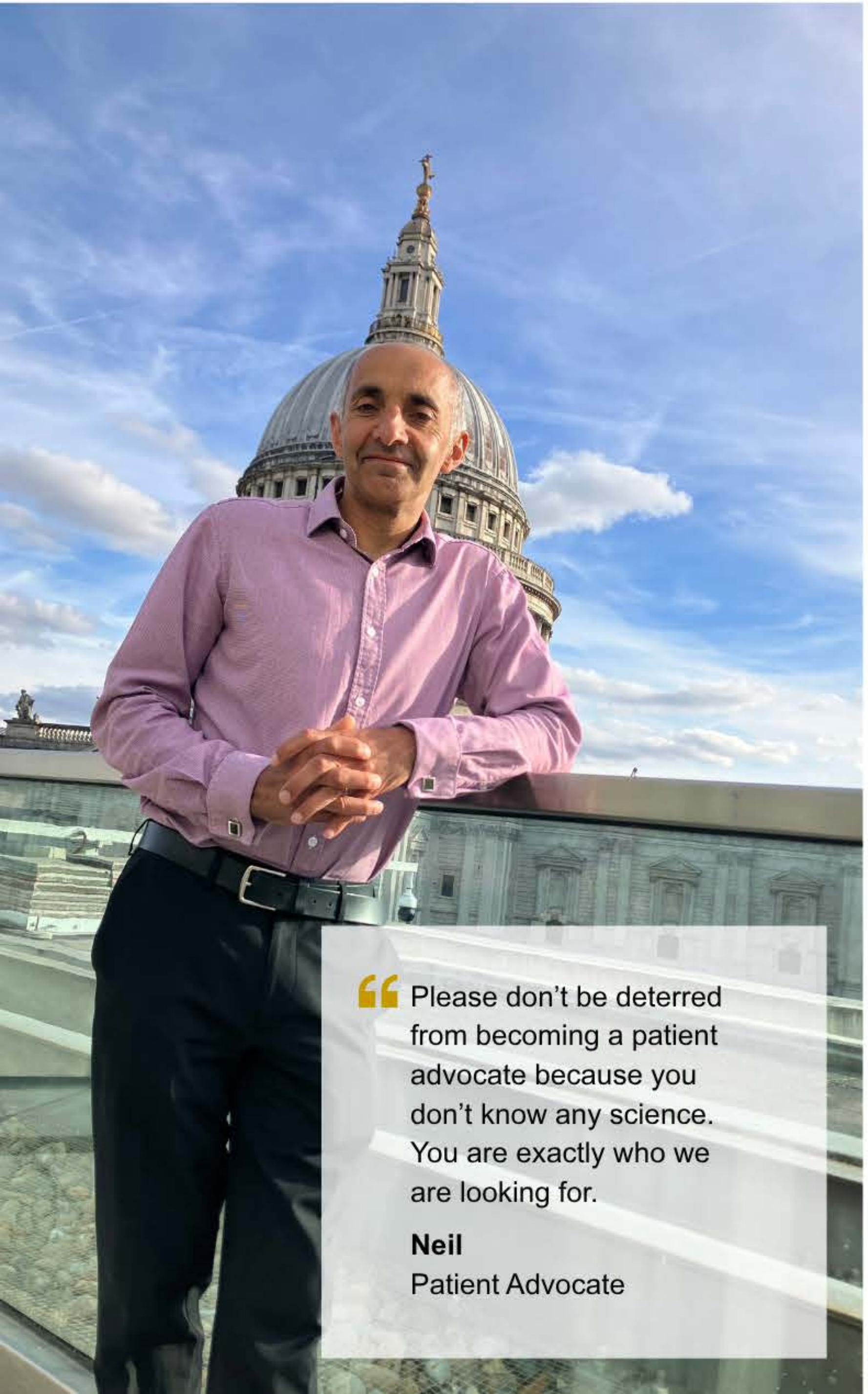

> Please don't be deterred from becoming a patient advocate because you don't know any science. You are exactly who we are looking for.
>
> **Neil**
> Patient Advocate

PPI Case Study

When a child or adult is asked to join a clinical trial, a nurse or doctor talks to them about the trial. They are given documents to take home and time to make a decision. These documents are written by researchers who understand the trial well but may not have experience as a patient. Clinical trials can be very complicated, so before documents are given to patients, they are reviewed by patient advocates.

BIOMEDE is a trial of new treatments for brain cancer in children and young people and involves tests such as MRI scans and biopsies. Researchers wrote documents for patients and their parents, including a patient information sheet which details the tests and treatment they would have if they took part. These were sent to Neil, who has personal experience of childhood cancer.

Neil reviewed the documents with a group he is part of (the Paediatric Oncology Reference Team (PORT)); they suggested adding a short explanation of what having an MRI scan involves, recognising that it can sometimes feel scary for younger patients. They also suggested that researchers add more information about what biopsies are and how they are done. Researchers changed the documents, making them better for patients and their families.

Neil's thoughts: "I have very little understanding of cancer. I didn't like science at school, and I work in IT and Finance. A lack of medical knowledge is often what we want from reviewers of documents for patients and their families. If I can't understand it, or there are big words I don't know, then I am confident other parents and patients won't understand the documents either."