

HDRUK
Health Data Research UK



HSC Public Health
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UK Health Data
Research Alliance

COVID-19 Health Data Research

29 September 2020 - Weekly update for SAGE & UKRI/DHSC

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COVID-19 Health Data Research recommendations – 29 September 2020

Health data research insights on COVID are continuing, with 111 research questions, 158 (+8) projects active within the national data Trusted Research Environments (TRE), 158 (-21) in development, and 781 pre-print publications and 46 published papers. Incremental progress across all recommendations.



#	5 Recommendations endorsed by SAGE on 11 June	Progress on SAGE actions identified on 11 June
1	All swab & antibody testing programmes data to be securely linked and used for research. Requires unparalleled cooperation across all four nations between NHS organisations, PHE, data custodians, academic endeavours, and technology partners, whilst building public trust.	SAGE ACTION: HDR UK to work with partners to plan and create a serology and testing data research asset that is linkable to other data sources. PROGRESS: Award made by UKRI/NIHR - proposal led by Philip Quinlan, Emily Jefferson and partners will commence 19 Oct.
2	Further research, undertaken collaboratively with international partners where appropriate, should address why BAME groups have a higher rate of severe COVID-19 outcomes. This will help to target the best interventions and inform the response to future public health crises.	PROGRESS: Further insights being generated (see next page). Special Interest Group, to include UK Health Data Alliance Data Officers Group, being set up to review current landscape and issues around ethnicity coding, towards enacting the Alliance Board commitment to improve consistency and quality of ethnicity coding, enabling data use to increase the representativeness of research.
3	Enhance data capture on patients and staff in care homes , in particular interconnections between settings, to enable research on health, transmission and outcomes. Clarify appropriate use of national Trusted Research Environments for consolidation of relevant care home COVID-19 data.	PROGRESS: Initial reviews of the NHS Digital adult social care management coronavirus status data collection show rapidly increasing data quality and completeness across CASPA members. CASPA are exploring using an opt-out model to increase provider coverage. Ongoing work to understand how care providers can access and use the data to inform service provision and to identify driver research questions to further explore data utility. Establishing a broader research response still requires more accessible individual-level data for care home staff, residents and domiciliary care (care within own home) sector.
4	Accelerate access to restricted national datasets , since lack of availability is holding back crucial research.	PROGRESS: England Testing data and CHESS available to priority studies to request but not yet via routine access requests and continued issues with missing data. Ongoing engagement with NHS Digital to understand and resolve issues.
5	Commission large scale collaborative analyses of the long-term impacts of health and social care changes during the COVID-19 lockdown on major diseases. This will require access to linked data from a range of sources (including from COVID-19 laboratory tests, primary and secondary healthcare, death registries, disease-specific audit/registry data). In addition, linkages to cross sectoral data beyond health will be essential to understand the wider impacts of COVID-19.	SAGE ACTION: HDR UK to work with ONS and others to accelerate linkage of cross-sectoral datasets. PROGRESS: HDR UK continues to identify and prioritise datasets and linkages to support priority research questions. BHF Data Science Centre: 19 cardiovascular analysts from 6 institutions actively working via access to linked datasets in the NHS Digital TRE, including primary care GPES data which includes over 4 billion journal data entries across population of over 56 million representing 97.5% of GP practices in England.

Priority research questions with new insights generated this week – 29 September 2020

Health data research on COVID-19 continues to grow, now reaching 781 (non peer-reviewed) pre-prints & 46 published papers



Topic	Insights from ongoing studies (links provide further details):
Surveillance	<ul style="list-style-type: none">Evidence of substantial ethnic inequalities was found in the risk of testing positive for SARS-CoV-2, ICU admission, and mortality, which persisted after accounting for explanatory factors, including household size. It is likely that some of this excess risk is related to factors not captured in clinical records such as occupation, experiences of structural discrimination, or inequitable access to health and social services. Prioritizing linkage between health, social care, and employment data and engaging with ethnic minority communities to better understand their lived experiences is essential for generating evidence to prevent further widening of inequalities.
Immunity	<ul style="list-style-type: none">The GenOMICC consortia study has identified genetic traits in those experiencing critical illness with COVID-19, relating to key host antiviral defence mechanisms, and mediators of inflammatory organ damage in Covid-19. Both mechanisms may be amenable to targeted treatment with existing drugs. Large-scale randomised clinical trials will be essential before any change to clinical practice.Evidence is emerging that suggests a moderately increased risk of COVID-19 mortality amongst people living with HIV. However in some cases, HIV antiretroviral therapy regimens were associated with a lower risk of adverse COVID-19 outcomes – these analyses are susceptible to confounding by comorbidities, so require further study.
Longitudinal health	<ul style="list-style-type: none">A study looking at access to health services and the influence of sex, ethnicity, socio-economic position (SEP) and burden of co-morbidities, found that the UK's lockdown approach during the COVID-19 pandemic appears to have deepened existing health inequalities, impacting predominantly females, ethnic-minorities and those with chronic illnesses. Authors recommend that public health authorities need to implement urgent policies to ensure equitable access to health and care for all in preparation for a second wave.Analysis of primary care data from a deprived urban population, found that diagnoses of common conditions decreased substantially between March and May 2020, suggesting a large number of patients have undiagnosed conditions. A rebound in future workload could be imminent as COVID-19 restrictions ease and patients with undiagnosed conditions or delayed diagnosis present to primary/secondary health-care services. Such services should prioritise the diagnosis & treatment of these patients to mitigate potential indirect harms to protect public health.
Treatments	<ul style="list-style-type: none">A significant proportion of COVID-19 patients have hypertension and are treated with medicines (e.g. angiotensin-converting enzyme I inhibitors, aka ACE inhibitors), which have been postulated to influence susceptibility to SARS-CoV-2. Analysis of a large primary care database showed no significant associations between prescription of either ACE inhibitors or ARBs (angiotensin II type-1 receptor blockers) and all-cause mortality during the peak of the COVID-19 pandemic.

Patient and Public Voice Feedback



Priority area of focus should be to explore chronic effects of COVID-19, particularly given the increasing number of people who are now exhibiting signs of Long Covid.

20 COVID-19 taskforce calls with **90** clinical and health data research leaders engaged



1430 academic, industry and NHS participants in COVID-19 Slack channel with 10 sub-channels



111 health data research questions identified – 42 prioritised



781 COVID-19 pre-print publications



Click [here](#) for a link to the full prioritised list of questions, status, and prioritisation process

COVID-19 dataset availability and status of projects using the data – 29 September 2020

Progress on data linkage to key UK wide project datasets including COVID-19 Clinical Information Network (CO-CIN) and COVID-19 Genomics (COG-UK) Consortium (COG-UK) as the study cohorts continue to increase in size. Overall reduction in TRE project pipeline.



Health Data Research UK

KEY

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

KEY UK WIDE PROJECTS:

[RECOVERY](#)

[CO-CIN \(ISARIC 4C\)](#)

[COG-UK](#)

[CARDIOVASCULAR CONSORTIUM](#)

[COVID-19 symptom study](#)

[GENOMICC](#)



Datasets available for COVID-19 research via national TREs for Wales, Scotland and England

1. Pillar 2 testing data for England continues to be available only by exception.

2. Daily flow of Welsh COVID-19 Test, Trace and Protect (CTTP) data now available in SAIL Databank.

3. Further reduction of 'in development' projects as more requests progress to active research and small number are no longer being pursued.

Core COVID-19 Datasets available for linkage	England (NHS Digital Data Processing Service)	Scotland (National Data Safe Haven)	Wales (SAIL Databank)	Northern Ireland (Honest Broker Service)
Primary Care				
Pillar 1 COVID-19 Testing Data				
Pillar 2 Testing data (UK Gov)	N/C Delayed: Was expected Aug			Missing results prior to 26 Apr
Pillar 3 & 4 Testing data	N/C No confirmed date		Pillar 3 available	Data flow in place, no tests yet
Community Prescribing				
Critical Care (CHESS, ICNARC, SICSAG)	N/C CHESS expected in DARS Sep			N/C - Under review
Personal Demographic Service				
Secondary Care	SUS only - not HES			
Death registry				
Census 2011				

# of COVID-19 Projects by TRE stage (change from previous report)	England (NHS Digital Data Processing Service)	Scotland (National Data Safe Haven)	Wales (SAIL Databank)	Northern Ireland (Honest Broker Service)	Total
In development	37 (-6)	29 (-13)	86 (-2)	6 (-)	158 (-21)
- a/w researcher	28 (-4)	Not available	63 (+1)	6 (-)	N/A
- a/w data custodian	9 (-2)	Not available	23 (-3)	0 (-)	N/A
Submitted for IG approval	10 (+6)	9 (+1)	1 (-)	0 (-)	20 (+7)
Approved but not yet active	1 (-1)	0 (-)	4 (+4)	2 (-)	7 (+3)
Active research taking place	50 (+6)	40 (+3)	68 (-1)	0 (-)	158 (+8)

4. COVID-19 Clinical Information Network [CO-CIN \(ISARIC 4C\)](#) now has data from over 82,000 hospitalised patients available for research. Application for linkage to routine English health data in advanced stage and already in place for Scotland, with request to Wales to follow. This will enable high impact research such as outcomes for patients on the shielding list, association between diabetes and in-hospital mortality and long term consequences for hospitalised survivors of covid-19.

5. COVID-19 Genomics (COG-UK) Consortium ([COG-UK](#)) has sequenced 58,175 (almost 70%) of 84,932 global viral genomes. This is now linked to key data fields from routine electronic health records to add detail on host (patient). Viral sequencing being provided to key studies including ONS Infection Survey and GENOMICC.

6. 134 active users on COVID-19 related projects within SAIL with mean time to project approvals of 3.4 days for September

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