

 **BADBIR PATIENT REPRESENTATIVE**

**ROLE AND SPECIFICATION**

*History of BADBIR and why a register is needed*

The concept of a register for biologic therapies in psoriasis was conceived during 2004 and a Biologics Steering Committee was formed. After discussion it was agreed that the work should be sub-contracted to the Arc Unit at Manchester University, who already ran a successful register for rheumatology. The Steering Committee then considered whether the project should be owned by the BAD or the BSF. In 2006 the group concluded that it should be the BAD and asked the Officers and CEO to take on the legal and financial responsibility of the BAD Biologic Interventions Register (BADBIR).

As with all treatments, biologic agents might cause unwanted side effects. As biologic, the long-term effects of biologic agents are not known. In order to inform both patient and clinician the BAD believe they are best placed to develop a long term study and a register of patients in order to learn about the impact of the drugs and disseminate the results appropriately.

*Structure*

* The BAD has established a separate company, BAD Biologics Register Limited (BADBRL). The BADBRL has entered into legally binding contracts with a number of Pharma companies to provide them with data from the register and the companies are paying the BADBRL substantial sums of money to support the collection of the data.
* BADBRL has sub contracted the coordination of the BADBIR to the arc Epidemiology Unit (arcEU) unit at the University of Manchester for an agreed fee.
* To comply with MHRA regulations the University of Manchester will act as the sponsor of the study.
* The Register, data and intellectual property is wholly owned by the BAD.
* The BAD/University of Manchester has recruited departments of dermatology throughout the UK to contribute to the data collection and will pay the departments agreed costs to support this activity
* All members of the BAD have free access to the data for the purpose of research. The University of Manchester has access to the data for internal research and teaching but not for external publication.

*Role of the Biologics Register Subcommittee*

The Biologics Register Subcommittee’s function is to deal with some of the day to day running issues of BADBIR. It deals with requests for information from pharmaceutical companies and other outside organisations. It reports to the BAD Executive Committee and the BADBIR Management Committee.

The full Subcommittee consists of approximately 25 members and meets at least three times a year. Each meeting typically lasts 3 hours, and takes place during February, June and October.

*Role of the Patient Representative within the Biologics Register Subcommittee*

This role definition is intended for use by a patient and/or carer representative, who has a relationship with a psoriasis patient support group, in the position on the BADBIR Steering Committee.

*Role Purpose*

* To share knowledge of the diverse needs, preferences and choices of psoriasis patients and carers to ensure these are considered and met in relation to the aims, objectives and delivery of BADBIR.
* To contribute to decision making processes to improve the experience and outcomes for future psoriasis patients.
* To act as a voice for patient/carer views and experiences and thereby, ensure that these are actively considered alongside other professional and clinical and academic views in forming plans.
* To identify and present cases for patient/carer issues of concern, particularly areas where you feel that care could be improved.

*Knowledge, Skills and Experience*

* No formal qualifications are required but must have a willingness to share personal experiences in a way to represent a patients' view
* An understanding of the experiences and needs of a wider network of patients and carer, e.g. as a member of a support group.
* To be able to contribute to the discussion in an objective and balanced way drawing on and using your own and other patient experiences and views.
* A willingness to convey the views of patients groups not represented in person.
* Some knowledge about the ethical and governance principles underlying clinical research is helpful but not essential.

*Skills*

* To act as an objective representative of other patients and carers *(please note that the BAD requires all members of BAD committees to declare any financial or professional interests they may have in any company or organisation which has an interest in the dermatological field – this can be submitted electronically and is held at the BAD Office)*.
* To read and critically appraise from the patient/carer perspective all relevant documentation in preparation for meetings, e.g. minutes, agendas, background and research papers.
* Good communication skills.

*Experience*

* Some experience of working as a member of a team and with a broad range of people.

*Other*

* Time to commit to the work of the group; to attend meetings, to do back ground reading, and comment on draft plans and proposals.
* Enthusiasm and commitment.
* Imagination to think constructively and practically.
* Reimbursement of travel costs if required to travel to meetings.