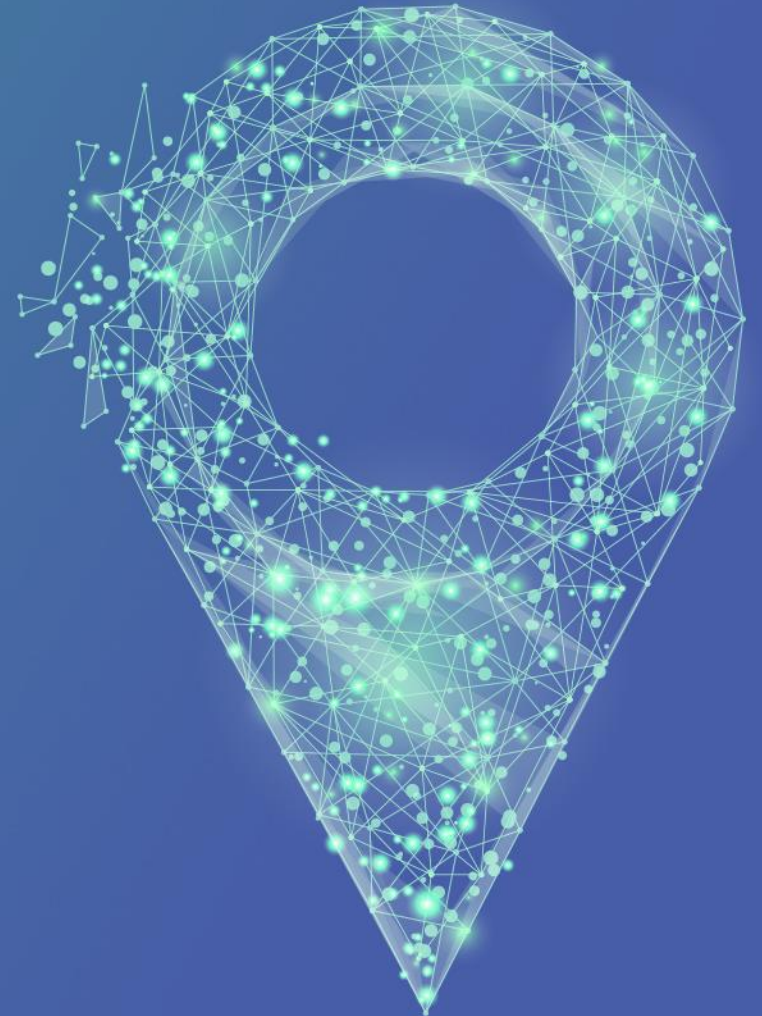**HDR**UK
Health Data Research UK

An introduction to... HDR UK

Caroline Cake, CEO

We are the national institute for health data science

Our mission is to unite the UK's health data to enable discoveries that improve people's lives.

Enabling greater public benefit from data

1-1 trusted relationships

Data custodian

Researcher

SECTOR MATURITY

Trustworthy systems, governance, policies, standards, technologies, benefit sharing, track-record to demonstrate: **competence, honesty and reliability**

Open Working Methods

Many-many trustworthy ecosystem

Many data custodians

FAIR

Many researchers & innovators

More impactful, more public benefit

Over the last three years we have created a four-nation UK institute to unite health data - 86 organisations across 32 locations
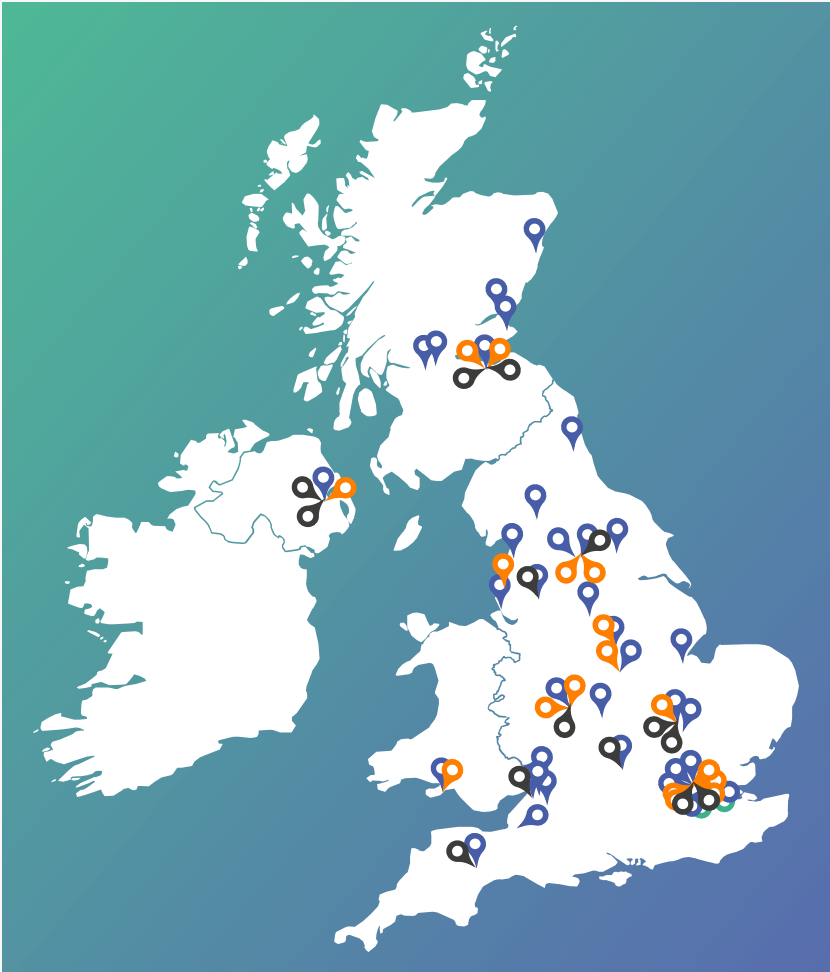

Wellcome Trust Great Ormond Street DRIVE Unit

CENTRAL TEAM OFFICES

HDR UK Cambridge
HDR UK London
HDR UK Midlands
HDR UK North
HDR UK Oxford
HDR UK Scotland
HDR UK South-West
HDR UK Wales and Northern Ireland

RESEARCH LOCATIONS

BREATHE
DATA-CAN
Discover-NOW
Gut Reaction
INSIGHT
PIONEER
NHS DigiTrials
BHF Data Science Centre
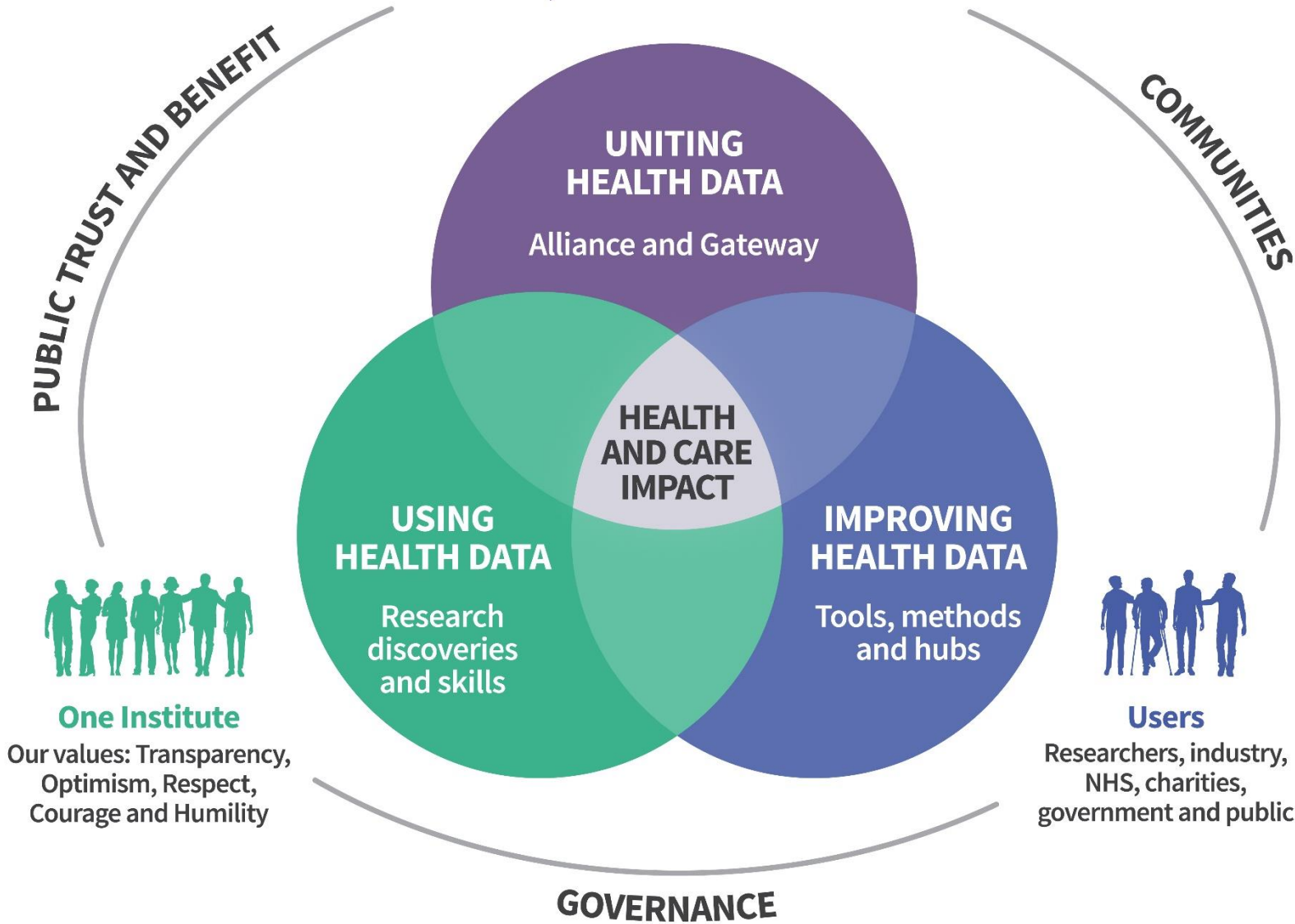DATAMIND
Alleviate

HEALTH DATA RESEARCH HUBS

Belfast	Oxford
Birmingham	
Bristol	
Cambridge	
Edinburgh	
Exeter	
Leeds	
London	
Manchester	

TRAINING LOCATIONS (Masters and PhD)

Uniting, Improving and Using Health Data

Public, Patients & Practitioners

HDR UK
Health Data Research UK

PUBLIC TRUST AND BENEFIT

COMMUNITIES

UNITING HEALTH DATA
Alliance and Gateway

HEALTH AND CARE IMPACT

USING HEALTH DATA
Research discoveries and skills

IMPROVING HEALTH DATA
Tools, methods and hubs

One Institute
Our values: Transparency, Optimism, Respect, Courage and Humility
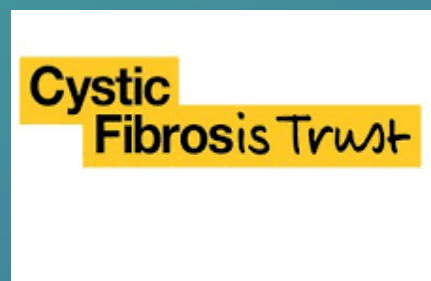
Users
Researchers, industry, NHS, charities, government and public

GOVERNANCE

With a growing community of researchers, innovators, technologists, clinicians, patients, & public across industry, NHS, academia and charities working together…
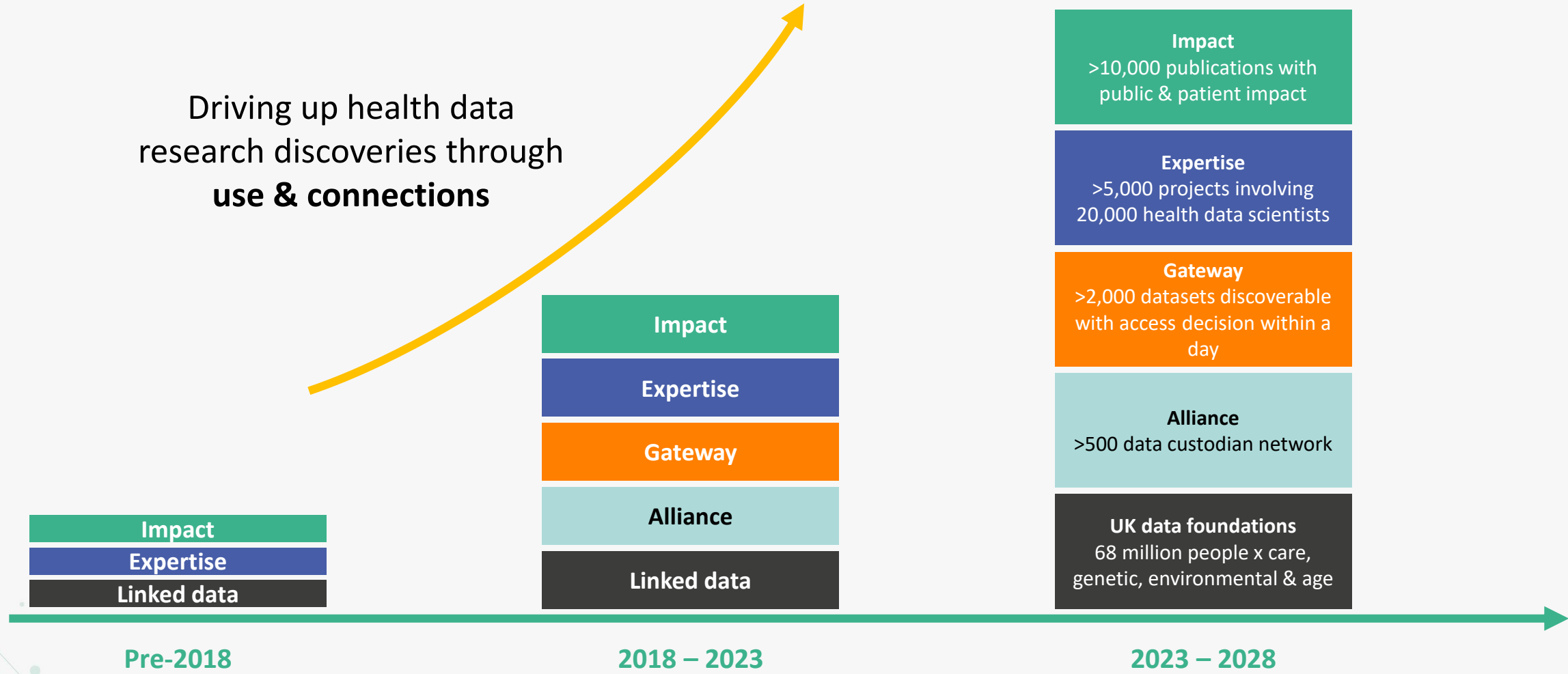
What's next?

Driving up health data research discoveries through **use & connections**

Pre-2018

- Impact
- Expertise
- Linked data

2018 – 2023

- Impact
- Expertise
- Gateway
- Alliance
- Linked data

2023 – 2028

Impact
>10,000 publications with public & patient impact

Expertise
>5,000 projects involving 20,000 health data scientists

Gateway
>2,000 datasets discoverable with access decision within a day

Alliance
>500 data custodian network

UK data foundations
68 million people x care, genetic, environmental & age

Unite a complex environment, which is broader than just health data…

**requires interoperability and federation….
to work across systems with no additional effort.**

Quinquennial review – 2023 to 2028

- An opportunity to collaborate and build joint strategy

- Information and events all listed at

https://www.hdruk.ac.uk/quinquennial-review/

- Please get in touch to discuss more

Quinquennial Review: the THIRD "Frontiers" Meeting
Monday, 15 November

HDRUK
Health Data Research UK

Join us at our upcoming 'Quinquennial Review: the THIRD "Frontiers" Meeting' – happening 14:00 Monday, 15 November!

Register now

Join us at our upcoming workshop "Pandemics and Outbreaks" 18th November, 9:30 – 11:00
Register now

Join us at our upcoming meeting, "Big Data for Common Complex Disease" 19 November, 11:00 – 13:00
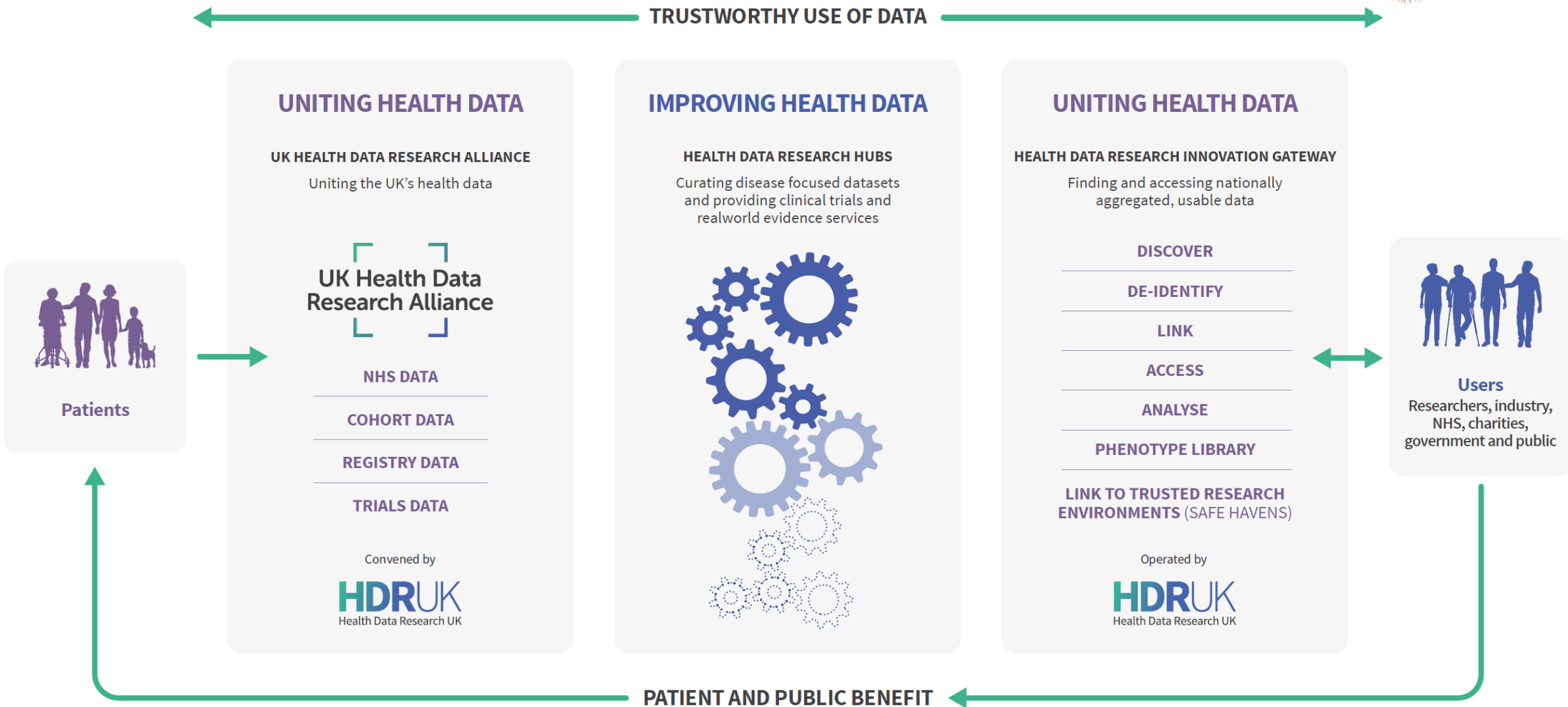**Register now**

Developing an open data ecosystem

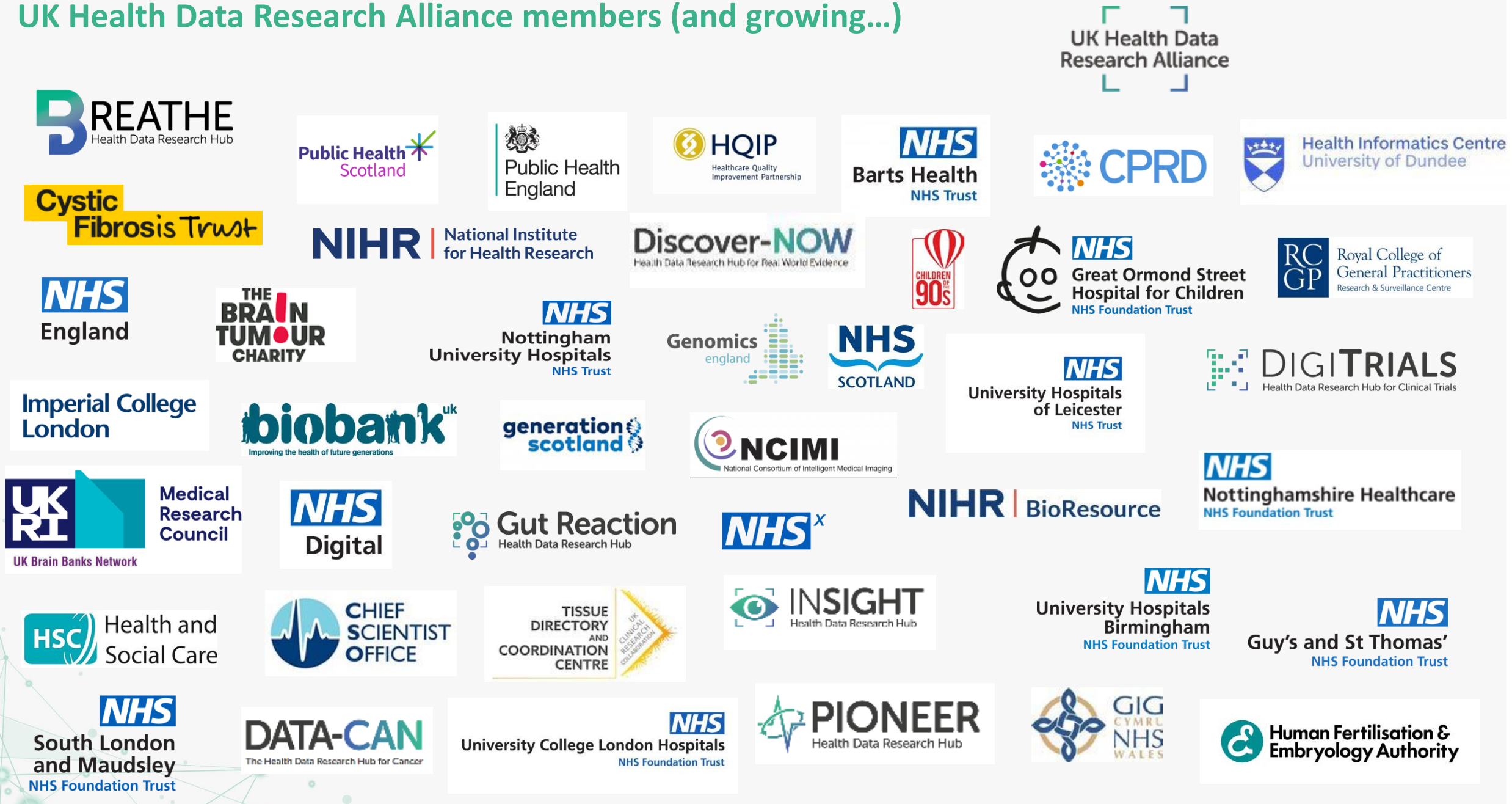**David Seymour, Alliance Executive Director**

10/11/2021

The key components of the infrastructure funded initially through Digital Innovation Hub workstream of the Industrial Strategy Challenge Fund (ISCF) Data to Early Diagnosis and Precision Medicine programme

UK Health Data Research Alliance members (and growing...)

The Alliance delivery sub-groups

UK Health Data Research Alliance

Improving Data Utility
Oversee, coordinate, and produce guidance and policy regarding data quality, standards, dataset publishing, data provenance, ontology / terminology services and use.

Engaging and involving practitioners, patients and the public
Understand the interests and values of practitioners, patients and the public in health data.

Aligning approaches to trusted research environments
Agree on requirements for secure analytic environments where researchers can bring analyses and algorithms to the data.

Enhanced discovery & access via the gateway
A one-stop-shop destination to discover, access, manage and drive the ethical and safe use of data through rich metadata and cohort discovery and collections.

Promoting participation and improving access
Ensure consistency and harmonise principles, definitions, process steps to develop a best practice for assessing requests to access UK health data.

Building *the* Gateway for researchers and innovators to discover and access data

New Data Utility Wizard Tool Try out our new tool which will help refine your search to only datasets that meet your data utility requirements- click the Advanced Search button below! Give Feedback on the tool

Health Data Research Innovation Gateway

Explore ⌄   Help ⌄   Usage Data ⌄   About Us ⌄   News   Community

🔍   + Add new   Sign in | Sign up

Gateway to health data and tools for research

Search, discover and request access to hundreds of datasets, tools and resources for your research. Join the thousands of researchers and scientists worldwide who are already using the Gateway for research and scientific discovery.

🔍 I'm looking for...

⭐ Advanced Search

Data Utility Wizard

Use this tool to find the datasets you require through 6 key data utility filters: allowable uses, time lag, length of follow up, data model, provenance and search terms.

Question 1 of 6
Allowable uses

Please select the identifier that is most relevant to you (optional)

○ Academic research
○ Student / educational project
○ Charitable or non-profit project
○ Commercial project

View 702 dataset matches   Next

datasets	tools	projects	courses	papers	dataset requests	registered users	searches last month
701	155	262	195	1,358	356	1,656	13,267

https://www.healthdatagateway.org/

A common, transparent approach to data access management based around the Five Safes framework

What did we recommend as the key principles for a standard?

	Recommendation
Recommendation 1: Transparency	All data custodians and controllers responsible for the collection, storage and sharing of data for the purpose of research, innovation and service evaluation should **publish a public record (data use register)** of approved research studies, projects and other data uses.
Recommendation 2: Frequency	Data use registers should, as far as possible, be **populated in near real time** directly from information provided through the Data Access Request process to improve timeliness and accuracy of entries.
Recommendation 3: Format	Data use registers should be made available in both **human-readable and machine-readable formats.**
Recommendation 4: Content	Data use registers should have **a consistency of format and content based on the Five Safes framework** and an agreed specification to enable ease of understanding and aggregation of registers.
Recommendation 5: Link to outputs	Researchers, data custodians and funders should use data use registers to close the loop on the impact of data use by **including, where possible, links to research findings and other outputs** as these become available.

Opportunities for your charity to get involved

- Join one of our Gateway Open door events to learn more (e.g., tomorrow, 11 Nov at 2:00pm)

- Work with HDR UK to make a disease thematic collection of the most relevant datasets in your subject.

- Promote the Gateway to your research community as a way to find relevant health data

- Use the Gateway to help fulfil commitments to make data generated through work you support more widely available. Request or require your funded researchers to use the Gateway to improve discovery and develop access mechanisms.

- Join the UK Health Data Research Alliance so your organisation can contribute to the development of practice and standards for data sharing at scale.

…uniting, improving and using data to enable discoveries that improve people's lives

Health Data Research Hub programme

James Pickett, Hub Development manager

10/11/2021

Health Data Research Hubs

- Take a national role in curating data and improving its quality and access
- Supports users with tools and expertise to deliver research and innovation
- Embeds public and patients at the heart of what it does
- Works with HDR UK to reuse the infrastructure and contribute to a national Hub network.

Introducing the BHF Data Science Centre

Partnership

HDRUK
Health Data Research UK

**British Heart
Foundation**

Our vision

To improve the cardiovascular health of the nation using the power of large-scale data and advanced analytics across the UK

The BHF Data Science Centre makes it easier for researchers across the UK to collaborate and securely access the latest and most relevant health data, speeding up research and helping to answer vital questions about heart and circulatory diseases to improve health in the UK and beyond.

We work on...
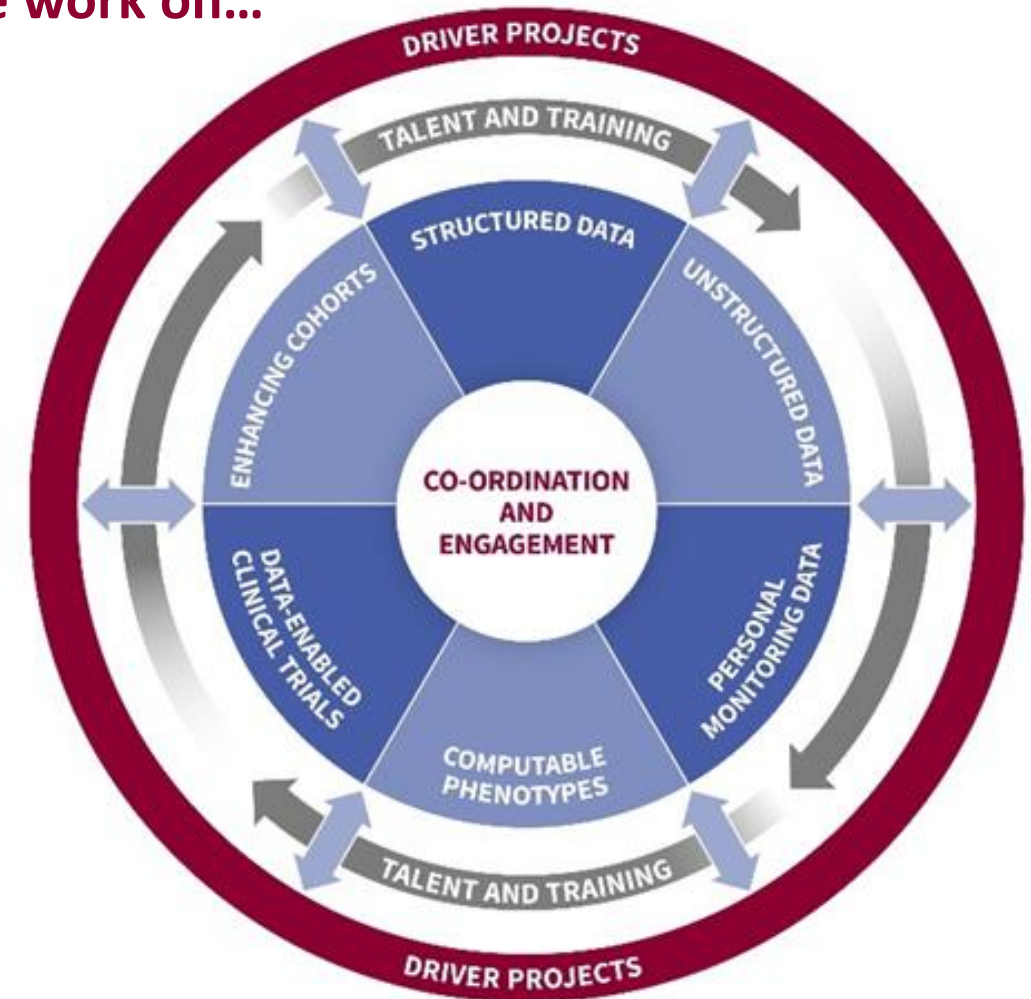
Health Data Research Hubs

Insights and Impacts on COVID-19

HDRUK
Health Data Research UK

What is our impact?

150
datasets available for research

400+
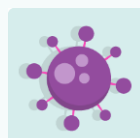contracts providing data services to industry, academia and the NHS

20000
contacts involving patients and the public in health data research

32
datasets at the top level of metadata quality

How our Research Hubs are shaping discovery

NHS DigiTrials
Provided access and linked data for the RECOVERY Trial, saving thousands of lives.
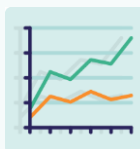
DATA-CAN
Estimated excess cancer patient deaths.
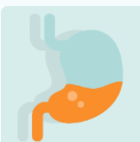
Gut Reaction
Enabled 34,000 people with inflammatory bowel disease to assess their risk.

BHF Data Science Centre
Enabled safe, secure access to health data for over 55 million people in the UK, to investigate the impact of COVID-19 on cardiovascular disease.

PIONEER
Analysis of real-time data discovered an increase in venous thromboembolic events (VTE); developed guidance which is now being used in over 60 hospitals

Discover-NOW
Supported a range of projects across London.

BREATHE
Provided policymakers maps and hotspot data from 4.4.m people using the ZOE/ Kings College London Symptom Study.

INSIGHT
Supported real world data analysis to identify impact on hospital eye services.

HDR UK can support both researchers and funders develop robust plans for a Hub

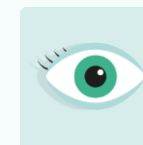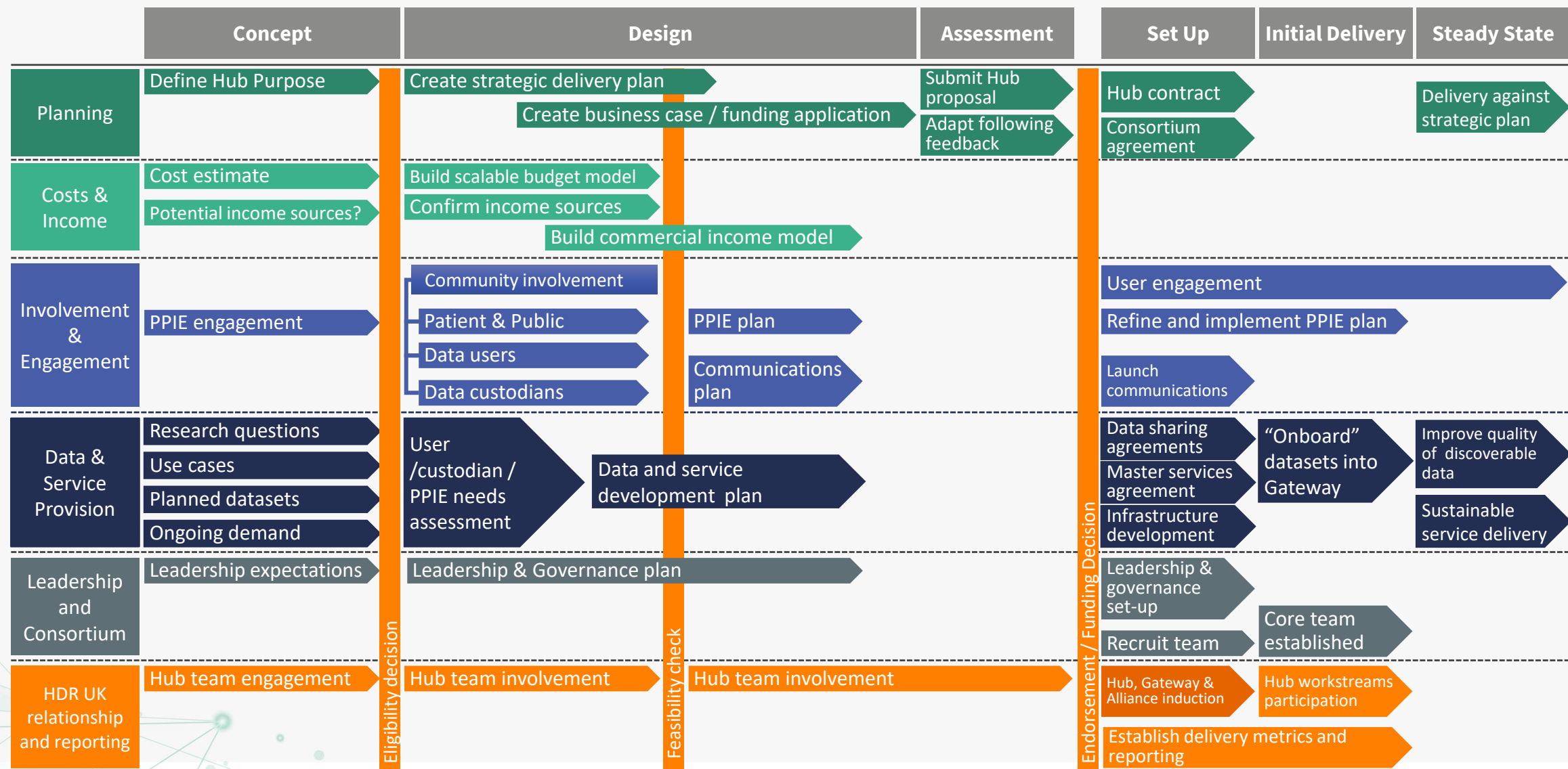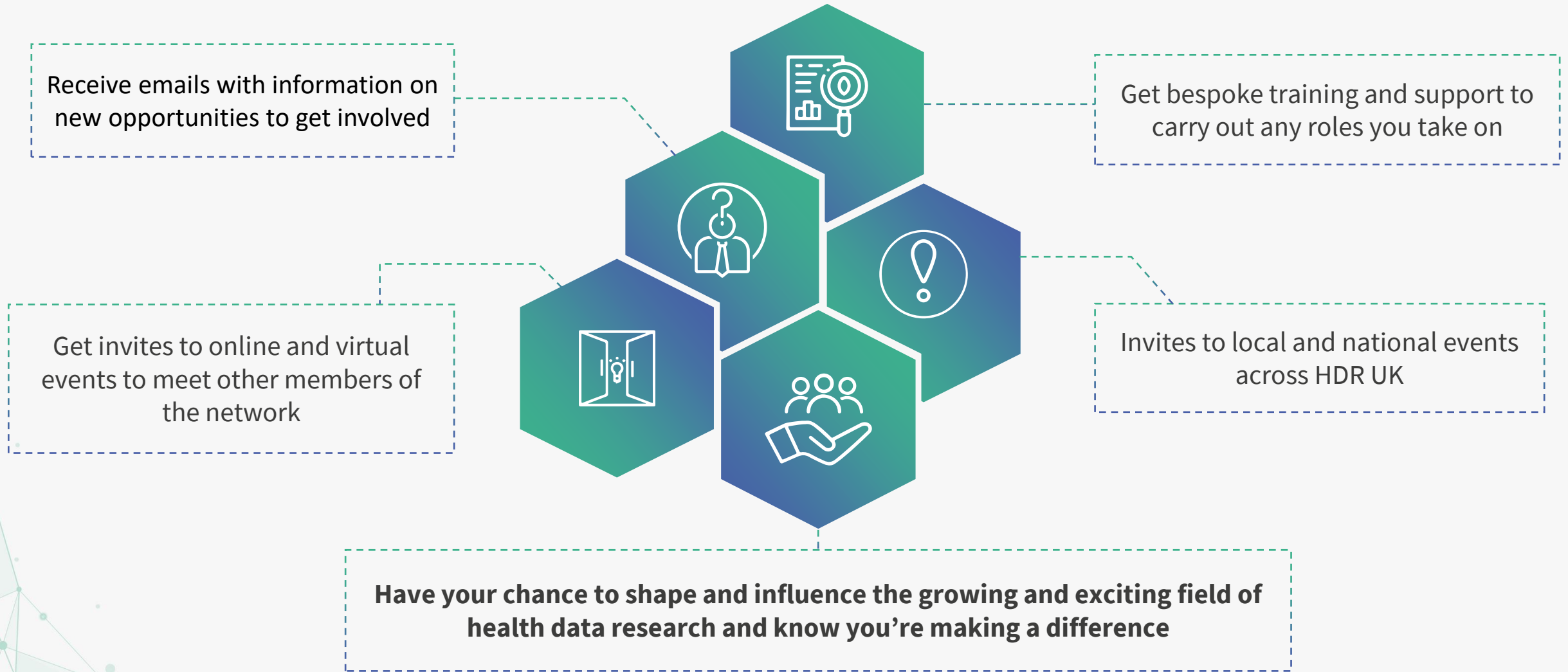|	Concept	Design	Assessment	Set Up	Initial Delivery	Steady State
Planning	Define Hub Purpose	Create strategic delivery plan / Create business case / funding application	Submit Hub proposal / Adapt following feedback	Hub contract / Consortium agreement		Delivery against strategic plan
Costs & Income	Cost estimate / Potential income sources?	Build scalable budget model / Confirm income sources / Build commercial income model				
Involvement & Engagement	PPIE engagement	Community involvement / Patient & Public / Data users / Data custodians / PPIE plan / Communications plan		User engagement / Refine and implement PPIE plan / Launch communications		
Data & Service Provision	Research questions / Use cases / Planned datasets / Ongoing demand	User /custodian / PPIE needs assessment / Data and service development plan		Data sharing agreements / Master services agreement / Infrastructure development	"Onboard" datasets into Gateway	Improve quality of discoverable data / Sustainable service delivery
Leadership and Consortium	Leadership expectations	Leadership & Governance plan		Leadership & governance set-up / Recruit team	Core team established	
HDR UK relationship and reporting	Hub team engagement	Hub team involvement / Hub team involvement		Hub, Gateway & Alliance induction / Establish delivery metrics and reporting	Hub workstreams participation	

Vertical orange bars: Eligibility decision | Feasibility check | Endorsement / Funding Decision

Patient and public involvement and engagement
Key to Hubs and all HDR UK work

Receive emails with information on new opportunities to get involved

Get bespoke training and support to carry out any roles you take on

Get invites to online and virtual events to meet other members of the network

Invites to local and national events across HDR UK

Have your chance to shape and influence the growing and exciting field of health data research and know you're making a difference

Sign up today - https://www.hdruk.ac.uk/about-us/patient-and-public-involvement-and-engagement/join-hdr-uk-voices/

Opportunities for your charity to get involved

- Reach out to current Hubs, or via HDR UK, to explore the data they hold. Several have highly-granular real world data that can describe care, services and treatments in your disease area.

- Explore creating a new Research Data Hub with us in your disease areas. Charities can make multiple roles as funders, delivery partners, and users of the Hub.

- Work with HDR UK to design, deliver, evaluate or promote your public and patient involvement data-science work

…uniting, improving and using data to enable discoveries that improve people's lives

Academic Programmes

HDR UK-Turing Wellcome PhD Programme in Health Data Science

Our PhD programme aims to develop future leaders in health data science. Its underlying philosophy is that health data science requires a combination of expertise spanning three fundamental areas: statistical, computational and health sciences.

Masters Programmes

Our 6 Masters programmes, delivered in partnership with 5 leading universities across the UK, are designed to provide the best possible foundation for a career in health data science.

Other Programmes

Apprenticeships – AI Apprenticeship Academy for Health (in partnership with Cambridge Spark)

Our Cambridge Spark apprenticeships offer expert-led, MSc equivalent 15-month apprenticeships that will bring major benefits to employers and employees alike. It is part of our drive to ensure that anyone with the ambition, talent and drive can have a career in health data science – no matter what your background or where in the UK you live.

Health Data Science Academic School

HDR UK runs an annual academic school targeted at PhD students, early-mid career researchers, and technology specialists working in health data science across academia, the NHS and industry, equip them with the necessary skills to respond to the very latest challenges in health data science.

Black Internship Programme

Health Data Science Black Internship Programme

"I am eternally grateful for being selected to be part of this programme as it has opened up a world of opportunities for me. I am mighty proud to be part of the first cohort of Health Data Research UK Black health data science interns!"

Dr Shukrat O. Salisu-Olatunji, Intern at National Institute for Health Research (NIHR)

"The interns completed their projects beyond initial expectations of the team."
2021 Host Organisation
"Don't hesitate to get involved in this incredible programme."
2021 Host Organisation

If you would like to find out how your organisation can take part and the benefits it can bring, please join our CEO, Caroline Cake, for a Q&A webinar on **16th November.**

Sign up here **https://www.hdruk.ac.uk/events/black-internship-programme-qa-session-for-host-organisations/**

HDR UK Futures

HDR UK Futures, our brand-new and completely free Virtual Learning Environment, hosts our growing catalogue of curated online learning content and now has 1,400+ registered users.
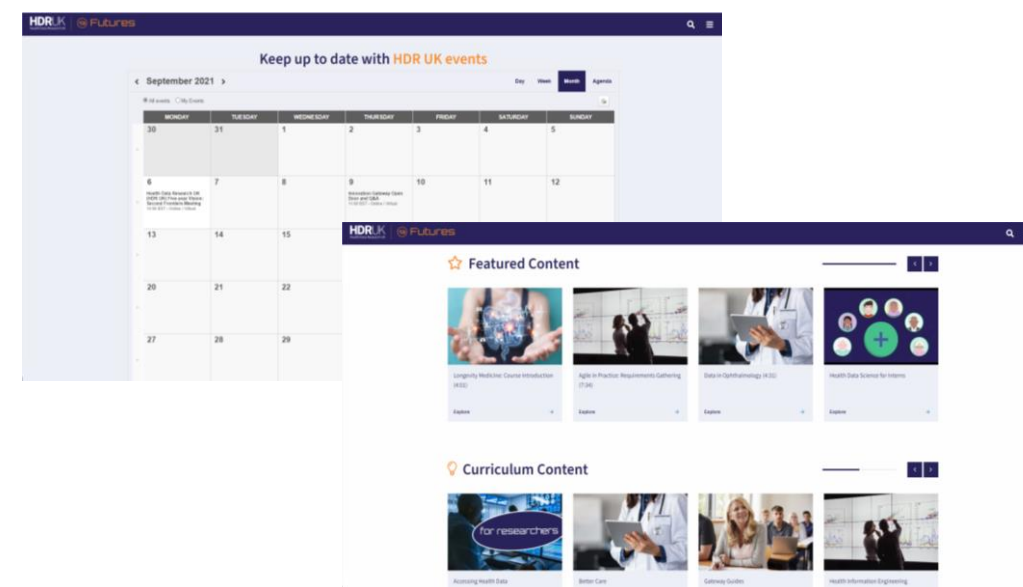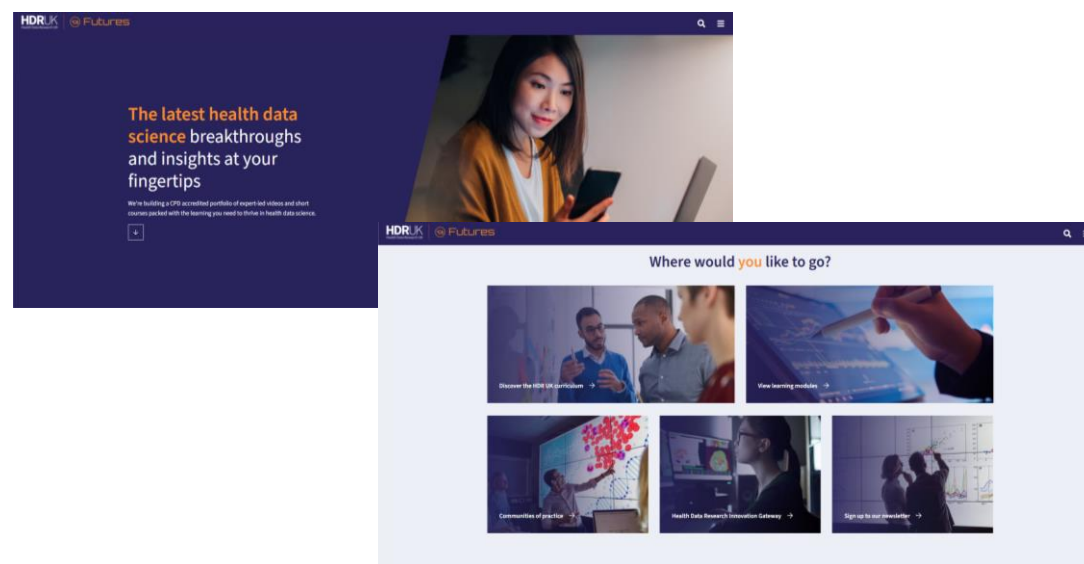
How we could collaborate on training

HDRUK
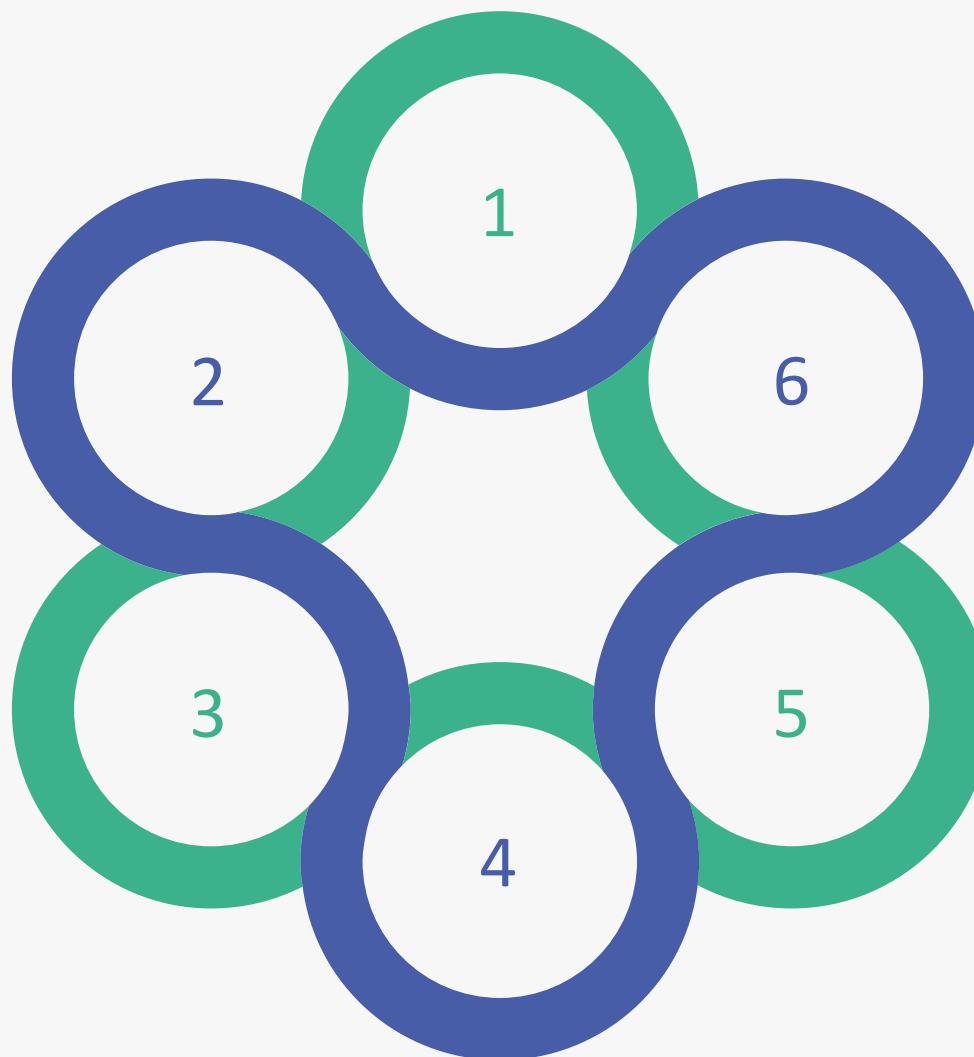Health Data Research UK

01
Can you host interns as part of our Black Internship Programme?

02
Can you help us shape a learning path for your sector? Do you have a suggested topic for a bite-size video that meets a need?

03
Can you deliver a relevant bite-sized video or do you know somebody that can?

04
We can promote your training events or career opportunities on social media, the website and our learning platform
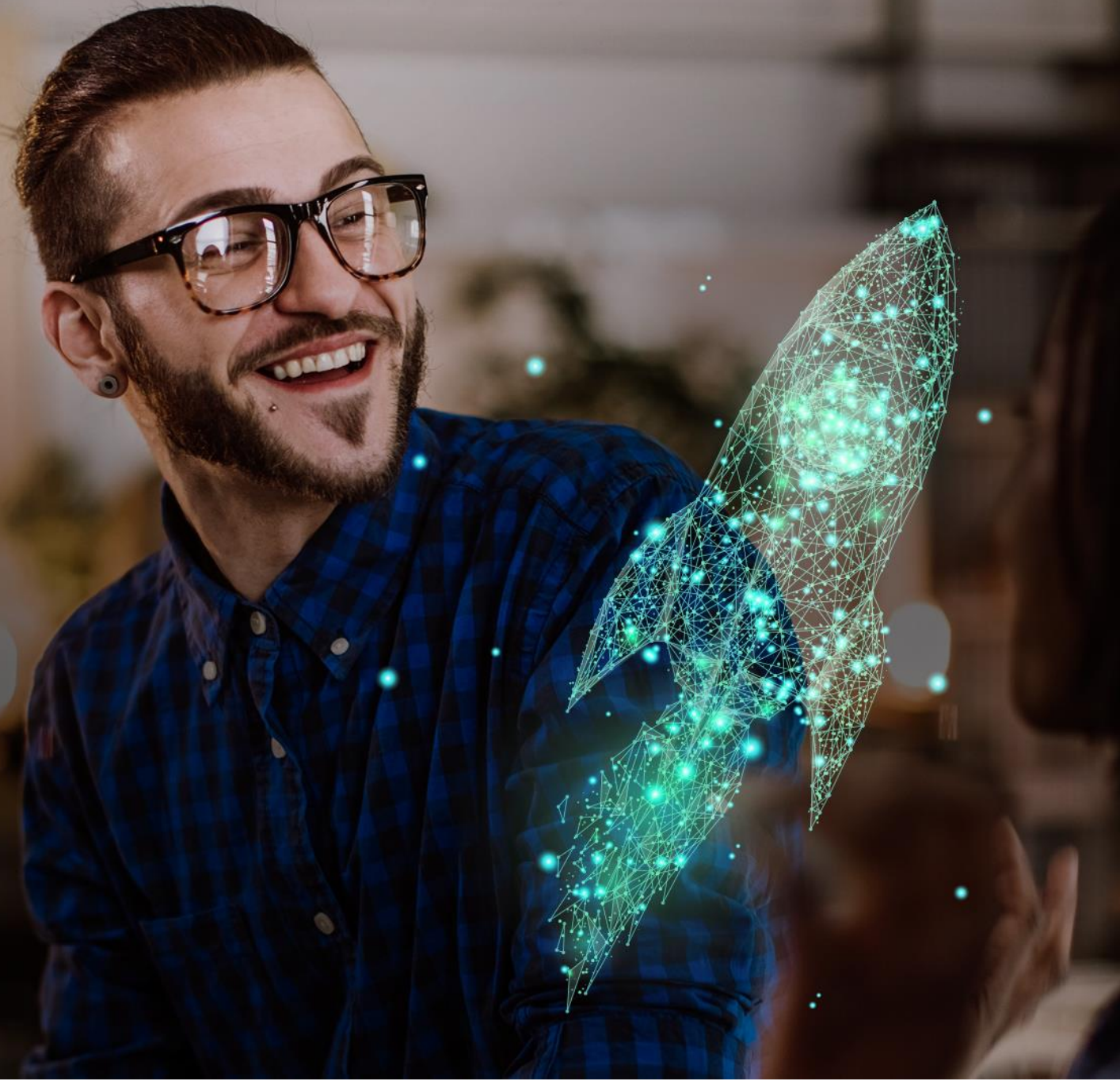
05
Is there a training event that you would like us to deliver?

06
Sign up to HDR UK Futures and access our training courses and join our community (https://hdruklearning.csod.com)

1

2

6

3

5

4

Thank you

Break outs – 3:30 – 3:55

10/11/2021

Breakout sessions – your chance to make contacts and follow ups

Room 1 - Developing Data Hubs – James Pickett

Room 2 - Making data open – Paola Quattroni

Room 3 - Skills and capacity – Sarah Cadman

Room 4 - Data landscape – David Seymour

Room 5 - Data at scale DATA-CAN – Monica Jones

You need to go to the bottom of your zoom screen and click the breakout room button, which will allow you to choose your breakout room from the list. Using the same button, you can choose to move to another breakout room at any time.

Wrap up – continuing the conversation

David Seymour

10/11/2021

Opportunities for your charity to get involved

1. Support wider discovery and access to datasets you fund and are relevant to your disease area

2. Explore what a Health Data Research Hubs could do for your field

3. Promote data science capacity building and training for your community

4. Join the UK Health Research Alliance to shape health data ecosystem

5. Share your public and patient involvement and engagement experience

6. Something else? Get in touch!

https://www.hdruk.ac.uk/about-us/partner-organisations/

Please complete our short evaluation

Our three key priorities at the onset of the COVID-19 pandemic

1 Co-ordinate and connect national data science driven research efforts related to COVID-19

2 Accelerate access to UK-wide priority data relevant to COVID-19 for research

3 Leverage the best of the UK's health data science capability to address the wider impact of the COVID-19 pandemic, supporting vulnerable groups that will be hardest hit

Support the UK government response through regular reporting to SAGE

Health Data Research UK @HDR_UK · 16 Mar
As the national institute for health data science, our HDR UK community is actively championing the use of health data to address the #COVID-19 challenge including work on risk factors, clinical trials, care pathways and surveillance.

Find out more:

Statement on Coronavirus Pandemic - HDR UK
hdruk.ac.uk

17   16

Impact Case Study 1:
Data enabled recruitment to PRINCIPLE

- **Developed and enabled near real-time, data-driven, ethical approach for enhancing recruitment into the PRINCIPLE trial -** by contacting people with a recent COVID-19 positive test result from the central NHS Test and Trace service within 24-48 hours of their test result.

- **Rapid Public Patient Involvement & Engagement survey** (>90 respondents) to gain insights on public perceptions - demonstrated an efficient process to rapidly inform the trial team's understanding and recruitment approach

- **Multi-disciplinary team** formed to solve the complex issues required to provide a near-real time feed of potential trial participants from test result data to the research team.

- **IMPACT: Rapidly increased weekly recruitment rate** allowing more rapid evaluation of treatments and increased safety for participants. PRINCIPLE has recruited **7,257 participants** as at 9-Nov-21 (from <1000 pre-data enablement)

- **Now employing approach across other National Core Studies and Urgent Public Health trials –** Roll out of this approach to support AZ trials. AZ have reported **global interest in approach.**

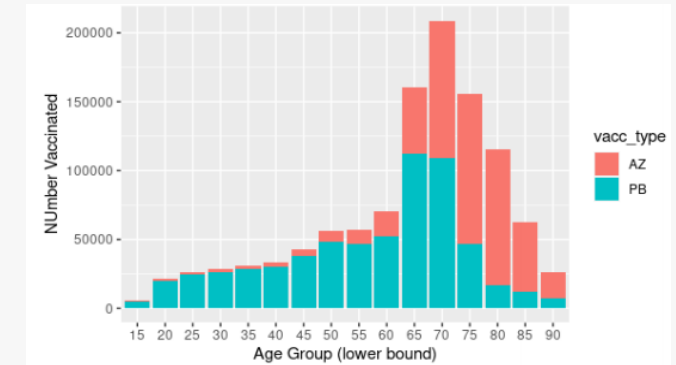# Impact Case Study 2: Vaccine Effectiveness

Challenge

- To **confirm the real-world effectiveness of COVID-19 vaccines** to establish the success of the roll out is urgent

Solution

- Enabling access to the <u>EAVE II dataset</u>, which links vaccination, primary care, COVID-19 testing, hospitalisation and mortality records for 99% Scottish population (5.4M people), through the Scottish National Safe Haven
- This setting provided access for approved researchers in a **safe and secure way** and allowed **rapid analysis to data**, with publication of findings within weeks of data collection

Effectiveness of First Dose of COVID-19 Vaccines Against Hospital Admissions in Scotland: National Prospective Cohort Study of 5.4 Million People

21 Pages · Posted: 19 Feb 2021

Impact

- Analysis showed that the Pfizer and AstraZeneca vaccines reduced hospital admissions by 85% and 94% respectively (and this result was maintained for adults >80 years)
- The results provided early insights that the **COVID-19 vaccination is working on a population-wide level and provides confidence in the continuing roll out**

"This study is the first to describe the country-wide effect of the approved COVID-19 vaccines on preventing severe illness and hospital admissions… the brilliant news is that this suggests the vaccine delivery programme is working."

**Dr Josie Murray,
Public Health Scotland**