



Terms of Reference BSPGHAN Motility Working Group

1. Proposal

The proposal is to set up a BSPGHAN working group to develop robust structures for the clinical care of children suffering from gut motility disorders in the United Kingdom

2. Terms of Reference of proposed group

Mission statement

To streamline and improve the clinical care and outcomes of children suffering gut motility disorders.

a. Background and overall aim

Gut motility disorders represent a vast and disparate spectrum of conditions varying from common to rare and complex. All carry a significant burden of disease reflected in financial and psychosocial costs to patients and their families as well as the NHS. Diagnosis and management is often difficult and complex and in some cases only offered by a few specialist units. There is often a lack of a robust evidence base and variation in clinical care offered to children. Hence not only is specialist care by a paediatric gastroenterologist with an appropriate MDT important in the care of such children but also formation of clinical networks integrating specialist centres with more local gastroenterology and general paediatric centres. The motility disorders working group will aim to improve the clinical care offered to and outcomes of patients with gut motility disorders. It will seek to act as a point of reference and expertise and identify and develop key areas in need of improvement and any research needed to support this.

b. Objectives

- i. To identify a portfolio of gut motility disorders to be focused on by the newly formed group, including common conditions as well as rarer, more complex ones.
- ii. To establish more accurate incidence and prevalence data for gut motility disorders in children in the United Kingdom.
- iii. To gather actual burden of disease data for various motility disorders to help inform targeted funding initiatives for clinical studies as well as health policy.
- iv. To ascertain available expertise across BSPGHAN for the investigation and management of gut motility disorders to inform training needs (e.g. trainees and associate professionals) and formation of managed clinical networks. These would function to support both current and future delivery of care.

- v. To establish managed clinical networks for the clinical care of patients, determined by geographical location and access to a relevant specialist centres
- vi. To develop protocols and guidelines for clinical care and create quality outcome measures for children with gut motility disorders based on the best available evidence and aim to implement these nationally.
- vii. To support BSPGHAN Members by providing a responsive and easily accessible forum of experts for advice and discussion.
- viii. To review and critically assess relevant publications, recommendations and legislation as they relate to children and young people with gut motility disorders and make recommendations to Council, or on behalf of Council, as appropriate.
- ix. To represent the interests of Council on national and international committees relating to children with gut motility disorders.
- x. To provide support and advice to national charitable groups in clinical and scientific matters relating to children with gut motility disorders.
- xi. To prepare and publish, as necessary, consensus statements on current issues where evidence may be lacking but clinical decisions are required by BSPGHAN Members and/or Council.
- xii. To oversee and support relevant national audit programs within the society on behalf of Council.
- xiii. To identify key areas of research into aspects of gut motility disorders and stimulate and support individuals and interactive groups to successfully perform such studies.

3. Membership

The Gut motility disorders membership will include:

Chair

Elected by council for a period of 3 years.

Secretary

Appointed by Gut Motility Disorders Members for a period of 3 years, with potential for further election.

Members

Membership of the group is open to anyone involved in the clinical care or research of children with Gut Motility Disorders. Membership is limited to a maximum of 10 members at any one time. It should include at least one member representing each of the following (i) a tertiary or quaternary centre that provides specialist care (investigation and management) for gut motility disorders; (ii) tertiary paediatric gastroenterology centre; (iii) paediatricians with an interest; (iv) associate professional (e.g. nurse specialist, physiologist) and (v) trainee member. All members commit to be active participants in the group throughout their membership, contributing positively to the priorities identified annually by the WG. New members are elected with sealed votes by existing

members. This is either on member resignation or after 3 years, whichever is sooner. Members may re-apply for election indefinitely.

a. 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.

b. Attendance by Members

There will be a minimum of 3 meetings per annum. 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, but be allowed to send a Deputy to one meeting per annum.

c. Attendance by Others

Other experts may be asked to attend as necessary, but shall have no vote.

4. Accountability and Reporting Arrangements

4.1 Members will be invited annually to publically declare any interests they might have which might conflict with the business of the Gut Motility Disorders WG.

4.2 The WG members will review and ratify at each meeting the minutes of the preceding meeting. The Chair will provide and the WG ratify an annual report for Council.

4.3 The Secretary of the Gut Motility Disorders WG will be responsible for keeping the WG webpage up to date.

5. Frequency

5.1 Meetings will be held a minimum of 3 times/year. Usually these will be face-to-face and fall at the BSPGHAN Annual Meeting, the BSG Meeting and at one other mutually convenient time. Where/when possible meeting will utilize tele/video conferencing.

5.2 Additional meetings/'brainstorming' days may be arranged when required to support priorities of the WG.

6. Monitoring Effectiveness

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

6.2 The WG will produce an annual report for Council, in line with best practice, which sets out how the WG has met its Terms of Reference during the preceding year.

6.3 The minutes of the WG will be formally recorded and available to Council

7. Other Matters

The servicing, administrative and appropriate support to the Chair and WG will be undertaken by the BSPGHAN Administrator. Such support may include audit of gut motility disorder related clinical work amongst membership. The Secretary will record minutes of the meeting and be responsible for their timely distribution. The planning of the meetings is the responsibility of the Chair.

8. Review

The Committee will review its Terms of Reference and work program on an annual basis as a minimum.

9. Finances

It is expected that costs will be kept to a minimum by holding meetings in conjunction with annual society meetings/conferences and in suitable geographical locations in accordance with the current WG membership. Proposed costs per annum include

- i. travel to/from meetings ± tele/video-conferencing costs - £1200
- ii. accommodation (for members traveling large distances) - £600
- iii. subsistence - £500
- iv. meeting room hire - £300