



Role Title:	Lived Experience Board Member
Term:	3 years from date of appointment. This term is not renewable
Role purpose:	<p>The Lived Experience Board Member brings the voices, insights and perspectives of people affected by IBD into the Alliance's leadership, strategy and decision-making.</p> <p>The role helps the Alliance's priorities, resources and work reflect real experiences of care, access, outcomes and support needs.</p> <p>The member will contribute on an equal basis to Board discussions, decisions and oversight, and will help the Alliance stay focused on what matters to people affected by IBD.</p> <p>This role has the same status and responsibilities as all other Board roles.</p>

Role contribution and responsibilities

The Patient and Lived Experience Board members will contribute fully to Alliance leadership, strategy and decision making. They will:

- Contribute to strategic discussion, priority setting and Board decision making
- Bring insight from lived experience to support the development of the IBD Standards, the IBD UK Benchmarking work and quality improvement activity.
- Help make sure the Alliance's priorities and outputs reflect real experiences of care, access and outcomes
- Support the Alliance to consider equity, access and differences in people's experiences of care.
- Help shape the Alliance's communications so they are clear, inclusive and accessible for different audiences.
- Provide constructive challenge and perspectives informed by lived experience
- Work collaboratively with clinical, professional and organisational Board members
- Support a culture of shared ownership, mutual respect and collective decisions
- Contribute to Working Groups and, where appropriate, act as a Board link for a group



Support and accessibility

The Alliance and Crohn's & Colitis UK are committed to full and equal participation. Support may include:

- Pre-meeting briefings
- Accessible papers and minutes
- Flexibility in meeting format and accessibility needs
- Named contact at Crohn's & Colitis UK for support
- Reasonable adjustments where required

Time commitment

- The Alliance and Crohn's & Colitis UK recognise that people may balance this role with caring responsibilities or health needs. We will support sustainable participation in Board activity.
- Board meetings: Appropriately 3 per year
- Membership meetings: Approximately 3 per year (aligned to Board cycle)
- Optional involvement in Working Groups.
- Preparation time for meetings and papers

Estimated time commitment, approximately 3-4 hours per month.

Person specification

Experience and Insight

You may bring experience through one or more of the following:

- Personal lived experience of IBD or IBD services
- Experience as a carer, family member, or supporter
- Involvement in patient groups, peer networks or community organisations
- Experience contributing to service improvement, research on engagement activity

We welcome applications from people with a wide range of experiences, backgrounds and communities

Knowledge and Understanding

- Insight into people's experiences of care and support, including family members and carers.
- Understanding of how services are delivered and improved, or a willingness to learn.
- Interest in improving care, outcomes and experience for others
- Understanding that lived experience can reflect wider perspectives, not only individual experience.



Strengths and Skills

- Ability to share views and perspectives clearly and constructively
- Willingness to contribute to group discussions (support is available).
- Openness to learning and to working in partnership
- Willingness to work collaboratively with people from different professional and lived experience backgrounds

Values and Ways of Working

- Commitment to improving care and experience for people affected by IBD.
- Respect for different perspectives and experiences
- Openness to learning and partnership
- Commitment to inclusion, fairness and reducing variation in experience of care

Equality, Diversity and Inclusion

We are committed to equity, diversity and inclusion. If you need information in a different format or any adjustments to take part as a Board member, please tell us.

Safeguarding and Wellbeing

We recognise that sharing lived experience can involve personal or sensitive information. We will support your wellbeing and work to make participation safe and supported.