

LAY SUMMARY

Background: We are currently working on a large mixed methods study (Continence in IBD, due to complete end of June 2010). Nearly ¾ of respondents with IBD report faecal incontinence at least some of the time and nearly 1/10 (9%) have regular bowel accidents. As part of that study, we have tested the ICIQ-B (International Consultation on Incontinence Questionnaire – Bowels) to see if it is suitable for people with IBD. The ICIQ-B assesses faecal (anal) incontinence and associated quality of life in the general population. It was not previously known whether the ICIQ-B is appropriate in assessing faecal incontinence and associated impact on and quality of life in people with IBD who may have very specific issues.

We asked participants in our Continence Study to complete the ICIQ-B and to comment on its suitability in assessing their situation and enabling them to accurately report their bowel symptoms, difficulties and concerns. We found that the ICIQ-B does **not** allow for accurate assessment of bowel continence in IBD, mainly because it does not enable respondents to record the changeable nature of the disease but requires them to answer for either relapse or remission. We also found that there were some areas of concern amongst our respondents which are not addressed in the current ICIQ-B – for example, worry about odour and noise when passing wind / stool, pain associated with bowel actions, and the practical difficulties caused by incontinence. Being able to measure these issues accurately is important, because it will help clinicians and specialist nurses gain a better understanding of the symptoms people with IBD experience, and the effect on their quality of life. Such understanding can then inform the way professional help is provided. Assessment tools are also very useful in helping people describe symptoms which are otherwise too difficult to explain. We propose to develop a new bowel continence questionnaire which will provide the first tool for accurately assessing the person's perceptions of their bowel symptoms in IBD, as well as the emotional impact and effect on quality of life. We will ask respondents from our current Continence Study to help us in the development, design and testing of the new questionnaire. As well as enabling accurate assessment and reporting of continence symptoms for people with IBD, we will also be in a stronger position to seek funding for future studies. The new questionnaire will be able to be used to robustly measure and compare findings in people with IBD receiving different forms of new and existing treatment for bowel incontinence.

Developing the questionnaire: We will ask Crohn's & Colitis UK members who responded to our Continence Study to take part in the development of the new questionnaire over a series of phases. We expect that a maximum of 4 phases will be required, each involving the following steps:

Step 1: development of new questionnaire design

Step 2: interview 10 respondents to our current study to test questionnaire for accuracy, content, and understanding

Step 3: research team (Dibley, Norton & Cotterill) evaluate Step 2 data; repeat from Step 1.

The phases will repeat until no further amendment / design is required. We then have to validate the new questionnaire. This means making sure it will do what it is designed to do, so we will ask 1000 people with IBD to complete it. We will check to see if the questionnaire is able to measure the same sort of things in the same person over a period of time.

Anticipated outcomes We expect to develop an IBD-specific Continence questionnaire which is recognised internationally, and to be able to seek further funding for an intervention study which will use the new questionnaire to measure symptom change following intervention.

Potential application of results, including benefits for people living with IBD The study will help C&CUK in reaching the *Improving Health Services for People with IBD* targets (Strategic Plan 2010-12) by carrying out research within the stated theme of 'Living with IBD.' Crohn's & Colitis UK members will be directly involved in the design and development of the new questionnaire, supporting current National Research Design Service recommendations to involve public and users in research. The new assessment tool will enable all those with IBD to accurately record and report their changeable bowel symptoms, and assist specialist IBD medical and nursing staff in the assessment and support of people with IBD-related incontinence. We will also be able to develop further research incorporating the new questionnaire.

Outputs from the research We will report study findings in the C&CUK newsletter and provide a full report to C&CUK. We will publish our work in relevant academic journals, and present at appropriate conferences, and provide a summary report to all participants.