

Your data, your choice



This leaflet provides information about:

- The use of patient data by the NHS
- The INSIGHT Health Data Research Hub
- The NHS national data opt-out



INSIGHT
Health Data Research Hub



insight.hdrhub.org



@INSIGHTeyehub
#DataSavesSight



INSIGHT
Health Data Research Hub

Why does the NHS collect patient data?

The NHS routinely collects and stores patients' medical data as part of everyone's individual assessment and care. UK law also allows the NHS to use this data for health planning and research.

If you have used NHS hospital services and have not opted out, your data could already be helping to make the health service better for everyone.

What will INSIGHT do?

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 due to the COVID-19 pandemic on patients with '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 your data will 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 organisations will make their eye data available through INSIGHT.

Do I need to give consent for the NHS to share my data?

No. The NHS follows the principle of presumed consent. When your data is collected as part of your treatment, you do not need to do anything if you are happy for the NHS to use it for research and health planning.

What if I don't want my data to be shared?

You can opt out of sharing your NHS patient data for research and health planning at any time using the NHS national data opt-out. To find out how:

Visit the NHS website:

nhs.uk/your-nhs-data-matters/manage-your-choice

Call the NHS Digital Contact Centre:

0300 303 5678 (Monday to Friday, 9am-5pm)

Use the NHS App:

go to 'Your health'



Will my NHS care be affected if I opt out?

No. If you choose not to share your data for research and health planning, this will not affect your individual care.

How can I find out more about how my data is used?

If you are a patient at Moorfields or UHB, you can find out more online or by contacting the Data Protection Officer:

Moorfields Eye Hospital

Website: moorfields.nhs.uk/content/how-we-use-your-information

Data Protection Officer
Information Governance Department
Moorfields Eye Hospital NHS Foundation Trust
162 City Road
London
EC1V 2PD

Email: moorfields.ig@nhs.net

Tel. 020 7253 3411

University Hospitals Birmingham

Website: uhb.nhs.uk/privacy-notice/patients

Data Protection Officer
Information Governance Team
3rd Floor, Nuffield House
Mindelsohn Way
Birmingham
B15 2TH

Email: InformationGovernance@uhb.nhs.uk

Tel. 0121 371 2000 (UHB switchboard)

Why do researchers need my data?

To ensure research can benefit the whole population, researchers need as much data as possible. This makes data from Moorfields Eye Hospital and University Hospitals Birmingham especially important, as it comes from patients across diverse communities, ages and walks of life. Together, they form some of the largest sets of eye data in the world, which makes them ideal for high quality research.

Who will be using my data?

INSIGHT only works in partnership with approved researchers who adhere to our strict guidelines: their research must benefit patients, and it must be conducted safely and ethically by a reputable organisation. This could be the NHS itself, a university, a charity, a pharmaceutical company or a health technology company. Data will not be available to insurance companies or for marketing purposes. You can find out how we assess applications to use INSIGHT data and see details of successful applications on our website: insight.hdrhub.org

Will researchers know who I am?

No. The data shared through INSIGHT is anonymous. This means researchers will not have access to anything that could identify you as an individual, such as your name, address or NHS number.