

# Patient, carer and public involvement in anaesthesia research: personal reflections from the PCPIE Group

Dr Olly Boney and Dr Cliff Shelton, PCPIE Group co-chairs  
 Jenny Dorey and John Hitchman, PCPIE Group lay members

We go behind the scenes of the NIAA’s Patient, Carer and Public Involvement and Engagement Group (aka the ‘PCPIE’ Group) to speak to some of its members about their work and how they believe it benefits research

## Dr Olly Boney and Dr Cliff Shelton

### What does PCPIE do?

**OB:** In a nutshell, we review research proposals and provide feedback from a patient and/or carer perspective. Our membership is very diverse, and most members have a completely non-clinical background so they are well placed to appraise studies through a patient-focused lens and suggest improvements to a study’s design to make it more patient-friendly.

### How can this improve research?

**CS:** I think there are two major benefits from the PCPIE Group’s work. First, PCPIE feedback helps make research more acceptable to patients: for example, making patient-facing information easier to understand, or highlighting excessive burdens of participation on patients which may lead to poor recruitment or high dropout rates. Secondly, the PCPIE input ensures that research is relevant to patients. Early feedback from non-clinical reviewers helps ensure that new research addresses problems that genuinely matter to patients, and arguably encourages researchers to focus their efforts towards issues with real patient impact.

### How did you both get involved?

**OB:** I took time out of training to get involved in research, and was lucky enough to lead two patient-centred research collaborations: the James Lind Alliance ‘Priority Setting Partnership’, and a ‘Core Outcome Measures’ initiative for anaesthesia and perioperative care. When the role of PCPIE deputy chair became available, I jumped at the opportunity to extend my interest in promoting patient-centred research in our speciality.

**CS:** My interest in patient-centred research grew mainly from my qualitative work on understanding what makes a ‘good anaesthetic’ for hip-fracture surgery, but I’ve always believed that research must first and foremost serve the patients we treat in everyday practice. Olly and I joined as co-deputy chairs at the same time, and since then I think we’ve both learnt a huge amount about how valuable non-clinicians’ contributions are when designing and delivering research.



**Are you considering (or already involved in) clinical research?**  
 If you think your study might benefit from PCPIE’s input, please see:  
[niaa-hsrc.org.uk/PCPIE-Resources#pt](http://niaa-hsrc.org.uk/PCPIE-Resources#pt) or email [info@niaa.org.uk](mailto:info@niaa.org.uk)

## Jenny Dorey

### How did you get involved with PCPIE?

I've served on the PCPIE Group for almost seven years, having joined when I became a member of the RCoA Lay Committee.

### Do you find being on PCPIE rewarding?

Research is really important for improving patient care, but to be successful it needs clinicians and patients to work in partnership. I hope my input helps ensure that study design is always patient-focused, and encourages greater patient participation in both the specific study and research more widely.

### What's the time commitment like?

The PCPIE Group meets every three months to discuss individual studies, and considers the research topic's importance, practicalities of the study design and – most importantly – whether the patient information is clearly written, comprehensive and easy to understand.

Sometimes we're asked for quicker, preliminary, feedback – which often happens virtually. Or sometimes the lead investigator approaches us about their trial directly, for example seeking a PCPIE volunteer to provide ongoing lay input.

Going forward, we hope to increase and improve non-clinician input at all stages of research: from identifying research priorities, through planning and conducting studies, ensuring meaningful dissemination of results to clinicians, patients and the public, and wider implementation of the learning.

### How has your involvement shaped the studies you've worked on?

I hope that my involvement has helped researchers to 'walk in the shoes' of patients participating in clinical research, resulting in improved study design leading to better patient outcomes and more efficient healthcare resource usage. It's often the little things that make a difference – a clearer explanation, avoiding unnecessary visits to hospital, or better understanding of patients' concerns.

Researchers are very committed to improving care for patients, but sometimes a 'second pair of eyes' helps make the research more accessible and/or acceptable to patients.

## John Hitchman

### How did you get involved with PCPIE?

In hindsight, I think personal medical encounters over the years have sparked my interest in improving care and patients' experiences. One that's particularly stayed with me occurred after a week of intensive inpatient treatment for our nine-month-old daughter. When I asked the consultant paediatrician what the diagnosis was, I got the answer, 'The child probably has an irritable nature like her father!' And that was it – off he drove in his Aston Martin, while we left with baby in our rusty Morris 1100. I learnt three things that day: that perhaps medicine is not the precise 'science' patients imagine, that communication skills are not always second nature to doctors, and that (as an architect) I was in the wrong profession.

So I was delighted when – as an RCoA Lay Committee member – I was offered the opportunity to join the PCPIE Group. To date, the group has reviewed and advised on the patient-oriented aspects of more than 80 really worthwhile projects, with excellent feedback from the study teams.

### Do you find being on PCPIE rewarding?

Absolutely! In addition to reviewing study proposals, we can be invited to join as co-applicants for specific studies or members of steering committees. This is a great entry into the world of research: being involved with OSIRIS (Optimising Shared Decision Making for High Risk Major Surgery) and CAMELOT (Continuous Rectus Sheath Analgesia in Emergency Laparotomy), two multicentre studies with great emphasis on patient experience, has furthered my understanding of cutting-edge research.

### What's the time commitment like?

While the PCPIE Group only meets face-to-face three or four times per year, contributing to research reviews requires regular input every month. Meanwhile the time commitment as a 'lay' member of a research team varies enormously.

### How has your involvement shaped the studies you've worked on?

Getting involved on study steering groups has been very enlightening for me personally, and hopefully adds value and relevance to the final results of the study.