

Executive Summary

More than half a million people in the UK live with Crohn's or Colitis, the two main forms of Inflammatory Bowel Disease (IBD). These conditions affect the gut or digestive system, the pathway through which we process food and expel waste. The symptoms of these conditions can seriously affect people's health and quality of life. Previous research by BUPA (2020) found that more than a third (35%) of people in Britain who were surveyed would be embarrassed about visiting a doctor to discuss possible symptoms of bowel cancer, which includes blood in poo, abdominal pain, bloating and a change in bowel habits.

In December 2022, Kohlrabi Consulting carried out mixed-methods research on behalf of Crohn's & Colitis UK, into the language used by various people when discussing poo-related topics and general toilet use in order to create public health messaging that is meaningful and acceptable to everyone.

Across England, Scotland, Wales and Northern Ireland, 400 members of the public took part in a survey, with ten survey respondents participating in follow up interviews to discuss their attitudes and preferred words in greater depth. Survey respondents spanned ages 18 to over 70 years, and were relatively well educated, with more than half having obtained degree-level or equivalent (60%). The largest ethnic group of respondents to the main survey identified as White (46%). The follow-up survey had a similar gender split (60% women: 40% men) and included participants of Black (n=3), East Asian (n=1), South Asian (n=3) and White (n=3) ethnicity, and younger to older participants. England was represented by four participants, with the Scotland, Wales and Northern Ireland represented by two participants each.

The survey asked participants to identify their comfort levels with talking about symptoms of Inflammatory Bowel Disease (IBD) in a range of contexts, and how they would describe those symptoms, specifically constipation, diarrhoea, bowel incontinence, farting, urgently needing the toilet, and blood in stools. Participants were also asked to describe key words they used to describe going to the toilet, words that made them uncomfortable and were given the opportunity to share anything else they wished the research team to know about their feelings towards poo.

Key points:

- The majority of respondents were comfortable searching for symptoms online (86%), telling a doctor (76%) or telling a loved one (74%). Only 16% of respondents were comfortable telling their employer. Men and people with degree-level education or equivalent were more comfortable discussing their symptoms. The lowest comfort levels by ethnicity were expressed by Gypsy or Irish Traveller participants (31%), irrespective of setting.
- Some symptoms had widely recognised and acceptable words, for example, constipation and diarrhoea. For identifying body parts and specifically the gut, stomach and tummy, were the most popular. The word 'poo' was more acceptable than 'stool', 'bowel movement', 'crap' or 'shit'.
- People did not appear familiar or comfortable with the medical terminology 'bowel or faecal incontinence'. There was a slight preference in use when talking to a doctor or searching online (50%), but people were relatively covert, with nearly 40% choosing 'I had an accident' in social situations, and a third indicating that they wouldn't disclose their symptom in workplaces (33%). Potentially older people are more knowledgeable of bowel incontinence as a medical diagnosis, with people

Language of Poo

aged 70+ years being twice as likely to chose that wording (74%) than those aged 18-24 years (37%).

- It was felt that some people may use potentially humorous or provocative terms toward themselves as a coping mechanism in social situations, but would use more neutral or clinical language when referring to other people out of respect.
- Generally, older people tended to be more covert in their language than younger people. For example, when describing the presence of blood in poo, almost half of people aged 18-24 years were direct, compared to 4% of people aged 70+ years. In interviews and survey free text, younger participants and participants with ethnically diverse backgrounds suggested that more direct language was less embarrassing and could result in being more easily understood and supported.

General recommendations for public health messaging

1. People may need more information on what specific symptoms would look and feel like to be able to seek help for when they occur.
2. Language that is direct enough to be easily understood, but distinct from medical terminology may help people discuss their experiences in a wider range of settings.
3. Avoiding the use of explicit language or slang terms in any setting may reduce the likelihood of alienating people or being misunderstood.
4. Medical or diagnosis language may help people express their experiences in difficult situations, such as in the workplace, thus this may be a focus for future support. At the same time, managers can look out for covert words such as 'accident' to help ameliorate embarrassment when documenting symptoms.
5. Language changes with different generations, sex, gender and cultural influences. Tailoring messages that respond to varying comfort levels may be helpful when working with specific demographics.
6. Public health wording could respond to the language most commonly used by groups who self-reported as uncomfortable, for example women compared to men, and Gypsy and Irish Traveller communities.