – new ground

Research and researchers have other pressures than patients' priorities

Involving patients/carers in priority setting is unusual, research community not used to it and historically it hasn't been valued

Danger of "lip service" – need to be thorough and transparent in what we do and achieve

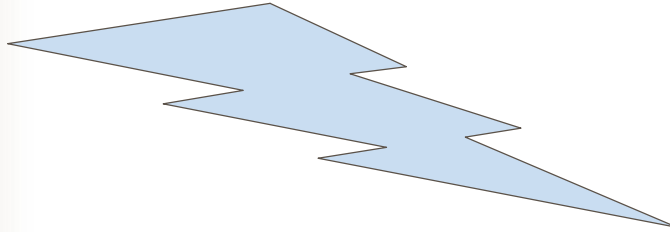
HOWEVER everybody is says it's a good idea!

What is the goal?

START



The total number of treatment uncertainties in urinary incontinence gathered – for example 300



A 'top ten' urinary incontinence treatment uncertainties, that are considered the most important by all involved in the process

FINISH



What are the milestones along the way?

START

- Harvesting uncertainties, a deadline for submission of uncertainties = a total number
- Collation activity i.e. establishing actual uncertainties, agreeing which ones can be combined, where there are significant different categories etc
- Setting a date for a priority setting workshop- *that gives enough time to prioritise up to 30 uncertainties to take forward to the workshop*
- Agreeing on priority setting methods (involving stakeholders here today) – *needs to fit with resources available*
- Final priority setting workshop - *we have this worked out!*
- FINISH

300



10

Factors that could influence which 30 treatment uncertainties go forward to the priority setting workshop

- How often the uncertainty has been expressed
- What others think about the uncertainty, based on their experiences
- How strongly people feel about it
- The burden on carers or health services
- The quality of evidence that suggests the uncertainty



and.....

- If sub categories of incontinence are used, are they treated as equal or do we assign some priority to these as well?
- The importance of symptoms/outcomes that the treatment prevents or is associated with
- The risks associated with the treatment uncertainty
- You may have others

To discuss in smaller groups.....

Methods for priority setting 300 uncertainties to 30 (Urinary incontinence DUETs module)

Options include:

- Specially convened meetings:
 - Of patient and clinician representatives
 - Of just clinicians
 - Of just patients/carers
- Meetings that are added on to existing meetings or opportunities where people are gathered already
- Electronic voting – using existing partner websites
- Postal voting
- Externally facilitated focus groups

Final priority setting workshop

- The JLA will undertake the majority of the work for this
- We have some tried and tested methods
- We can accommodate about 30 people
- We can fill you in on this detail nearer the time!



In groups of 4 please



1. Discuss the list of factors that could shape priority setting on the handout provided, and rank them in order of your *group value placed on using the factor in priority setting* – 20 minutes!
2. Whilst the JLA collate these and come up with an overall list of factors, please discuss the pros and cons of the methods (again on a handout) and make a note of ones that fit your preference and resources
3. Finally we will discuss all of this as a large group

Appendix 4 – factors

Ranking the factors that could be used in prioritising treatment uncertainties

- Discuss the list of factors below that could be used in priority setting urinary incontinence treatment uncertainties
- If you feel that there are other factors please use the empty boxes at the bottom of the table
- Rank them in order of your group value placed on them: 1 = most important 8 = least important
- You have 20 minutes to do this exercise

Factor	Rank
The number of times the uncertainty has been expressed by patients/carers (frequency)	
What others think about the uncertainty, based on their experiences	
The strength of feeling about a treatment uncertainty	
If sub categories of incontinence are used, are they treated as equal or do we assign some priority to these as well?	
The importance of symptoms/outcome that the treatment uncertainty is associated with	
The burden of the treatment uncertainty for example: <ul style="list-style-type: none"> • Is it very expensive for the NHS or does it represent good value for money? • Does it potentially make caring for the patient much easier? 	
The risks associated with the treatment uncertainty	
The quality of published evidence that suggest the uncertainty – e.g. Cochrane Review	

Appendix 5 – methods

Methods	Pros	Cons
<p>Specially convened meetings: whereby uncertainties are discussed and suggestions for priorities made:</p> <ul style="list-style-type: none"> • Of patient and clinician reps • Of just clinicians • Of just patients/carers 		
<p>Meetings that are tacked on to existing meetings or opportunities where people are gathered already</p>		
<p>Electronic voting – using existing partner websites</p>		
<p>Postal voting</p>		
<p>Externally facilitated focus groups – whereby uncertainties are discussed and suggestions for priorities made</p>		