

National Eczema Society 'Expert by Experience' Member Terms of Reference

Purpose

The 'Expert by Experience' Membership is established by the National Eczema Society to ensure that the perspectives and experiences of patients living with eczema are considered in all aspects of the Society's work. The 'Expert by Experience' membership aims to:

- Provide insights and feedback from a patient's perspective on the Society's activities, initiatives, and materials.
- Promote patient-centred approaches in the Society's projects and research.
- Act as a voice for the eczema patient community within the Society and to external stakeholders.

Objectives

- To represent the views and interests of eczema patients in the decision-making processes of the National Eczema Society.
- To review and provide input on the Society's policies, publications, and educational materials to ensure they are patient-friendly and relevant.
- To contribute to the planning and implementation of patient-focused events and initiatives.
- To support the Society's research agenda by identifying patient priorities and participating in research advisory groups where appropriate.
- To help raise awareness about eczema and advocate for better patient care and support.

Membership

- The 'Expert by Experience' members will consist of members who are patients living with eczema or caregivers of eczema patients.
- Membership will aim to reflect the diversity of the eczema patient community, considering factors such as age, gender, ethnicity, socio-economic background and geographical location.
- Members will be appointed through an open application process and will serve a term of 12 months, with the possibility of reappointment for one additional term.

Roles and Responsibilities for members:

- Attend and actively participate in 'Expert by Experience' meetings and activities.

- Provide input and feedback on materials and initiatives from a patient perspective.
- Engage with the wider patient community to gather insights and represent their views.
- Contribute to sub-committees or working groups as needed.

Meetings

- The 'Expert by Experience' members will meet at least once a year, with additional meetings scheduled as necessary.
- Meetings may be held in person or virtually to accommodate members' locations and availability.
- A quorum for meetings will be 2/3 members present.
- Agendas and meeting materials will be distributed at least 5 working days in advance.
- Minutes of meetings will be recorded and circulated to all members and relevant NES staff.

Review

- These terms of reference will be reviewed annually to ensure they remain relevant and effective.

Confidentiality and Conduct

- Members are expected to maintain confidentiality regarding sensitive information discussed in 'Expert by Experience' member/s meetings.
- Members should declare any conflicts of interest and act in the best interests of the National Eczema Society and its patient community. All 'Expert by Experience' members must sign the NES conflict of interest policy before taking up their posts.
- 'Expert by Experience' members will operate in a manner consistent with the values and policies of the National Eczema Society.
- NES is committed to upholding and fostering a respectful and inclusive environment. We explicitly prohibit any form of bullying, harassment, or discriminatory behaviour amongst panel members, whether based on race, gender, disability, or any other characteristic. All members are expected to treat each other with dignity and professionalism, ensuring that differing opinions and experiences are valued without fear of hostility or intimidation. Violations of this policy will be taken seriously and may result in disciplinary actions, including removal from future involvement with NES, to maintain a safe and supportive atmosphere for all participants.

Experts by Experience Panel October 2024/November 2024

Next review scheduled: November 2025