

From: [REDACTED] On Behalf Of Cabinet Secretary for Health and Sport
Sent: 23 April 2021 09:41
To: Public Engagement Unit
Cc: Cabinet Secretary for Health and Sport
Subject: FW: Progress in UK health data research - April 2021

OR

From: Andrew Morris and Caroline Cake
Sent: 22 April 2021 16:22
To: Freeman J (Jeane), MSP
Subject: Progress in UK health data research - April 2021

Dear Jeane,

Health data research is providing enormous value to people across the UK, made possible by recent advances in data and infrastructure, including those set out in this letter. However, there continue to be significant challenges to overcome, including issues around data linkage and access, gaps in acute hospitalisation data flows and capacity of the system to manage the pace of change. To tackle these challenges and create a legacy from the pandemic response we seek your support to embed collaborative and trustworthy health data science across the NHS, academia, industry, charities and government.

Profound public benefit

The tremendous benefit of health data science through the pandemic is indisputable. HDR UK and our partners have provided [28 detailed reports](#) on health data science to SAGE, and a summary of the [research impacts](#) include:

- The NHS DigiTrials Health Data Research Hub and HDR UK led work with the [PRINCIPLE trial](#) to accelerate recruitment of participants within 24 hours of a positive SARS CoV-2 result in the community, which enabled the addition of the [budesonide treatment](#) arm. This has since become the first widely available, inexpensive drug found to shorten recovery times in the community.
- The world's first real world data on single dose vaccine effectiveness: The BREATHE Health Data Research Hub and the EAVE II project produced a national (5.6m people) data infrastructure which enabled the first whole

country estimates of Astra-Zeneca and Pfizer-BioNTech vaccine effectiveness by vaccine type in different age groups. This was announced by the Prime Minister in February 2021 and influenced national regulatory strategy in the UK, Canada, Denmark, France and Germany (Lancet 2021).

Advances in data and infrastructure

The UK's largest linked health data research asset: the national data infrastructure, enabled by the [Data and Connectivity National Core Study](#) is supporting 885 researchers, working on 323 research projects across five national trusted research environments. As part of this and by working in partnership with NHS Digital and the BHF Data Science Centre, we have created a [new linked health data resource](#) covering 54.4 million people –over 96% of the English population (BMJ 2021). This is led by the CVD-COVID-UK consortium and is available to UK researchers to collaborate in NHS Digital's new secure research environment. It is the largest research resource in the UK and is being extended to 67 million people through federated working. It is already being actively used by over 50 researchers, with all code fully open and accessible via Github.

UK Health Data Research Hubs: In their first 18 months, the Hubs have made 157 datasets discoverable on the [Health Data Research Innovation Gateway](#), have delivered 300 multi-sector projects, with over 20,000 meaningful patient and public interactions, and 2,300 training activities. Our latest report [Improving UK Health Data: Impacts from the Health Data Research Hubs](#) shows how the Hubs have informed UK policy decisions on the effectiveness of COVID-19 vaccines, created tools to improve clinical decision-making in the management of patients with vascular disease, and supported research in cancer, heart disease and hospital care pathways by linking routinely-collected data. We are excited to announce that two new Hubs will join our network next month to support data research in pain and mental health, funded by the MRC.

HDR UK Data Utility Framework: This [new framework](#) shows the usefulness of data for research, it has over 100 datasets evaluated against it and is now integrated into the Gateway. Other organisations in the UK, such as NICE and NHSX, are seeking to

adopt the framework, and there is considerable interest internationally from colleagues in the USA, Singapore and Israel. Key papers from the community are in development and consultation, including the data standards green paper and Trusted Research Environment white paper, which will be published in May.

Gateway: We achieved a major step forward in achieving the federated data ecosystem vision, with the launch of [cohort discovery research](#) within the [Gateway](#). This enables, for the first time, researchers to search across datasets to find cohorts of patients with specific, defined characteristics; opening up a huge potential for increased discovery, while maintaining safety and security, helping researchers get to impact faster.

This month we reached the milestone of 1,000 researchers registered on the Gateway. With over 11,500 searches each month from around the world and 640 datasets now discoverable, the Gateway is becoming the “go to” place for researchers to discover and request access to UK health datasets with the added benefit of giving much-needed transparency to the UK public on what data is available, how they are used and why.

As highlighted by the [National Data Guardian](#) and partners, the public expect more transparency over how health and care data are used and how decisions are made, at a systemic level. Public and patient involvement and engagement, open science and open code are at the heart of HDR UK’s developments, including:

- Our consultation with the public on [vaccine research prioritisation](#) elicited over 800 responses that demonstrated vaccine safety was the primary public concern and has been used to inform the work of the National Core Studies.
- Over [150 resources available](#) on Github. We are accelerating reproducible science by bringing together repositories of open standards, data and source code, tackling some of the most important challenges in wrangling multi-model data and generating replicable insights.

Next generation of health data scientists

Our [Black internship programme](#), in partnership with the UK Health Data Research Alliance, has 54 interns (60% women) this summer. Not only will this bring diverse

perspectives and skills to our health and science community, it provides an opportunity for young Black people to flourish in STEM careers.

Our ambition to train over 10,000 health data scientists is moving forward at pace.

Later in the Spring, we will be unveiling the next stage of this strategy with the launch of an open, virtual learning environment with hundreds of courses to build skills in data science.

We have events scheduled throughout 2021 to engage with the wider health data research community, both in the UK and internationally. These include our joint event with the Government Office for Science on 24 June the [National Core Studies for COVID-19 Symposium](#) and our annual [Scientific Conference – Data Insights in a Pandemic](#) - on 23 June. You are warmly welcomed to both events.

We greatly value your support in these exciting developments and look forward to our ongoing collaboration and partnership.

Director, HDR UK Chief Executive Officer, HDR UK

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HDR UK Stakeholder

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