



# Statement on collaboration with the pharmaceutical industry

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## 1 Background to this statement

The mission of the IBD Registry is to improve care and treatment for people with inflammatory bowel disease (IBD) through better understanding of patient populations and real world outcomes enabled by IBD data.

In this mission we recognise the key stakeholders who have a vital interest in what we do: patients, clinical teams and also the pharmaceutical industry as well as other commercial entities. The different contributions they each make to help us achieve our mission.

Relationships with and also services for the pharmaceutical industry and commercial companies provides the IBD Registry with sustainable income. However, given that this gives rise to considerations around privacy and conflicts of interest, this approach must be balanced with needs of other key stakeholders, most notably patients and clinical teams.

The Board of the Registry, therefore recognised that a framework is required that sets out principles for clear, transparent, independent and strategically-focused work with industry; and further, to be successful, this framework has to be well communicated, publicised and understood.

## 2 Purpose of this statement

The purpose of this policy is to provide clear principles and guidance about how the IBD Registry works with pharmaceutical companies and other commercial entities. Such partnerships enable us to achieve IBD Registry's mission and must be conducted without compromising the principles of independence and integrity of all parties. This policy exists to clarify and notarise these principles within this working partnership, to ensure the ongoing trust of patients and clinicians, as well as other stakeholders.

Pharmaceutical companies have a critical role to play in advancing the medications, treatments and technologies that can improve the lives of those with IBD. Collaborations between independent registries (such as ours) and pharmaceutical companies have the potential to deliver significant benefits for patients, for clinicians and wider society by reporting on the use and safety of new and existing treatments to produce better health outcomes.

As a not-for-profit organisation, the IBD Registry must source income to fund its work. We raise this income from a variety of sources, of which pharmaceutical companies form an important strand. This can be in the form of unrestricted sponsorship or educational grants, or commercial fees for services provided by the IBD Registry. Fee funding will always be realistically set against the funding required for the Registry's ongoing operations, in order to have a sustainable Registry that can support developing better understanding of IBD.

Public concern about commercial interests influencing public benefit organisations in a negative way have to be taken seriously and therefore a framework which makes any such relationships clear and transparent is necessary.

The Registry's goal is that all relationships with industry are subject to clear guidelines for joint working, to ensure openness, independence, transparency and impartiality. This statement therefore lays out our policy on collaboration with industry. This policy governs the relationship between all members of the IBD Registry staff, including Board members and volunteers, and representatives of industry partners, including consultants and agencies.

The principles that guide us in this are:

## **2.1 Strategic fit**

We will only seek, and accept, support, promotion or collaboration from industry or other commercial partners for projects that directly support our strategy. The outcome of any project undertaken is to advance the field of understanding of IBD, benefiting people affected by IBD by supporting the work of the Registry to achieve its mission.

Where any requests fall outside our strategy, they will be considered on a case-by-case basis by the appropriate oversight group appointed by the Board for this purpose.

Our mission statement can be viewed on our website.

## **2.2 Impartiality and independence**

We will seek positive working partnerships that enhance reputations. We will avoid any partnership that may damage our reputation, and will terminate any relationship that, in our view, becomes a threat to our reputation or adversely impact on people living with IBD.

We will remain clearly independent. We will not collaborate or accept support from any entity that seeks commercial advantage either through direct influence on Registry policy or direction, or indirectly via policy makers, through association with the IBD Registry.

All projects and studies that are financially supported by collaborative working with industry will be governed by the IBD Registry and led by the principal investigator(s) approved by the Registry's research committee. Following initial consultation, where

beneficial to project design, industry partners will take an arms-length role and the academic lead will work independently for the duration of the project.

We will ensure that our editorial independence is maintained and recognised as such, so that any commentary we may wish to make about pharmaceutical or other commercial entities and their products will be valued accordingly by patients, clinical teams and other interested parties.

The involvement of the IBD Registry in any project, collaboration or similar should be a very positive public endorsement of that project, and that we want to ensure complete clarity of understanding around our involvement. Where Registry data is used, appropriate and agreed acknowledgement will be required. Any other use of the IBD Registry's name and/or logo will be closely governed by an appropriate policy.

## **2.3 Openness and transparency**

We will actively make publicly available both this framework and our activities under it. For commercially sensitive and restricted projects, we will do so as governed by the guidelines of the established disclosure frameworks.

We will publish a summary of the financial contributions, gifts in kind and fees received from industry and commercial partners within our annual reporting. The IBD Registry will also comply with the ABPI Code of Practice, a self-regulatory system that is supported by the law, and to which the pharmaceutical industry is bound. We are especially mindful of Clause 27, Relationships with Patient Organisations.

We will work within the industry principles set out in the AMRC (Association of Medical Research Charities), specifically their recommendations of independence, integrity and transparency.

Where we are working in a partnership arrangement, we will ensure that an appropriate contract or grant agreement will be in place outlining the terms of engagement between the parties, to maximise positive outputs and avoid misunderstanding. Where there is an externally funded project, all major communications promoting sponsored projects will clearly state who the sponsor is.

We will ensure that we have a feedback channel readily available (which can be confidential) whereby patients, clinicians and other stakeholders may raise concerns and we will commit to responding to these.