An Introduction to Ataxia UK's Research Involvement Network

The Research Involvement Network enables people affected by ataxia, including family members, friends and carers, to contribute their lived experience to research. This is often referred to as Patient and Public Involvement and Engagement (PPIE).

What is PPIE?

Patient and Public Involvement and Engagement (PPIE) means working alongside people who have lived experience to shape research, helping ensure it addresses the issues that matter most to those affected. It means research is carried out with or by people rather than to, about or for them.

What experience is required?

No previous experience is required to join the Research Involvement Network. We are interested in your experiences living with or supporting someone with ataxia. To join the Network, you should be interested in the research done on ataxia, be willing to read documents, and provide feedback. The Network has up to 30 places, offered on a first-come, first-served basis.

What does the Research Involvement Network do?

The Research Involvement Network provides feedback on research documents, such as patient information sheets and consent forms for clinical trials. This feedback could be about whether the language used is easy to understand, or whether any important information is missing. Direction on the type of feedback to provide will be given with every request. Members of the Network will also be given opportunities to provide PPIE in other ways. This could be by joining focus groups or research project advisory boards, often run by third parties.

What does being in the Network look like in practice?

When Ataxia UK receives a request to provide PPIE, we will send an email to the Network. In cases where specific attributes are required (e.g. a specific type of ataxia), we will send requests to a subgroup of the Network. Directions on how to provide feedback or the next steps for joining a PPIE activity will be given in every email. There will never be any obligation to respond to requests for PPIE, and you can leave the Network at any time. In order to ensure members of the Network remain engaged, if a member doesn't respond for 12 months they will be removed from the Network. There is no maximum term.

Membership of the Research Involvement Network is an unpaid role. In some cases, opportunities will be paid by third parties. In these cases, we operate on a first-come first-served basis. Where feedback is required, this will mostly be given over email. If you are interested in joining the group but would need us to make adjustments for this to be possible please get in touch so we can discuss how we can help.

To enquire about joining the Research Involvement Network, or if you have any questions, please email Ataxia UK's Research Department on research@ataxia.org.uk