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23 March 2021 - Fortnightly update for SAGE, National Core Studies & UKRI/DHSC

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Health data research community highlights this period



taskforce calls
with **183** clinical
and health data
research leaders
engaged

1,193 COVID-19 pre-print publications

779 academic, industry and NHS participants in COVID-19 Slack channel with 10 sub-channels

111 health data research questions identified



Patient and Public Voice Feedback:

Following a year since the introduction of the first lockdown, whilst significant advances have been made, we must not lose momentum especially given the number of unanswered research questions that remain, particularly around:

- Vaccines effectiveness in different populations, effect on transmission rates and factors that influence vaccine uptake.
- COVID-19 has shown to affect referral, diagnosis and treatment, particularly in cardiovascular disease and cancer to what extent does this affect other health conditions too and are particular groups and populations are affected more than others?
- After being in a range of restrictions for a year, whilst we start to move out of it on a long-term basis, this change could cause mental health problems and further research is needed to understand the true extent to better prepare services for the coming months.
 Click here to read more feedback





Click <u>here</u> for a list of regularly updated COVID-19 research questions from the health data community

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Research topics with new insights generated in last 2 weeks



Health data research outputs on COVID-19 continues to grow, now reaching 1,193 (+16) non-peer-reviewed pre-prints & 125 (+5) published papers.

Topic	Insights from ongoing studies (links provide further details):
Surveillance & Epidemiology	 Data from >2000 participants of the Genetics Of Mortality In Critical Care (GenOMICC) and the Coronavirus Clinical Characterisation Consortium (ISARIC 4C) studies indicated that a common variant of a transmembrane protein occurring in ~25% of the population is associated with a reduced likelihood of developing severe COVID-19 — suggesting that this could be a promising drug target in the treatment of COVID-19. Using patient-level data from more than 2000 patients from the CAPACITY-COVID project, researchers found the incidence of acute ischemic stroke in patients hospitalised with COVID-19 was ~2%, and patients with COVID-19 and stroke were twice as likely to have a blood clot in the lungs — indicating an urgent need for further research. Using primary care records, latest research on drugs commonly used to treat high blood pressure, provides reassurance that angiotensin-converting enzyme I (ACE) inhibitors are safe to use during the pandemic-whereas angiotensin II receptor blockers (ARBs) were associated with a small increase in risk of COVID-19. Research combining surveillance data from the UK Zoe COVID Symptom Study and the UK UMD-Facebook COVID-19 Symptom Survey found 25% of individuals with symptoms do not get tested; improved public health messaging around symptoms and test sites may address this gap.
Immunity & Vaccines	 New findings from Public Health England's routine testing of NHS Blood and Transplant blood donations show that 70-84 year olds are mounting a good immune response to a single vaccine dose; 75.8% of older adults had COVID-19 antibodies and only 5.6% were from natural infection. Analyses of linked patient-level data for >17 million people in England indicate that people with learning disabilities are more likely to be hospitalised and die from COVID-19; and the risk is higher for people with Down Syndrome and Cerebral Palsy. These data highlight the importance of updating learning disability registers and reinforce the UK's recent policy change to prioritise all people with learning disabilities for vaccination. A longitudinal study of >13,000 vaccinated healthcare workers shows 2 doses of vaccine provide levels of protection similar to natural immunity, including against the UK variant; whilst a study linking multiple health and occupational records of 144,525 NHS Scotland healthcare workers and 194,362 of their household members found that vaccination of healthcare workers substantially reduced COVID-19 cases in household contacts – suggesting that vaccination reduces transmission.
Longitudinal health & wellbeing	• Researchers using NHS England's Monthly Diagnostic Waiting Times and Activity data detected a marked reduction in endoscopic procedures such as colonoscopies during the pandemic. Models suggest that even with mitigation measures in place it could take more than a year to clear this backlog.
Transmission & Environment	 Analyses of antibody tests linked to national SARS-CoV-2 testing programme data from >2000 staff and residents across 100 long term care facilities in England as part of the VIVALDI study, suggest that antibodies provide high levels of protection against reinfection. Researchers monitoring >180,000 hospital discharge events in the first wave using individually linked health records from the SAIL Databank found that hospital discharge to care homes played a minor role in COVID-19 transmission. Estimates suggest ~1.8% of patients discharged from hospital may have been infected. Analyses of NHS Test and Trace data alongside genomic data from the COVID-19 Genomics UK (COG-UK) consortium revealed that travel restrictions are effective in reducing onwards transmission of COVID-19. The use of genomics in monitoring travel-related cases is important as the government considers reopening the borders for holidays.
Clinical Trials	• The most recent results from the Randomised Evaluation of COVid-19 therapy (RECOVERY) trial involving 11,558 patients indicate that convalescent plasma does not improve survival in patients hospitalized with COVID-19. These results were consistent across subgroups of patients, including people of different ages and ethnicities.

Data & Connectivity National Core Study: COVID-19 dataset availability – 23 March

Vaccine data now available for Wales and England and will soon be available for Scotland. Viral genome data also soon to be available for Scotland.								
Core COVID-19 Datasets available for linkage	Office for National Statistics Secure Research Service	England (NHS Digital Data Processing Service)	<u>Scotland</u> (<u>National</u> <u>Data Safe Haven)</u>	<u>Wales</u> (SAIL Databank)	Northern Ireland (Honest Broker Service)			
C-19 vaccine data collection	To be made available shortly. Accepting applications now	Vaccines Events & Adverse Reactions	Available in TRE, available via Gateway shortly.	COVID Vaccination Dataset	Vaccine Management System Operational – Data to be transferred to Data warehouse			
COG-UK viral genome	Awaiting data flow from Public Health England	Awaiting data flow from Public Health England	Subset linked to CO-CIN data Remaining data being transferred, available shortly.	Awaiting data flow from Public Health Wales	Governance agreed, automation of data flow to PHA in progress			
Pillar 1 COVID-19 Testing Data	To be linked to Test and Trace data	COVID-19 Second Generation Surveillance System (SGSS)	Electronic Communication of Surveillance in Scotland (ECOSS)	COVID-19 Test Results	COVID antigen testing - Pillar 1			
Pillar 2 Testing data (UK Gov)	To be linked to Test and Trace data	COVID-19 UK Non-hospital Antigen Testing Results (Pillar 2)	Electronic Communication of Surveillance in Scotland (ECOSS)	COVID-19 Test Results	Missing results prior to 26 Apr – Data quality issue			
Primary Care	GPES linked to census, mortality and hospital data for internal access only	GPES extract – 98% practice coverage, large subset of codes (4bn items) Community Prescribing	Albasoft ESCRO GP Extraction* Prescribing Information System	80%+ coverage of full longitudinal record, with 100% coverage for COVID codes	Enhanced Prescribing Database as proxy			
Secondary Care	Census-Mortality-HES linked data asset now available (ONS/NHSD)	100% coverage – HES. SUS via DARS extract only, available in TRE soon	100% coverage	100% coverage	Admissions & Discharges			
Personal Demographic Service	Internal use only	100% coverage (via DARS extract only)	100% coverage	100% coverage				
Death registry	Provisional Monthly Extract & Linked Census and death occurrence	100% coverage Civil Registrations - Deaths	100% coverage	100% coverage				
C-19 Infection Survey (CIS)	Linked to Test and Trace data	N/A	Awaiting DEA accreditation	Awaiting decision on data access	Awaiting decision on data access			
COVID-19 Clinical Information Network (CO-CIN)	Being linked to 2011 census	Data for English CO-CIN participants available in Scottish Nation Data Safe Haven	Limited metadata. Includes English linked data, and COGUK/CO-CIN data asset	Awaiting decision on data access	Discussions ongoing to collect data in NI			
Census 2011	Household structure	N/A			N/A			
Covid Opinions Survey		N/A	N/A	Awaiting decision on data access	N/A			
Business Impact of Covid Survey	c. 5,000 businesses	N/A	N/A	Awaiting decision on data access	N/A			
Labour Force Survey	40,000 households, 100,000 individuals	N/A	N/A	Awaiting decision on data access	N/A			
Intensive Care data	HES Critical Care, ICNARC	HES Critical Care Reviewing IG to share ICNARC.	SICSAG (updated weekly)	ICNARC COVID weekly, ICNARC quarterly all admissions and critical care routine data (CCDS) monthly	Critical Care Minimum dataset to be acquired			
Pillar 3 Testing data (NHS labs)	Captured within Test and Trace data	N/A		COVID-19 Test Results				
Pillar 3 Testing data (iELISA)	N/A	COVID-19 UK Non-hospital Antibody Testing Results (Pillar 3)			Data to be validated			
Other Pillar 4 Testing data	VIVALDI, REACT II							
				LIK wide (unlinked)				

ZOE Symptom Study App Data

Finalising data sharing agreement





KEY

- 1. Custodian engagement
- 2. Dataset available in secure Trusted Research Environment



UK wide (unlinked)

Wales (linked)

4. Datasets available for COVID-19 research via **Gateway**

Further information about Data & Connectivity can be found **here**. Including the recently published **Sprint 5 report.**

Linked census, mortality and hospital episode statistics now available as a joint data asset between ONS and **NHSD**

Status of COVID-19 projects using the data - 23 March 2021

6 new research projects now active, taking the total number of active research projects to 310. SAIL have closed 75 project enquiries which did not progress. 20 data access requests covering 83 data assets now submitted via the Gateway for the 12 rapid funded projects. 4 of 12 project requests approved so far.

# of COVID-19 Projects by 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	6 (-7)	38 (-)	36 (-2)	20 (-75)	3 (-1)	103 (-85)
Submitted for Information Governance approval	0 (-5)	12 (+2)	7 (+1)	0 (-)	1 (+1)	20 (-1)
Approved but not yet active	6 (+2)	4 (+3)	8 (-1)	2 (-1)	2 (+2)	22 (+5)
Active research taking place	16 (-)	97 (+2)	71 (+2)	125 (+2)	1 (-)	310 (+6)
Completed projects	Coming soon	Coming soon	Coming soon	Coming soon	Coming soon	
Active Number of Researchers	273 (+94)	52 (-)	200 (+6)	249 (+25)	1	774 (+84)
Average time from application to active research	90 days	Not yet available	9 days	3 days	Not yet available	

Participation in key UK wide studies:

- PRINCIPLE: 4,613 participants (+2% in last 2 weeks, with continuing data flow of Pillar 2 COVID +ve test results to support recruitment)
- <u>RECOVERY</u>: 39,326 participants across 181 active sites (+2% in last 2 weeks, and +1 active site)
- CO-CIN (ISARIC 4C)
 - 195,253 Tier 0 (case report) (+2% in last 2 weeks)
 - 646 Tier 1 (single sample)
 - 1,659 Tier 2 (serial sampling)
- GENOMICC: 11,940 participants (+3% in last 2 weeks) across 212 ICUs with a total of 5091 intensive care beds
- COVID-19 ZOE symptom study: 4,633,105
- COG-UK: 359,845 viral genomes sequenced (+8% in last 2 weeks)

<u>Data & Connectivity National Core Study projects</u> now underway. Examples include:

- Can phenotypes developed from enhanced remote primary care assessment of COVID-19 be used to identify a cohort of community cases, and enable comparison of recovered and long COVID led by Professor Greenhalgh, University of Oxford
- How is COVID-19 impacting women and men's working lives in the UK? led by Professor Tracey Warren, University of Nottingham
- Uptake and comparative safety of new COVID-19 vaccines by age, sex, region, ethnicity, comorbidities, medication, deprivation, risk level and evidence of prior COVID infection led by Professor Hippisley-Cox, University of Oxford





Data Access Registers

For more information on the active projects:

- ONS Secure Research
 Service: List of
 accredited researchers
 and research projects
 under the Research
 Strand of the Digital
 Economy Act)
- NHS Digital: Register of approved data releases (includes all access)
- <u>Scotland:</u> Public Benefit and Privacy Panel approvals
- SAIL Databank: COVID-19 projects listed on gateway
- NI Honest Broker
 Service: Projects
 currently being carried out.