

**Patient Advisors for Genomics Education (PAGE) – terms of reference**

**Introduction**

As the NHS continues to integrate genomics into mainstream care, all healthcare professionals, and not just genomics specialists, need to have a good understanding of the relevance of genomics and its potential to impact the diagnosis, treatment and clinical management of people in our care.

The Genomics Education Programme (GEP), established in 2014, produces education in genomics and contributes to genomics educational initiatives for NHS staff. It has produced a wide range of educational resources, from web pages, films and online courses to more formal academic and training programmes including the country’s first Master’s in Genomic Medicine.

As part of the England Rare Diseases Framework Delivery Group, which was established by the Department of Health and Social Care, the GEP is also committed to broadening the scope of its education to include non-genomic rare disease, in order to better support improvements in care for anyone living with a rare condition.

**Purpose and role**

The purpose of establishing this group is to ensure that:

* the patient voice is a key factor in decision-making;
* patient views are invited, gathered and acted on as part of the GEP’s education, training and workforce planning process; and
* educational resources developed by the programme are imbued with the experiences of patients and families as well as clinicians.

The role of the Patient Advisors for Genomics Education (PAGE) is:

* to input to the GEP’s work plan and proposals for education and training initiatives;
* to provide advice and guidance during the development of educational content;
* to provide advice and guidance on GEP communications campaigns, for example the annual #GenomicsConversation week of action; and
* to participate in, on a voluntary basis, recorded interviews, case studies and blog articles that tell patient stories – as well as seeking new ones as and when needed.

The focuses of the group will be:

* to ensure that the work of the programme is inclusive and representative of those with lived experience of genomic and rare conditions and diagnoses;
* to assist us in adopting a tone of voice and terminology that are acceptable and understandable to patients; and
* to guide the programme in addressing the skills, behaviours and attitudes needed in the NHS workforce to meet the needs of patients and carers.

**Ways of working**

Members of the PAG will:

* champion the NHS Constitution;
* place patient benefit at the centre of all discussions;
* allow all members to have an equal voice;
* respect confidential data and information; and
* support the need for openness and sharing of knowledge and best practice.

**Membership**

The PAGE is made up of individuals, or those who care for them, who have lived experience with inherited cancer susceptibility syndromes or rare diseases. Its members will have some experience of the genomic testing process, including those who may have no diagnosis. The group is co-chaired by Charlotte Murray, stakeholder engagement manager, and Amelia McPherson, editor, with support from Ben Armstrong, project editor, all from the GEP.

**Meetings and input**

The group will come together either in person or online, twice a year, at a date and time convenient to participants. In person meetings will take place at 23 Stephenson Street, Birmingham, B2 4HQ.

Outside of the meetings, the PAGE members will operate as a virtual network. Advice may be sought by members of the GEP team on a project-by-project basis.

Members will be re-imbursed for any expenses incurred travelling to and from a group meeting, members will also be remunerated for their time spent working on specific projects.

The GEP will take all reasonable steps to ensure that members of the group who may need additional support are enabled to participate. Examples of additional support include wheelchair accessibility, providing large print versions of documents or providing a rest area if needed.

**Information governance and reporting**

The forum maintains summary minutes of its meetings, with agreed actions recorded.

The use of any photographs, biographies and contact details on a dedicated webpage will be cleared with members first so they may understand where and how the information is to be used. Any information held about individual members will be reviewed after 12 months when the membership of the group is reviewed. All data will be held for a 12 month period, unless the participant withdraws within that time, in which case the data will be deleted.

A SharePoint site and Yammer group will be created to ensure continuous communication amongst all members.

**Review**

These terms of reference (including membership) will be reviewed annually to ensure the arrangements are fit for purpose.

Date: September 2022

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