



### **60 Seconds with Ellie, patient/ public contributor**

Ellie is a public patient committee member on the NIHR i4i and Artificial Intelligence panels and has collaborated with many Queen Mary, University of London colleagues on medical research and publications. She is also a lay representative on the Surgical Board and Strategy Board at Barts Health NHS Trust. More recently, Ellie has become involved in the COVID-19 research efforts both locally at Barts Health and nationally, as a lay representative with the [Urgent Public Health Group](#) and the NIHR CRN Patient and Public Involvement and Engagement (PPIE) COVID-19 research forum.

Her contributions have included reviewing the scientific proposals for some of the nationally prioritised studies and helping to create 'plain English' summary sheets as well as reviewing patient-facing documents and the scripts for two short videos Barts Health and Queen Mary research staff produced. The [films](#), which described what interventional and observational research is, have been translated into a number of different languages and are also shared by the NIHR on the [Be Part of Research](#) website.

#### **Why did you get involved in COVID-19 research? What motivated you?**

I became involved because I have a strong commitment to public involvement in medical research. I am unable to work or volunteer on the front lines at present and I am trying to do things that fit within my skills and experience. If ever there were a disease that needs the public as researchers, it's this one: COVID-19 affects everyone.

Some of the horrifying features of COVID-19 are its disproportionate impacts on minority communities, the elderly, people with disabilities, and underserved communities. I find this devastating. We all have a duty to try to ensure that our society moves towards equality, not away from it. Ensuring that research answers why we are being impacted in this way is critical.

The British public - and the global public - has become deeply interested in medical research, epidemiology, and public health. I hope the public takes part not only in COVID-19 studies but also in other medical research into illnesses and conditions that impact them.

#### **What benefits do you think you personally received? Also, any negative experiences?**

I think that I have been privileged to contribute to the development and delivery of COVID-19 research, and alongside patients, clinicians, researchers, administrators, and communicators who are stellar. I am lucky to be working with them towards a common goal.

Online meetings can be frustrating if you don't have the literal bandwidth, but it is spectacular to be able to speak with people in wholly distant parts of the country and globe, something that might be rare otherwise.

#### **What benefits do you think COVID-19 research will bring to patients in the future? Also, any perceived negative impacts?**

People might be concerned that they will be guinea-pigs; that their anonymity will be compromised, and, at worst, that this is all a hoax - a line sadly promulgated in my own country.

There are reasons that we have international agreements and national laws governing medical research and ethics. These laws are strict and were developed out of sad knowledge of the past. If you get involved in research you can ensure that these laws are being followed. If you think something needs to be done differently, then you can be there to help it change. Run towards research, not away from it. Ask tough questions: these are why you should be involved. Science deserves not to be dismissed because it saves lives.



I hope that one good thing to come out of COVID-19 is greater public health education and awareness, far greater funding for the NHS, and greater involvement of the UK public in medical research.

**If you had to list some positive things that came out of your experience of being involved in COVID-19 research - what would they be and why?**

Selfishly speaking, this has been an education for me and has drawn me closer to my friends. I've learned more about epidemiology, certain kinds of medications, research ethics, data analysis, and biology than I ever thought possible in such a short time. Friends of mine on 6 continents have pored over COVID-19 research with me. I feel closer to them, so far away, working towards a common goal, albeit in different roles.

**In a nutshell how has being involved in COVID-19 research development activities had a positive experience on your life?**

COVID-19 is a serious disease with devastating health consequences that has also destabilized practical aspects of everyone's lives. Every one of us can all contribute to the research that will beat this disease. Run towards the fire. Contribute to finding a cure. And repeat this lesson for the next illness that comes your way. We'll all be the better for it.