

Press and Publications Guide

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1. Introduction

The purpose of this guide is to set out when and how the IBD Registry should be referenced when its data, analysis or publications are used in any way.

This includes references to outputs on our website and in our papers and publications as well as studies and research undertaken that involve our data and/or our analysis and expertise.

Being adequately and accurately acknowledged is important in forming and maintaining a good reputation for the IBD Registry. It is also essential to ensure that organisations and groups that have supported us are appropriately recognised. All requirements in this guide must be followed, unless a specific project agreement is in place. Where a specific project agreement is in place, the clauses in this agreement will supersede the relevant clauses in this guide.

2. General citations and reference

2.1 Use of the IBD Registry name, logo or brand

The IBD Registry's logo or branding materials must not be used by external parties without written permission from the IBD Registry.

Unless explicitly stated, permission to use the IBD Registry's branding does not constitute endorsement. No wording or branding should be used that implies endorsement.

Logos for inclusion in publications and reports are available on request from and with the permission of the IBD Registry. Use of our logo by external parties should be checked and approved by the IBD Registry before publication.

2.2 Use of data and information published by the IBD Registry

Data published in IBD Registry reports and on our website have been placed in the public domain, but where this data is re-used or a report cited, including our website itself, the IBD Registry must be acknowledged as the source of the

The IBD Registry makes its work publicly available for re-use but retains copyright under a Creative Commons licence. The terms of the licence are given [on our website](#). Authors are asked to respect the terms of the licence with the following citation, written to be from the point of view of the authors:

“This analysis was published by the IBD Registry in [year], licensed under [CC BY-NC-ND 4.0](#). More information about how the IBD Registry collects and analyses data can be found at ibdregistry.org.uk”

3. Press releases

Where we have collaborated on or funded research or a study, or IBD Registry data has been substantially* used, any media communications relating to the research or study must reference the IBD Registry appropriately. Details must be outlined in the initial agreement. For example:

- A press release being issued through the researchers' host or partner organisation
- A press release being issued by the journal, funder or research partner
- A researcher taking part in interviews for press or broadcast.

Please get in touch with the IBD Registry communications team as soon as you and your organisation's media team have decided to issue a press release or prepare for media activity. Please also supply a copy of the research paper/report, where appropriate.

We should be given adequate time to review a planned press release, respecting all embargoes and confidentiality requirements.

3.1 What to include in the body of the press release

A press release relating to research or a study that substantially* uses IBD Registry data should acknowledge the IBD Registry as the source of the data.

*'Substantially' is where the data forms a key and fundamental part of the data body involved, which may be viewed in terms of numbers of records, or of contribution of each record, or of contribution of rarer and value-adding data items (even if few in number). Whether a study makes substantive use of data or not will have been established at the start of the study.

Examples:

- A study based on IBD Registry data
- A study including IBD Registry data
- Data from the IBD Registry was used.....

Where the IBD Registry additionally supported the study (which may be in-kind support of time and assets rather than funding), press releases must acknowledge IBD Registry support for the research or study by naming and linking to the IBD Registry, ideally in the first or second paragraph of the body of the press release.

The examples below refer to 'support' as we do not typically provide funding for research.

Examples:

- Researchers supported by the IBD Registry
- Study collaborated on with the IBD Registry
- Research collaborated on with the IBD Registry
- Researchers at the University of Surrey working in collaboration with the IBD Registry
- IBD Registry research(ers) at the University of Leeds...'
- An IBD Registry study at

3.2 What to include in the 'Notes to Editors'

Please include the following IBD Registry boilerplate in the 'Notes to Editors' section of your press release:

"The IBD Registry brings together health data from people living with inflammatory bowel disease (IBD) across the UK to help improve understanding of IBD treatment and care and facilitate research. We are the national registry for Crohn's disease, ulcerative colitis and other types of IBD. We are a not-for-profit organisation owned by the British Society of Gastroenterology, the Royal College of Physicians and Crohn's & Colitis UK."

You may also wish to include in the 'notes to editors' additional information about the specific IBD Registry theme that the press release relates to.

3.3 Acknowledge the role of patient data

The IBD Registry recognises and values the role of patient data, both in enabling and underpinning improvements in care, better treatments for patients and vital research.

Examples of types of patient data used in research that relate to the IBD Registry include:

- Data in large patient cohorts, such as the IBD Registry
- Clinical audits
- Patient surveys, for example Patient Reported Outcome Measures (PROMs)
- Hospital Episode Statistics
- Prescribing databases
- Information collected during clinical trials and cohort studies

We ask researchers who use our data (which includes patient data) to acknowledge it by incorporating a data citation, in publications and stories that would not have been possible without access to this data. This expectation also extends to related press releases.

Please use the following data citation after the IBD Registry boilerplate in press releases:

“This work is based on analysis of patient data held by the IBD Registry. We thank everyone with inflammatory bowel disease (IBD) who has given permission for their data to be collected by the IBD Registry, and IBD hospital teams for their help and support in building this valuable data resource.”

Please use this citation in all press releases. It is very unlikely that the research or study does not use patient data in any form, but if you feel that this is the case, please contact us to confirm.

3.4 Use of the IBD Registry logo(s) in press releases

The IBD Registry logos should only be used in press releases with written permission from the IBD Registry.

4. Publications, presentations and posters

4.1 Involvement of the IBD Registry

The IBD Registry’s involvement in a publication may be in a number of ways:

- Supported in
- Collaborated on
- Funded (this is atypical but listed here for completion)
- Partnership with
- Simple or small use of data
- Reference to pre-existing publication

There are a variety of ways in which the Registry can be recognised, as most appropriate to the circumstances.

4.2 Acknowledgement in publications

All written and oral research outputs should acknowledge the IBD Registry involvement in full.

The style of the acknowledgment will depend on the involvement of the IBD Registry, including whole or part funding support in kind through the provision of data or support in kind through the provision of analytical or statistical support.

Examples:

- The IBD Registry provided analytical /or statistical support for this study/research
- The IBD Registry collaborated on analytical /or statistical work for this study/research
- The IBD Registry prepared the specific dataset for use in this project
- The IBD Registry collected and prepared the data used in this project

Chief investigators/lead researchers should refer to their data access agreement to ensure that they comply with any specific terms and conditions regarding naming and acknowledging the IBD Registry appropriately in study or research publications.

4.3 Website acknowledgement

Use of data and results published on our website:

“This analysis was published by the IBD Registry in [year], licensed under [CC BY-NC-ND 4.0](#). More information about how the IBD Registry collects and analyses data can be found at ibdregistry.org.uk”

4.4 Simple acknowledgement

For the simple or small use of data, where no statistical or clinical input and analysis has been received from the IBD Registry, or if data from the IBD Registry are used for a report or publication without any statistical or clinical input from IBD Registry staff, use of IBD Registry data must be acknowledged along with a disclaimer:

“We thank the IBD Registry for providing access to their database, which made the analysis in this report/study/publication possible.”

4.5 Authorship

This includes the IBD Registry annual report and abstracts for posters and oral presentations to be given at any external (non-IBD Registry) meetings, together with any published papers from studies undertaken using our dataset.

IBD Registry staff must be included as co-authors in any publication or report when statistical or clinical input and analysis has been required, or where significant project-specific data preparation has been required.

Where the design of the publication or study has been led by the Registry, the lead or corresponding author will be the designated Registry clinical lead or, where non-clinical, operational lead.

Any document to be distributed or published must be made available to the IBD Registry for review in advance of the distribution or publication date. Guidelines for this will normally be included as agreed in the data access agreement.

4.6 Citations

Any manuscript that makes substantive use of data from the IBD Registry should include the IBD Registry itself as an author, as follows:

IBD Registry¹

¹IBD Registry, 3 St Andrews Place, Regent's Park, London NW1 4LB, UK.

Where IBD Registry staff have played a substantive role in the work for the publication, which may typically include data preparation, analysis and statistical production, they should be included in the authorship list, as above.

Where IBD Registry staff have played a smaller but necessary role, they should be included in the acknowledgments list as non-author contributors.

The position of the IBD Registry citation is typically alphabetical but may also be agreed on a case-by-case basis.

4.7 Use of IBD Registry branding and logo

Where the publication (includes posters, presentations, etc) has been funded (including in kind support) by the IBD Registry, the final product should be presented with prominent IBD Registry branding to reflect this.

Where the publication has been significantly supported by the IBD Registry, we would request our logo to be included.

The logo should be used on visual and digital outputs, such as research posters, research slides and websites (but not in original research papers or your host institution's press release about your research). It should be positioned along with an acknowledgment, and a disclaimer as follows:

- On websites above the fold but not in the header i.e. so that it is visible without scrolling down the page.
- In print, such as on your institution's templates for research posters and patient leaflets, below the fold/in the bottom half of the page.
- In research slides, use the 'IBD Registry funded' logo on the first slide and the appropriate acknowledgement, identifier and disclaimer on the final slide.

Posters and visual displays should use or be sympathetic to the IBD Registry's publications style of fonts and colours. These can be requested from the IBD Registry's communications team.

For research posters, as an alternative you can use an IBD Registry template, to which you can add your host institution logo.

5. Contact details for press and publications

For any enquiries regarding press releases, publications, use of logo and/or branding, etc. please contact the IBD Registry at comms@ibdregistry.org.uk