

INSIGHT Data Hub PPI Group Role Description

We are looking for patients, family members and members of the public to join our INSIGHT patient and public involvement group. This is a group set up with the aim of helping to give feedback on and influence research for the future of eye health and use of patient data. We would like to invite you to get involved, so we can ensure that the public, people who have conditions, and those that care for them remain at the centre of our research.

What is INSIGHT?

INSIGHT works with the NHS to support research that will benefit patients. It does this by allowing researchers to access anonymous eye health data in a secure, efficient and strictly controlled way. For example, the NHS has used INSIGHT data to predict the impact of missed hospital appointments on sight loss due to the COVID-19 pandemic in a condition called 'wet' age-related macular degeneration. INSIGHT was created to speed up the development of cures, treatments and diagnostic tools – not just for eye diseases, but for other conditions, such as diabetes and dementia. You can find out more about the potential benefits of INSIGHT on our website: insight.hdrhub.org

Whose data is available through INSIGHT?

INSIGHT is led by two NHS Foundation Trusts, Moorfields Eye Hospital and University Hospitals Birmingham (UHB). If you have ever been an eye patient at Moorfields or UHB, it is likely that anonymised data could be included in INSIGHT. This means that you are already contributing to

research to improve healthcare and the NHS. In the future, we anticipate more NHS hospitals will make their eye data available through INSIGHT.

Why get involved?

The highest priority of the INSIGHT Data hub Patient & Public Involvement Group is to ensure the patient and public voice of Birmingham and surrounding areas is heard when reviewing applications to access data through the INSIGHT hub.

The group will be made up of patients and members of the public from Birmingham and surrounding areas. This ensures this group represents the diverse population that UHB hospitals serve. If you join the team, you will be part of data access applications. These important discussions will direct the INSIGHT team as to the benefits of each project. You will also have the opportunity to contribute to the INSIGHT team with other impact; such as workshops, conferences and important academic papers, if you wish too.

You do not need to have any healthcare data, scientific or medical knowledge. We are looking for people who are interested in contributing some of their free time. We hope that people who join this group want to discuss the use of health data for the benefit of all patients. We wish for people to join this group to be able to voice their opinions from any background to help ensure that NHS data is used to help NHS patients past, present or in the future. We hope that the research will also have wider reach and may help address global healthcare problems.

How does the INSIGHT application process work?

All NHS hospitals securely store your clinical visit data as part of your health record. INSIGHT, and other health data research hubs, have been approved through the National Research Ethics Service to potentially use NHS data for research if the appropriate consideration for the researchers and the project are met. Any person (including researchers, healthcare professionals and people on behalf of industry) can apply to use the anonymised data for research projects, through a thorough application process in which they are carefully vetted, and where NHS and patient benefit are demonstrated. The vetting processes are conducted by:

1. The INSIGHT team
2. The hospital governance team at UHB hospitals
3. The PPI Group, for which you may become a member.

This happens before applications are submitted to the Data Trust Advisory Board (DataTAB). The DataTAB are an independent group that advise on the applications. More information on the DataTAB can be found here [Data Trust Advisory Board | INSIGHT \(hdrhub.org\)](https://hdrhub.org/DataTrustAdvisoryBoard).

What will I be doing?

- Help the INSIGHT team ensure that the patient is our “North Star”. This means anything we do puts our patient’s needs over everything else.

- Attend an introductory workshop to meet the team and other members. This meeting will give information about your role and responsibilities as part of the INSIGHT PPIE Group meetings.
- Provide feedback (written or attendance at meetings) on between one to three INSIGHT data applications every quarter. Please know that you would be provided with documents to read and understand before the meetings. We would always give good time to allow you to do this. You would be able to ask questions before the team meeting. Constructive feedback on INSIGHT research applications at this stage is important as we would be able to change how the research is done before it is submitted to the DataTAB.
- You would be bringing your experiences or those of your family or friends to help guide important research projects in relation to healthcare.
- Contribute to discussions during the meetings to ensure there is a mix of thoughts and balance of opinions in a way that is **always respectful** of the views of others.
- Attend meetings every two calendar months. These will be virtual/online with the potential for occasional face-to-face meetings.
- There will be the opportunity to contribute to publications and articles that are written for INSIGHT.
- There will be the opportunity to provide feedback and guide on the PPI section of the INSIGHT website.

Importantly, we respect all opinions and request that we ensure that we all:

- Maintain group confidentiality.
- Declare conflicts of interest where appropriate.

Payment & expenses

We are able to offer PPI members honorarium for their time in the form of a high street gift voucher, in line with the National Institute of Health Research (NIHR) payment guidance. The team will talk you through the processing of claiming these during the introductory session. The meetings will be held virtually in the first instance, but there might be future opportunities to have face-to-face meetings, attend conferences and workshops. If this happens, we will be able to organise travel and expenses for you. If you have any special requirements which affect your ability to participate remotely, please let us know and our team will try our best to support you.

You can contact Jazz Gill and the INSIGHT team at University Hospitals Birmingham NHS FT via email or phone:

Email: INSIGHTPPIE@uhb.nhs.uk

Phone: 0121 371 8148

Find out more about INSIGHT at [Eye health data research | INSIGHT \(hdrhub.org\)](https://www.eyesight.org.uk/eye-health-data-research-insight-hdrhub.org)

Closing date for expressions of interest: Monday 31st October with the view to have an introductory meeting week commencing 21st November