

# IBD Registry Patient Advisory Group (PAG)

## Terms of Reference

### Background

The purpose of the IBD Registry is to improve the health of people living with inflammatory bowel disease (IBD) in the UK by the collection and analysis of data to improve understanding of the care of people with IBD and their treatments, and to facilitate research.

We do this by collecting and analysing data from IBD patients nationally. With over 60,000 records, we are one of the largest IBD registries in Europe.

The IBD Registry is a not-for-profit limited company owned by the Royal College of Physicians, British Society of Gastroenterology and Crohn's & Colitis UK.

The IBD Registry involves collecting and using personal health data. We want to work in the Patient Advisory Group (PAG) with people who have IBD or are involved with the support or care of people with IBD to make sure that this data is used in ways that are aligned with the expectations of patients and the public.

Our PAG offers the opportunity to help shape one of the largest IBD patient registries in Europe.

### Purpose of the Group

The purpose of the PAG is to represent the voices of people with IBD in the activities and development of the IBD Registry.

### Role and responsibilities

1. To take part in at least two meetings each year
2. To be aware of and engaged with the Registry's public profile and social media work
3. To offer advice to support the IBD Registry in ensuring there is appropriate patient engagement in its work
4. Providing challenge and questioning where the group feel that people and the public have not been sufficiently involved in the work of the IBD Registry.
5. Advocate on behalf of IBD Registry to raise awareness among the IBD community of the value of participating in the IBD Registry

6. Support activities that inform policy makers to further the interests of the IBD community
7. Be able to work on ad hoc projects with IBD Registry staff, for example: contributing to the drafting of written materials, reviewing documents and event planning

## **Membership**

8. The PAG will consist of up to ten members.
9. Membership should represent the broad spectrum of those involved with or impacted by IBD including:
  - People living with IBD
  - Carers of those living with IBD
  - IBD charity representatives
  - Health professional groups
  - Patient and public campaign groups
  - The wider IBD healthcare data community
10. Membership is open to people 16 years or older
11. Membership will be reviewed annually and is expected to last for up to three years.

The group may wish to invite subject matter experts or representatives of other groups and professions as required

## **Proceedings**

12. There will be at least two formal meetings each year, with teleconferences and email communication as required between meetings.
13. Members of the PAG may be asked to join (their availability allowing) smaller task groups to focus on specific projects of work
14. Meetings of the PAG will be led by the Chair selected by the members of the group supported by a representative of the IBD Registry
15. Any confidential or sensitive information shared with PAG will be clearly identified. All discussions and notes from the meetings should be held in confidence. Outcomes will be communicated via a public facing page on the IBD Registry website, the content of which will be agreed by the PAG.

## Accountability

The PAG is represented at Board level by the Caldicott Guardian, who will report on activities to the Board . Minutes and actions of the PAG will be made available publicly on our website

## Remuneration

This is an unpaid (voluntary) role. Expenses for pre-agreed travel will be reimbursed.

## Support

The PAG will be supported by an assigned member of the IBD Registry staff. Support will include:

- Admin support for meeting papers, minutes and actions
- The supply of any additional materials members may request
- Support between meetings if additional activities or information is required
- Arranging travel as needed for members in accordance with the travel policy

## Conflicts of Interest

16.The Chair and IBD Registry representative are responsible for determining conflicts of interest and reserve the right to ask a member not to attend a meeting if conflicted. Examples of conflict might include employment with an organisation wishing to access health data from IBD Registry.

17.If the Chair of the PAG has a conflict, then another member will be asked to take on his/her role during the discussion of the business related to the conflict.

18.All conflicts will be recorded in the minutes of the meeting which will act as the conflict register.

## Review

The terms of reference will be reviewed annually (May 2020)

This document is approved on the date below by the following people:

Role	Name	Date
Caldicott Guardian	Dr Stuart Bloom	29 May 2020
Chief Executive	Liz Dobson	29 May 2020