

COVID-19 research PPIE advisory group

Terms of Reference

Background

[COVID-19 \(also called novel coronavirus\)](#) is an illness that can affect the lungs and airways and at present, there is no vaccine or treatment for it. As it is a new disease we need to find out as much as we can about it, as soon as possible. [Research allows us to answer questions about COVID-19](#). By gathering information about a disease we can find ways of diagnosing it faster and better ways of looking after and treating people with the disease.

There has been much activity across Barts Health hospitals to set up a number of different [COVID-19 research studies](#), many of which have been deemed to be of Urgent Public Health interest.

We'd like to invite you to join our COVID-19 research PPIE advisory group, to explore ways in which we can work together with our patient representatives and advisors to raise awareness of the importance of research into coronavirus at this time.

Purpose - why do we need a COVID-19 PPIE PPAG?

The COVID-19 Patient and Public Involvement/Engagement advisory group has been established in response to the COVID-19 pandemic, primarily to provide a forum for those who are interested in working together to promote COVID-19 research and related patient and public involvement/engagement. The subsequent aims of the group are:

- To exchange knowledge and ideas and facilitate a shared understanding of PPIE as it relates to COVID-19 research;
- To undertake activities that help to raise awareness of the importance of COVID-19 research - e.g. taking part in studies, sharing evidence-based knowledge;
- To facilitate better understanding of the research available, the benefits of being involved and the opportunities to become involved or engaged in COVID-19 research;
- To identify, discuss and address issues of common concern and avoid unnecessary duplication of effort;
- To support the dissemination of research results in line with the [HRA guidelines of research transparency](#).

Overview of Duties - What will I be asked to do?

- To actively raise the profile of COVID-19 research undertaken within the Trust by ensuring that general, as well as study-specific, information about clinical research is made readily available to patients and the public in ways, online initially and then across the Trusts/GP/local community centres etc.
- To share skills, knowledge, ideas and resources freely and in a timely way to support effective PIE, and to help identify and address obstacles across the system.
- To build a collective understanding of the main barriers to participation in COVID-19 research and develop innovative and sustainable approaches to overcoming these.
- To cascade information to relevant patient or staff groups.

- To stay informed, and keep contributors/peers and colleagues informed - in a timely way - of developments in COVID-19 research across Barts Health.
- The above is by no means an exhaustive list of duties and it is envisaged that the group will identify and act upon other priorities as they arise.

From time to time sub-groups may be formed to support specific projects or tasks.

Membership

The group will be open to those who have an interest in, and wherever possible, and are able to **actively** help us develop and deliver COVID-19 research PPIE projects. Membership will comprise, amongst others:

- Associate Director, Research Engagement & Diffusion (advisory group lead)
- Patient representatives to advise on different aspects of COVID-19 studies virtually and quickly – e.g. reviewing patient literature or advising on dissemination activities etc.
- Patient Research Champions - as above
- Staff representative(s) from Barts Health CAGs and hospitals

Group members:

- are committed to helping and supporting the advisory group to be successful
- are willing and able to make an active contribution
- are representative of the diverse population the Trust serves
- have the ability to work in a team and to advise and comment in a timely and constructive way
- are willing to gather views from, and share public information with, their own contacts and groups where relevant
- have internet access and are able to join virtual meetings online
- have some experience or knowledge of health and/or social care services

Engagement and Diffusion will provide appropriate training and other resources to support and guide advisory group members.

Frequency and administration of meetings

- It is envisaged the group will initially meet once a week and that this frequency will be subject to change.
- Brief minutes (documenting action points) of each meeting will be taken, circulated to all members of the Group and agreed by those who attended the meeting. Progress against agreed actions will be reviewed at each meeting.
- Meetings will be chaired by the Associate Director, Research Engagement and Diffusion.
NB: Members of the group are invited to chair meetings and/or take notes.