

Which social and economic factors have the biggest impact on people living with Crohn's and Colitis in the UK? A summary for partners and participants.

1. Objectives

Crohn's & Colitis UK commissioned Egality to explore:

1. Which socioeconomic factors (income, education, etc.) have the biggest impact on people living with Crohn's and Colitis in the UK
2. How this impact varies for people from different ethnic and socioeconomic backgrounds
3. Which socioeconomic factors should be a priority for Crohn's & Colitis UK to address

2. Partners

Five community organisations (Caribbean and African Health Network, Chronically Brown, South Asian IBD Alliance, Iberians & Latin Americans in Wales, and the Latin American Community Association of Edinburgh) and one health influencer (@mrcolitisrohns) were partners on the project. They delivered recruitment and provided strategic advice as required.

3. Overview of Methodology

3.1 Recruitment:

Egality worked in partnership with five community organisations representing diverse ethnic and socioeconomic backgrounds and one health influencer above to recruit 12 people from diverse ethnic and socioeconomic backgrounds. Together they delivered a recruitment campaign across 30+ social media channels, newsletters, and WhatsApp groups. 143 potential participants signed up and the team then ran analysis to identify 12 participants living with Crohn's and Colitis representing diverse ethnic and socioeconomic groups in the UK. To choose the participant sample, researchers looked at income, postcode, ethnicity, gender, education, condition, and age when recruiting, selecting a diverse range of people across these demographic groups.

3.2 Insights Gathering:

Egality used a methodology that allowed safe exploration of lived experiences and identification of impactful socioeconomic factors, this included:

- **Semi-structured narrative interviews:** to explore participants' lived experiences of Crohn's and Colitis and identify impactful socioeconomic factors.
- **Thematic analysis:** to identify 37 socioeconomic factors from the interviews and prioritise these into a shortlist of 12 factors.
- **Prioritisation workshop:** to discuss the factors, identify nuances in experience, and prioritise the shortlist of 12 factors to understand which factors have the most impact on people living with Crohn's and Colitis.

4. Findings and discussion

Twelve socioeconomic factors were identified and prioritised through the interviews and workshop.

1. Financial pressures	7. Inability to take part in hobbies
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<ol style="list-style-type: none"> 2. Lack of awareness or understanding of IBD 3. Poor mental health and helplessness 4. Limited social life and feeling isolated 5. Poor health and care services and support 6. Social stigma and negative societal perceptions 	<ol style="list-style-type: none"> 8. Structural barriers at the workplace 9. Strong family support (positive) 10. Time needed to prepare before work/social commitments 11. Mobility and transport issues 12. Intimacy and relationships
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Points of interest on these factors are noted below:

- **Financial Pressures:** Everyone included financial pressures as a top priority factor, drawing on the significant impact on all other factors. Financial security was seen as the foundation for health and wellbeing.
- **Social Factors:** Lack of awareness/understanding, limited social life/isolation, and social stigma all emerged as key, interrelated factors. There was a clear theme across these of feeling unheard and unaccepted. It's notable that social factors ranked higher than other daily impacts like work barriers and social anxiety.
- **Impact on Health:** Poor mental health and systemic healthcare issues were prioritised as having a significant impact. Mental health was seen as another foundational factor, that impacted, or was impacted by all others. In the health service, participants felt unheard, poorly cared for, and some felt discriminated against due to ethnicity. Wider social factors such as health and social care funding were seen as having a detrimental impact.
- **Interdependencies:** The majority of factors had an impact on, or were impacted by, other factors. For example, lack of awareness and understanding also impacted people at work, as colleagues did not understand their condition. If this led to a person leaving the workplace, this could also lead to financial pressures.
- **Commonalities in experience:** There was broad consensus across participants on the factors identified, with no-one questioning these in the workshop. From discussions it was clear that participants also broadly agreed on the prioritisation of factors.
- **Nuances in experience:** While socioeconomic background influenced concerns about financial pressures, other variations were largely linked to diverse ethnicities. Lack of awareness, stigma, and specific cultural challenges like food limitations and healthcare discrimination were highlighted by participants from Black, Latin American, and South Asian communities.

5. Impact and next steps:

This research provides valuable insights for Crohn's & Colitis UK to prioritise and resource research and support that is tailored to the needs of a diverse community. The identified factors encourage addressing financial burdens, and promoting understanding and acceptance of IBD in society, and across cultures, as top priorities.

Other complementary projects are gathering further insights to inform Crohn's & Colitis UK's strategy to improve lives for all people living with Crohn's and Colitis in the UK. Plans include the launch of a digital dashboard in late 2024 that provides a visual representation of impact on quality of life for those living with Crohn's and Colitis and can be used to track improvement or deterioration over time.