



# Role profile: Patient Advisory Group and Lay Members

## Background

The BHF funds over £100 million of research every year into heart and circulatory conditions (including stroke, diabetes and vascular dementia). We help scientists undertake pioneering research into many different heart and circulatory conditions, their causes, prevention, diagnosis and treatment.

We receive more than 500 research grant applications each year from research teams all over the UK. Eligible applications are reviewed by experts in the field, and their judgments inform the funding decisions made by our research grant committees, which are made up of independent scientists.

This objective and rigorous review process ensures we fund applications of the highest scientific quality. We are a response-mode funder, believing that the most effective way of tackling heart and circulatory conditions, is to allow the research community to identify the gaps in knowledge and generate the research ideas and approaches needed to fill those gaps. We support a broad portfolio of basic science, through to translational and clinical research, totaling around 1,000 active research grants at any one time.

As outlined in our 2015-2020 [Research Strategy](#), BHF aims to support more clinical research, which is research undertaken on patients in hospitals and clinics. Trials of new or established treatments lead to better patient care, and our ambition is to fund more clinical trials either independently or in partnership with other funders.

Our Clinical Studies Committee (CSC) decides which clinical research applications are awarded funding from the BHF. To help ensure the applications we fund are important and relevant to the needs of patients, two lay members (also called patient representatives) sit on the CSC. The lay members are supported by, and are also part of, a wider Patient Advisory Group (PAG).

## Clinical Studies Committee

The CSC is made up of approximately 14 members, including two lay members. Other members include scientists and experts in the field.

The CSC meets twice a year (in May and November) to assess the high value clinical study applications that have been received over the previous six months. The CSC will make the final decision on which grants are awarded funding and which are rejected.

## The Patient Advisory Group and Lay members

The Patient Advisory Group (PAG) supports the role of the lay members who sit on the CSC. It is made up of 12-15 members who have been affected by heart and circulatory conditions. The PAG meet prior to each CSC meeting, to discuss and

provide feedback on all the research applications, and in particular focus on assessing:

- the quality of the plain English summaries
- the importance of the research question to people affected by heart and circulatory conditions
- commitment to patient and public involvement (PPI), both in the development of the research question and design, and proposed plans for ongoing involvement
- study recruitment and retention plans, for example helping to identify any unnecessary burden on patients, or barriers to people taking part in the research
- plans for dissemination and keeping in touch with study participants

At PAG meetings, people's views are discussed, and an overall view on each application agreed. Lay members will then be responsible for relaying the PAG view to the CSC, to ensure the views of patients are taken into account in funding decisions about clinical research. Feedback from the PAG is also sent to researchers for them to respond to in advance of the CSC, to help improve the quality of the applications.

### **The impact you'll make:**

The Patient Advisory Group gives people with experience of heart and circulatory conditions the opportunity to influence the clinical research funded by the BHF. As a PAG member you will help to ensure that the BHF invests in research that will make a difference to people affected by heart and circulatory conditions, and to ensure it is conducted in a way that has maximum benefit to patients.

### **Role Description – PAG member**

#### **Responsibilities**

PAG members will be expected to:

- attend at least two PAG meetings per year, in March and September
- participate in mandatory training and other activities as agreed
- prepare in advance for meetings - including reviewing research grant applications
- respond in a timely manner to all email communication between PAG members as required
- contribute thoughtfully and constructively to discussions from the perspective of someone affected by a heart or circulatory condition
- share your views in a considered and respectful way, and be receptive to the views of others
- treat all applications that you review as confidential
- provide ongoing feedback to help further develop and refine the process for involving patients in the review of clinical research funding applications

#### **Skills and attributes**

PAG members must have the following skills and attributes:

- have a personal experience of a heart or circulatory condition such as stroke, diabetes and vascular dementia, either as a patient or carer, and an awareness of how heart and circulatory conditions can affect people
- be enthusiastic about research, and willing to familiarise yourself with medical and research language
- ability to read and absorb complex information, seeking further information and clarity where needed
- good communication skills with an ability to listen to and to respect differing opinions, and to express your own view clearly and appropriately
- confidence to voice your opinions clearly and to participate constructively and objectively in meetings with a large number of other people
- IT literate - grant applications are viewed using an online system
- it is desirable that some PAG members have experience of taking part in a clinical trial.
- the BHF understands the importance of diversity and inclusivity and is committed to increasing diversity across its Patient Advisory Groups. We encourage applications from all backgrounds, but in particular, we would welcome those from young people and from black, Asian and minority ethnic backgrounds.

### **Lay member – additional skills and responsibilities**

Two lay members from the PAG will sit on the Clinical Studies Committee to feed back the PAG views on research applications. In addition to the responsibilities as a PAG member, **lay members** will be required to:

- attend and take part in two CSC meetings a year, confidently communicating perspectives from the wider PAG
- participate in group discussions, listen to, understand and synthesise differing opinions
- undertake additional work to collate feedback from PAG meetings to ensure that the views of the PAG are reflected at CSC meetings, and in funding decisions.
- prepare in advance of PAG meetings as well as CSC meetings
- be confident in communicating the views of the PAG at CSC meetings with scientists and experts in the field
- be objective and representative in communicating the views of the wider PAG

### **Length of membership**

Membership to PAG is for 3 years, after which the membership will be reviewed.

### **Time commitment and dates**

- Training and induction session on **Thursday 13th February 2019** in London, for which we will cover any travel or accommodation costs.
- A minimum of two meetings of PAG a year, approximately six weeks prior to the CSC meetings which take place in May and November. The first PAG meeting will take place on **16<sup>th</sup> March 2019**.
- A couple of days to prepare and review applications prior to each PAG meeting (from home).

## Support

To ensure you can contribute effectively in your role, you will be asked to attend a mandatory training and induction session. We will also assign you a key contact within BHF who will be in regular contact with you through email or telephone for information, advice and support.

If you are interested in the role but are unable to commit to daytime meetings, please do get in touch with us and we'll be able to discuss about alternative ways of getting involved.

## Expenses

We will reimburse reasonable expenses for travel and overnight accommodation where necessary and agreed in advance. We are also able to book your travel and accommodation for you prior to any meetings / training if necessary.

## Application process

To apply for the role of Patient Advisory Group member please complete the expression of interest form, and return this to [heartvoices@bhf.org.uk](mailto:heartvoices@bhf.org.uk). The deadline for applications is **2<sup>nd</sup> December 2019**.

Those who are shortlisted for the role will be invited for a telephone interview in the week commencing **6<sup>th</sup> January 2020**. For the lay member role, we will have in-person interviews in the week commencing **13<sup>th</sup> January 2020**. If you have any questions, please email [heartvoices@bhf.org.uk](mailto:heartvoices@bhf.org.uk) or call 0207 554 0394.