



## Identifying important areas of uncertainty in the treatment or management of urinary incontinence



### Uncertainty in making decisions about health care

Every day patients, carers and clinicians have to make choices between different treatments or different methods of management for health problems. The choice made can have an important impact on the life of the person involved. Therefore it is best if information based on up to date research is available which patients, carers and clinicians can discuss together to help them make the right choice.

But sometimes not enough up to date information exists and as a result patients, carers and clinicians are faced with uncertainty regarding the best choice to make. We are calling these situations “clinical uncertainties” - questions and choices in the treatment or management of bladder control problems which cannot currently be informed by up to date information based on research evidence.

We want to identify bladder problems and treatments where there is not enough information available to help people come to a decision. When we have done so, the information can be used to ensure that future research addresses these issues. This will be a great help for similar people facing the same decisions in the future.

### What can be done about this?

The James Lind Alliance Working Partnership on Urinary Incontinence is a partnership of organisations representing patients, carers and clinicians.

Its aim is for patients, carers and clinicians to work together to:

1. identify important areas of “clinical uncertainty”;
2. assemble and publish these in the Database of Uncertainties about the Effects of Treatments (DUETS);
3. decide which of these uncertainties are most important.

A list of the most important uncertainties will then be published and provided to organisations that fund research, to promote the search for the evidence needed to make sure that it will become easier to make well informed decisions about treatment.

The James Lind Alliance is supported by the Medical Research Council and the Department of Health. More information about the James Lind Alliance, DUETS and this project is available at [www.lindalliance.org](http://www.lindalliance.org) and [www.duets.nhs.uk](http://www.duets.nhs.uk)

**Whether you are a patient, a carer or a clinician, you can help to ensure future research addresses important areas of uncertainty by using this questionnaire to tell us about uncertainties that have affected you.**

## **How to tell us about “clinical uncertainties” that have affected you**

If you or someone you care for is affected by bladder control problems and have been faced with uncertainty when making choices about health care, you can help us by telling us what the uncertainty was. Perhaps you had to choose between different medications, types of surgery or ways of managing the problem, but health care professionals or patient organisations have not been able to provide you with information about which is likely to be best.

If you are a health care professional working with people affected by bladder control problems, we would like you to tell us whether there is a particular clinical decision where the lack of good evidence regularly affects your practice.

We would like you to answer the following questions to help us understand the uncertainty you are concerned about.

After answering the questions, return the completed form to the organisation which provided it to you, where all the forms will be gathered and forwarded to the James Lind Alliance.

**For each uncertainty that has affected your health care choices, please answer the three questions on the next page.**

**Here are some examples of the way you could answer them:**

### **Example one**

**What is the basic bladder problem?**

Bedwetting in an eight year old child

**What information would have helped you to decide about treatment?**

Which is most effective for stopping the bedwetting: a bedwetting alarm or Desmopressin tablets or both?

**Where have you looked for the information you wanted to help you decide?**

I have asked my doctor and phoned a patient organisation but none knew for sure.

### **Example two**

**What is the basic bladder problem?**

Urinary incontinence in an adult male following prostate surgery

**What information would have helped you to decide about treatment?**

Do pelvic floor exercises help men with incontinence after prostate surgery?

**Where have you looked for the information you wanted to help you decide?**

I have consulted the Cochrane Library but it seems that up-to-date systematic reviews have revealed continuing uncertainties about treatment effects.

## **The JLA Working Partnership on Urinary Incontinence Questionnaire**

**What is the basic bladder problem?**

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**What information would have helped you to decide about treatment?**

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**Where have you looked for the information you wanted to help you decide?**

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**Are you (tick one):**

- ☐ A health professional
- ☐ A patient
- ☐ A carer/parent

**This form should be returned to the patient or professional organisation from which you received it.**

**Alternatively, it can be posted to:**

JLA WP on UI  
James Lind Alliance Secretariat  
James Lind Initiative  
Summertown Pavilion  
Middle Way Oxford  
OX2 7LG

## CONSENT AND CONTACT INFORMATION

### CONSENT

As part of this research process, we may publish the uncertainty you have identified in DUETS. (Your name or the name of your organisation will **NOT** be published in association with the uncertainty.) Do we have your permission to do so?

Yes

No

Signed \_\_\_\_\_

Date \_\_\_\_\_

### CONTACT DETAILS

**You do not have to give us your name and address.** However, if you do so we will be able to contact you if we want to ask you for more details about the information that you send to us or if we feel that we can help with the uncertainty that you have identified.

Name \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

**Thank you very much for your help with this important project.**