

NIHR Newcastle BRC Dermatology Patient Advisory Group Role Description

Background

The National Institute for Health and Care Research (NIHR) Newcastle Biomedical Research Centre (BRC) works to transform lives **through world-leading research in ageing and multiple long-term conditions**. It is the only BRC in the North East of England, an area that has a rapidly growing older population with significantly greater health needs. The Newcastle BRC focuses on eight areas of research expertise (themes) where we can offer significant impact to drive forward health improvements in ageing and multiple long-term conditions (multimorbidity).

Skin Disease, Oral Disease & Immunogenomics Theme

Skin diseases are the most common reason for going to the GP in the UK. Approximately 800,000 people per year are then referred to secondary care dermatologists. The Newcastle BRC Skin, Oral Disease and Immunogenomics theme has active programmes of research involving patients living with multiple long term conditions, skin inflammation and rare diseases involving the skin.

At the NIHR Newcastle BRC, we use the findings from our studies in healthy volunteers as well as in psoriasis, atopic eczema, periodontitis and critical care cohorts, to evaluate the effect of ageing and other age-related co-morbidities (diabetes, hypertension) on inflammatory response, disease evolution and response to treatment.

Purpose of the Group

The dermatology patient group will help to make sure the research being carried out is relevant to patients. Using their lived experience, the group will provide feedback and advice to researchers on current research as well as share what is important to them, helping to inform research priorities.

Role Responsibilities

- Provide constructive feedback and advice to researchers at different stages of their research, including the design, conduct, dissemination, and evaluation.
- Help to inform research priorities
- Review and assess newly proposed research

Commitment

- You will be asked to attend 2 meetings per year.
- Meetings will take place in Newcastle upon Tyne and last for 1-2 hours.

- There may be ad hoc meetings or activities throughout each year. This might include additional in-person meetings or providing feedback online via email.
- Membership of the group will be for 2 years (2025-2027) in accordance with the current NIHR Newcastle BRC funding award.
- Members commit to adhere to the group's Terms of Reference.

Criteria

We are looking for people over the age of 18 with lived experience of skin conditions and diseases including:

- Eczema
- Psoriasis
- Skin cancer
- Lynch syndrome
- Ichthyosis
- Ectodermal Dysplasia
- Birt-Hogg-Dube syndrome
- CYLD cutaneous syndrome

Please note this list is not exclusive and if you have a skin condition which isn't listed here you are still welcome to apply to join the group.

As a member of the group you must also:

- Be comfortable with actively contributing to meetings in a group setting
- Be able to maintain confidentiality
- Be able to attend regular meetings and read any pre-reading materials
- Be open to listening to other people's view and experiences
- Be able to attend in-person meetings in Newcastle upon Tyne

Support for you

- Meeting documents and materials will be provided in advance via email (or post if required)
- Training and resources will be provided as and when needed
- Regular updates and feedback will be provided
- Payment for your time and involvement in line with NIHR guidelines
- Travel expenses (within the North East of England)

How do I apply?

If you are interested in becoming a member of the group, please complete this short application form: <https://forms.office.com/e/XYGeJ25dKn>

The closing date for applications is 02/02/2025

After the closing date, we may get in touch to have an informal chat as an opportunity to meet and answer any questions you might have. After this we will let you know if you have been selected to be a member of the group.

Contact

If you have any questions, please get in touch with Katherine Jacques, Patient and Public Involvement and Engagement Manager for the BRC Skin Disease, Oral Disease & Immunogenomics research theme by email: katherine.jacques@newcastle.ac.uk