

## **GMC Patient Public Forum Role Outline**

### **1. Background**

We recognise the importance of patient and public involvement in developing, promoting, supporting the delivery of genomic medicine in the south west. The experience of patients, service users and carers is fundamental and a valued source of knowledge that will help improve the way in which the tests are delivered and supported.

In March 2017, the NHS England Board set out its strategic approach to build a National Genomic Medicine Service (GMS), building on the NHS contribution to the 100,000 Genomes Project. The overall aim of the GMS is to ensure equitable access to all forms of genetic testing, timely return of results to patients and clinical teams and use of genetic results to improve healthcare. As part of this approach, 7 Genomic Laboratory Hubs (GLH) were created to support genomic testing as a single national testing network, consolidating and enhancing the existing laboratory provision. The services to be provided are set out in the 2019/2020 National Genomic Test Directory which identifies the genomic tests commissioned by the NHS in England, the technology by which they are available, and the patients who will be eligible to access to a test.

### **2. Outline**

#### ***Key Responsibilities – lay members***

- To participate in the promotion and development of a genomic medicine service in accordance with the specific aims of the committee, group or specified activity.
- To attend actual or virtual meetings and to provide lived experience relevant to the committee, group or specified activity
- To offer a personal perspective from their own experience or to formerly represent a particular group of users through a recognised organisation.
- Where a member is unable to attend a meeting, to send apologies in advance of the meeting.

#### ***Key Responsibilities – Group/activity organiser***

- To provide a clear remit for the group or activity.
- To provide adequate notice of any meeting times, locations and venues and any meeting cancellations.
- To provide papers in advance of any meeting and in printed form if required.
- To arrange transport on behalf of the lay member if required.
- To provide access to payment of expenses as outlined in local policies and with the agreement of the lay member.

#### ***Key Working Relationships –***

- PPI Lead Facilitator

#### ***Essential Criteria -***

- A person, family member or carer with lived experience or an understanding of relevant health issues or genetic testing
- An ability to maintain confidentiality at all times
- A willingness to engage in any relevant training and support activities

#### ***Desirable Criteria –***

- Ability to travel occasionally
- A good communicator
- The confidence to share views and information with others

### **3. Support and Training:**

Appropriate training and support will be offered to lay members by staff at the trust or through approved organisations.

Training may be accessed through learning sessions, on-line information or mentoring.

### **4. Payments and Expenses:**

Lay members should not be financially disadvantaged through their voluntary involvement. All reasonable out-of-pocket expenses will be reimbursed. However, there are strict rules surrounding the payment of expenses and when those payments may count as income. Please refer to local organisation policies for full details about what may or may not be covered.

For further information on how payments may effect benefits please go to:  
[www.invo.org.uk/resource-centre/benefits-advice-service/](http://www.invo.org.uk/resource-centre/benefits-advice-service/)