

## **Incontinence in neurological disease (IND) Scoping Workshop: NICE Offices (Manchester) 27<sup>th</sup> May 2010**

The stakeholder scoping workshop is held in addition to the scoping consultation on the first draft of the scope, which is scheduled from 2<sup>nd</sup> July 2010 until the 30<sup>th</sup> July 2010.

The objectives of the scoping workshop were to:

- obtain feedback on the key clinical issues included in the first draft of the scope
- identify which patient or population subgroups should be specified
- seek views on the composition of the Guideline Development Group (GDG)
- encourage applications for GDG membership.

The scoping group (Technical Team, NICE and GDG Chair) presented a summary of the guideline development process, the role and importance of patient representatives, the process for GDG recruitment and proposed constituency for this group, and the scope. The GDG Chair facilitated a structured discussion around the following discussion points:

### **Points of discussion**

Stakeholders discussed the following areas:

- is the population included appropriate?
- are the interventions included relevant?
- can the proposed interventions be prioritised?
- are the outcomes included the correct ones?
- which clinical area(s) have important economic implications?
- is the proposed GDG composition appropriate?

### **Discussion outcomes**

#### ***A. Population***

The stakeholders agreed that the scope should cover all ages and all conditions. They also agreed that the short title of the guideline should be 'Lower urinary tract dysfunction in neurological disease' rather than 'Incontinence in neurological disease'

#### ***B. Key clinical issues***

Stakeholders agreed that the guideline should include aspects of service delivery (including assessment, referral and follow up) as well as efficacy and safety of specific interventions. The technical team agreed to check whether some of the physical interventions to aid storage (eg pelvic floor muscle therapy (exercise and stimulation)) are already covered in other guidelines.

Some stakeholders questioned whether it was appropriate to include the range surgical interventions which were only applicable to minority of patients (those with non progressive conditions who are at high risk of upper urinary tract complications).

Most stakeholders agreed that the following interventions can be omitted:

- Sacral anterior root stimulation (SARS)
- Detrusor myectomy
- Capsaicin and its analogues
- Cannabinoids

Most stakeholders agreed that the following interventions should be added:

- Urethral bulking agents

### **C. Outcomes**

Stakeholders agreed with the proposed list of outcomes

- Number of micturitions in 24hr
- Number of incontinence episodes per week
- Severity of incontinence
- Symptoms: urgency
- Symptoms: frequency
- Symptoms: nocturia
- Quality of life
- Patient/care perception of improvement in incontinence
- Adverse events including urinary infections renal complications and bladder stones
- Treatment compliance
- Kidney function

No other issues were considered specific to this guideline

### **D. Economic aspects**

Stakeholders identified the following areas as having economic implications:

- Drug costs
- Single use catheters
- Cost of management vs containment
- Follow up

### **E GDG membership**

The stakeholders were asked for feedback on the following GDG constituency:

#### **GDG constituency**

- 1x GP
- 2 x nurses with experience in incontinence in neurological diseases, eg district/community nurse, specialist nurse
- Paediatric urology nurse
- Continence advisor
- Doctor with special interest in uro-neurology
- Paediatric urologist
- Urology surgeon
- Geriatrician with special interest in incontinence
- Rehabilitation physician with interest in neurology
- Neurologist with interest in managing urinary symptoms in neurological disease
- 3 patient /carer representatives (1 x patient/carers organisation, 1 x adult patient/carers, 1 x carer of child/young person)

The stakeholders agreed with the proposed GDG composition subject to addition of an Allied Health professional (AHP) eg Physiotherapist or Occupational Therapist with special interest in uro-neurology.

### ***E. Closing Remarks***

The Chair closed the meeting by explaining that the scoping group will subsequently meet to summarise all key themes that emerge from the workshop and will update the scope accordingly.

The Chair also encouraged stakeholders to submit all their comments more formally through the scoping consultation process and to apply for membership of the GDG.