

Terms of Reference

Background/Context

- The IBD Audit Programme came to an end in 2016, with the IBD Registry now the main vehicle for ongoing data collection at the point of care
- The UK IBD Standards need to be reviewed – a more outcomes-focused approach may be needed going forward
- The BSG is in the early stages of developing new Quality Improvement Measures for Gastroenterology. IBD is in the vanguard of the sub-specialty work streams
- There is no longer ‘one NHS’ – there are many differences in each of the ‘home nations’, with different systems, structures and priorities
- There is a need to build on the work of the UK IBD Audit and Registry and further embed a culture of quality improvement in IBD services and care in order to deliver continued progress
- It is widely recognised and agreed that there needs to be an overarching UK wide ‘strategy’ group/partnership to represent all the key organisations responsible for improving services and outcomes for people with IBD.

Overarching Goal

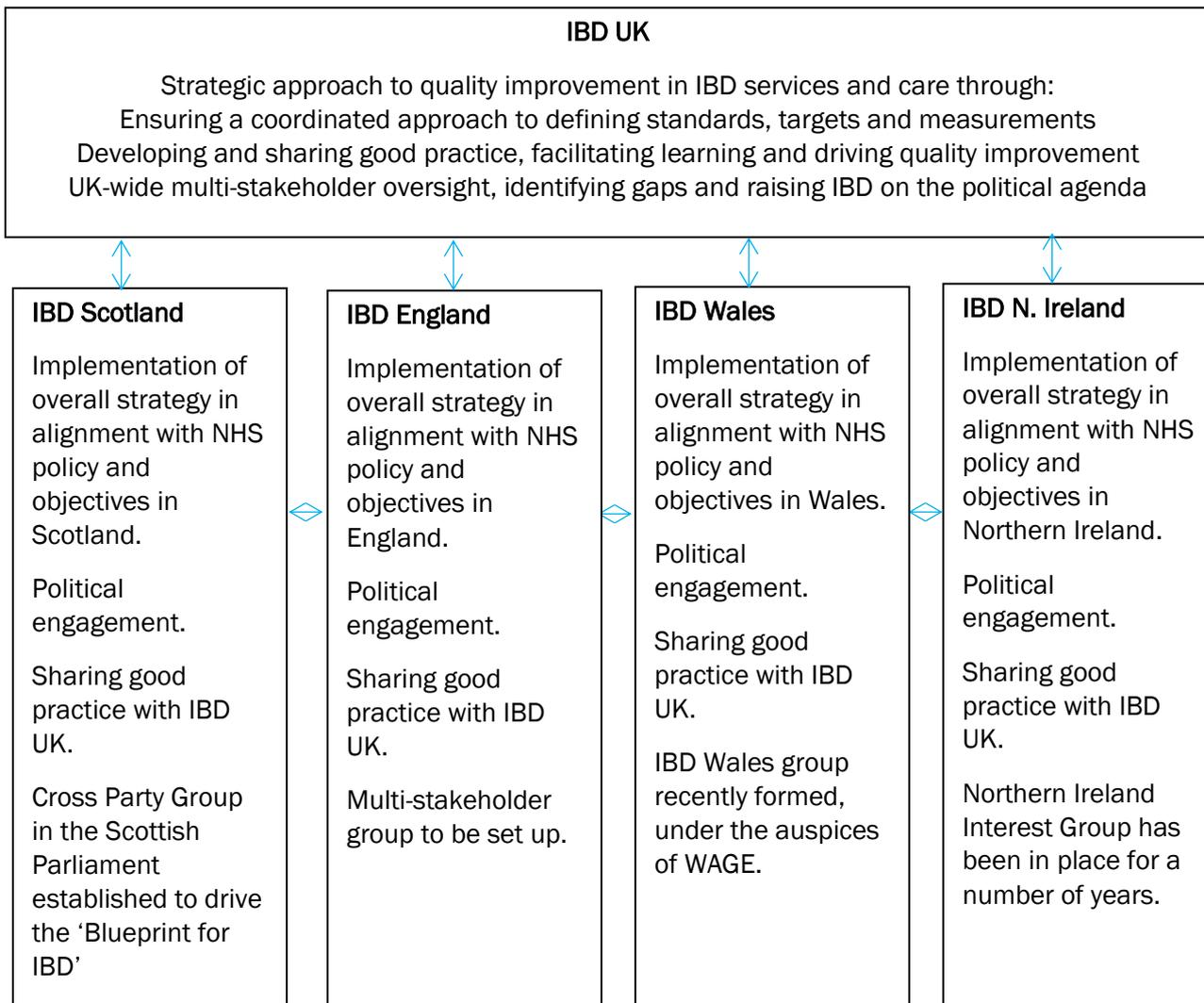
To ensure that people with IBD receive consistently high quality, person-centred care wherever they live in the UK and have the best possible outcomes.

Purpose of the new group

The work of the group will be underpinned by five key strategic areas of importance/focus as follows:



The overarching group will have a UK-wide remit/focus, but will have representation on the group from the respective chairs or nominated representatives from home nation IBD groups.



Specifically the group will:

1. Help to define quality measures for good patient centred care

Specifically:

- Work to support the British Society of Gastroenterology in defining, developing and agreeing a new framework for quality improvement measures
- Advise on effective ways to roll out and support the take up of any new quality improvement measures
- Support and feed into the work of stakeholder organisations in the delivery of quality improvement measures within their activities

2. Define and help to embed research and quality improvement in IBD Services and Care

Specifically:

- Review and, if required, update the UK IBD Standards and/or develop an appropriate outcomes framework for IBD
- Work to define an overarching approach and framework to drive standards and quality improvement in IBD services and care throughout the UK
- Act as a multi-stakeholder advisory panel for the IBD Registry in respect of audit and research planning
- Promote quality improvement in IBD

3. Share good practice and facilitate communication

Specifically:

- Facilitate the sharing of good practice between home nation groups
- Provide a forum for discussion and support
- Facilitate learning from quality improvement developments in other long-term conditions

4. Raise the political profile of IBD

- Engage with politicians, policy and decision makers at a UK-wide level to increase awareness, understanding and commitment to resourcing and delivery of IBD services
- Deliver responses to relevant consultations (eg NICE, SMC etc)
- Develop key messages for use in engagement work across the UK

5. Benchmark, monitor and report on progress

Specifically:

- Maintain UK-wide oversight
- Report on progress to inform and drive further improvements
- Identify and develop proposals to address gaps in research and knowledge about IBD
- Identify the need for and develop appropriate work streams

Composition

- The group will be chaired by the Chief Executive of Crohn's and Colitis UK and may consist of representatives from the following organisations:
 - Association of Coloproctology of Great Britain and Ireland
 - British Association for Parenteral and Enteral Nutrition
 - British Dietetic Association
 - British Psychological Society
 - British Society of Gastroenterology (Chair of the IBD Section and a representative of the Clinical Research Group)
 - British Society of Gastrointestinal and Abdominal Radiology British Society of Gastroenterology
 - British Society of Paediatric Gastroenterology, Hepatology & Nutrition
 - Chair of IBD England; IBD Northern Ireland; IBD Scotland; IBD Wales)
 - CICRA – Crohn's in Childhood Research Association
 - Crohn's and Colitis UK
 - IA – The ileostomy and internal pouch Support Group
 - IBD Registry Executive
 - Patient representatives
 - Primary Care Society for Gastroenterology
 - Royal College of Nursing (Adult & Paediatric representatives)
 - Royal College of General Practitioners
 - Royal College of Pathologists
 - Royal College of Physicians
 - Royal Pharmaceutical Society
 - UK Clinical Pharmacy Association
- Appointment term for representatives will be three years, after which membership/ contribution to the group to be reviewed.

Proceedings

- Each organisation will be invited to nominate a leading representative (and an alternate) who will be required to attend at least two meetings a year and at other times as required. Members will also take part in working/task and finish groups on behalf of the organisation they are representing.
- Representatives will have a responsibility to consult within their organisation and to report back to its membership on activities undertaken.

- Chairs, or nominated representatives of the home nation groups will act as a point of liaison between these groups and will sit as part of the overarching strategy group
- There will be two face-to-face meetings each year, with teleconferences and email communication as required between meetings.
- Task and finish groups may be set up to focus on specific projects or programmes of work.
- It is envisaged that the UK IBD Standards group would be subsumed into this new group.
- Crohn's and Colitis UK will form the secretariat