

*Helen Craig, Patient Involvement and Engagement (PPIE) Manager at [UCLPartners](#), speaks to Ron Collins, a patient volunteer, to find out about the impact that ten years of patient involvement at the Barts NIHR Biomedical Research Centre PPIE has had – both on the work of the centre, and on the people who take part.*

The Barts NIHR Biomedical Research Centre and their Patient and Public Advisory Group are celebrating ten years of focusing on public engagement and patient involvement. Over this time, they've built an active and committed group of patient and public members who are involved in the work of the BRC at all levels. I spoke with one member, Ron Collins, to find out what it means to him.

*"Has volunteering saved my life? I don't know but it has made it worth living! I am convinced that it has actually benefitted my physical and mental health a great deal over the past ten or eleven years."*

Ron Collins, patient volunteer

For Ron, his journey into PPIE began with taking part in a clinical trial at the William Harvey Clinical Research Centre at Barts. "The whole team made me feel at home and absolutely nothing was too much trouble for them," he explains. This led him to join [TrialsConnect](#), a group that draws on the experience and professional expertise of current and previous clinical trials patients to highlight the power of patient experience and stories. TrialsConnect features a place to discuss clinical trials, for patients to sign up and learn about ongoing work, and acts as a repository for patients' stories.



Picture Source: TrialsConnect [Photo Gallery](#)

Over the past year, their work has responded to COVID-19 – the website provided a valuable space for sharing details of recruitment onto COVID-related trials, as well as responding to news of further lockdowns, and celebrating the lives of people who passed away. . And patient expertise was also able to support the centre in less expected ways – when they were asked to work with the new Nightingale hospitals and create a plan for asking patient permission to take part in research, the

“Legal Eagles” team of patients with experience in law were able to use their experience to support the researchers.

There have been many highlights over the years but the recent activity that has meant the most to Ron was supporting medical students to recruit patients to a COVID vaccine trial – he hears that the group they supported was able to recruit more than any other single unit in Great Britain!

It was also via the centre that Ron met Jane Batchelor, Centre and Events Manager at the Barts NIHR BRC, and through her work became involved in the BRC Patient and Public Advisory Group. The aim of the group is for patients and the public to have a say in heart research and related activities. The team undertake traditional PPI activities such as ensuring patient information sheets are informative and appropriate and advising on research grants from a lay perspective. But they also support the wider communications work of the centre. This year meetings have been held virtually but the group has been in regular contact in between times.

*“The University recently won the Engage Watermark Gold Award for excellence in public engagement – we couldn’t have done it without the group member’s input into the application.”*

Jane Batchelor, Centre and Events Manager, Barts NIHR BRC

All of this work comes together in large-scale events like the Barts and Queen Mary Science Festival aimed at older secondary schools pupils. Previously the festival and Let’s talk hearts seminars which Barts NIHR PPAG actively supports ([free heart talks for the general public](#)) have been held in person but this year were both held virtually due to the pandemic; the future form of the festival and other PPAG supported activities will of course be adapted as appropriate to the changing world we now live in.

The festival focuses on interactive games and demonstrations, and the chance for attendees to meet people working in research and medical care. This year festival resources are online due the pandemic.



Picture source: Moorfields Blog

Whatever form the festival takes it is a space for external groups and partners to come together. For example, since 2018, the NIHR Moorfields Biomedical Research Centre have been one of the many groups who take part, sharing their expertise and the excitement of research with attendees.

*“I thoroughly enjoyed the day I wish it had gone on for longer! My favourite moment was finding out about the students own interests and seeing their faces when they learnt something new!”*

*Vasilis Theofylaktopoulos, research assistant working in adaptive optics.*

Presenting at a science festival recognises the expertise that patients bring to their work in involvement, and demonstrates the importance that research today places on patient and public involvement and engagement. The partnerships and connections made in PPIE can be surprising. Ron says, “there have actually been times when I have exclaimed to myself “how on earth did I get into this!” but the last ten years show the value of working in an involved way, both for research and for participants like Ron themselves.

*Barts NIHR Biomedical Research Centre is part of the UCLPartners Academic Health Science Centre, and is one of more than 15 research and innovation organisations represented on the UCLPartners Patient and Public Involvement Committee. The Committee meets regularly to share learning and best practice and identify opportunities for collaborative working to ensure that patients, families, carers and the public inform health research, innovation and service development across our partnership.*