

Patient and Public Forum Genomic Medicine Centre South West

Terms of Reference

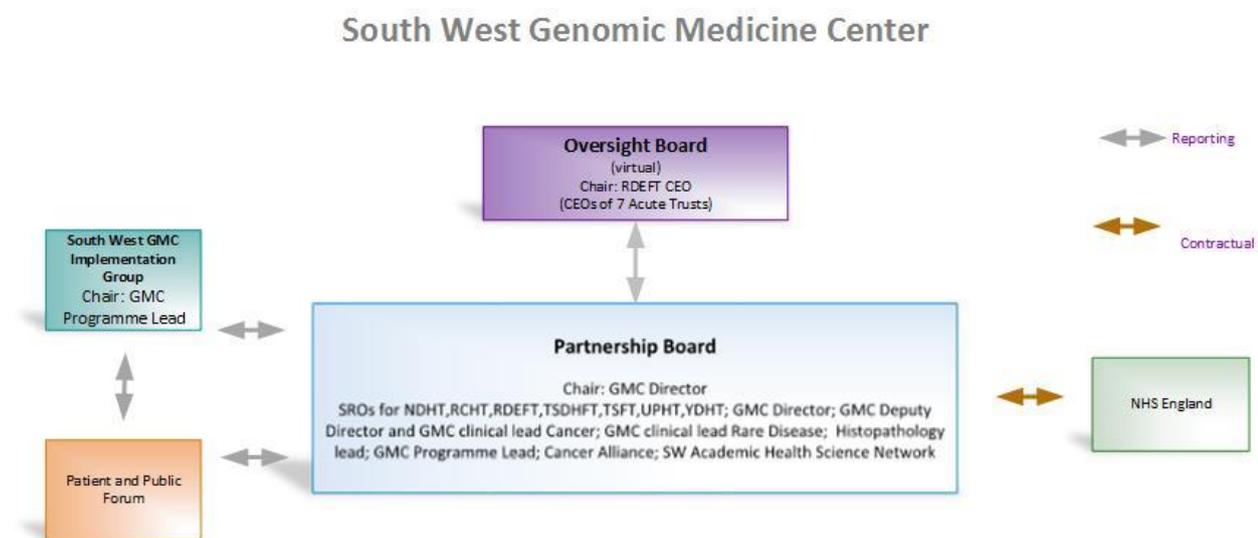
Background:

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.

Accountability:

Patient and Public Forum 100,000 Genomes Project South West Genomic Medicine Centre is accountable to the SWGMC PPI lead and the SWGMC Programme Lead



Purpose:

The Patient and Public Forum 100,000 Genomes Project South West Genomic Medicine Centre will act as an advisory group to the South West Genomic Medicine Centre (SW GMC). Activities are centred on informing and developing strategies to support the delivery of Genomic Medicine in the southwest and to ensure continued and appropriate management of samples and data, including results, relevant to participants of the 100,000 Genomes Project.

This will be achieved by the following activities:

- Review processes to support equity of access for families and individuals in the southwest to the tests available on the National genomic Test Directory
- Advise on communications materials and communication strategies to ensure appropriate engagement with both staff and members of the public
- Support working with Local Delivery Providers (LDP) and local organisations and groups to ensure the transformation aims of the project are delivered
- Provide feedback from lived in experience

Membership:

Membership will include the SWGMC PPI Lead, local participants in the 100,000 Genomes Project, representatives of LDP's and interested groups and organisations. A chair should be selected through an agreed selection process.

Meetings and Frequency

The Forum will meet quarterly. Some activities may be required in a virtual arena by email and letter. Every attempt will be made to ensure that 4 weeks' notice will be given for any meeting and that draft meeting minutes will be circulated within 15 days of the meeting. The minutes will be considered as accepted by the members if, within 30 days from receipt, no member has objected in writing to the PPI lead.

Payments and Expenses:

Volunteers 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.