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Involving children in guideline development - an innovative, multi-method pilot project

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Aim: To pilot the involvement of children in NICE guideline development.

Objectives: 1. To gain children's views on the scope of the NICE Idiopathic Childhood Constipation clinical guideline and ensure children's priorities are included. 2. To consult with children on the guideline recommendations. 3. To test the feasibility and added value of involving children in guideline development.

How this was achieved: 1. Scope consultation with children. A 6-item open-ended questionnaire was developed by the guideline development group and administered face to face and by post to children attending clinics for treatment of constipation. Comments from 35 children were used to inform the scope of the guideline.

2. Guideline consultation: A stakeholder meeting with children will be held in October 2009 to gain children's views on the guideline recommendations. An on-line consultation is also planned using "Wikis" in order to provide an opportunity for a wider stakeholder consultation with children for those unable or less willing to take part in a meeting. This on-line consultation with children will be conducted alongside the usual NICE stakeholder consultation process.

3. Findings from the process and outcomes of stakeholder consultation with children will be used to inform future decisions regarding whether or not to directly involve children in NICE clinical guideline development, and how this can be undertaken.