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26 January 2021 - Fortnightly update for SAGE, National Core Studies & UKRI/DHSC

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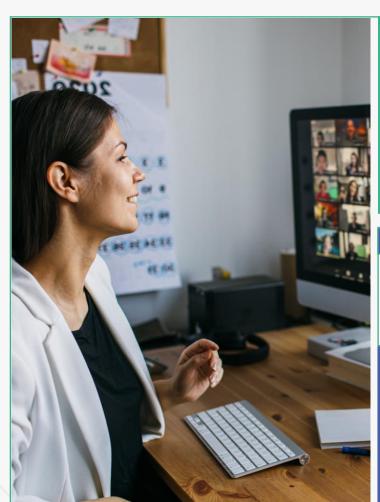
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Health data research community highlights this period*





taskforce calls
with 183 clinical
and health data
research leaders
engaged

1,163 COVID-19 pre-print publications

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

111 health data research questions identified



This Week's Patient and Public Voice Feedback:

The access, use and analysis of data from the vaccine programme roll-out continues to be of great public interest and concern and needs to be a major priority area of work. Meaningful patient and public involvement in this area of research needs to be embedded to build public trust and ensure research questions of importance to the public are addressed to help build and sustain vaccine uptake.

Click here and to read more feedback



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

*Following on from the establishment of the National Core Studies Programme we will be tracking the SAGE-endorsed recommendations from November 10, 2020 through this report going forward.

Research topics with new insights generated in last 2 weeks

others where slow recruitment is a barrier to trial delivery.

HDRUK Health Data Research UK

Health data research on COVID-19 continues to grow, now reaching 1163 (+10) non peer-reviewed pre-prints & Office National Off



Topic	Insights from ongoing studies (links provide further details):
Surveillance & Epidemiology	 Early serological data from over 12,000 healthcare workers as part of Public Health England's SIREN (SARS-CoV-2 Immunity & Reinfection Evaluation) study, indicate that antibodies from past COVID-19 provide some immunity lasting for at least 5 months though a small number of people with antibodies may still carry and transmit the virus. A retrospective cohort study leveraging data from 114 hospital trusts in England has found that increased bed occupancy is associated with mortality in Intensive Care Unit (ICU) patients. This work highlights the need to keep ICU capacity low by controlling COVID-19 incidence and prevalence. Using hospital electronic health records in UK, Norway & China, researchers found the National Early Warning Score system, currently used by most UK NHS Trusts to predict severe COVID-19 outcomes in patients, is moderately successful in the short term (3 days), but only poor-to-moderate success in the medium-term (14 days). The latest analyses from the community survey, REal-time Assessment of Community Transmission study-1 (REACT-1), indicate an increased prevalence of SARS-CoV-2 associated with large household size, living in a deprived neighbourhood, and Black and Asian ethnicity. Of note, keyworkers (including health and social care workers) were more likely to test positive for SARS-CoV-2 compared to other workers.
Immunity & Vaccines	 Analyses using an <u>openly accessible tool integrating SARS-CoV-2 genome sequence, immunological, and mutation data</u> indicate that transmembrane proteins (Orf3a) may be a suitable target for diagnostic tests. This online tool is likely to prove useful in monitoring for mutation as vaccination programmes introduce new selection pressures on the virus. Initial data showing a <u>small drop in effectiveness of the Pfizer BioNTech vaccine (BNT162b2) against mutated forms of SARS-CoV-2 is limited to only 23 participants (and <u>similar small samples from Moderna)</u> - reinforcing the need for large scale, systematic data collection as vaccine programmes are rolled-out across the UK and globally.</u>
Longitudinal health & wellbeing	 Analysis of primary care data on the OpenSAFELY platform, suggests <u>adaptive changes in primary care during the UK's first COVID-19 wave</u>: low priority tests decreased, such as those for cholesterol, whilst some high priority tests remained stable. Ongoing monitoring of these data is essential to support continuity of high priority services. Using population-based datasets spanning England, researchers have shown a <u>sustained reduction in the number of people referred, diagnosed, and treated for colorectal cancer with 3,500 fewer patients beginning treatment between April and October 2020</u>. These findings add to the body of evidence on the detrimental effect of the pandemic on cancer detection and management and the growing backlog of undetected cancers within the NHS. An observational retrospective matched cohort study involving using care records of nearly 50,000 patients in England has revealed that <u>individuals discharged from hospital following acute COVID-19 face increased rates of mortality, readmission and multi-organ dysfunction</u>.
Transmission & Environment	• New estimates from a random sample including 185,342 UK households show that the new UK SARS-CoV-2 variant leads to higher infection rates but is not adapted to any particular age group, and likely less transmissible than previous estimates.
Clinical Trials	• In response to the current urgency to alleviate slow recruitment to the PRINCIPLE trial (Platform Randomised trial of INterventions against COVID-19 In older peoPLE), a method using near-real time NHS Test and Trace data to recruit participants complemented by unique access to the Summary Care Records (SCRs) to ensure safe prescribing, has been developed and implemented as part of this key national therapeutic trial. The approach, which increased recruitment, should be considered by

Data & Connectivity National Core Study: COVID-19 dataset availability – 26 January 2021

ONS/NHS Digital joint health data asset launching imminently, significant work to understand and establish C-19 vaccine data flows.

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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)	
Data flow established – agreeing process for providing access	Consulting on joint controllership		Expected this week		
	Finalising governance	Awaiting IG sign off	Governance agreed, to be linked shortly	Governance agreed, to be linked shortly	
				Missing results prior to 26 Apr – Data quality issue	
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	
HES – available for internal access only 100% coverage	100% coverage - HES SUS via DARS extract only	100% coverage	100% coverage		
100% coverage	100% coverage (via extract only)	100% coverage	100% coverage		
Provisional Monthly Extract & Linked Census and death occurrence	100% coverage	100% coverage	100% coverage		
	N/A		Awaiting decision on data access		
Being linked to 2011 census	English CO-CIN data available in Scottish Nation Data Safe Haven	Limited metadata	Awaiting decision on data access		
Household structure				N/A	
	N/A	N/A	Awaiting decision on data access	N/A	
c. 5,000 businesses	N/A	N/A	Awaiting decision on data access	N/A	
40,000 households, 100,000 individuals	N/A	N/A	Awaiting decision on data access	N/A	
HES Critical Care	ICNARC – internal use only. HES critical care available via DARs	SICSAG (updated weekly)	ICNARC COVID weekly, ICNARC quarterly all admissions and critical care routine data (CCDS) monthly	3 datasets being explored	
Available in CIS data New!	Internal use only				
Available in CIS data New!				Data to be validated	
VIVALDI, REACT II					
			UK wide (unlinked) Wales (linked)		
	Office for National Statistics Secure Research Service Data flow established – agreeing process for providing access GPES linked to census, mortality and hospital data for internal access only HES – available for internal access only 100% coverage Provisional Monthly Extract & Linked Census and death occurrence Being linked to 2011 census Household structure c. 5,000 businesses 40,000 households, 100,000 individuals HES Critical Care Available in CIS data New! Available in CIS data New!	Office for National Statistics Secure Research Service Data flow established – agreeing process for providing access Finalising governance GPES linked to census, mortality and hospital data for internal access only HES – available for internal access only 100% coverage 100% coverage 100% coverage (via extract only) Provisional Monthly Extract & Linked Census and death occurrence N/A Being linked to 2011 census Household structure N/A c. 5,000 businesses N/A 40,000 households, 100,000 individuals HES Critical Care Available in CIS data New! Available in CIS data New! Internal use only New!	Office for National Statistics Secure Research Service Data flow established – agreeing process for providing access Finalising governance Consulting on joint controllership Finalising governance Awaiting IG sign off Awaiting IG sign off Finalising governance Awaiting IG sign off Awaiting IG sign off Awaiting IG sign off Awaiting IG sign off Finalising governance Awaiting IG sign off Awaiting IG sign off Awaiting IG sign off Awaiting IG sign off Finalising governance Awaiting IG sign off Awaiting IG sign	Control of National Statistics Securic Research Service Serv	





KEY

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



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

Further information about Data & **Connectivity** can be found here. Including the Sprint 3 report.

First industry dataset accessible via Innovation Gateway (GSK Salford Lung Study dataset). New Trusted **Research Environment** collection added to Gateway collections.

Status of COVID-19 projects using the data - 26 January 2021

11 additions to active research taking place takes total over 250. Largest number of new projects enabled by the Office for National Statistics. Rapid Call projects starting to complete data access requests via Gateway.

# 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	17 (-5)	31 (-1)	36 (+6)	90 (-)	6 (-)	176 (-)
- a/w researcher	10 (-)	19(-5)	Not available	56 (-)	6 (-)	N/A
- a/w data custodian	3 (-5)	12(+4)	Not available	34 (-)	0 (-)	N/A
Submitted for Information Governance approval	3(-6)	8 (+5)	4(+1)	1 (+1)	0 (-)	18 (+1)
Approved but not yet active	6 (-1)	1 (-3)	9 (+2)	2 (-)	1(-)	19 (-4)
Active research taking place	11 (+5)	84 (+2)	67 (+2)	91 (+2)	1(-)	253 (+11)
Active Number of Researchers	Not yet available	Not yet available	Not yet available	202 (+22)	Not yet available	
Average time from application to active research	Not yet available	Not yet available	Not yet available	3 days	Not yet available	

Participation in key UK wide studies:

- PRINCIPLE: 3,743 participants (+16% in last 2 weeks, with continuing data flow of Pillar 2 COVID +ve test results to support recruitment)
- <u>RECOVERY</u>: 32,212 participants across 177 active sites (+18% in last 2 weeks)
- CO-CIN (ISARIC 4C)
 - 161,586 Tier 0 (case report)
 - 657 Tier 1 (single sample)
 - 1,672 Tier 2 (serial sampling)
- GENOMICC: 9,246 participants across 211 ICUs with a total of 5091 intensive care beds
- COVID-19 ZOE symptom study: 4,562,628
- COG-UK: 214,039 viral genomes sequenced

Data & Connectivity National Core Study projects now underway

Six studies now undergoing Data Access Requests (DARs) process via Innovation Gateway. Examples include:

- Economic scarring from the COVID-19 induced crisis: monitoring inequality in economic and education outcomes: led by Professor Stephen Machin, LSE
- 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 Julia Hippisley-Cox, University of Oxford
- How can NCS healthcare data be connected with wastewater surveillance of COVID-19 in a privacy-preserving fashion to inform epidemiological models and democratise data access? Led by Professor Till Hoffman, Imperial College London





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: COVID19 projects listed on
 gateway
- NI Honest Broker
 Service: Projects
 currently being carried
 out.