

Questionnaire on the need for a decision aid to support choice of urinary drainage procedure following cystectomy

Why we would like your help

Currently ileal conduit and orthotopic neobladder are the options for urinary drainage following cystectomy. Balancing the benefits and risks of each in order to make a choice that is 'best' for a particular individual is a complex task and our own experience is that it is difficult to provide sufficient support within the new cancer care pathway. Decision aids given to patients prior to consultation can help people make the choice that is best for them and so we are planning to design an aid to assist patients and clinicians decide between conduit and neobladder. The first step is to find out about current practice - and your participation in completing this anonymous questionnaire would be very helpful.

1. When do you most typically discuss the options with patients? – Tick one

- At the same consultation as selection of cancer treatment
 - At time of admission for cystectomy
 - Consultation with specialist nurse only
 - During a further consultation after cancer treatment decision
 - Joint consultation with specialist nurse after cancer treatment decision
 - Other – *specify below*
-

2. How long in total do you spend discussing the urinary drainage options with patients on average prior to cystectomy? – Tick one option

- < 15 minutes
- 15 - 30 minutes
- 31 - 45 minutes
- 46 - 60 minutes
- > 60 minutes

3. What resources do you currently use in helping the discussion with patients? – Tick as many as apply

- Existing patient or support group
 - Internet
 - Leaflet and/or Diagrams
 - Specialist nurse
 - Spouse or family member
 - Video
 - Other – *List below*
-

4. In general who do you feel has most input in terms of making the decision regarding choice of urinary drainage procedure? – Tick one option

- Patient
- Specialist Nurse
- Spouse or other relative
- Surgeon
- Other – List below

5. On average considering the 'typical' patient how easy/difficult is it to decide the form of urinary drainage? – Underline one option

1 2 3 4 5
Very Easy Quite Easy Neutral Quite Difficult Very Difficult

6. Which issues do you commonly associate with difficulty in making a decision? – Tick as many as apply

- Conflict between benefit and risk
- Inadequate clinical support
- Inadequate information resources
- Individual patient characteristics
- Lack of clinical evidence
- Lack of patient knowledge
- Patient expectations
- Unclear patient values
- Others – List below

7. How many patients do you feel receive the urinary drainage option that is 'best' for them in the long term? – Tick one option

- < 25%
- 25 – 50%
- 51 – 75%
- 76 – 100%

8. Patient's individual circumstances and lifestyle are currently taken into account when making the decision – Underline one option

1 2 3 4 5
Strongly Disagree Disagree Neutral Agree Strongly Agree

