

Joining the NHS East Genomics Patient and Public Voice (PPV) Panel

We're looking for patients, carers and members of the public to join our Patient and Public Voice (PPV) Panel as part of NHS East Genomics

About us

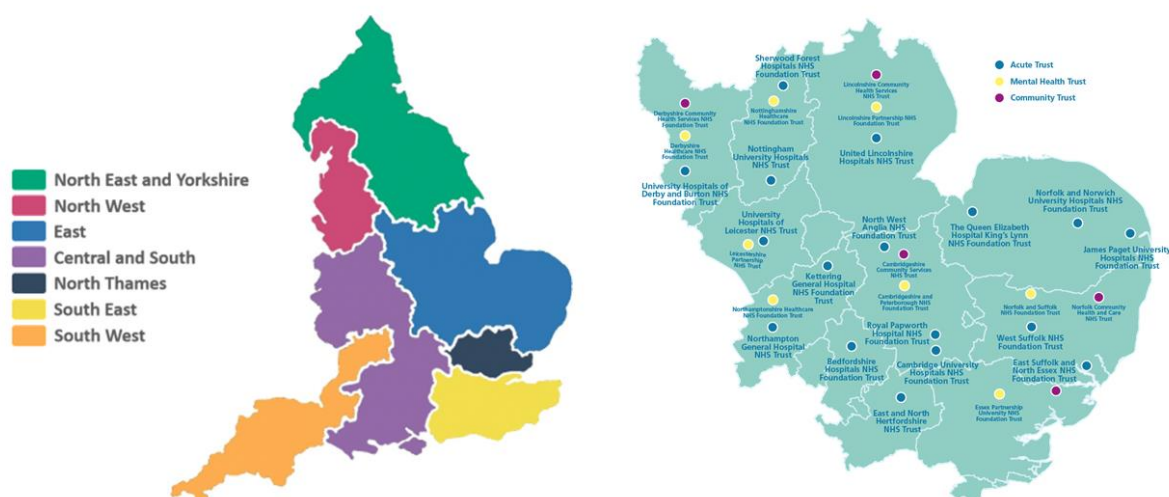
East Genomic Medicine Service Alliance (East GMSA) has been set up to ensure all eligible patients across the East Midlands and East of England can access and benefit from appropriate genomic tests when required, providing high-quality and personalised treatment. East GMSA will ensure there is equal access to the nationally commissioned genomic tests set out in the [National Genomics Test Directory](#), no matter where people live or which hospital they use, supporting the establishment of testing pathways for **cancer and rare diseases**, assisting clinicians in **requesting genomic tests** and introducing **new models of care** that support early access to genomic testing.

East GMSA is led by a Partnership Board representative of the four NHS Trust partners that have direct responsibility for delivering the service.

- Cambridge University Hospitals NHS Foundation Trust
- Nottingham University Hospitals NHS Trust
- University Hospitals of Leicester NHS Trust
- Norfolk and Norwich University Hospitals NHS Foundation Trust.

Working closely with the **East Genomic Laboratory Hub (GLH)**, together with healthcare professionals, networks, alliances, academia and patients and public representatives across the East Midlands and East of England, the East GMSA brings together the vital multi-disciplinary clinical leadership and other operational and digital functions that are necessary to embed genomic medicine into mainstream clinical care.

Together the East GMSA and East GLH form **East Genomics**, which is our public branding on our websites, social media and newsletters.



Left: 7 GMSAs across England, Right: Geography of East GMSA

1. The role

We have an established [PPV Panel of 8 members](#). The panel is led by our Interim Chair, Chris Hind, in collaboration with and with support from the East GMSA Communications and PPI Manager, Ian Kingsbury.

The panel helps ensure that the views of patients, carers and families are at the heart of East GMSA, informing relevant discussions and decision-making. The panel review patient- and public-facing communications, and are involved in pathway development of genomic services in hospitals. The role of the panel will evolve over time, and with that we expect there will be a wider set of engagement and involvement opportunities the panel will be offered.

We are interested in hearing from people with lived experience of undergoing genetic testing – either as a patient, carer or family member – within the last three years. We would also welcome applications from members of the public without experience of genetic testing but with an interest in improvements in the NHS through whole genome sequencing and genetic testing. Familiarity of the way NHS health and social care works, and basic knowledge of whole genome sequencing is crucial for all members of the panel, as is the ability to actively participate in group discussions, advise, and make recommendations.

You will either live in or have received care in the East of England or East Midlands region or have a connection with the area. We are particularly keen to hear from people from marginalised communities, and people from ethnic minority groups.

1.1. Time required

Meetings will be held every month, for a maximum of 1.5 hours per meeting. You will normally be required to read some papers in advance. There will occasionally be electronic communications and work required between meetings. It is anticipated this role will take between 2hrs – half a day per month.

1.2 Location

Currently PPV Panel meetings take place virtually via Microsoft Teams. Our Terms of Reference state that we aim to have a face-to-face meeting every quarter (4 times a year) at one of our main NHS Trust sites (either Cambridge, Leicester, Norwich or Nottingham).

1.3 Expenses

Travel to physical meetings will be reimbursed. There will always be a virtual joining option.

1.4 Remuneration

This is a voluntary role with reimbursement of “out of pocket” expenses paid. You will be remunerated in accordance with the NHS document, ‘Working with our Patient and Public Voice Partners – Reimbursing

expenses and paying involvement payments’ to acknowledge your contribution to the panel. Any involvement payments may be classed as earnings or income by Her Majesty’s Revenue and Customs service (HMRC) or the Department for Work and Pensions (DWP). You would be responsible for declaring this income to HMRC, DWP, Job Centre plus or other agencies as appropriate. If you are in receipt of state benefits, you should seek advice from the relevant agency, for example JobCentre Plus, ideally in advance of applying and certainly

before accepting an offer of a role which attracts an involvement payment, even if you intend to decline the payment.

1.5 Length of commitment

One year, at which point membership of the panel will be reviewed.

2. Application details

To apply, please read the information below (Section 3.) and then email the following details to Communication and PPI Lead ian.kingsbury@nuh.nhs.uk

Please tell us a bit about yourself, and your experience – both as a patient/carer if relevant – and why you are suitable for, and interested in, joining this panel (max 400 words). You can either include this information in the body of an email or attach as a Microsoft Word document or PDF. We will acknowledge your application by email.

People who are shortlisted will be invited to join a virtual (Microsoft Teams) group interview on a date to be confirmed.

2.1 Contact

Please do get in touch if you would like more information by contacting Chris.Hind@nnuh.nhs.uk or ian.kingsbury@nuh.nhs.uk

3. Person Specification

Life Experience

Be either:

- a carer for patients who have accessed NHS services (within the last two years) **OR**
- you or someone you care for has undergone genetic testing in the past three years

Skills and aptitude

- Good communication and influencing skills
- Ability to form and maintain working relationships
- Good time management skills
- Desired: Established networks/connections in a specific geography or for a specific disease/condition

Personal qualities

- Ability to proactively raise issues in meetings
- Openness and transparency
- Takes initiative
- Conscientiousness
- Ability to consider multiple perspectives
- A commitment to the [Nolan Principles of Public Life](#)

- An understanding of issues relating to equality, diversity and inclusion in healthcare
- Ability to be objective about one's own patient or carer experience and use this experience where relevant in order to positively contribute to the advisory panel
- Appreciation of the complexity of working across organisational boundaries and joint working
- Lives in or have received care in the East of England or East Midland region or have another connection with the area

Knowledge

- Some understanding of whole genome sequencing, and issues around genomic testing
- Awareness of national health and social care issues