

# **‘Being part of the conversation’: developmentally appropriate communication in inflammatory bowel disease**

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## **Background:**

Youth with inflammatory bowel disease (IBD) face gaps in disease-specific knowledge and mental health challenges that influence their engagement in care. While IBD transition guidelines emphasise developmentally appropriate communication, little is known about the nuanced communication needs of the young person. This study, part of a broader program on adolescent health communication and literacy, explores the communication needs of youth with IBD and elements of developmentally appropriate communication.

## **Methods:**

Semi-structured interviews were conducted with youth aged 17-24 attending Liverpool Hospital IBD service. Interviews were audio-recorded, transcribed, and analysed using reflexive thematic analysis. Sample size was guided by data adequacy and richness.

## **Results:**

Forty young adults participated. Seven interrelated themes emerged:

**Knowledge and health literacy:** Participants reported limited understanding of IBD, red flags, and medication side-effects. Parents often raised issues and asked questions.

**Executive functioning:** Many struggled to track symptoms, recall history, ask questions, retain information after appointments, and adhere to medications.

**(Inter)personal values:** Sensitive topics (e.g., bowel symptoms, sex, alcohol) were difficult to raise; perceptions of the clinicians and others in the room influenced engagement.

**Psychosocial impact:** IBD affected education, career, social life, and mental health. Its unpredictable and isolating course took a toll and warranted open discussion. Developing social independence supported self-management.

**Parent role:** Parents usually supported disease management. Participants emphasised autonomy and gradual responsibility transfer.

**Clinician as facilitator:** Gastroenterologists were central, valued for trust, source of knowledge, and orienting young people to the ‘culture of medicine’.

**Institutional factors:** Continuity of care, familiarity with staff, and clear contingency plans were critical.

## **Conclusion:**

Supporting young people with IBD requires communication that recognises their evolving knowledge, executive functioning, identity, and social roles, while fostering health literacy and agency, and addressing psychosocial needs. Clinicians play a key advocacy role by attending to youth communication needs to scaffold engagement.

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