

Information for Patient and Public Involvement (PPI) Members

What is NCEPOD?

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is an independent organisation and registered charity that works to improve the quality of healthcare. We do this by reviewing the care provided to patients and identifying opportunities for improvement.

Our work brings together healthcare professionals, patients, parent/carers, and members of the public to explore important aspects of healthcare and make recommendations that support safer, higher-quality care.

Our reports are based on careful review by experienced healthcare professionals and are widely used and respected across the NHS and wider healthcare community. They are used by healthcare organisations, professional bodies, and policymakers to help improve services across England, Wales, Northern Ireland, and Jersey.

We value the perspectives of people with lived experience and members of the public. By involving patients, parent/carers, and members of the public in our work, we can ensure that our studies, reports, and recommendations are clear, understandable, and reflect what matters most to patients, families, and the wider public.

This information pack explains what the Patient and Public Involvement (PPI) group is, what taking part involves, and how your experience can help improve healthcare for others. Our *Patient and Public Involvement Privacy Notice* can be accessed [here](#).

Who Can Join?

The PPI Group brings together people with lived experience and members of the public with an interest in healthcare to help ensure that NCEPOD's work is understandable, accessible, relevant, and reflects what matters to patients, families, and the wider public.

You do not need any clinical knowledge or previous experience in research or healthcare quality improvement to be involved. We will provide any information and support you need to help you contribute confidently.

PPI members should be aged 16 or older. We are committed to creating an inclusive group and welcome people with a wide range of backgrounds and experiences to join.

What Can I Expect as a Member?

As a member, you will share your experience and perspectives to help ensure our work is clear, relevant, and meaningful.

There is no expectation that you will contribute to every study or attend every meeting. We recognise that people have different experiences, interests, and availability, and there will be opportunities to contribute in ways that suit you.

You may be **invited to:**

- Co-produce and review documents, reports, and recommendations.
- Suggest ways that documents could be clearer, more accessible, or easier to understand.

- Attend online PPI, Study Advisory Group, Steering Group, results, and stakeholder meetings.
- Share views on issues that are important to patients, families, and the wider public.
- Support the development of future studies where appropriate.
- Identify where PPI perspectives could be better reflected in NCEPOD's work.

You are not expected to represent the views of all patients, families, and the wider public. Instead, we encourage you to share your own experiences and perspectives while listening to and respecting the views of others.

Time Commitment

The level of involvement is flexible and will depend on your interests, availability, and the activities you choose to contribute to. **There is no minimum time commitment**, and you can choose which opportunities you would like to take part in. For example, you may choose to review a single document, attend a meeting (with online and in-person options), or contribute to a study more extensively.

As a guide, members who choose to be more involved may contribute **up to approximately 20 days per year per study**. This could include:

- Four PPI meetings a year (online only).
- Two study advisory group meetings per study.
- One results meeting per study.
- Reviewing documents, questionnaires, reports, recommendations, and other study-related materials.
- One stakeholder meeting approximately one-year post-publication of each study.

Reimbursement and Expenses

PPI group members are reimbursed £28 an hour for time spent contributing to NCEPOD activities, in line with NCEPOD's reimbursement policy.

For in-person meetings, reasonable travel and other agreed expenses will also be reimbursed.

Please note that receiving payment may affect benefits or tax in some circumstances. If you are unsure, we encourage you to seek independent advice before accepting payment.

Terms of Reference

The PPI group exists to ensure that independent patient and public perspectives are embedded throughout NCEPOD's work. The group will:

- Provide advice and feedback from a patient and/or public perspective.
- Ensure NCEPOD's work is accessible, understandable, and relevant.
- Contribute to the development of patient-centred recommendations.
- Advise on meaningful patient and public involvement across NCEPOD's work.

Members are **asked to**:

- Share their experience and perspectives constructively.

- Review documents, co-produce materials, and provide feedback when requested.
- Attend PPI-specific meetings and wider meetings involving multidisciplinary groups and healthcare professionals where possible and actively participate in discussions.
- Respect the views and experiences of others.
- Maintain confidentiality where required.
- Declare any relevant conflicts of interest.
- Notify NCEPOD when they no longer wish to be a member of the group.

Members are **encouraged to:**

- Feel confident contributing to discussions with multidisciplinary groups, including experienced and senior healthcare professionals.
- Ask questions, speak up, and share different perspectives, including where these differ from healthcare professionals.
- Respond to requests within agreed timeframes.
- Act in accordance with NCEPOD's values of independence, integrity, and collaboration.

Support and Accessibility

We want everyone to feel comfortable contributing. If you need any reasonable adjustments or additional support to help you participate, please let us know. We will do our best to accommodate your needs.

Next Steps and Contact Information

Whether you're ready to join or would simply like to find out more, we would be happy to hear from you: engagement@ncepod.org.uk