HDRUK

Health Data Research UK

UK Health Data Research Alliance

Health Data Research Innovation Gateway

Allofus together

UK Health Data Research Alliance Symposium

Tuesday 1 December 2020

→ #HDRAlliance20 | #HealthDataTogether







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1 Introduction

All of us together: UK Health Data Research Alliance Symposium

This event will celebrate the transformation of health data research infrastructure in the UK, the impact this is already having on our knowledge, understanding and response to COVID and other conditions. With interactive and engaging sessions from leaders in the sector, we will explore the possibilities of scaling this up to improve people's lives and the future of healthcare – both in the UK and internationally.

Together we will reflect on the achievements so far, including identifying priority datasets for COVID research, starting to streamline data access through the Gateway, and the use of Trusted Research Environments for safe and secure data analysis. Then we will look to the future with sessions that will stimulate thinking on scaling up computing, AI and other analysis tools, services and how data about each of us is used through our lifetimes.

Over 400 people from the NHS, industry, universities, charities and government with patients and the public – both across the UK and internationally – are signed up to join the event. We hope you will be inspired by the possibilities of what we can all achieve as public, patients, clinicians, researchers, engineers and innovators working together. We are realising the benefits of using health data at a scale to respond to global health challenges both today and in the future.

By working together, we are making history.

Caroline Cake

CEO, Health Data Research UK

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2 | Joining a session

This is a virtual conference run via Zoom. Each session has its own individual joining link, which can be found in the next section of this brochure <u>3. Links to join - at a glance</u>. To join a session simply click on the links provided in this pack. In the unlikely event that the joining links fail, please visit the Zoom website, select 'Join a Meeting' and enter the Webinar ID provided.

For breakout sessions, there will two or three streams running simultaneously. We suggest you review the options and choose one breakout session ahead of time so that you can attend for the full duration of the session. To attend your chosen session, follow the relevant link provided. All sessions will be recorded and shared on our website in due course.

The optional networking session will be facilitated by Zoom breakout rooms. You will join the main session and be randomly assigned to a breakout room to network and chat with a small group of attendees. Your video and audio will be enabled, however you can disable either if you wish.

To find out more about Zoom and how to use it best to participate in the conference please see section **6. Participating in the conference and using Zoom**.

3 | Links to join - at a glance

TIME	TITLE	LINK TO JOIN
09:30 - 10:35	Opening plenary: Welcome and keynote	→ Join opening plenary session
10:45 - 11:35	Breakout stream 1: Priority datasets to answer priority questions	→ <u>Join breakout 1</u>
10:45 - 11:35	Breakout stream 2: Trusted (and productive) Research Environments for safe research	→ Join breakout 2
10:45 - 11:35	Breakout stream 3: Streamlined access and authentication	→ <u>Join breakout 3</u>
11:45 - 12:35	Plenary: Innovation Gateway demo, drop-in session, and Lightning Talks	→ <u>Join Innovation Gateway and</u> <u>Lightning Talks plenary session</u>
13:30 - 14:20	Breakout stream 1: Scaling up computing for Al and data tools	→ <u>Join breakout 1</u>
13:30 - 14:20	Breakout stream 2: Scaling up data services to meet national and global challenges	→ <u>Join breakout 2</u>
13:30 - 14::20	Breakout stream 3: Data through our lifetimes	→ <u>Join breakout 3</u>
14:30 - 15:00	Plenary: Federation and a look to the future	→ <u>Join Federation plenary session</u>
15:10 - 16:00	Breakout stream 1: Federated analytics	→ <u>Join breakout 1</u>
15:10 - 16:00	Breakout stream 2: International open research and data sharing	→ <u>Join breakout 2</u>
16:00 - 16:40	Closing plenary: Keynote and closing remarks	→ <u>Join closing plenary session</u>
16:40 - 17:00	Networking session	→ <u>Join optional networking session</u>

4 | Full agenda

	→ <u>Click here to join</u>			
	Webinar ID: 861 5280 3189			
09:30	Chair's welcome and introduction Caroline Cake, CEO, Health Data Research UK			
09:35	Opening: The importance of health data for research and innovation Ottoline Leyser, Chief Executive, UK Research & Innovation			
09:45	A generation of future leaders: Black Interns Health Data Science Programme Caroline Cake, CEO, Health Data Research UK Martin Levermore, Chair, External Advisory Board, PIONEER - The Health Data Research Hub for Acute Care			
09:55	Facing COVID together: the story and role of health data research Caroline Cake, CEO, Health Data Research UK			
	Panellists: - Derek Stewart, Patient Representative, Health Data Research UK and PA Consulting - Jill Hopkins, Global Head, Ophthalmology Personalised Care, Roche-Genentech - John Danesh, Research Director, HDR UK Cambridge - Amitava Banerjee, Associate Professor in Clinical Data Science and Honorary Consultant Cardiologist, University College London Hospitals NHS Trust			
10:35	BREAK			
10:45	BREAKOUT GROUPS: TRUSTWORTHY ACCESS TO HEALTH DATA (COVID AND BEYOND)			
	Stream 1: Priority datasets to answer priority questions	Stream 2: Trusted (and productive) Research Environments for safe research	Stream 3: Streamlined access and authentication	
	→ Click here to join Webinar ID: 832 8067 1321	→ Click here to join Webinar ID: 838 1713 4465	→ Click here to join Webinar ID: 896 5327 9592	
	Chair: Alison Pritchard, Deputy National Statistician and Director General for Data Capability, Office for National Statistics (ONS)	Chair: Susheel Varma, Director, Engineering, Health Data Research UK	Chair: David Ford, Professor, Health Informatics, Swansea University Panellists: - Alex Bailey, Programme Manager,	

4 | Full agenda

	→ Click here to join Webinar ID: 860 2760 7717		
	Creating the UK portal for data and tools in partnership: a demonstration of the UK Health Data Research Innovation Gateway Panellists: - Peggy Barthes-Streit, Technology Partnership Director, Health Data Research UK - Susheel Varma, Director, Engineering, Health Data Research UK		
12:05	PLENARY: LIGHTNING TALKS		
	Lightning talks: Innovating together		
	Chair: Peggy Barthes-Streit, Technology Partnership Director, Health Data Research UK 34,000 IBD patients. 176 hospitals. 8 days from idea to go-live: Helping both IBD patients and their clinical teams with COVID-19 risk assessments Liz Dobson, CEO, IBD Registry		
	Human Centric Drug Discovery in migraines using UK health data Zameel Cader, CSO, Human Centric Drug Discovery		
	The use of AI to empower patients and enable self-management of key healthcare services Ron Burdis, Business Consultant, EBO Improving outcomes for patients with high blood pressure through data driven therapy personalisation Hakim Yadi, Co-Founder & CEO, Closed Loop Medicine Ltd		
12:35	LUNCH		
13:30	BREAKOUT GROUPS: SCALING UP - COVID AND BEYOND		
	Stream 1: Scaling up computing for AI and data tools	Stream 2: Scaling up data services to meet national and global challenges	Stream 3: Data through our lifetimes
	→ Click here to join Webinar ID: 845 0952 5953	→ Click here to join Webinar ID: 842 0977 8310	→ Click here to join Webinar ID: 823 1577 6256
		Chair: Ben Gordon, Executive	

4 | Full agenda

14:30	PLENARY: FEDERATION AND A LOOK TO THE FUTURE			
	→ Click here to join Webinar ID: 836 8976 6542			
	How will data transform the future of healthcare? Douglas Gurr, Head, Amazon UK and Chair of the Board of Trustees, British Heart Foundation			
	In conversation with Caroline Cake, CEO, Health Data Research UK			
15:00	BREAK			
15:10	BREAKOUT GROUPS: FEDERATION – WHAT'S NEXT?			
	Stream 1: Federated analytics	Stream 2: International open research and data sharing		
	→ Click here to join Webinar ID: 833 1580 2357	→ Click here to join Webinar ID: 853 5473 6557		
	Chair: Dave Robertson, Interim Director, HDR UK Scotland	Chair: Georgina Humphreys, Clinical Data Sharing Manager, Wellcome Trust		
	 Panellists: Mandy Chessell, Distinguished Engineer, IBM Emily Jefferson, Director, Health Informatics Centre (HIC), University of Dundee Roger Noble, Founder & Chief Executive Officer, Zegami 	Panellists: - Phaik Yeong Cheah, Associate Professor, University of Oxford - Gary Saunders, Human Data Coordinator, ELIXIR - Tim Smith, Head of Collaboration, CERN - Rachel Plachcinski, HDR UK Public Advisory Board		
	CLOSING PLENARY			
	→ Click here to join Webinar ID: 852 9254 2232			
16:00	Standards for genomic medicine, GA4GH and its use in research Ewan Birney, Director, European Bioinformatics Institute			
16:35	Closing remarks Andrew Morris, Director, Health Data Research UK			
16:40	OPTIONAL NETWORKING SESSION			
	→ Click here to join Webinar ID: 859 2296 8298 Passcode: HDR UK			
	The optional networking session will be facilitated by Zoom breakout rooms. You will join the main session and be randomly assigned to a breakout room to network and chat with a small group of attendees. Your video and audic will be enabled, however you can disable either if you wish.			
17:00	CLOSE			

5 | Session summaries

10:45 Breakout Groups:

Trustworthy access to health data (COVID and beyond)

Stream 1:

Priority datasets to answer priority questions

→ Click here to join Webinar ID: 832 8067 1321

Session Objectives:

Showcase examples of how data is being used for impactful research.

Session Overview:

This session will highlight the value of using health data in a trustworthy manner to answer important research questions, such as management of the COVID-19 pandemic. Leading experts will outline how the data, for example from electronic health records, has been used to answer questions about diseases and their impacts, and also how important the questions are in shaping the development of the data assets.

Stream 2:

Trusted (and productive)
Research Environments for safe research

→ Click here to join Webinar ID: 838 1713 4465

Session Objectives:

Present the vision for safe and productive use of health data for research.

Session Overview:

Trusted Research Environments (TRE) are analytical platforms that researchers can access remotely to work on data, thus reducing the risks associated with moving data. Speakers in this session will provide their perspective, building on concepts presented in the recent HDRUK TRE green paper, and will explore how it is possible to meet researcher needs and support research productivity while maintaining trust.

Stream 3:

Streamlined access and authentication

→ Click here to join Webinar ID: 896 5327 9592

Session Objectives:

Propose new ways to accelerate research through safe access to health data.

Session Overview:

Use of health and social care data for research is fundamental to generate insights that will benefit patients and the public. Often researchers find it difficult to navigate through the necessary processes in place to ensure confidentiality. It can take a long time before they can practically access the data they need and start their research. The speakers in this session will discuss current work to tackle this problem and will discuss solutions to facilitate trustworthy data-driven research.

13:30 Breakout Groups:

Scaling up - COVID and beyond

Stream 1:

Scaling up computing for Al and data tools

→ Click here to join Webinar ID: 845 0952 5953

Session Objectives:

Showcase how Artificial Intelligence and data tools can help generate insights from health data.

Session Overview:

In this session leading speakers from Google, Microsoft and research institutes will explore applications of Artificial Intelligence and data tools to draw insights from health data. With particular focus on how increased availability of data, faster processing capabilities and newly developed techniques are making a difference, we will explore the impact of Al in health and care.

Stream 2:

Scaling up data services to meet national and global challenges

→ Click here to join Webinar ID: 842 0977 8310

Session Objectives:

Highlight how better data and increased data capabilities help address global healthcare challenges.

Session Overview:

With new health care models and digital technologies fast evolving and increased use of health data, there is a need to improve data, information sharing between organisations and to ensure that systems are interoperable and follow agreed standards. The panellists in this session will discuss how integrated ways of working across nations, based on setting the standards for high quality data can help deliver better

Stream 3:

Data through our lifetimes

→ Click here to join Webinar ID: 823 1577 6256

Session Objectives:

Learn about the experience and the value of following a patient over time.

Session Overview:

In this session, we will hear about some of the most renowned population cohorts created in the UK to follow patients over the course of their lives and collect information on their health, educational and social development. The reach and invaluable data collected through longitudinal studies provides unique insights that would not be possible in any other way, allowing researchers to look at changes over time.

15:10 Breakout Groups:

Federation - what's next?

Stream 1:

Federated analytics

→ Click here to join

Webinar ID: 833 1580 2357

Session Objectives:

Present the concept of federated data infrastructure to improve research.

Session Overview:

In a world where data is large, diverse and highly distributed, it is not possible to assume that all the data needed for research can be brought in a single central place for analysis. In this session, panellists from both industry and academia will discuss the benefits of accessing and using data in a federated manner, where instead of bringing the data together for analysis, you take the analysis to the data.

Stream 2:

International open research and data sharing

→ Click here to join

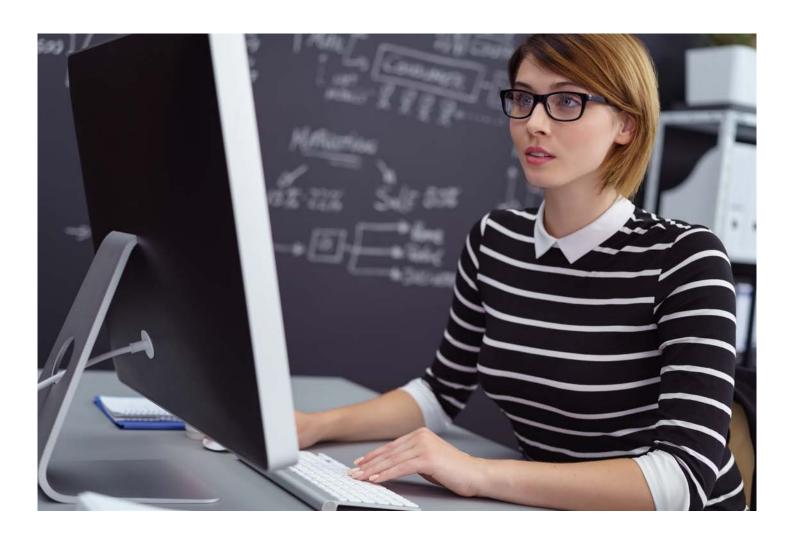
Webinar ID: 853 5473 6557

Session Objectives:

Highlight how different sectors have applied open research practices and what this means for health data research.

Session Overview:

Open Research is about making research more transparent, collaborative and efficient. Since the start of the open access movement in the early 1990s, many open research practices have been developed and are now used across sectors around the world. In this session, we will hear from some leading international open science advocates and will learn how we can apply more open and collaborative practices to achieve more from health data research.



6 | Participating in the conference and using Zoom

Joining the meeting

To join a session please use the relevant link either found in:

Section 3. Links at a glance – for a brief overview and links to use

Section 4. Full agenda - for a detailed description of each session and links to use

In the unlikely event that the joining links fail, please visit the Zoom website, select 'Join a Meeting' and enter the Webinar ID provided.

If you are using Zoom on your computer or laptop, you should not need to download Zoom or have a Zoom account to join.

If you are joining via your smartphone you will need to download the Zoom app for iPhone or Android.

Asking a question

Please use the Q&A function to raise any questions for the panellists, this will be monitored at all times and we will endeavour to answer as many questions as possible in the time available.

Top Tip

Keep guestions concise to allow for speakers to answer as many as possible

You are welcome to use the chat function to introduce yourselves, engage in the conversation, and interact with your fellow attendees, but please save your direct questions for the speakers for the Q&A tool so that they don't get lost in the chat as this will not be monitored.

Continuing the discussion

Please feel free to use the chat function to add your thoughts and comments. We encourage participants to tweet their thoughts and contributions using #HDRAlliance20 and #HealthDataTogether.

Speakers will include their contact details at the end of their slides where they are happy to be contacted by attendees.

Sessions will be recorded, and where possible we will publish the recordings and any slides on the HDR UK website approximately a week after the conference.

Questions

If you have queries about the Symposium you can email us on: events@hdruk.ac.uk

For general queries relating to HDR UK please contact: enquiries@hdruk.ac.uk



7 | Inclusivity and conduct

The conference is open to everyone across the health data science community, and we are delighted to welcome participants from across the UK and internationally.

Where possible, we will publish slides at:

www.hdruk.ac.uk/HDRAlliance20

We are pleased to provide live closed captioning for this event from AI-Media. To view the captions during the event within Zoom, simply click the CC (Closed Captioning) button at the bottom of the Zoom screen.

For any other accessibility requirements please contact events@hdruk.ac.uk and we will do our best to accommodate these.

We ask all participants to abide by our values of transparency, optimism, respect, courage, and humility and to treat all speakers and participants with respect, courtesy, and professionalism.







8 | About HDR UK and the Alliance

Our work is structured around three key themes:

- 1 UNITING HEALTH DATA
 - which includes the UK Health Data Research Alliance and the Health Data Research Innovation Gateway
- 2 IMPROVING HEALTH DATA
 - which includes tools, methods, Health Data Research Hubs and the BHF Data Science Centre
- 3 USING HEALTH DATA

which includes research discoveries and skills development across four national priority areas: Understanding the Causes of Disease, Clinical Trials, Public Health and Better Care

We are delivering this strategy through our inclusive, team-oriented One Institute ethos - bringing together NHS, universities, research institutes and charities - built on our values.



About the Alliance

The UK Health Data Research Alliance is an independent alliance of leading health, care and research organisations united to establish best practice for the ethical use of UK health data for research at scale. By combining expertise and a shared commitment to work collaboratively, we are helping scientists to answer some of the most difficult questions and address the most important health challenges faced in the UK. We aim to accelerate progress in health and care by encouraging widespread and responsible access to structured and unstructured clinical, administrative, imaging, genomic and other molecular data.

Visit <u>www.ukhealthdata.org</u> for more information.

"We're delighted to have joined the UK Health Data Research Alliance earlier this year, sharing our unique expertise to make an important contribution to improve clinical research in the UK, as well as health data science more broadly. The Alliance is crucial in enabling better access to health data for research that will improve lives in the UK."

Stephen Lock

The National Institute for Health Research Clinical Research Network (NIHR CRN) UK Health Data Research Alliance member



About the Innovation Gateway

The Health Data Research Innovation Gateway is a portal to find and request access to UK health datasets controlled by members of the UK Health Data Research Alliance. The first phase of the Gateway provides detailed descriptions (meta-data) of these datasets, which researchers can search, browse and request access to health data. It does not hold or store any patient or health data. It aims to increase transparency around accessible datasets and processes associated with their access. The Gateway is part of the UK-wide capability for the responsible use of health data for research and innovation, funded by the Industrial Strategy Challenge Fund (ISCF).

Visit <u>www.healthdatagateway.org</u> for more information and to test out the Gateway.



About HDR UK

Health Data Research UK is the national institute for health data science in England, Wales, Scotland and Northern Ireland. Its mission is to unite the UK's health data to enable discoveries that improve people's lives. It is a not-for-profit public benefit company funded by UK funded by UK Research and Innovation, the Department of Health and Social Care in England and equivalents in Northern Ireland, Wales and Scotland, and leading medical research charities.

Visit www.hdruk.ac.uk for more information.

Get in touch

Follow us on Twitter: oehDR_UK

Follow us on LinkedIn: Health Data Research UK

General enquiries: enquiries@hdruk.ac.uk

Events enquiries: events@hdruk.ac.uk

Media enquiries: media@hdruk.ac.uk

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Join one of our upcoming virtual events

Health Data Research Innovation Gateway Drop-In and Q&A: December

Tuesday 15 December 09:00 - 09:45 GMT

Click <u>here</u> for more information and to register for the session

Launching the development of Population Research UK

Wednesday 16 December 11:00 – 12:00 GMT

Click <u>here</u> for more information and to register for the session

UK Health Data Research Alliance and HDR UK Partners

Alliance Members







































































Health Data Research Hubs

















HDR UK Partners











The Alan Turing Institute







To find out more:

Visit our website www.hdruk.ac.uk or follow us on Twitter @HDR_UK