

Lay summary

Why the research is important

The National Institute of Health and Clinical Excellence (2007) has recognised people with IBD as a potentially high risk group for faecal incontinence (FI), who should be proactively asked about continence status. There is no evidence that active case-finding is happening in clinical practice. We do not even know approximately how many people with IBD have a continence problem. Continence and access to toilets is a major concern for people with IBD. Symptoms include urgency, unpredictability, frequency and incontinence. Uncertainty as to when symptoms might happen can be just as restricting as frank FI – if you never know if today will be good or bad, it may be best to avoid activities or situations “just in case”. Many people find these symptoms extremely embarrassing and humiliating and are unwilling to talk about them, either to health care professionals or even to friends and family. Although loss of bowel control is one of the top 10 concerns of people with IBD, there has been remarkably little research on the management of FI in IBD.

Aims of the proposed investigation

1. Determine the prevalence of continence problems and concerns in people with IBD
2. Determine whether an existing validated faecal incontinence assessment questionnaire (ICIQ – B) covers the continence issues of people with IBD.
3. Understand the experience of people with IBD and continence-related issues and their needs or desire for continence services.
4. Understand how people with IBD and continence symptoms manage their problem with a view to designing future intervention studies.

Plan of investigation and methodology

Phase 1: Survey

We will conduct a survey of 10,000 NACC members. Those agreeing to participate can choose to receive questionnaires by post or complete a secure online survey.

The questionnaires will be:

- Basic demographic data (e.g. age, gender, ethnicity), medical history and history of IBD (including fistulae or pouch surgery)
- ICIQ –B and IBD Quality of Life questionnaire (IBDQ)
- Crohn's Disease Activity Index or Ulcerative Colitis Disease Activity Index
- A questionnaire asking about continence issues, professional help received, views on what help is needed and acceptable, and whether the ICIQ-B is acceptable and reflects their situation and concerns.

We anticipate 4,000 questionnaires will be available for analysis. We will determine the prevalence of continence issues and whether this relates to disease history or severity or other factors (such as age or childbirth). Of people reporting FI we will determine whether there is a significant unmet health need and desire for professional help. We will also gauge views on the usefulness of the ICIQ-B.

Phase 2: Interviews

People (approximately 20) responding to the above questionnaire will also be asked if they are willing to be contacted to undertake a 1 hour interview. Interviewees will be selected to deliberately include a range of ages, diagnoses, ethnic backgrounds and both genders. From this information we will develop a rich understanding of the continence issues faced by people with IBD. We will also determine if the ICIQ-B needs adapting before it is used as an outcome measure in studies of continence interventions in IBD. For example some questions might need to be added, deleted or modified to capture all issues of importance to people with IBD. We will also gather information on what types of help people with IBD feel they need so that we can plan future interventions based on these opinions.