COVID-19 Health Data Research

19 May 2020 - Weekly update for SAGE & UKRI/DHSC

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COVID-19 Health Data Research recommendations – 19 May 2020

Insights from health data are now being generated at pace, fuelled by new data sources made accessible in safe environments. In particular, there has been a big increase in the use of the Welsh and Scottish national data and progress with primary care data in England. However, national testing data remains an issue.

Recommendations for SAGE and UKRI/DHSC based on current health data research insights:

1. Commission independent meta-analysis on ethnicity analyses within the UK and with international studies, distinguishing between “population fatality rate” and “infection fatality rate”

2. Support SAGE sub-group to enhance data capture on patients and staff in care homes to enable research on health, transmission (“R” in care homes) and outcomes to the equivalent depth in NHS settings

3. Further develop, extend and utilise open “risk calculators”, symptom trackers (e.g. ZOE app) and surveys, integrated with targeted public health messaging and actions

4. Commission meta-analysis on outcomes across major disease groups compared with previous 5 years (e.g. cancer, cardiovascular disease, diabetes, respiratory, dementia)

5. Create COVID-19 registries for the four nations to provide an ongoing source of data on COVID-19 patients, akin to the national cancer registry

6. Ensure data flows from national testing programme are available for linkage, within trusted research environments
Priority research questions, studies & insights – 19 May 2020

<table>
<thead>
<tr>
<th>Priority research questions</th>
<th>Studies already working on this:</th>
<th>Insights</th>
<th>SAGE Recommendation</th>
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</thead>
<tbody>
<tr>
<td>1. Why do BAME groups have an increased risk of severe COVID-19 outcomes (RQ34, 37)?</td>
<td>• University Hospitals Birmingham, Pioneer Health Data Research Hub &amp; DECOD</td>
<td>National Cumulative, but inconsistent insights emerging, potentially due to difference in terminology, in particular 'risk' for population fatality rate vs 'risk' for infection fatality rate (see details of insights from individual studies here).</td>
<td>Initiate meta-analysis of COVID-19 studies concerned with incidence and severity of COVID-19 in different ethnic groups and regional variations., e.g. NIHR Complex Reviews Unit (CRSU). Include international comparisons to compare outcomes for different ethnic groups by geography.</td>
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<td>2. What impact has COVID-19 having on care home patients? (RQ63)</td>
<td>• HDR UK North – University of Sheffield &amp; Lancaster • UCL • University of Bristol</td>
<td>Expanding and implementing local data collection to increase the specificity and power of research and avoid contradictory insights – exploring the potential value of a shared data resource to build on existing research enabled trusted research environments.</td>
<td>Enhance data capture on patients and staff in care homes to enable research on health outcomes to the equivalent depth in NHS settings. Develop routine care home data specification. Identify care home population in existing electronic medical records.</td>
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<td>3. How do we best understand and protect vulnerable populations? (RQ 22, 32, 36, 62) to inform an effective phased lockdown release: Risk prediction Social &amp; mental health Vulnerable groups</td>
<td>• HDR UK London (UCL) &amp; Uni of Cambridge and Oxford/Aston Turing Institute • University of Edinburgh • University of Swansea • University of Bristol • UCL</td>
<td>National • Online, prototype risk calculator (OurRisk CoV) shows underlying health conditions increase 1-yr risk of death from COVID-19 5-fold (see Lancet study here). • Early results from HAPPEN-at-home study show both positive (e.g. more active, sleeping better) and negative (e.g. more screen time) effects of lockdown on children. • Covidlife study shows that ‘lockdown’ has raised major concerns about future employment and the economy, particularly in young adults and are accompanied by high levels of anxiety and depression. • Similar results from ALSPAC, which shows a worsening pattern in wellbeing/anxiety in adults of parental age. • Study on homeless people shows the positive impact of temporary accommodation to enable care &amp; self-isolation upon onset of symptoms. International Dataset from Wuhan used to ID patients at risk of developing severe COVID-19, adds to growing evidence that simple blood tests are strong predictors of risk of serious disease.</td>
<td>Open, risk based tools (such as OurRisk CoV ) are further developed &amp; integrated into targeted public health messaging. Government alignment to facilitate cross-departmental data linkage e.g. Health (NHS Digital) and Dept of Education is essential to understand the impact of COVID-19 on children and other vulnerable populations.</td>
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<td>4. What is the impact on treatment and outcomes for non-COVID-19 disease (e.g. cardiovascular &amp; cancer) (RQ29)</td>
<td>• BHF Data Science Centre and UK-wide CVD COVID UK consortium</td>
<td>National 76% reduction in urgent cancer referrals and 60% reduction in chemotherapy attendances compared to pre-COVID-19 levels (details here). Substantial declines in presentation of acute coronary syndrome and Percutaneous Coronary Intervention activity to hospital (details here). International Netherlands - drop in cancer diagnoses overall by 26% (60% for skin cancer diagnoses); US - significant changes in cancer services, e.g. drops in cancer screening for cervical, breast and colorectal cancer (83% for PAP smears, 87% for mammograms, 90% for colonoscopies respectively - details here)</td>
<td>Commission meta-analysis on outcomes across major disease groups compared with previous 5 years (e.g. cancer, cardiovascular disease, diabetes, respiratory, dementia) – including research, frontline clinical teams and existing disease registry experts.</td>
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</table>

9 COVID-19 weekly taskforce calls with 67 clinical and health data research leaders engaged
1296 academic, industry and NHS participants in COVID-19 Slack channel with 10 sub-channels
62 volunteers in HDR UK’s COVID-19 Public & Patient Group
72 health data research questions identified – 28 prioritised
75 COVID-19 pre-print publications

Click here for a link to the full prioritised list of questions, status, and prioritisation process
Priorities to scale-up data use: 1) national testing data
2) continue moving projects from development to IG scrutiny

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

### Core COVID-19 Datasets available for linkage

<table>
<thead>
<tr>
<th>Dataset Type</th>
<th>England (NHS Digital Data Processing Service)</th>
<th>Scotland (National Data Safe Haven)</th>
<th>Wales (SAIL Databank)</th>
<th>Northern Ireland (Honest Broker Service)</th>
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<tbody>
<tr>
<td>Primary Care</td>
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<tr>
<td>UK Gov Testing data</td>
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<tr>
<td>Community Prescribing</td>
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<tr>
<td>Critical Care</td>
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<td>Options under review</td>
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<tr>
<td>Personal Demographic Service</td>
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<tr>
<td>COVID-19 Surveillance Testing</td>
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<tr>
<td>Secondary Care</td>
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<tr>
<td>Death registry</td>
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### # of COVID-19 Projects by TRE stage (change from previous week)

<table>
<thead>
<tr>
<th>TRE Stage</th>
<th>England (NHS Digital Data Processing Service)</th>
<th>Scotland (National Data Safe Haven)</th>
<th>Wales (SAIL Databank)</th>
<th>Northern Ireland (Honest Broker Service)</th>
<th>Total</th>
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<tbody>
<tr>
<td>In development</td>
<td>30 (-)</td>
<td>25 (+1)</td>
<td>38 (+7)</td>
<td>3 (+3)</td>
<td>96 (+11)</td>
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<tr>
<td>Submitted for IG approval</td>
<td>6 (+4)</td>
<td>2 (-)</td>
<td>0 (-)</td>
<td>0 (-)</td>
<td>8 (+4)</td>
</tr>
<tr>
<td>Approved but not yet active</td>
<td>2 (-)</td>
<td>2 (-2)</td>
<td>1 (-2)</td>
<td>0 (-)</td>
<td>5 (-4)</td>
</tr>
<tr>
<td>Active research taking place</td>
<td>3 (+1)</td>
<td>12 (+9)</td>
<td>16 (+2)</td>
<td>0 (-)</td>
<td>31 (+12)</td>
</tr>
</tbody>
</table>

### KEY UK WIDE PROJECTS:

- RECOVERY
- CO-CIN (ISARIC 4C)
- COG-UK
- CARDIOVASCULAR CONSORTIUM
- COVID-19 symptom study

### NOTES

- TRE - Trusted Research Environment
- IG - Information Governance
- DPN – Data Provision Notice
- Datasets available for COVID-19 research via national TRES for England, Scotland and Wales.

### 3. COVID-19 symptom study app developed by King’s College London, Twins UK and health science start-up ZOE is being widely used to support research with projects representing most of the active research projects reported by SAIL Databank which hosts the research data.

- Launched under two months ago it has 3.6m UK users who are reporting regularly. Highlighted loss of *sense of smell or taste* as a strong predictor of coronavirus as very early insight (1 Apr);
- Data securely transferred to SAIL Databank and listed on Health Data Research Gateway to enable access for non-commercial researchers beyond the original collaborators. Being accessed at local (e.g., councils and NHS trusts) and national level (e.g., Welsh Government, Food Standards Agency, MoD, DfE).