



Data & Connectivity National Core Study

Sprint 1: 5th October – 4th November, 2020

OUTCOMES

What were our aims for Sprint 1?

- 1. To make core datasets relevant to COVID response available to approved researchers
 - Pillar 1 COVID antigen testing data
 - Pillar 2 COVID antigen testing data
 - Primary care data
 - Secondary care data
 - Mortality
 - C-19 Infection Survey, CO-CIN (stretch goal)
- 2. Data to be made available in **secure cloud-based national Trusted Research Environment (TREs)** in England, Northern Ireland, Scotland, Wales
- 3. Evidence to show that both the technical and governance requirements for linkage exist
- 4. All above datasets to be **discoverable to researchers through a single "shop window"**, the Health Data Research Innovation Gateway

What has been achieved in Sprint 1?

Supporting National Core Studies

- 1. National Core Study use cases supported
 - a. Clinical Trials Therapeutics NCS: The PRINCIPLE Clinical Trial, led by Chris Butler, has received
 dedicated support to enable daily access to positive C-19 test results within 24 hours to
 increase recruitment.

This support has included

- daily problem solving and management scrums
- in-depth engagement with the ICO
- a public survey with over 90 responses
- engagement with multiple data custodians
- review by NHS Digital's IGARD
- NHS Digital's Trial team are now addressing the remaining actions to support data flow

Provides confidence in concept for future trials that require incident COVID cases





2. Earning Trust - Public, patient and practitioner involvement and engagement (PPPIE)

- a. A consultation on the Data and Connectivity aims, objects and delivery approach has been completed across seven national and UK-wide patient and public networks and collected 168 responses. This feedback has been used to inform ongoing programme development and identify areas for more detailed follow-up.
- b. **Three public contributors** have been involved in regular sprint planning, delivery group meetings and planning and provided oversight of PPPIE activities.
- c. Consultation with **92 people** to inform decisions on methods and process for clinical trial recruitment (see use cases above).

Making Data Discoverable

- 3. Data has been made available during the sprint:
 - a. Linked **Census/mortality data**, and **C-19 infection survey data**, available in the Office of National Statistics (ONS) Secure Research Service.
 - b. Test and trace data from DHSC available on internal ONS systems.
 - c. Remote access to NHS Digital secure data environment, providing access to mortality and Hospital Episode Statistics (HES) data alongside NHS Digital's General Practice data for 55M residents of England accessible for ONS internal users and available to request access via the Gateway..
 - d. Approval for linkage of primary and secondary health data for England to CO-CIN (ISARIC 4C) has been established with data flows from NHS Digital expected to commence by early November.
 - e. Continued provision of **extensive national linked data assets for Wales and Scotland** through respective delivery partners.
- 4. New linkages that have been created during the sprint
 - a. ONS owned Census 2011 for England and Wales linked to:
 - ONS owned mortality data for England and Wales, 2011 to most recent data available
 - HES data for England from NHS Digital, 2017/18 to most recent data available
- 5. Enhancements to meta-data, making the data discoverable and useful for researchers
 - a. **32 National Core Study priority datasets are now listed on the Gateway** with detailed technical metadata for 22
 - b. Datasets collected by the **ONS** and **Northern Ireland Honest Broker Service** are listed on the Gateway, making administrative data and data from across the four nations discoverable to researchers in one place for the first time.





Enabling Data Access

- 6. **Progress with streamlined access management** across datasets
 - a. A **Data Access Request form** aligned across all TRE delivery partners has been developed and undergone User Acceptance Testing by all delivery partners.
 - b. Current work is focused on confirming requirements to **integrate the form** into the existing systems used by TRE delivery partners to allow live deployment.
 - c. **Northern Ireland** have completed a pilot of the SAIL remote access TRE platform and are now in a period of stakeholder consultation to enable next steps.

Establishing the Data and Connectivity National Core Study

7. Rapid turnaround of contract arrangements

- a. Five delivery partners have joined the study and participated in Sprint 1. Each delivery partner offers a TRE for research.
- b. Each delivery partner has received a Letter of Intent and draft contracts setting out requirements, ways of working and funding.
- c. Award letter received from UKRI and assurance through GDS commenced.

8. Building and connecting a delivery community

- a. Established a regular schedule of weekly delivery group meetings.
- b. >40 attendees from across study delivery partners, (ONS, Health & Social Care Northern Ireland, NHS Digital, University of Swansea, SAIL Databank, Public Health Scotland, HDR UK / PA Consulting Health Data Gateway); National Core Study teams and wider system stakeholders (HDR UK Public Advisory Board, ADR UK, JBC, ICO, CO-CONNECT, BHF Cardiovascular Data Science Centre, Genomics England, COG UK, OpenSAFELY, Wellcome Trust).
- c. Meeting materials circulated to **75 attendees and broader parties** to ensure connectivity and awareness.
- d. **Regular interaction** with all NCS teams through delivery group meetings and bilateral touchpoints, to align Data and Connectivity study with needs of all NCS.

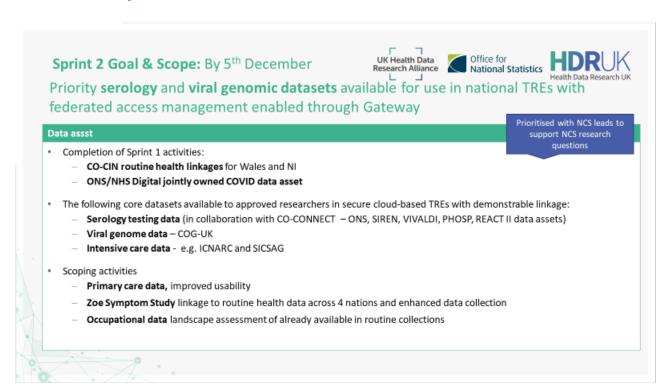




What we have learnt for next Sprints and key risks to delivery?

- 1. We can achieve a lot in 4 weeks by working together across a national network of delivery partners.
- 2. To realise the benefits of the positive progress with the data assets, we **now need to have researchers set up** in the Trusted Research Environments with **research questions** that use this data.
- 3. The challenge is to communicate the available data asset and **mobilise the research community to respond.**
- 4. A very clear overarching NCS narrative that articulates the public outcomes and benefits that the NCS are collectively working to deliver by 31 March 2021 is essential. This will help to guide prioritisation of linkages, data flows and use cases.
- 5. **Legal barriers to data sharing**, and the timeframe required to resolve these, risks our ability to achieve sprint deliverables at pace. We have made important progress on "proof of concept" activities, enabling data sharing from NHS Digital to ISARIC for linkage to the unconsented CO-CIN cohort and supporting recruitment to the PRINCIPLE clinical trial by recontact individual post-COVID testing, however IG and legislative barriers will continue to be monitored and escalated to the Oversight Committee where necessary.

Outline for Sprint 2

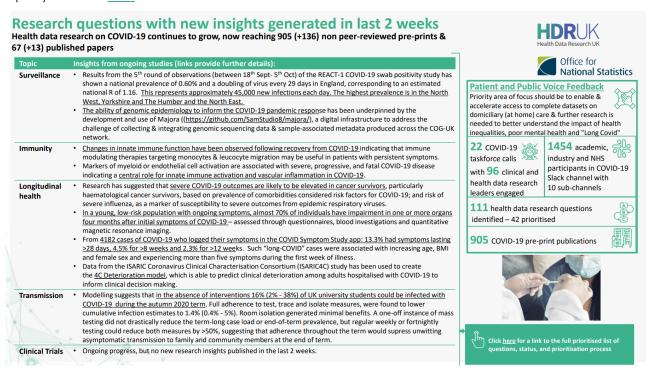






Annex: Current Status of Health Data Research (SAGE Report 27th October 2020)

Openly available here



COVID-19 dataset availability and status of projects using the data - 27 October 2020

Recent BMJ Open publication provides excellent explanation of approach taken through SAIL to support Welsh COVID response. Progress on dataset availability increasingly being captured and shared via Innovation Gateway, and continued shift to active project

- 1. The protocol of the data linkage work undertaken in Wales (through SAIL) to support COVID-19 response has been published in BMJ Open 2. Further improvements
- in dataset discoverability including first ONS and HSC
- 3. Eight new projects now active with small reduction 'in development'

4. Northern Ireland Honest **Broker Service physical** Data Safe Haven has had to be closed as part of COVID-19 infection control measures.

Core COVID-19 Datasets available for linkage	Office for National Statistics Secure Research Service	England (NHS Digital Data Processing Service)	Scotland (National Data Safe Haven)	<u>Wales</u> (<u>SAIL</u> Databank)	Northern Ireland (Honest Broker Service)		
Primary Care	To be onboarded						
Pillar 1 COVID-19 Testing Data	Being used in SRS						
Pillar 2 Testing data (UK Gov)	Being used in SRS	Introduction Ongoing			Missing results prior to 26 Apr		
Pillar 3 & 4 Testing data	Infection survey	Pillar 3 - Introduction Ongoing		Pillar 3 available	Data flow in place, no tests yet		
Community Prescribing							
Critical Care (CHESS, ICNARC, SICSAG)		Available as an extract			N/C - Under review		
Personal Demographic Service							
Secondary Care	HES	SUS only - not HES					
Death registry							
Census 2011							
Covid Opinions Survey					•		
Business Impact of Covid Survey							
# of COVID 10 Projects by TRE	Office for National Englan	d (NUC Digital		Northern			

# of COVID-19 Projects by TRE stage (change from previous report)	Office for National Statistics Secure Research Service	England (NHS Digital Data Processing Service)	Scotland (National Data Safe Haven)	Wales (SAIL Databank)	Northern Ireland (Honest Broker Service)	Total
In development	to be added	30 (-4)	34 (-)	87 (+2)	6 (-)	157 (-2)
- a/w researcher	for	18 (-12)	Not available	61 (+3)	6 (-)	N/A
- a/w data custodian	future	12 (+8)	Not available	26 (-1)	0 (-)	N/A
Submitted for IG approval	reports	6 (+2)	5 (-)	0 (-)	0 (-)	11 (+2)
Approved but not yet active		2 (-1)	0 (-)	0 (-)	2 (-)	4 (-1)
Active research taking place		60 (+4)	46 (+4)	77 (-)	0 (-)	183 (+8)
Active Number of Researchers	to	be	added	for	future	reports
Average time from application to active research	to	be	added	for	future	reports

Office for National Statistics **HDR**U

- Data flows specified but not yet agreed
 - Data flows agreed but not yet available for linkage

PRINCIPLE CO-CIN (ISARIC 4C) PHOSP-COVID COVID-19 symptom study GENOMICC

England

NOTES

N/C – No change

TRE - Trusted Research Environment
IG - Information Governance
DPN – Data Provision Notice

CHESS - COVID-19 Hospitalisations in England Surveillance System
SICSAG - Scottish Intensive Care Audit
Steering Group
HES – Hospital Episode Statistics
SUS – Secondary Uses Service