

**Anderson Barnes Suite, The British Medical Association BMA House,  
Tavistock Square, WC1H 9JZ.  
18<sup>th</sup> August 2017 - 12.15pm-5.00pm**

**IBD UK members present:**

David Barker - Crohn's and Colitis UK (Chairman)	Katie Keetarut - BDA
Anne Demick - IA	Richard Gardner - BSG
Dr Barney Hawthorne - BSG & Wales National Rep	Dr Nicola Burch - BAPEN
Dr Fraser Cummings - UK IBD Registry	Jackie Glatter - Crohn's & Colitis UK
Helen Terry - Crohn's and Colitis UK	Rod Mitchell - CICRA
Dr Jenny Epstein - BSPGHAN	Mr. Steve Brown - ACPGB&I
Margaret Lee - CICRA	Kay Crook - RCN
Nick Posford - CICRA	Graham Bell - Patient Rep
Dr Rafeeq Muhammed - BSPGHAN	Sr. Vicky Garrick - RCN
Dr Stuart Bloom - UK IBD Registry	Alex Ledger - Adviser (Decideum)
Susan Murray - Adviser (RCP)	
Anja St Clair-Jones - RPS & UK Clinical Pharmacy Association	
Prof. Stuart Taylor - British Society of Gastrointestinal and Abdominal Radiology	

**Unable to connect via conference**

Dr Charlie Andrews - Primary Care Society  
Andrew Murdock - NI IBD Interest Group

**Apologies:**

Dr Gauraang Bhatnagar - British Society of Gastrointestinal and Abdominal Radiology	
Dr Kevin Barrett - PCSG	Bev Davies - Patient Rep
Dr Ian Shaw - RCP	Dr Ian Arnott - RCP
Andrew Greaves - Adviser	Jackie King (IA)
Zara Evans - Patient Rep	Sr. Lisa Younge - RCN
Uchu Meade - RPS & UK Clinical Pharmacy Association	

**In attendance:**

Carrie Lynch - Crohn's and Colitis UK (Minute taker)

**Meeting papers sent in advance on 3rd August 2018:**

IBD UK Meeting Schedule	IBD UK Attendees/apologies
IBD UK Biographies	IBD UK QI Frame work proposal BSG
IBD UK Terms of Reference	RCP Collaborative flyer
RCP IBD Trifold document	RCP IBD Programme

**Circulated during meeting**

Group Membership Principles

## Welcome and Introductions

DB welcomed everyone to the inaugural meeting of IBD UK. He mentioned that this new initiative really benefits from the individual and collective knowledge and experience of an impressive list of organisations. He said that Crohn's and Colitis UK was proud to be leading it.

Members' biographies have been updated due to a few changes and it was noted that these would be added to the IBD UK website once it has been built. DB introduced the Group Membership Principles for review (see attached). He asked that any members who feel unable to commit to the principles to let him know.

**ACTION:** All members to review the 'Group Membership Principles' document.

## How we got here

DB introduced 'The road to excellence' slide (see slide 3) highlighting the successes there had been to date in terms of initiatives across IBD. It was agreed that there has been real progress over many years but there was a significant amount still to do. DB mentioned there had been numerous discussions over the last 12 months with a number of organisations who all felt the time was right for the formation of IBD UK.

DB reminded the Group of the objectives of the meeting (slide 4).

## Our Terms of Reference

HT outlined the proposed Terms of Reference (TOR) for the new group. She thanked the many people involved in helping to shape the TOR and mentioned that today was an opportunity to discuss and stress test the TOR in order that they could then be finalised, agreed and formally adopted.

The five target areas were highlighted (see slides 6-11) and each was briefly introduced:

- Defining quality - what does good look like and how is it measured (BH)
- Embedding quality improvement in IBD services and care (BH)
- Sharing good practice and communication (HT)
- Raising IBD on political agenda (AL)
- Monitoring & reporting on progress (JG)

BH discussed 'Defining and Embedding Quality in Inflammatory Bowel Disease Services' (see slides 12-22) the key role with informatics, IBD clinical teams, patient support and the complexities of the overlap. BH outlined 'What National Standards are available' and the possibility of this group being a great forum to help shape and support the work the BSG is undertaking in terms of defining quality improvement measures.

HT discussed 'Sharing Good Practice' and the definition of IBD UK and how this relates to the home nations. She highlighted that this group is not a talking group but a strategic group that will be responsible for taking project work forward and progressing best practices for the IBD community.

HT identified that IBD groups in Wales, Scotland are progressing well; however, England has a more complex structure and requires more focus. A stakeholder workshop day to explore potential for IBD England is to be held in September.

AL discussed IBD UK's influence with senior policymakers (see slides 23 - 29). Raising awareness and political attention for the disease area is crucial. IBD and GI are disease areas which are not

sufficiently raised, or given attention to compared to other illnesses. There is a tangible link between what is heard in parliament and healthcare policy. Competition between politicians and constituents exists and should be used to further benefit IBD. Solutions for home nations may be individual, but use of each country's information can be utilised better across all devolved HC trusts.

Best practises can be shared, borrowed and used elsewhere. Providing examples of best practice where evidence is not available, which can be shared between countries, trusts and coordinated by a wider movement, is recognised by policy makers. Due to its strong membership, AL mentioned that IBD UK was an encouraging initiative that would provide a strong platform for future political influencing.

JG outlined the importance of reporting and monitoring as a lever to drive improvements to support lobbying and health care policy, support cohesive working, highlight gaps and proposed solutions. (Slide 30) This will include both an element of horizon scanning and forward thinking.

The meeting split into small discussion groups followed by feedback on the proposed Terms of Reference.

The TOR were broadly supported with some suggested areas for amendment/addition. DB committed to make the suggested changes and recirculate the final TOR for final approval. Feedback was also given regarding widening the group to include a research presence and a representative of the British Psychological Society.

**ACTION:** IBD UK Secretariat to make suggested amends to Terms of Reference and circulate for final approval

**ACTION:** IBD UK Secretariat to discuss with BSG potential for a nominee from the BSG Clinical Research Group

**ACTION:** IBD UK Secretariat to identify potential representative from the British Psychological Society

### **Developing Quality Improvement measures**

BH gave background to the BSG QI measures project and talked through the proposed sections from the paper that was circulated in advance of the meeting. Groups then discussed:

- Whether the circulated document makes sense?
- Whether anything was missing?
- How the work and measures be 'marketed' effectively to gastroenterology teams across the UK?

Feedback from groups on the proposed measures was positive with a strong sense that they are covering the right areas. It was mentioned that the IBD Registry was a key partner in looking at ways in which the relevant measures could be captured.

There was a strong feeling that clear thought needed to be given to how best to roll this initiative out and how it could most effectively be 'marketed' to teams across the UK. Some concern was raised that if this was not considered it would simply land on a desk with little or no action being taken. There were mixed feelings about whether or not this document could be a precursor to accreditation but it was felt that if some of the measures could be mandated (similar to Quality Accounts & Biologics audit) this would add real weight.

It was suggested that the old RCP web based IBDQIP tool (or something equivalent) might, with some rethinking/re-purposing, be a suitable platform for teams to use to measure and plan for quality improvement. Whatever was devised it needed to ensure real value to local teams, be quick, simple and easy to use; ideally be web based.

BH thanked the group for the suggestions and feedback and said that these would be taken back to the BSG and fed into the next stage thinking.

### **Identifying priorities & developing next steps**

DB said that this new group would be judged on action (i.e. what it delivered) rather than it simply being seen as a talking shop. He asked the group to consider what priorities it felt that IBD UK should focus on and achieve over the coming year. It was agreed that much of the detailed work would take place outside of the main meetings via task and finish/working groups and feedback to the full group for comment and input via email.

Discussion took place on what the Group felt might be suitable priorities over the next 12 months. These were as follows:

#### **1) UK IBD Standards**

Strong consensus that a small task and finish group should be convened to look at where the IBD Standards needed to be taken next. They were last updated in 2013 and much has happened since then. DB suggested that a simple brief be drawn up for the group and asked IBD UK members to let Crohn's and Colitis UK know if they would be interested in joining this Task/Finish group.

**ACTION:** Brief for IBD Standards task and finish group to be drawn up

**ACTION:** IBD UK Members to inform Jackie Glatter if able/interested in supporting this work

#### **2. Support for the UK IBD Registry**

SB felt that the new IBD UK Group could play a key role in supporting the work of the IBD UK Registry. Three areas specifically were mentioned:

- IBD UK support for Registry's application to Quality Accounts and equivalent processes in Scotland, Wales and NI.
- IBD UK could possibly help define data fields within the Registry for a potential QI metric for 2018.
- IBD UK could provide a multi-stakeholder forum for the Registry rather than recreating another one made up of the same people.

**ACTION:** IBD UK Secretariat to meet with Registry Team to define what the requirements might be and feed back to full IBD UK Group.

#### **3. Build a website for IBD UK**

Strong consensus that IBD UK needed an online home. Over time, this should become the go to place for relevant information on the work of IBD UK and potentially act as a useful 'hub' for other relevant IBD information. Initial work should focus on getting a simple website built with information about the new group, its membership and any work plans. DB suggested that the biographies of members should be included (with pictures)

**ACTION:** IBD UK Secretariat to identify potential companies to build a web presence

**ACTION:** Everyone to feed any thoughts or ideas for potential website content

#### **4. Communications plan for the group**

A clear plan needs to be drawn up for how the work of the group can be communicated. This should include clinical teams, policy makers and patients. It was noted that a Twitter account has already been set up (@IBDUKTeam) and had already attracted over 140 followers.

**ACTION:** IBD UK Secretariat to develop a Communications plan

#### **5. Form a Public Affairs Strategy**

It was felt that a clear plan for IBD UK public affairs work would be helpful to ensure there was a clear focus to the work of the group. This should include thoughts on any key messages or calls to action that the group feels are important.

**ACTION:** IBD UK Secretariat to discuss with their Public Affairs Agency Decideum

#### **6. BSG Research Strategy**

RG mentioned the work that the BSG is currently undertaking on its research strategy. He suggested that IBD UK would be a good sounding board for the work.

**ACTION:** Richard Gardner to provide further details on this strategy for circulation to the IBD UK group.

Outstanding questions were identified about how this Group will fit into the wider research groups (BSG, Crohn's and Colitis UK, CICRA, ECCO) i.e.:

- Should a platform be provided on the IBD UK website to share ideas and disseminate research findings?
- Could research themes supported by this Group be taken to NIHR to lend weight to topic identification?

**ACTION:** All to feed into the Secretariat any additional thoughts/ideas they may have on this.

#### **Next Steps & Wrap up**

DB outlined that actions and next steps would be captured in the notes of the meeting. As per our guiding principles, these would be sent out within a week of the meeting.

A brief discussion took place on future funding of the group. Crohn's and Colitis UK are currently funding the work of the group but it was noted that any significant costs that might emerge going forwards would need some consideration - either through the member organisations or possibly through consideration of pharmaceutical company support.

#### **Next meeting:**

Agreed that meetings every 6 months would be a good way to start - although any work carried out between meetings would be reported back to the full group for input and advice.