

BSPGHAN IBD Working Group

Terms of Reference

1. Constitution

BSPGHAN has established an IBD Working Group (IBD WG), which, via its Chair, is directly responsible to the President and Council. The IBD WG has no executive powers other than those specifically delegated in these Terms of Reference.

2. Mission statement

To pursue the constant improvement in clinical care and long-term health outcomes of children and young people with IBD

2.1 Background

IBD in children is uncommon, however the incidence is increasing.

Specialist care by a paediatric gastroenterologist within a clinical network is recognized as essential care for children and young people with IBD. Although provision of specialist services within networks is improving, diagnostic delays remain a concern.

Better communication with primary and secondary care services is required to facilitate timely referral for accurate diagnosis and ensure optimal patient care within local networks.

Managing children with IBD is a major part of the activity for most paediatric gastroenterology units. Despite this, the evidence base for clinical management for this population remains limited.

The investigation and management of children with IBD is complex, meaning significant variations in clinical practice exist.

2.2 Objectives

The IBD WG has a number of specific objectives.

1. To pursue the constant improvement in clinical care of children with IBD.
2. To lead in developing outcome measures for children with IBD and work towards their nationwide acceptance and application

3. To explore how best to support BSPGHAN Members by providing a responsive and accessible forum of expert opinion for advice and practical support.
4. To review relevant publications, recommendations and legislation as they relate to children and young people with IBD and make recommendations to Council, or on behalf of Council, as appropriate.
5. To represent the interests of Council on national and international committees relating to children with IBD. To provide support and advice to national charitable groups in clinical and scientific matters relating to children with IBD.
6. To prioritize and provide representation for those national IBD programs that are consistent with the objectives of BSPGHAN and the IBD WG.
7. To liaise with adult gastroenterologists with IBD expertise, particularly the BSG 'IBD' and 'Young Adult' Sections, in order to promote better transitional care and further mutual understanding.
8. To stimulate and support research activity in children with IBD, promoting collaborative prospective studies within the society.

3. Membership

The IBD WG membership will include:

3.1 Chair

Appointed by Council for a period of 3 years. The planning of the meetings is the responsibility of the Chair.

3.2 Secretary

Appointed by IBD WG Members for a period of 3 years. The secretary will formally record the minutes at each meeting and distribute these within 2 weeks.

3.3 Members

Membership of the group is open to anyone within BSPGHAN involved in the clinical care or research of children with IBD. The IBD WG aims to maintain a balanced representation amongst units and professional groups. The group should invite a representative nominated by BAPS, a dietetic and nursing representative, a trainee and a 'SPIN'. A Patient & Parent Representative should be invited to join the group.

Election of Members:

- Membership is limited to about 15 members. Other experts may be asked to attend as necessary, but shall have no vote.
- The group should avoid replacing more than 30-40% of members at any one time in order to maintain continuity of purpose.
- As the posts of Chair and Secretary become vacant after 3 years, members of the IBD WG, may express an interest in taking on these roles. The remaining group should vote and suggest suitable Chair to council.
- At the end of the 3-year term, a call will be put out to BSPGHAN for expressions of interest to fill vacant posts. New applicants (that may include existing members for a further term) are appointed by the Chair and Secretary to reflect the objectives and mission of BSPGHAN and the IBD WG.
- The representative members for 'trainee, nursing, dietetic, surgical and "with an interest" colleagues should also become vacant every 3 years. These posts should be offered to the Chairs of national groups for nomination of new (or existing) members.
- Membership changes should be completed for announcement at each January BSPGHAN AGM, when the new group should meet.

Members serve a three-year term, which may be extended once for a further 3-year term. On leaving the WG members may apply to rejoin the group at the next call for new members.

All members commit to be active participants in the group throughout their membership, contributing positively to the priorities identified annually by the WG.

3.4 Quorum

Business will only be conducted if the meeting is quorate. The group will be quorate if 5 or more members are present, with one being either the Chair or the Secretary.

3.5 Attendance

The Chair and Secretary will be expected to attend 100% of the meetings. Other WG members will be required to attend a minimum of two meetings per annum, although allowed representation by deputy to one meeting per annum. If a member does not attend for three consecutive meetings without due cause, their membership is assumed to have lapsed.

3.6 Meetings

Meetings will be held a minimum of 4 times/year. One of these will be a meeting at BSPGHAN January Meeting. Additional meetings may be arranged when required to support priorities of the WG.

4. Accountability & Reporting

4.1 Declaration of Interests

Members will be invited annually to publically declare any interests they might have, which might conflict with the business of the IBD WG. These will be published on the WG webpage.

4.2 Minutes & Annual Report

The WG members will review and ratify minutes taken at each meeting. The minutes of the WG will be published on the website and made available to Council.

The Chair will produce an annual report for the membership, after ratification by members of the WG.

4.3 Budget

The Chair will submit a proposed budget before each Annual Meeting, which will be in line with the society's financial guidance.

5. Monitoring Effectiveness

5.1 Work Program

The WG will establish a work program, which will be reviewed annually.

5.2 ToR Review

The WG will review its Terms of Reference every 3 years.

6. Other Matters

6.1 Administrative support

The BSPGHAN Administrator will provide appropriate support to the Chair and WG when requested.