

Lay advisor: Terms of reference

Patient and public involvement (PPI) in research is when patients or members of the public become actively involved in the research process. We believe that having PPI makes research more relevant, and can lead to treatments that better meet the needs of our patients.

Royal Brompton & Harefield NHS Foundation Trust is keen to encourage patients, carers and the public, who are interested in contributing to the future development of our research work, to become lay advisors and join our lay advisory groups.

The contribution of lay advisors includes becoming involved in the design, execution and dissemination of our research, and in raising public awareness and interest in our research through a range of promotional activities.

We work closely with Imperial College London, with many of our researchers holding joint appointments across both the Trust and Imperial College. Some research projects are also carried out in collaborations with other universities in London and across the UK, including King's College London and University College London as well as charity organisations. However all research that is reviewed by lay advisors will be directly linked with research being carried out at the Trust or research carried out by staff employed by the Trust.

Who we're looking for

The role of lay advisor is open to any patients, carers or members of the public with direct experience of, or interest in, cardiovascular and/or respiratory conditions.

What the role involves

The role of lay advisor is flexible and allows individuals to do as much or as little as they are able to do. The list below outlines some of the types of activities we would like lay advisors to get involved with but it is not an exhaustive list.

- Act as a voice for patient/carers of Royal Brompton & Harefield NHS Foundation Trust patients in relation to research projects
- Attend meetings (where possible*) with other lay advisors and researchers, to inform research relating to patient care.
- Review research proposals for your research area of interest, at meetings or via email
- Provide feedback on patient literature, including patient information sheets.
- Advise us on patient recruitment to clinical trials and research studies.
- Attend and/or take part in research events where relevant (internally or externally).
- Assist researchers to develop their research proposals through meetings or interview panels.
- Help to coach new lay advisors on their role.
- Help to identify new ways for lay advisors to become involved.

Lay advisory group meetings

The main function of the lay advisory group meetings is to provide patient and public views on relevant matters arising from our research activities at the Trust.

Lay advisory group meetings occur approximately every 3 months and are dependent on the number of research projects we receive that require lay input.

* In order to provide individuals who live a considerable distance from the hospital the opportunity to participate we will be investigating methods for them to join meetings using on-line connections, e.g. Skype.

Lay advisor responsibilities

As a lay advisor you will be expected to;

- Respect the anonymity of discussions and opinions expressed by fellow lay advisors.
- Maintain confidentiality and declare any conflicts of interest.
- Respect the views expressed by others.
- Read through information and documents sent in advance of meetings.
- Offer constructive feedback as appropriate and take an active role within group discussions.
- Give your opinion freely.

Trust responsibilities

We are keen to support lay advisors as best as possible and will ensure that we;

- Provide new lay advisors with a 1-to-1 meeting with the Patient Public Involvement (PPI) coordinator to discuss the role, as well an opportunity for new lay members to meet with existing lay advisors.
- Provide training and support as necessary.
- Provide a named person (see details below) to support lay advisors and be available to discuss any successes or problems.
- Provide lay advisors with references as required for any external positions/situations as necessary.
- Adequately inform (and within reasonable time) lay advisors of the research topics prior to meetings
- Provide remote access to meetings, where feasible, via video/telephone call.
- Provide feedback from researchers where lay advisors have had input on research projects.

Duration of role

The role of lay advisor is open ended but will be reviewed on a periodical basis.

Support and training

All lay advisors will be offered an initial induction to familiarise them with the research process and the Trust. We will provide suitable support and training for lay advisors as their role develops. All lay advisors will have access to the PPI coordinator (Zahra Aden) for support.

Payment and expenses

This position is on a voluntary basis only; there is no salary involved. Reasonable travel expenses for meetings and events will be reimbursed and lunch will be provided at meetings.

Confidentiality

All lay advisors are required to sign a confidentiality agreement and to disclose any conflicts of interest that may arise for them i.e. involved in a similar capacity with another research institution.

Further information

For any questions or queries about the role or what it entails please contact Zahra Aden at z.aden@rbht.nhs.uk or call 020 7351 8575.