

Genetic Counsellor Registration Board (GCRB) Public Interest and Participation (PIP) group Terms of Reference (TOR)

Purpose of the group

GCRB wants to put the voices of patients, the public and carers at the heart of its work to ensure genetic counselling in the UK is safe.

GCRB has established an accredited register of practitioners for genetic counsellors under the Academy of Healthcare Science (AHCS). The GCRB advises on standards of practice to assure patient and public safety.

The purpose of the PIP panel is to ensure that the views of patients and the public and carers are at the heart of the GCRB. The experiences and lay expertise of the PIP representatives will inform decisions in the development, operation and regulation of the GCRB.

Purpose of the role

We are looking for patient and public representatives to input into the activities of the GCRB board.

The PIP group will include but not limited to:

- Commenting on written literature – occasional review of documents e.g. AGM slides, briefing papers
- Commenting on the GCRB website updates, particularly the Public section
- Commenting on GCRB policy decisions
- Annual review of GCRB activities including complaints against Registered Genetic Counsellors and the GCRB, and Indicative Sanctions Panels may be required by AHCS
- Comment on change if professional title, equivalence & statutory regulation, activities of the GCRB
- May require sitting on Fitness to Practice panels

You will play a key role in ensuring that the voice of patients, carers and families is heard in decisions made by the board.

Time commitments

The group will be asked to comment on and work on specific defined priority areas as defined by the GCRB through electronic communications such as email.

It is anticipated that there will be an initial induction period. Following this it is anticipated this role will take around 3.5 hours per annual quarter. This will include a PIP group meeting twice a year virtually for a maximum of 1 hour per meeting. One member of the GCRB will be present for these virtual PIP group meetings.

In Addition to this, the group chair will be expected to attend board meetings twice a year for 1 day and feedback on the work of the group.

Reimbursement / Expenses

PPC panel members will be able to claim reimbursement and expenses in line with standard NHS England and NHS Improvement policies. Panel members are entitled to claim an involvement payment of £75 per half day of work and £150 for a whole day. This included attendance at GCRB meetings, which is often held in London but may be in other parts of the UK.

Any other necessary funding costs will be explored by the GCRB on an ad hoc basis.

Communications / Confidentiality

Communications between the GCRB and PIP panel between meetings will be done primarily by email and, where necessary, virtually using Microsoft Teams.

Where email is used, panel members giving express permission for the GCRB to use their personal email addresses will be Copied in (NOT Blind Copied), to enable them to share ideas between meetings.

Unless explicitly stated otherwise, it should be assumed that all matters discussed in meetings (and in any email correspondence between meetings) are to remain confidential and should not be discussed outside the membership of the group.

Panel members who do not maintain confidentiality may be removed by the GCRB group, in agreement with the Chair.

Experience

Ideally you would have experience of being a member of a board.

Membership

We are looking for members of the PIP Group will be patient and public representatives who have experience of commenting on genetic activity and its acceptability to NHS patients and the public but who are not professionals working in clinical genetics. The PIP group chair will also require experience of sitting on a board or committee. We will endeavour to seek appointment to the PIP group from individuals from a variety of backgrounds and protected characteristics.

The PIP group will comprise of the following members;

- 1 PIP group chair; appointed by the PIP group members for a term of four years for continuity of the group's work and eligible for re-appointment at the end of their period of office.
 - Decisions about reappointments will be made by the GCRB; the Chair has no absolute right to be reappointed.
- 3 group members; appointed for a minimum period of three years based on personal experiences and interest in the field of genomics.
 - Membership will be reviewed after this period and can be extended at the discretion of the GCRB. Members may decide to discontinue involvement at their discretion.

As priorities are defined and the strategy of the panel evolves, the potential to increase the size of the panel may be discussed.

All members of the PIP group will be asked to declare any interests in writing.

How to Apply

If you are interested in joining our PIP group please apply with a CV and a statement of interest to: enquiries@gcrb.org.uk

Deadline: 20th November 2023