



# An introduction to the UK Health Data Research Alliance

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# What is the Alliance?

The Alliance is a growing partnership of leading healthcare and research organisations who have united to establish best practice for the ethical use of large-scale health data for research.

The UK has rich and diverse health-relevant data which provides exceptional opportunities for research and innovation. The Alliance brings together stakeholders from around the UK to promote development of standards, policies and tools and enable access to data in a secure, trustworthy and ethical way which is fully visible to the public.

The Alliance's aim is to accelerate improvements in human health and care by encouraging widespread and responsible use of structured and unstructured clinical, administrative, imaging, genomic and other molecular data. To achieve this, we are working together to create a trustworthy, federated and co-ordinated approach to health data research infrastructure.

We have developed standards and best practice in areas including: involving and engaging patients and the public with health data research, the ethics and governance of data access, trusted research environments and data quality and transparency. The Alliance secretariat is currently funded through the UK Government's Industrial Strategy Challenge Fund and convened by Health Data Research UK (HDR UK) – the national institute for health data science.

**To find out more about the alliance: [ukhealthdata.org](https://ukhealthdata.org)**





# Who are the Alliance members?

Alliance members bring new approaches to developing tools and techniques for data research at scale to make improvements to people's lives through research.

They are drawn from national bodies, NHS trusts, public health agencies, medical research charities, biobanks, cohort studies, clinical audits, health data research hubs and Artificial Intelligence Imaging Centres of Excellence. To date we have more than 70 members, including: Nottingham University Hospitals NHS Trust, the Brain Tumour Charity, Clinical Practice Research Datalink, Genomics England, NHS Scotland, UK Biobank and the Royal College of GPs.

Membership is steadily growing and we want to welcome more organisations into the Alliance, such as the NIHR Biomedical Research Centres, universities, biobanks and medical research charities. We expect the Alliance to continue to grow, retaining the Alliance's UK-wide focus and seeking to work in partnership with international organisations to create a broader, more inclusive network that counts many of the world's leading health data research platform providers among the Alliance's members.







See the Alliance's full list of members: <https://ukhealthdata.org/members/> and read on to find out more about the benefits of joining the Alliance and what we expect of the Alliance's members.

## 70 Alliance members



# What are the benefits of joining the Alliance?

## By joining the Alliance you can:

-  Be part of a recognised community of experts who work together to address common problems with scaling up, developing and adopting health data research innovations.
-  Actively shape the design and delivery of a coherent, UK-wide, federated health data research landscape.
-  Take advantage of opportunities for networking, introductions and information sharing via Alliance events.
-  Meet funding requirements through collaboration and partnership: embedding transparency and patient and public involvement in everything you do and contributing to a trustworthy and efficient infrastructure for health data research.
-  Access valuable services provided through the Innovation Gateway – the Alliance’s portal for data discovery and access, to make datasets FAIR, including:
  - Assets, tools and services that make data more **findable**
  - More **accessible** data through use of an online Data Access Request management system (based on the Five Safes framework – safe people, projects, settings, outputs and data).
  - Better **interoperability** of datasets (ie the ability of the dataset to function across different systems) through the ongoing development of the Gateway.
  - More **reusable** data by employing data use registers and links to outputs within the Gateway.
-  Contribute to the development of Green and White papers that provide the Alliance’s position of topics that contribute to a responsible and ethical infrastructure for UK health data.



To find out more about what is involved in joining the Alliance and its benefits, see the Alliance’s **Principles for Participation**.

# What will you work on as a member of the Alliance?

Senior leaders from partner organisations join the Alliance Board to provide oversight and direction of the Alliance. Alliance Board meetings take place every quarter and are chaired by Andrew Morris, HDR UK's Director.

Members attend and play an active role in Alliance workstreams meetings to address key issues as they arise and drive development of standards for data use. Currently, the Alliance have established four strategic areas we would like to explore with members, which are:

-  **Development of a technology services ecosystem**
-  **Building trust and transparency in health data infrastructure**
-  **Improvement of data interoperability and usability**
-  **Improvement of skills and expertise in data science**

Members commit to making the data they hold available for research and innovation. Data assets can be made discoverable for research via the Innovation Gateway by sharing datasets associated metadata information. Members also publish a register of active projects using the data under their custodianship along with new data access requests received. In January 2022, the Alliance published recommendations for a data use register standard to be adopted by organisations responsible for the safe sharing of data used for research and innovation. All Alliance members can implement this standard by using the Innovation Gateway **Data Use register**. The Gateway Data Use Register shows more than 800 data uses.





# Alliance's priority areas

Alliance members work together to coordinate researchers' adoption of tools, techniques, conventions, technologies and designs that allow health data to be used in a trustworthy and ethical way for research and innovation. By developing and sharing best practice and demonstrating trustworthiness in the use of health data, the Alliance aims to make sure that health data research benefits as many people as possible across the UK and beyond.



## The Alliance's four priority areas for 2022 and beyond are:

**Technology services ecosystem:** Alliance members have a key role in shaping an ecosystem of services that enable linkage of data from many custodians and federated analysis across trusted research environments. By bringing together technologists, custodians, TRE providers and the NHS the Alliance ensures a collaborative approach that enables greater patient and public benefit than any single organisation can achieve alone.



**Trust and transparency:** Alliance members focus on enabling and demonstrating trustworthiness in health data research so that more people are better informed and have greater confidence in their data being shared and reused for research purposes. Pooling the Alliance's efforts gives us the reach and influence to develop more joined-up public and patient engagement.



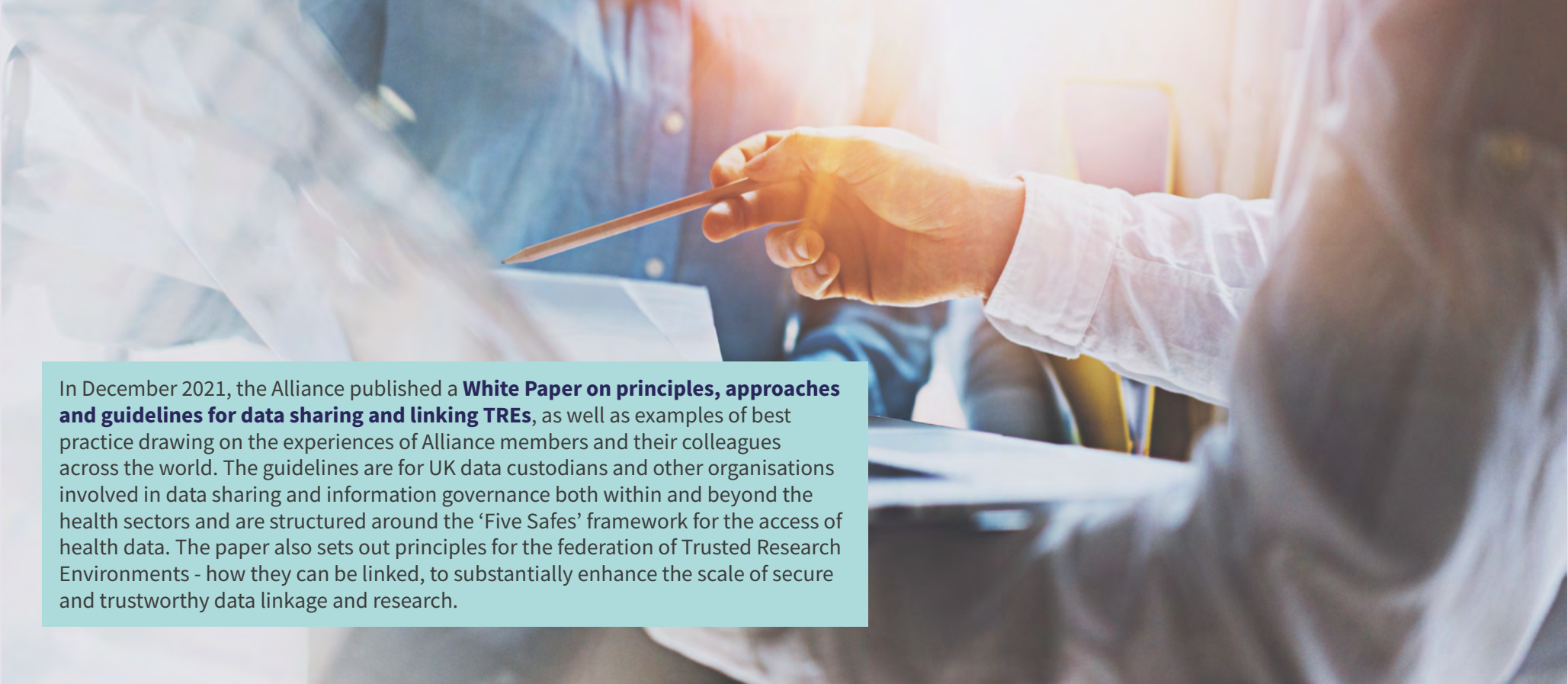
**Usable data:** The aim of this workstream is to support researchers identify data that meet their needs, and to minimise the data curation work they must do to make the data research-ready. The Alliance focuses on developing and driving adoption of consistent standards and formats for data and metadata.



**Capacity building:** Development of solutions to upskill healthcare workforce and training future data science experts is crucial to build UK-wide capability that drive health data science. The Alliance brings UK and international partners together to address skills gaps in health data science including training for researcher accreditation, data management and federation.



# Alliance output: Best practice guidelines for building Trusted Research Environments



In December 2021, the Alliance published a **White Paper on principles, approaches and guidelines for data sharing and linking TREs**, as well as examples of best practice drawing on the experiences of Alliance members and their colleagues across the world. The guidelines are for UK data custodians and other organisations involved in data sharing and information governance both within and beyond the health sectors and are structured around the 'Five Safes' framework for the access of health data. The paper also sets out principles for the federation of Trusted Research Environments - how they can be linked, to substantially enhance the scale of secure and trustworthy data linkage and research.



# Alliance output: A new standard for data use registers

A data use register – also known as a data release register or list of approved projects – is a public record of how data is being used for research, by whom and most importantly for what purpose, and it offers a clear demonstration of the benefit and value of using health data. In January 2022, **the Alliance published recommendations for a data use register standard** to be adopted by organisations responsible for the safe sharing of data used for research and innovation, following consultations and workshops with health data research organisations, universities, data custodians, patient and the public. The Alliance is now working with data custodians to support adoption of this standard and improve transparency in data use.



# Alliance output: Establishing standards for healthcare data

Health data research to improve people's lives relies on a set of common standards for healthcare data and metadata. The Alliance has carried out data user and custodian surveys with academic researchers, charities, data custodians, healthcare providers, life science companies and AI and technology companies to understand the current use of health data standards and opportunities for greater alignment. These identified a higher level of data standards expertise in industry compared with academia, that two thirds of health data users had basic or no data standards expertise and that almost 90% of users were in support of a core set of data standards to enable health data research. Data custodians and data users were also discovered to be using a wide range of data standard and data models.

Based on this work, in November 2021 the Alliance **published a White Paper** making recommendations for data standards. The paper encourages improvements in data usefulness and usability and was developed with input from the health data community, patients and the public.



# The Black Internship Programme

Black people are heavily underrepresented in the science, technology, engineering and maths (STEM) community with only 65 Black and 310 mixed and other individuals making up the total of 10,560 science professors in the UK. Through the Alliance, 54 interns have joined the HDR UK Black internship programme, which was launched in the summer of 2021 in collaboration with the 10,000 Black Internships initiative. This has provided paid work experience to future Black data scientists as they work with 25 of the Alliance member organisations, providing the opportunities for young Black people in the UK to flourish in their future STEM careers.

# 54

interns have joined the HDR UK Black internship programme

# 65 BLACK AND 310 MIXED OUT OF 10,560

science professionals in the UK

“Having interviewed an outstanding group of candidates – and part-funded by NIHR Manchester Biomedical Research Centre – we are delighted to have appointed three new colleagues under the Black Internship Programme to support data projects across our Trust, hosted infrastructure and Clinical Data Sciences Unit (CDSU). I look forward to welcoming our new colleagues to the MFT Innovation Team.”

**Dr Katherine Boylan**

Head of Innovation at Manchester University NHS Foundation Trust (MFT)





# Members spotlight

“

Being part of the UK Health Data Research Alliance will help us deliver on our commitment to make the best use of data to help people live healthier lives for longer. Collaborations like this will ensure we are using data in the most trustworthy and ethical way, which is an essential part of creating a world-leading resource for health research.

### Andrew Roddam

CEO of Our Future Health (designed to be the UK's largest health research study, with a recruitment target of 5 million participants)



“

One of the most important lessons of the last 18 months is that collaboration is key. The incredible impact of health research in supporting the response to the COVID-19 pandemic has not been achieved by one organisation or in siloes. It has been a genuine success story for 'Team Science'. By joining the Alliance, we're committed to maintaining that approach.

### Professor Sharon Peacock

Executive Director and Chair at COG-UK, and a Professor of Public Health and Microbiology in the Department of Medicine at the University of Cambridge



“


Joining the UK Health Data Research Alliance is a significant step for the UK Renal Registry and the Renal Association.

We look forward to the research collaborations that will arise from working within the Alliance, the findings of which will improve the health and outcomes of the Alliance's patients through better use of their data.

### Professor Dorothea Nitsch

Director of Informatics Research, The Renal Association





“The work of the Alliance to develop and produce green and white papers on key areas of data policy have been hugely influential. I would call out the recommendations on Trusted Research Environments and Data Use Registers as particularly helpful in defining standards.”

**Alastair Denniston**

Co-Director of INSIGHT, Consultant Ophthalmologist,  
University Hospitals Birmingham NHS Foundation Trust  
and Honorary Professor, University of Birmingham



# How can you join the Alliance?

We ask that all members of the Alliance sign a non-binding Letter of Intent that confirms the intent to be a partner and sign up to the Principles for Participation. For prospective members, the first step is to read and review the Alliance's Letter of Intent and Principles for Participation and contact us if you have any questions:

<https://ukhealthdata.org/join-the-alliance/>

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## Further information

Frequently Asked Questions for Alliance members:

<https://hdruk.box.com/s/83l7lhm7jnh6x03hpouignszlh2s325w>

Read about the UK Health Data Research Alliance's achievements and outputs to date:

<https://ukhealthdata.org/alliance-outputs/>







“By joining the HDR UK Alliance, we are demonstrating our commitment to open data standards and excellence in managing patients’ data confidentially. This is an exciting opportunity working with our Midlands health and academic partners and also gives us the ability to contribute to exciting national initiatives.”

**Andy Carruthers**

Chief Information Officer at University  
Hospitals of Leicester NHS Trust

