

**The Princess Room, The British Medical Association BMA House
Tavistock Square, WC1H 9JZ.
21st February 2018 - 12.15pm-5.00pm**

IBD UK members present:

David Barker - Crohn's and Colitis UK (Chairman)
Dr Kevin Barrett - PCSG
Graham Bell - Patient Rep
Dr Gauraang Bhatnagar - British Society of Gastrointestinal and Abdominal Radiology
Dr Stuart Bloom - UK IBD Registry
Mr. Steve Brown - ACP
Kay Crook - RCN
Dr Fraser Cummings - UK IBD Registry
Anne Demick - IA
Dr Jenny Epstein - BSPGHAN
Omar Faiz - ACP
Melissa Fletcher - Patient Rep
Richard Gardner - BSG
Jackie Glatter - Crohn's & Colitis UK
Andrew Greaves - Decideum (Adviser)
Dr Barney Hawthorne - BSG & Wales National Rep
Dr Rafeeq Muhammed - BSPGHAN
Andrew Murdock - NI IBD Interest Group
Nick Posford - CICRA
Anja St.Clair Jones - RPS & UK Clinical Pharmacy Association
Helen Terry - Crohn's and Colitis UK
Lisa Younge RCN

Apologies:

Vicky Garrick - RCN
Jackie King - IA
Dr Nicola Burch - BAPEN
Zara Evans - Patient Rep
Dr Ian Shaw - RCP
Dr Ian Arnott - RCP
Katie Keetarut - BDA
Prof. Stuart Taylor - BSGAR
Dr Charlie Andrews - PCSG
Rod Mitchell - CICRA
Uchu Meade - RPS & UK Clinical Pharmacy Association
Margaret Lee - CICRA
Prof. Roger Feakins

In attendance:

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

Meeting papers sent in advance on 7th February 2018:

IBD UK Website Architecture Outline
IBD UK Website - Costs Breakdown
IBD UK Website - Project Timeline
IBD Standards Framework Starter for Ten
IBD UK Communications
IBD UK Public Affairs Strategy

Circulated with the minutes:

Presentation on the IBD Standards Framework Starter for Ten
RCP QI work streams overview

1. Welcome, apologies and declarations of any conflicts of interest.

There were no conflicts of interest raised.

2. Minutes of last meeting & matters arising.

Approval of the 21st August meeting minutes was confirmed.
HT will follow up representation from a psychologist on the group and report back.
Matt Brookes will join the group representing the BSG Research Strategy Group.

3. Update on current work strands - Website Development

DB presented an overview of the proposed structure of the website
The aim would be to include links to other websites/professional sites, wherever relevant to do so.

The question was raised if there would be a forum for questions within the website and, if so, who would answer these? It was felt that this could be managed by including some FAQs.

The structure of the website was broadly agreed, but there was a query about the costs and whether this could be done more cost-effectively, possibly even pro bono - a request was made for any contact details for web delivery companies or others who could be approached to be passed to the secretariat.

**Action - Any possible web company suggestions to be sent to the secretariat (All).
Short project brief to be drawn up (Secretariat).**

4. Updates on current work strands - IBD Standards Task and Finish Group

JG briefed the group on progress from the Task and Finish Group meeting.
The group had met twice and, in their first meeting, reviewed the current IBD Standards and other initiatives, including ICHOM and the BSG QI framework, focusing on what was needed and the strengths and weaknesses of what we have now.

They concluded that the IBD Standards, as updated in 2013, have significant strengths and we should seek to build on these, but:

- Some elements need to be given greater prominence, such as paediatrics, primary care and surgery
- The structure could be improved possibly following a patient journey approach
- Outcome and patient-reported measures/KPIs should be incorporated.

In the second meeting, which had taken place earlier in the day, a starter for ten framework had been considered. The group had also looked at some examples of work by other organisations in different disease areas which had been helpful.

In looking at the options for potential NICE involvement, it had been felt that NICE endorsement would be more beneficial than accreditation, which would take much longer and could negatively affect what was included. Endorsement is a simpler process and it was agreed that having this could help some services to gain support for implementation of the standards

BH had presented the status of the BSG IBD guidelines and it was agreed that these needed to inform the standards, especially those concerning aspects of service delivery. BH will circulate these to the Task and Finish Group to ensure appropriate alignment.

FC had presented on the IBD Registry data structure to inform a discussion about how this could support implementation and benchmarking in the future.

The Task and Finish Group will consider next steps and schedule a teleconference at the end of April to review progress

Those present considered the starter for ten framework. It was suggested that symptoms and diagnosis could be brought together and surgery included within inpatient care. The emphasis on MDT working needed to be emphasised and tools would be important to support implementation and benchmarking.

There was a query as to how some of the service delivery aspects in the current standards which are considered very important (e.g. composition of an MDT, patient engagement, research and IT) would be included. More recent developments (e.g. theronostics) should also be included. The cost and impact section would be very important.

Measurement and the role of the IBD Registry was discussed and it was felt that the QIP tool which had been developed for the organisational audit could be explored. This had provided an opportunity for teams to come together to look at their service and for reports to be generated which could be shared with managers to facilitate improvement. Regular national and local audits were felt to be important.

It was confirmed that this could be supported by the IBD Registry over time and patient-entered data was felt to be important going forward to reduce the burden of collecting information.

Action: The Task and Finish Group will develop these ideas further and report back to the full IBD UK group.

5. IBD Facts and Figures

The group discussed developing a consistent set of facts and figures about IBD which could be used consistently across the community. Currently there is some variation in what is used, e.g. in terms of prevalence.

It was agreed that this was needed and would be important in presenting clear and consistent messages that could be trusted to national policymakers. UK and devolved nation stats would be useful. Some data is available, although it may not be definitive. Investigating primary care databases might be helpful to consider. It could be funded by a consortium of companies with a shared interest or a research fellow might be interested in taking it on.

Action: NP agreed to draw up an initial list of what this might include, with input from AG, and share this with the group.

6. RCP QI Work Programme

Aimee Protheroe, Quality Improvement Manager at the RCP presented to the group on the RCP QI programme. Of most relevance to IBD are the proposed collaboratives and virtual hub.

A pilot collaborative had brought 8 IBD teams together in workshops and with coaching to learn QI methodology and apply this to a specific priority that they had identified. Evaluation of this is currently underway and a summary will be shared with the group. It is currently proposed to run 1-2 further IBD collaboratives for a total of up to 20 IBD teams - these could take place in the north and south (London and Liverpool) if funding can be secured for two collaboratives, with these running concurrently and there is potential for IBD UK to be partners with the RCP in delivering these.

The virtual hub is still to be scoped and will not seek to replicate any other similar resources (e.g. IBD UK website), but rather to signpost to these. There is scope for this to be adapted to whatever would be most useful and contributions would be welcomed.

In response to queries, Aimee clarified that:

- While not all teams can benefit from this opportunity, case studies can be captured and it starts to embed QI methodology in IBD service delivery
- Teams were invited to apply for the pilot through an open invitation - it was filled within 24 hours with a waiting list
- Teams were selected to take part on a first come, first served basis - it requires a high level of engagement so people need to be committed and keen and able to make the most of the opportunity. There is likely to be a new application process going forward
- Teams selected their own priorities to work on, including an MDT, virtual clinic, biologics pathway and transition clinics, but one or more themes could be looked at and had been applied in other condition areas

- The collaboratives are being progressed quite soon - details of timescales will be circulated to the group
- There is a 2 year commitment to this area of work from the RCP which may become longer
- On a clinical level, the RCP and RCGP are better connected than on an ops level - however, this presents an opportunity for collaboration with the RCGP, RCS and RCN. This is the value of partnering with IBD UK.
- There is funding for 10 teams, with 2 cohorts in London and Liverpool. A team equates to 4-5 MDT colleagues, although this is not prescriptive.

It was raised that joined-up thinking on QI would be needed in terms of the approach being developed by the BSG. RG said that the BSG is looking broadbrush and would not want to hold back specific programmes.

Consideration should be given to workshops being planned by the IBD Registry and if there is potential for an integrated approach - an initial conversation had taken place with Clare Munro and this will be followed up.

The group agreed in principle that this would be a good project for IBD UK to be involved with and would welcome further information from the RCP so that the details can be considered further and how it might be best taken forward. An MOU would probably be needed.

Agreed: IBD UK to be a partner in the forthcoming RCP IBD Collaborative

Action: Further details will be circulated to the group and consideration given to establishing a Task and Finish Group to support taking this forward.

7. Developing a Communications Strategy

The group discussed the need for communications about IBD UK and its work and who the key audiences for this might be. Initial thoughts about how this might be approached had been circulated.

It was felt that, while this was clearly important, it would be most beneficial to consider communications when we have progressed our programmes of work further and have something tangible to communicate.

AG commented that the public affairs strategy would be one aspect of a communications strategy and he would be happy to help define a creative brief for this area of work.

Action: Secretariat to develop a creative brief for communications agencies to more clearly define what is needed.

8. Developing a Public Affairs Strategy

AG presented on the value of public affairs for this group and how this could be approached.

He recognised that this condition area struggles for visibility with policy makers, but suggested that a well-reasoned argument supported by as many people/organisations as possible and a clear commitment to work with policy makers can be effective. Concentrating on the key people and demonstrating benefit, through reducing costs, improving quality, can make the difference. Ideally there will be zero budget impact - if budget is required, we need to be able to demonstrate that we have looked at every option available. We should present the cost of not doing anything against the cost of interventions and focus our messages on things that policymakers are measured on.

AG shared a proposed timetable which would begin with an environmental audit and stakeholder mapping activity - he will need to speak to IBD UK members to inform this. In terms of funding this work, budget has been set aside from Crohn's and Colitis UK, as this will enable the organisation to meet operational objectives. Crohn's and Colitis UK are one of Decideum's adopted charities and offer a discounted rate.

Action: Decideum will begin developing the strategy.

9. Financing IBD UK

The group discussed funding for its activities. Currently, Crohn's and Colitis UK support the cost of meetings and can also cover the public affairs work and potentially the website development, but there is no funding for other work (e.g. IBD Standards development).

One potential funding source could be pharma - this would require careful thought and complete transparency.. The group discussed the pros and cons of accepting potential funding from pharma and agreed the following:

- Ideally the group should try to secure funding from other sources other than pharma ie Trusts, Foundations, Academic Health Science Networks.
- Pharma funding to support IBD UK at a high level was not felt to be acceptable as it was critical that this group was seen as an independent body not reliant on pharma as a funding source.
- However, further work should be explored to look at if there might be potential for any form of unrestricted educational grants for specific projects such as the website development etc From a patient perspective, corporate funding from pharma would have to demonstrate very clearly that there was no direct link to the work or influence over the group. This could be seen negatively.

Any funding 'policy' should be included within the group's TOR to clarify the limits and conditions of industry funding. This is consistent with the approach taken by charities. AG mentioned that he had worked with another group that had adopted this approach and agreed to send some further information onto the secretariat of IBD UK

Action: AG to forward a TOR which addresses this for review by the group and inform the development of wording which can be incorporated into the IBD UK TOR.

Consideration also needs to be given about how IBD UK receives monies as currently it is not a legal entity or company/charity etc.

There could be opportunities for pro bono work, university or government funding. It was felt that pro bono support might be available for the website development within the IBD community.

Action: Develop a list of projects, with budget estimates (All). Identify potential pro bono support for web development (DB). Consider governance (Secretariat).

10. Next Steps

- Any possible web company suggestions to be sent to the secretariat - All. Short project brief to be drawn up - Secretariat.
- The Task and Finish Group will develop these ideas further and report back to the full IBD UK group. - JG
- Draft template for facts and figures for IBD - NP
- Define partnership arrangement for RCP collaboratives. Further details will be circulated to the group and consideration given to establishing a Task and Finish Group to support taking this forward -JG
- Development communications agency brief - Secretariat
- Move ahead with environmental audits/public affairs strategy - AG
- Identify pro bono support for web development - DB
- Develop a 'shopping list' of projects for funding - All
- Amend TOR and consider governance - Secretariat

Next meeting - 22nd August.