

An overview of INSIGHT, the health data research hub for eye health

What is INSIGHT?

INSIGHT makes anonymous eye data available for research that benefits patients and the NHS

INSIGHT:

- Is focused on eye data and eye health
- Makes anonymous eye data available for research that benefits patients and the NHS
- Could lead to improved treatment and diagnosis for many eye conditions
- Could lead to breakthroughs in conditions affecting the whole body, including diabetes and dementia
- Applies the highest standards of data safety
- Is committed to transparency
- Prioritises the interests of patients and the NHS

INSIGHT is an NHS-led partnership that uses eye health data collected during routine hospital appointments. We make the data available for research that benefits patients and the NHS.

INSIGHT aims to revolutionise the way diseases are diagnosed and treated. We do this by allowing researchers to access anonymous patient data in a safe and efficient way. This makes it easier for them to harness cutting-edge technology, such as machine learning and artificial intelligence (A.I.).

Although INSIGHT is focused on eye health, it could lead to breakthroughs in a wide range of conditions, including diabetes and dementia.

How will INSIGHT affect the future of eye care?

A simple eye check-up could be used to assess our overall health

Using computers and a process called ‘machine learning’, researchers can rapidly analyse large amounts of data – in this case, images of the eye and related health records. Combined with artificial intelligence (A.I.), this process has already led to significant breakthroughs. For example, using

120,000 eye images, researchers have taught a computer to detect sight-threatening diabetic eye disease with 100% accuracy*. If approved for use, this technology could prevent sight loss for thousands of people, saving the NHS an estimated £10 million every year in England alone.



Photo credit: Moorfields Eye Hospital (library shot)

*Paper published June 2020 in the British Journal of Ophthalmology

How will INSIGHT affect other areas of healthcare?

Researchers have already discovered that subtle changes at the back of the eye can be early signs of conditions affecting other parts of the body, including high blood pressure and dementia. In future, this could mean that a simple eye check-up provides enough information to assess our overall health. For example, an eye scan could predict how likely we are to develop diseases such as stroke, diabetes or Alzheimer's disease. However, more research and more data are needed to develop solutions that could help diagnose and treat these conditions.



INSIGHT also aims to accelerate research in an area of healthcare known as 'personalised medicine'. This is where healthcare is tailored to the needs of the individual patient. An eye scan could tell doctors how urgently a patient needs treatment, how likely they are to react to different types of medicines, or the best way to prevent them from developing certain conditions.

Researchers are discovering new ways to use patient data all the time, but it can be hard to find data that is reliable,

consistent and safe. That is why INSIGHT has been set up, along with several other health data research hubs. Our aim is to make it easier for trusted researchers to find and use the data they need, at scale.

It may soon be possible to predict the risk of stroke, diabetes or Alzheimer's disease using eye data

Whose data is available through INSIGHT?

Across the UK, eye care accounts for more outpatient appointments and surgery than any other area of healthcare. The NHS collects 25 million eye images every year, creating an exceptional resource for research.

Currently, the data available through INSIGHT comes from our two NHS partners, Moorfields Eye Hospital and University Hospitals Birmingham, which hold some of the largest sets of eye data in the world. Our ambition is for eye data from other NHS organisations to be available through INSIGHT in the future.

Every three months, new data is added to INSIGHT, and the data of patients who have opted out of sharing their data for research is removed. For more information about how your NHS data is used for research and how you can opt out, visit our website: insight.hdrhub.org

The more people who contribute their data to INSIGHT, the more valuable it will become as a resource. To ensure that the whole of society benefits from new treatments and cures, researchers need as much data as possible, from a large and diverse group of patients. INSIGHT is well placed to provide this due to the range and size of the communities served by our NHS partners, Moorfields and UHB.

Who can use data from INSIGHT?

Any researcher requesting access to data through INSIGHT must show how their research will benefit patients. Applications to use the data could come from within the NHS itself, universities, charities, or pharmaceutical and technology companies. However, only applications from reputable organisations with a clear commitment to patient benefit are considered for approval. We will never share any data with insurance companies or for marketing purposes.

How will INSIGHT keep patient data safe?

Data safety is a core principle of INSIGHT. We only allow researchers to access anonymous data. This means any information that could identify individual patients is removed, including names, addresses and NHS numbers.

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Our top priority is ensuring that patient data is stored and processed securely. We follow a set of principles for data storage and access known as the 'Five Safes', which have been adopted by the UK Office for National Statistics.

The Five Safes are:

- Safe data – ensuring data is held securely
- Safe projects – ensuring data is used only for research that will benefit patients
- Safe people – ensuring researchers are trustworthy
- Safe settings – ensuring that data is kept securely, and there is no misuse of data at any stage
- Safe outputs – ensuring individual patients cannot be identified

Who is behind INSIGHT?

INSIGHT is a partnership led by two NHS Foundation Trusts:

- Moorfields Eye Hospital
- University Hospitals Birmingham (UHB)

It also includes two industry partners:

- Google Health
- Roche

An academic partner:

- The University of Birmingham

And a partner from the charity sector:

- Action Against AMD

Together, the INSIGHT partners represent world-leading expertise in eye care, patient advocacy, health technology and data management. By working together, we are able to speed up cutting-edge research in a way that no organisation, public or private, could achieve on its own.

INSIGHT is one of several health data research hubs set up by Health Data Research UK (HDR UK), a UK Government-funded organisation that promotes the safe use of health data for medical research. You can find out more about HDR UK on their website:

hdruk.ac.uk

INSIGHT is an NHS-led partnership

What is the Data Trust Advisory Board?

The Data Trust Advisory Board (DataTAB) was set up to provide independent scrutiny of applications to use the data held by INSIGHT. It ensures that the views of patients, public and independent experts are represented in INSIGHT's decision-making. The DataTAB is made up of ten people from a range of backgrounds covering patients, the public, the charity sector, academia and the NHS. Together, they represent a broad range of opinions, expertise and life experiences.

The DataTAB assesses whether research applications meet INSIGHT's strict guidelines for the safe and ethical use of patient data. The DataTAB's

recommendations inform INSIGHT's decisions about which research is approved. Details of successful applications are listed on our website, as well as the criteria used by the DataTAB to assess all applications: insight.hdrhub.org/datatab

INSIGHT also draws on the advice and experience of a separate group of public and patient advisors set up by the NIHR* Moorfields Biomedical Research Centre. The advisors meet four times a year to review our processes and decisions, and help us communicate with the wider public. You can find out more about the advisors here: moorfieldsbrc.nihr.ac.uk/brc-advisors

*National Institute for Health Research

How does INSIGHT involve patients and the public?

The views of patients and the public inform INSIGHT's decision-making at every level. We are committed to transparency about how INSIGHT works, how we decide who can access the data, and which research projects have been approved. Our Data Trust Advisory Board (DataTAB) is central to this.

Photo credit: Anton Webb / UCL Institute of Ophthalmology

How is INSIGHT funded?

INSIGHT is one of several health data research hubs that have received initial funding from the UK Government through Health Data Research UK (HDR UK). Our costs include processing applications to use the data, ensuring all identifying information is removed, and ensuring data is consistent enough for research.



Where can I find out more about INSIGHT?



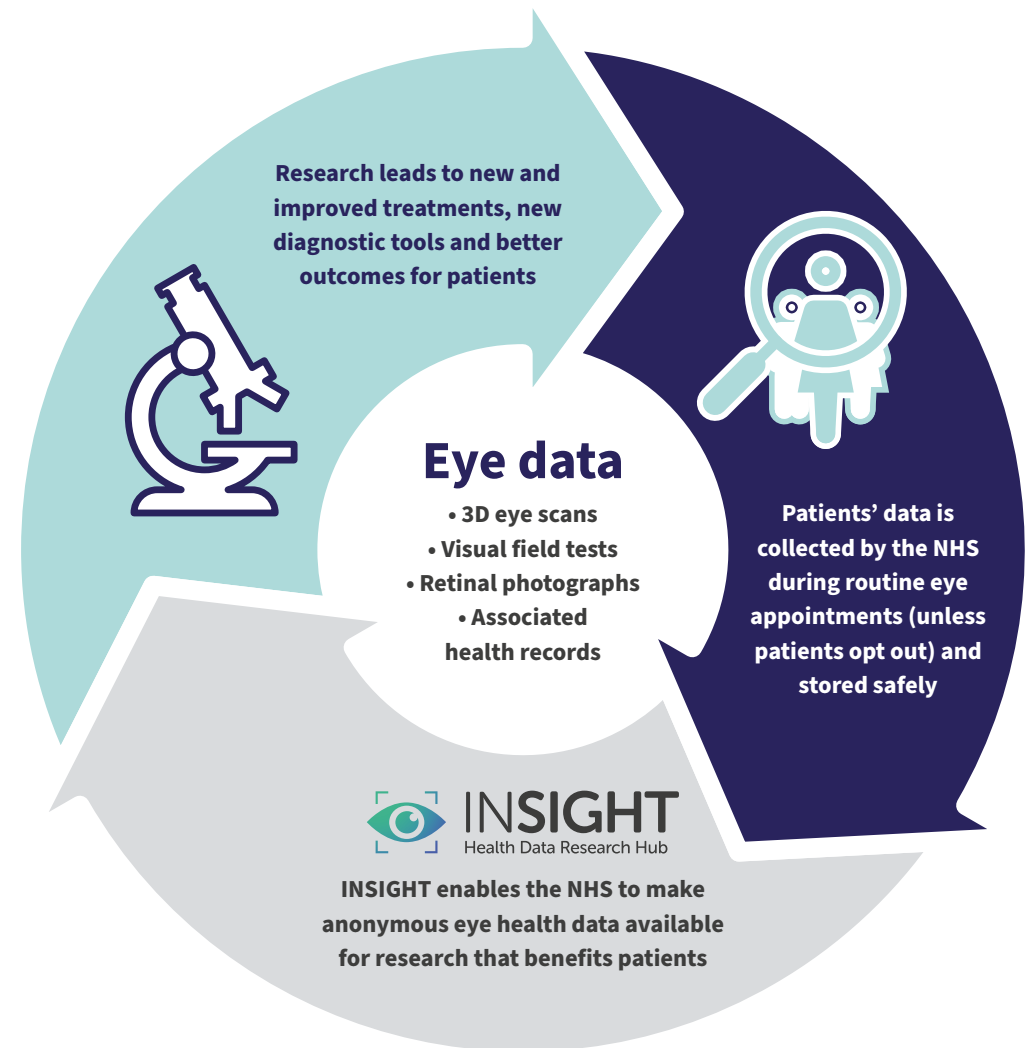
Visit our website: insight.hdrhub.org



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INSIGHT in brief

INSIGHT exists to make anonymous eye data work better for patients and the NHS. Ultimately, the benefits from research using this data will come full circle, improving eye care and healthcare for everyone.





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