

Data Access and Discovery

Improving transparency in the use of health data for research: Recommendations for a data use register standard



Agenda

Session

Welcome and introduction (to Ruth and new event)

Intro to Health Data Research UK and work of the Alliance

Background on data use registers and key achievements

Guest speaker: Angela Coulter, Chair of HDR UK Public Advisory Board

Guest speaker: Victoria Yorke-Edwards, Research Fellow at MRC Clinical Trials Unit UCL

Q&A

Upcoming events and close

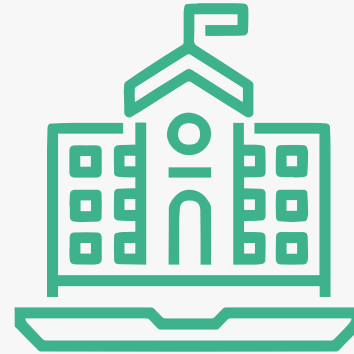
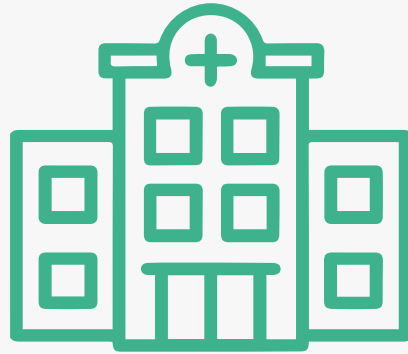
We are the national institute for health data science

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

Working in partnership with patients, the NHS, universities, business & charities to create a world-leading and robust health data infrastructure



We are an independent legal entity, a charity, with 86 organisations across 32 locations in the UK, working in partnership to deliver core platform, interoperability, standards, governance and metadata dictionaries



Uniting health data

By convening community of custodians and researchers

Improving health data

By working in partnership to provide services to researchers

Using health data

By enabling data science and innovation

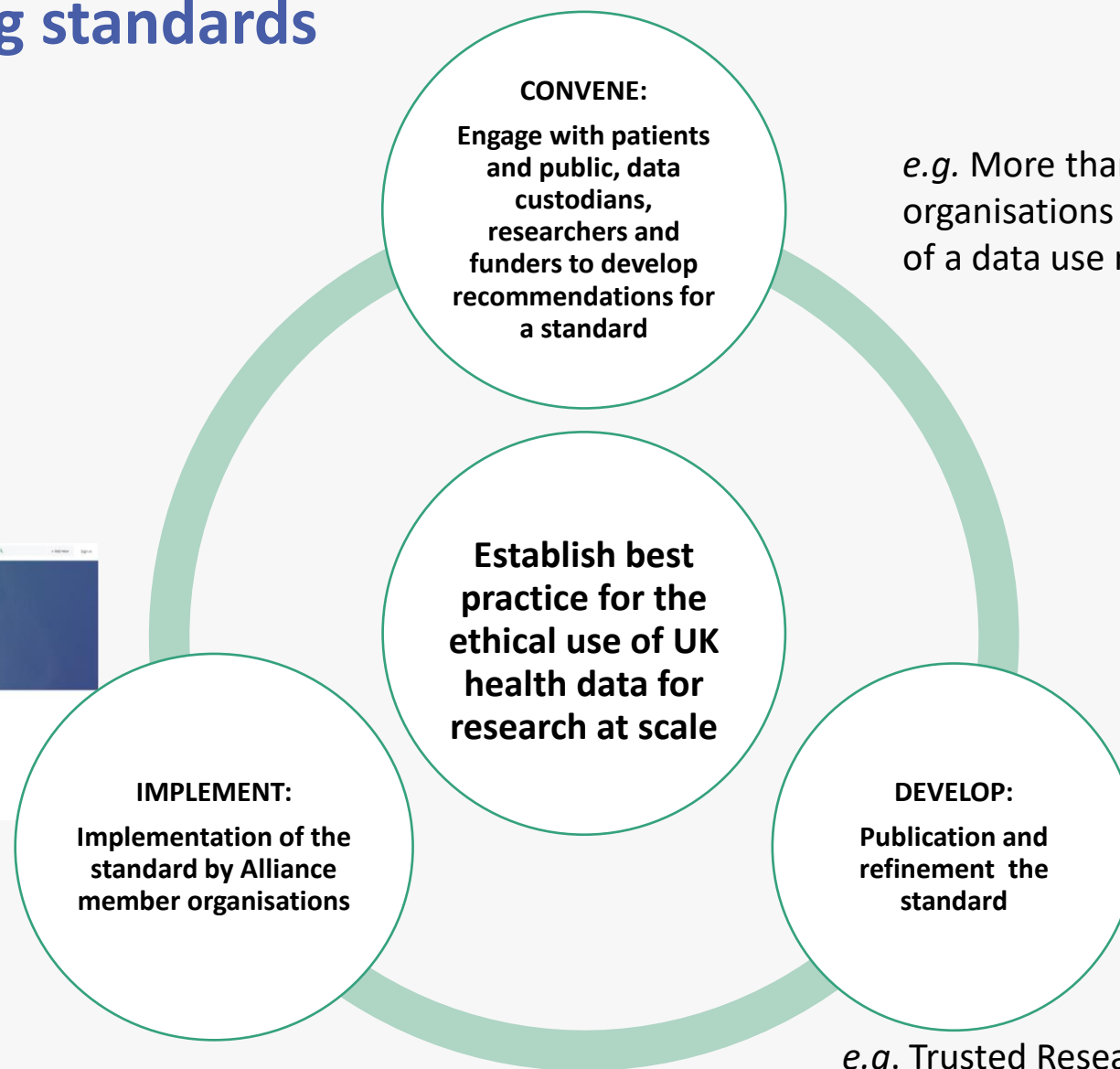
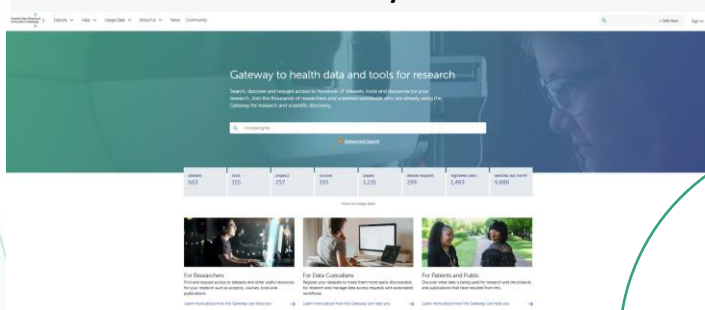
UK Health Data Research Alliance

The **UK Health Data Research Alliance** is an independent alliance of leading healthcare and research organisations united to establish best practice for the ethical use of UK health data for research at scale.



The Alliance approach to convening community, developing and implementing standards

Implementation via the **Innovation Gateway**, a portal for data discovery and access



CONVENE:
Engage with patients and public, data custodians, researchers and funders to develop recommendations for a standard

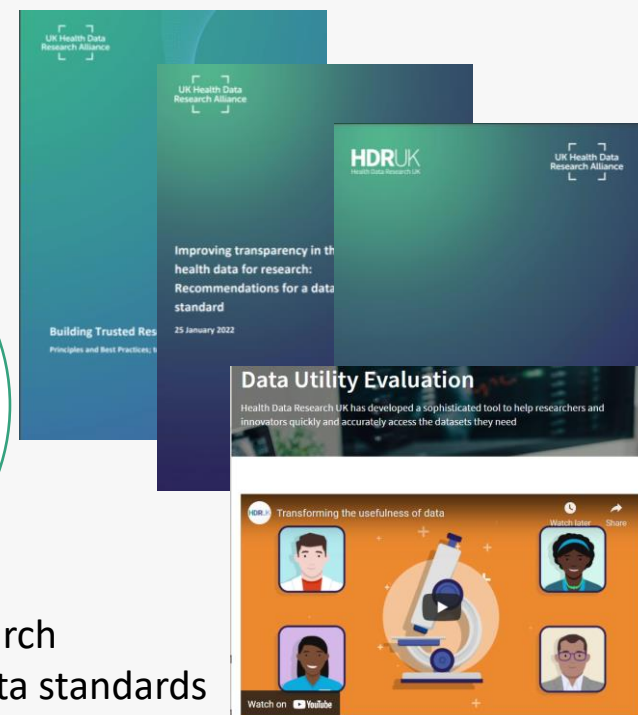
e.g. More than 100 people and 50 organisations contributed to development of a data use register standard

Establish best practice for the ethical use of UK health data for research at scale

IMPLEMENT:
Implementation of the standard by Alliance member organisations

DEVELOP:
Publication and refinement the standard

e.g. Trusted Research Environments, Data standards



Background



- A **data use register** is a list of approved projects or a public record of data an organisation has shared with other organisations and for what purpose.
- The challenge we face is that this information is not always made public. As well as, lack of consistency or standardisation when it comes to the content, functionality and purpose of these registers

2020/21 Applications approved by HSC-PBPP to 28th February 2021.

Application Reference	Applicant	Applicant's Organisation	Title of Study	Outcome	Level of Approval	Clocked time (days)
1920-0272	Diogo Marques	Public Health Scotland	SARS Co-V-2/COVID-19 enhanced surveillance	COVID19 Approved with recommendations	COVID19 rapid review panel	5
1920-0088	Dr Iain Atherton	Edinburgh Napier University	What is the health and social circumstances of military veterans in Scotland? A data linkage study	Approved with conditions	Tier 1 Panel Meeting	11
	Prof Jennifer L. ...	University of Oxford	Neonatal complications of coronavirus disease (COVID-19)	COVID19 Approved with recommendations	COVID19 rapid review panel	4
		Scottish National Blood Transfusion Service (SNBTS)	Convalescent Plasma collection and distribution for management of COVID 19	COVID19 Approved with recommendations	COVID19 rapid review panel	5
		Moorfields Eye Hospital NHS Foundation Trust	National Prospective Cohort Study and Surveillance of Sympathetic Ophthalmia in the United Kingdom in association with the British Ophthalmological Surveillance Unit (BOSU)	Approved	Tier 1 Review	45
		Liverpool School of Tropical Medicine	Holistic counselling and decision-making regarding mode of delivery for singleton breech babies in spontaneous preterm labour – building evidence from a large-scale Scottish retrospective birth cohort study	Approved	Tier 1 Review	22
			MEDICI (Mammographic Predictors of Cancer	Approved with		

Data Release Register

Data released from NHS Digital

01 February 2021 to 28 February 2021

Contents

Data Releases - a list of all datasets released under a Data Sharing Agreement by NHS Digital

Purpose Statements - purposes under which each dissemination was made

Further Explanation Of Terms - explanation of the Legal Basis and Common law duty of confidentiality

Amendments To Previous Registers - corrections or additions to previously published registers

Registry data requests

Lead researcher	Project details	Institution	Data provided	Publication
Jennifer Taylor-Cousar	Impact of Parenthood on Health Outcomes in Adults with CF	National Jewish Hospital, USA	Mar-21	
Annie Trumbull	Specific ethnicities or general "Caucasian, Asian, African, Hispanic... Our main interest is in Southeast Asian populations in the regisq5tries	Stanford University, California	Mar-21	
Ursula Peaple	NHS England would like to understand how many patients in England (or UK if easier) would be eligible for treatment if the FDA license definitions are used for kafrtio.Also if we could do the same for ivacafior and Symkevi	NHS England	Feb-21	
Katherine Holdsworth	Use and development of statistical mediation techniques to understand the survival gap between males and females with cystic fibrosis	The London School of Hygiene & Tropical Medicine	Jan-21	
	How many children on the UK CF registry have an unclear diagnosis of CF following a positive newborn			

cpdr.com/protocol-list

Title

The Impact of COVID-19 lockdown on the lives of People with Obesity (PwO): A UK primary care based study

Healthcare utilisation, symptoms, prescriptions and new disease in people with COVID-19 managed in the community or hospital

CORYLUS UK: A retrospective observational cohort study of the impact of COVID-19 on systemic lupus erythematosus patients in England using data from linked primary and secondary care databases

Risk of cardiovascular and related diseases in asthma patients and bronchodilator users in the UK

Prevalence, patient characteristics and treatment patterns of adult Atopic Dermatitis in UK primary care

Surgical interventions to treat severe pressure sores - The SIPS study

Exploring the role of electronic Frailty Index (eFI) using routine primary care electronic health care records data to predict hospitalization and mortality in older patients with type 2 diabetes

Glycaemic Control in Type 2 Diabetes Patients after Switching from Basal-Bolus Treatment to Biphasic Insulin Aspart 30/70: a Descriptive Study

Trend and mechanism of socioeconomic disparity in infant mortality

Area, maternal and child determinants of MMR uptake

Examining methodology to identify patterns of consulting in primary care for different groups of patients before a diagnosis of cancer: a matched

What do we want to achieve?

- By establishing a core set of standards on data use registers, we hope to
 - **increase transparency in the use of health data for research and innovation** – Alliance members also agree to transparency of governance and operations when the signing the Letter of Intent
 - demonstrate the **value and benefit of using health data** - National Data Guardian and Understanding Patient Data highlight that **‘transparency cannot be separated from public benefit’**
 - develop a **culture of openness** amongst data custodians
 - **generate better insight into data use** and data access
 - **build public trust** and advocacy for data use

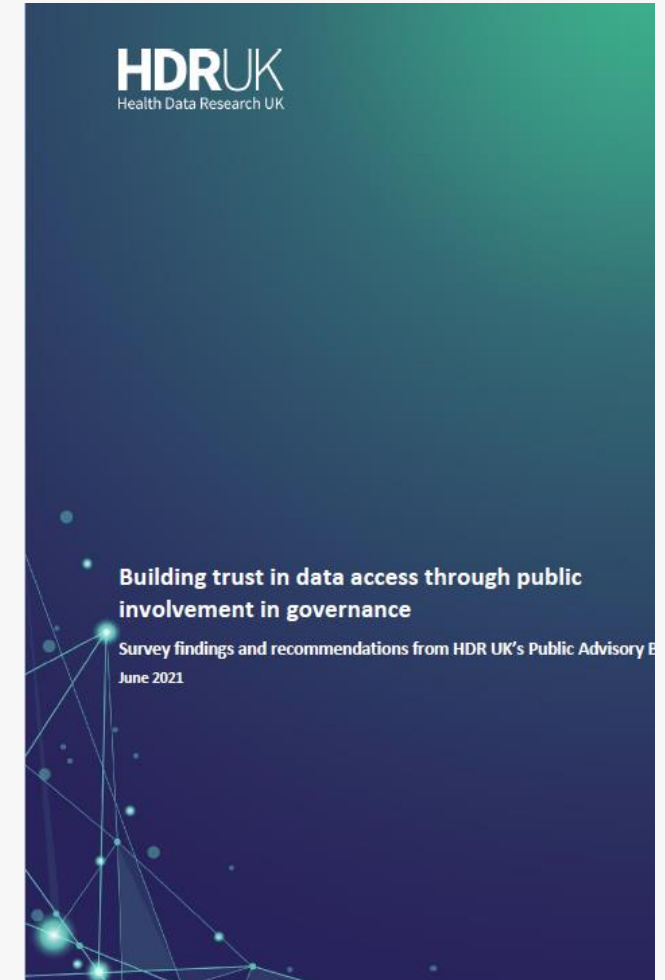
“Being clear how data is used a vital step to ensure the whole process is meaningful and trusted, in terms of outcomes, cost effectiveness and public trust.”

- Public contributor-

The public perspective

“We call on senior leaders within Alliance organisations to acknowledge the importance of patient/public involvement in data access processes and take a lead on this. Specifically to:

- ✓ Enable public involvement in all data access procedures, both researcher and custodian work.
- ✓ Standardise data access processes, as far as possible based on the Five Safes model.
- ✓ **Demonstrate transparency in data access and use through a publicly available register, in line with the principles and recommendations set out above. Purpose for data use is key.**
- ✓ Establish an Alliance forum to encourage shared learning across organisations, drawing on the views and experiences of patient/public members involved in existing approval processes. ”



What have we done so far?

Widespread community involvement and engagement:

- Collaborative approach with input from public and lay representatives, data custodians, researchers, policy makers and funders (more than 100 people and 50 orgs contributed to the standard)

Preprint analyses published in May 2021:

- Analysis conducted on 48 data custodians (reviewing content, format, update frequency and accessibility of data use registers)
- Key takeaway: nearly 50% of data custodians reviewed do not publish information about data use

Public consultation on green paper recommendations in July 2021

- Green Paper has been downloaded 1,263 times
- Recommendations were supported by 93% of respondents

Publication of White Paper on data use register standard in Jan 2022

- Recommendations presenting a minimum standard for data use registers

Development of a Gateway data use register underway

- To provide transparency of data uses approved for datasets published on the Innovation Gateway, a portal for data discovery and access



What have we recommended in the 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 and actively promote 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.

What is the added value of these recommendations?

Confidence, reliability, trust in the data/information accuracy and authenticity

- Alignment to the **Five Safes Framework***
- Data custodians can demonstrate that access is only granted to appropriately qualified individuals, in secure settings, and for purposes with a clear legal and ethical basis that serves the public interest.

Demonstrating impact of research: linking data use to research outputs

Recognised by many of our contributors as an ambitious target but essential step in demonstrating impact and value of data use

Requires a system wide effort involving researchers, data custodians, funders, and regulators.

Data use registers can help researchers and data custodians demonstrate trustworthy access to and use of data by being transparent about the purpose of research and the impact on public benefit

**<https://www2.uwe.ac.uk/faculties/bbs/Documents/1601.pdf>
Office for National Statistics*

Guest speakers

Angela Coulter

Chair of HDR UK Public Advisory Board



<https://www.hdruk.ac.uk/people/angela-coulter/>

Victoria Yorke-Edwards

Research Fellow in Trial Conduct Methodology, MRC Clinical Trials Unit at UCL



Twitter: [@VickiYE](https://twitter.com/VickiYE)

<https://www.mrcctu.ucl.ac.uk/>

Q&A



Related resources and upcoming events

Useful links:

- Read our White Paper on a data use register standard: <https://zenodo.org/record/5902743#.YgOzOurP1Pa>
- Read the preprint: Analysis of data use registers: <https://www.medrxiv.org/content/10.1101/2021.05.25.21257785v1.article-metrics>
- Access the Health Data Research Innovation Gateway: <https://www.healthdatagateway.org/>
- Learn more about our work on improving transparency in data use: <https://ukhealthdata.org/projects/improving-transparency-in-data-use/>

Hear more from us:

- Signup to our monthly Gateway Newsletter: <https://www.hdruk.ac.uk/access-to-health-data/health-data-research-innovation-gateway/>
- Follow HDR UK on Twitter: @HDR_UK https://twitter.com/HDR_UK
- Contact Ruth: ruth.milne@hdruk.ac.uk
- Next Data and Discovery Event: Thursday 14 April <https://www.eventbrite.co.uk/e/265211363327>

Data Access & Discovery

11:00 - 11:45

Thursday, 14 April 2022

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Innovation Gateway 

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Thank you

