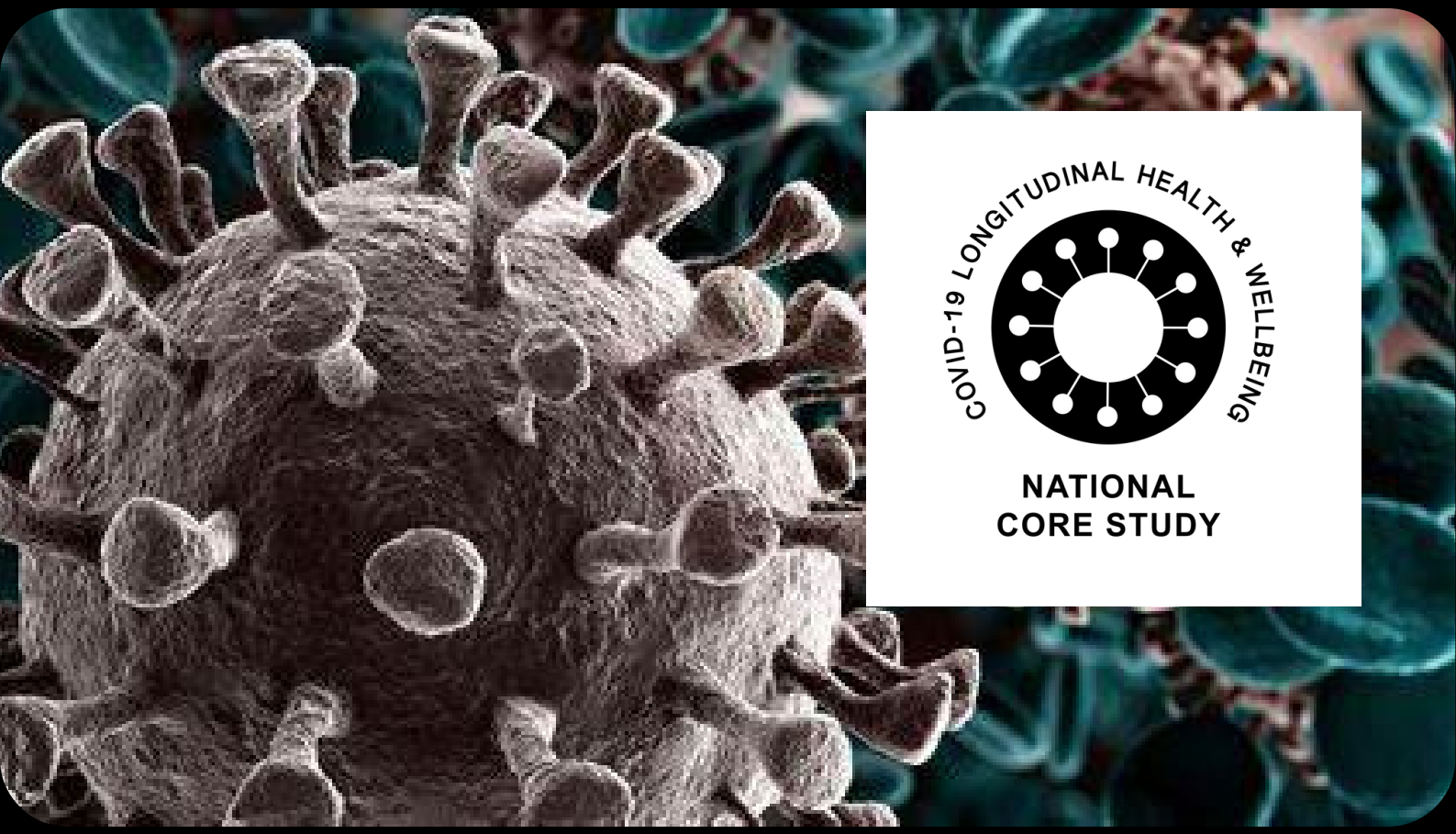


COVID-19 LONGITUDINAL HEALTH & WELLBEING

NATIONAL CORE STUDY

Insights and Impact

COVID-19 Longitudinal Health and Wellbeing National Core Study

2022

UKRI Medical Research Council

Since October 2020, the Longitudinal Health and Wellbeing National Core Study (LH&W NCS) has been investigating the health, social and economic impacts of the COVID-19 pandemic and informing policy

COVID-19 LONGITUDINAL HEALTH & WELLBEING
NATIONAL CORE STUDY

To achieve this, the LH&W collaborative:

- Formed a multidisciplinary team of >100 scientists from leading UK institutions
- Pooled and aligned complementary resources and skill sets
- Created new infrastructure/national electronic health record platforms
- Brought together longitudinal population studies at an unprecedented scale

Electronic Health Records (EHR)

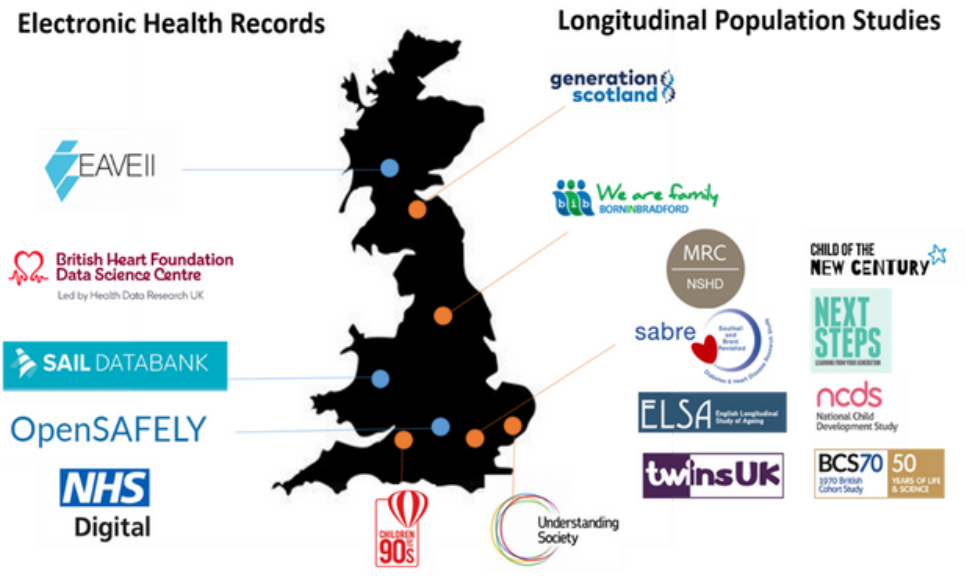
63 million people
Near whole-population coverage with data linkage

The UK Longitudinal Linkage Collaboration

280,000 LPS participants with linked EHR data in a new, secure Trusted Research Environment

Longitudinal population studies (LPS)

200,000 participants with detailed pre-pandemic information who completed repeated COVID-19 surveys



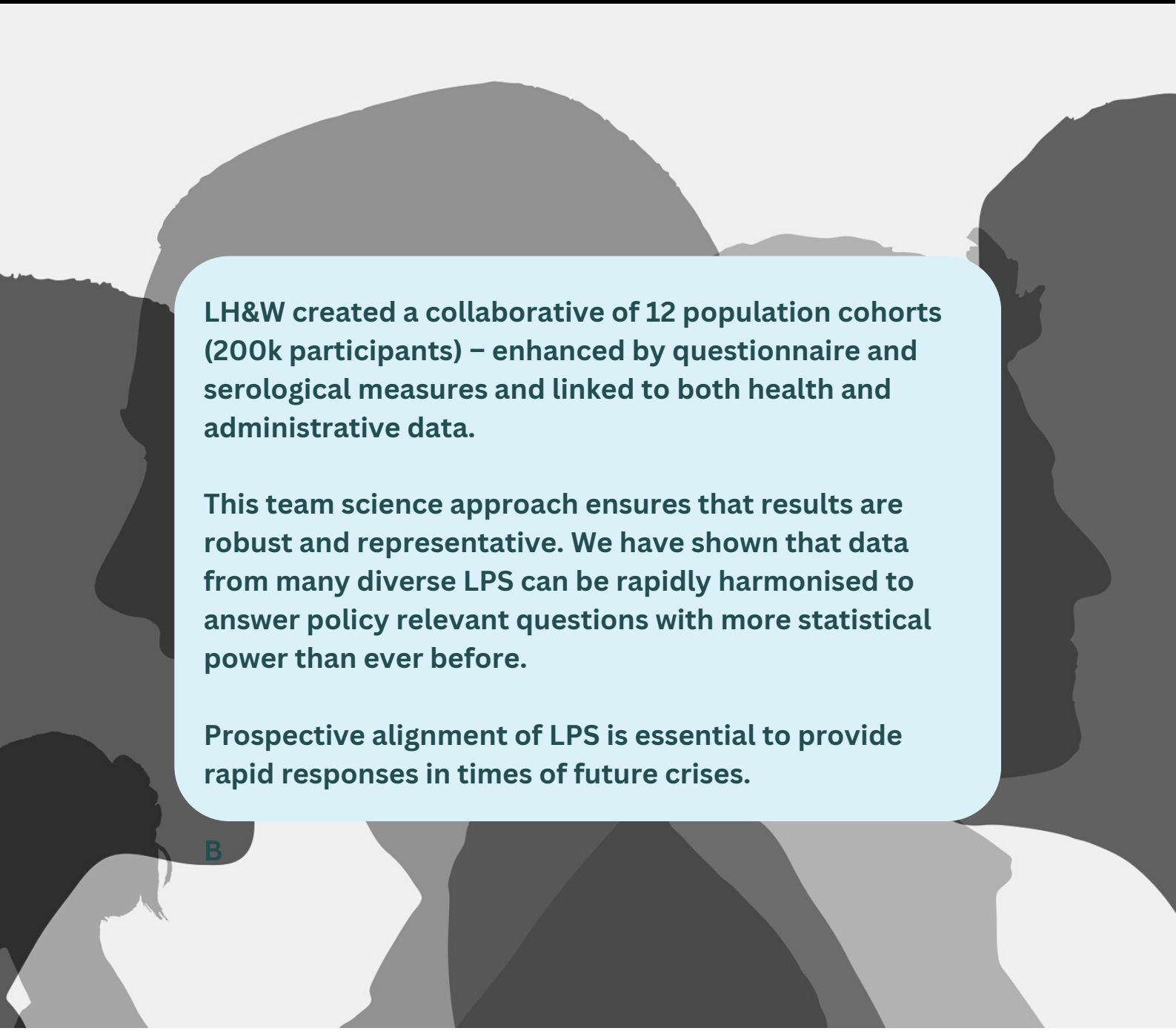
The Team

Team Science

The LH&W NCS is an example of team science at unprecedented scale

- Unique, cross-institution, multidisciplinary collaboration of biomedical, social and data scientists
- Cross study data capture and analyses
- Enhanced Early Career Researcher to Principle Investigator network
- Open approach to analysis and code sharing
- Systematic approach to protocol development
- Trained data scientists
- Secure linked LPS and EHR resource: UK LLC

New way of working for LPS



LH&W created a collaborative of 12 population cohorts (200k participants) – enhanced by questionnaire and serological measures and linked to both health and administrative data.

This team science approach ensures that results are robust and representative. We have shown that data from many diverse LPS can be rapidly harmonised to answer policy relevant questions with more statistical power than ever before.

Prospective alignment of LPS is essential to provide rapid responses in times of future crises.

B

ELSA English Longitudinal Study of Ageing

1946 National Survey of Health and Development

UKRI Medical Research Council

sabre Southall and Brent Revisited – Diabetes and heart disease research

generation scotland

BCS70 1970 British Cohort Study

CHILD OF THE NEW CENTURY

twinsUK

Understanding Society

NEXT STEPS LEARNING FROM YOUR GENERATION

ncds National Child Development Study

bib We are family BORNINBRADFORD

CHILDREN OF THE 90S

World leading infrastructure

The NCS have established the UK as a world leader in harnessing the power of national electronic health records platforms, such as OpenSAFELY and the NHS Digital TRE established by the BHF Data Science Centre. These and the new Longitudinal Linkage Collaboration (UK LLC) linked dataset will provide unprecedented opportunities for research that improves population health in the coming years.

The team have embraced, modern open approaches to data science such as sharing code openly to the whole community, as the bedrock of deep technical collaboration; working closely with research software engineers alongside traditional domain experts with research knowledge; and moving away from "manual labour" on datasets towards "reproducible analytic pathways", with well tested and re-executable codes, in line with best practice in data science.

They have also developed new methods for preserving patients' privacy which allowed an unprecedented scale of data access.

UK Longitudinal Linkage Collaboration

OPEN SAFELY

British Heart Foundation Data Science Centre

Led by Health Data Research UK

EAVE II

NHS Digital

SAIL DATABANK

Strengths

Open Science

Novel approach to team science that prepares us for future crises

The co-ordinating of research to answer specific policy questions at pace

Bidirectional relationship with policy makers

New way of working in the LPS community

New generation of data scientists

PPIE is embedded into the research process

New world leading infrastructures have been developed

Legacy

The legacy of the LH&W NCS is a responsive system comprising both infrastructure and a network of LPS willing and able to come together to coordinate responses to emerging crises and areas of policy

Policy Impact

During lockdown the LH&W Team identified instances of inappropriate switching of blood thinners (from warfarin to Direct Oral Anticoagulants). This triggered a national alert to GPs

GP National Alert

The team have provided evidence to NHSE/I on long COVID GP coding, healthcare access issues, the increased risk of blood clots after infection and the use of anti-virals to treat COVID-19

NHS England and Improvement

SAGE Reports

Policy makers have been provided with information on long COVID burden of disease, risk factors, definition and long term outcomes via cabinet briefing reports and SAGE reports.

NICE Guidelines for COVID-19 Treatment

We demonstrated that we can study drug use and effectiveness in near-real time, across the population. NICE used this Real World Evidence in their COVID-19 treatment report and to inform a technology appraisal.

We reported low levels of long COVID GP coding. This work led to a NHS enhanced service specification, directed at GPs, to drive an increase in long COVD coding.

NHS Enhanced Service Specification

A teach in session provided the cabinet office with the latest updates on long COVID risk factors, GP coding, and healthcare access issues.

Cabinet Office Teach In

NICE Living Guidelines

NICE used our long COVID findings in its evidence review for risk factors, the analysis played an important role in the evidence assessment.

UK-US long COVID Taskforce

Our long COVID findings were shared at a UK Foreign, Commonwealth & Development office joint meeting between key UK long COVID projects and US initiatives.

Briefing notes have been submitted addressing inequalities in healthcare disruption, mental health decline during lockdown, the impact of furlough on health behaviour and mental health and reasons for a low antibody response.

Cabinet Briefing Notes

We deployed a rapid bespoke survey (3 weeks) that showed that voluntary measures substantially reduced the projected impact of the SARS-CoV-2 Omicron variant. This was passed onto SPI-M, SAGE and the Cabinet Office.

Rapid response SPI-M

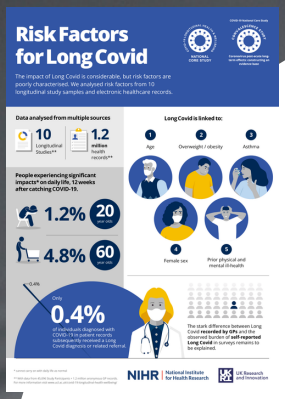
Vaccination

OpenSAFELY was among the first to provide the Chief Medical Officer with a quantification of vaccine side effects and the first to point out that people with learning disabilities should be prioritised for vaccination. Our analyses also identified differences in vaccine uptake among ethnic groups.

Importance of the Booster

Data from the LPS informed policy makers that the third vaccination increased absolute antibody levels for almost all individuals and reduced relative disparities compared with earlier vaccinations, in support of triple vaccination policy.

Wide Impact



64
Publications and Preprints

28,140
Social Media Mentions

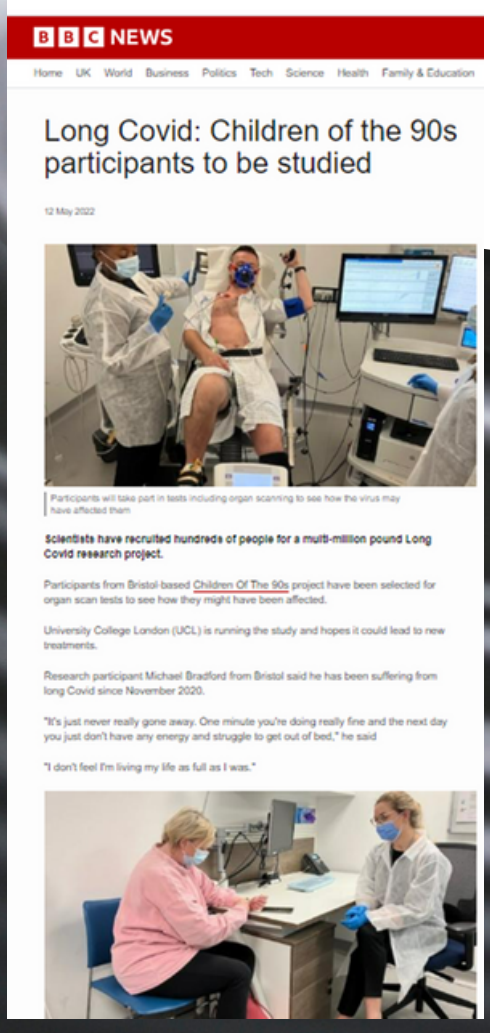
1748
News and Blog Articles

>150
Policy Documents and Citations

HDRUK
Health Data Research UK

GPs recording low numbers of long Covid compared with survey estimates

Research finds number of recorded cases is nearly 100 times smaller than adults estimated to have had condition



Findings

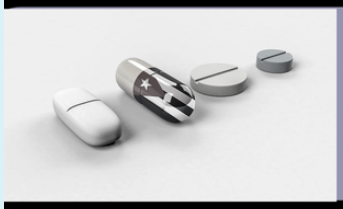
Mental Health

Society and Health

Healthcare Disruption

Serology

Vaccination



Treatment

Long COVID

UK Longitudinal Linkage Collaboration

UK Longitudinal Linkage Collaboration

Mental Health

The pandemic had immediate and long-term effects on people's mental health, and the extent of these effects has varied from person to person.

Our research showed that people with pre-existing poor mental health experienced wider impacts from the pandemic, including healthcare and economic disruptions.

We also showed that mental health deteriorated during the early stages of the pandemic, with severity varying by demographics and mental and physical health history. This mental health decline did not recover when lockdown was lifted.

We also provide some of the first evidence from population based longitudinal studies on the mental heath aspects of mild and moderate COVID-19 infection.

This research demonstrates the importance of using longitudinal studies and other population-based data to understand the mental health impacts of the pandemic, rather than relying on convenience samples.

Policy Implications: It is important to consider inequality between people with and without mental health problems when providing support during and after the pandemic

Society and Health

We investigated the impact of furlough and home working on mental and physical health and health behaviours during the pandemic.

We found that furlough had a protective effect compared to those who lost their job, but was not as beneficial as remaining at work. Furloughed workers were at greater risk of psychological distress and loneliness compared to those who remained working. However, there was little evidence to suggest that social protection policies, like furlough, had adverse effects on population health behaviors.

There was no clear evidence of an association between home working and mental wellbeing, but further monitoring of health inequalities is required.

Long COVID can lead to worse subjective financial wellbeing, new benefit claims, and decreased household income, which suggests extending employment protection and financial support to people with long COVID may be necessary.

Policy Implications: The evidence shows that social protection policies should be implemented in the post-pandemic recovery period and during future economic crises

Healthcare Disruption

Using a 3 nations EHR approach we showed that hospital care for non-COVID diseases fell substantially, with reductions persisting for at least six months. The most deprived and minority ethnic groups were impacted more severely.

LPS data showed that females, ethnic minority groups and those in a more disadvantaged social class were more likely to report healthcare disruptions.

In linked LPS-EHR data, more than 1 in 3 people (35%) reported that they experienced some form of disrupted access to healthcare during the COVID-19 pandemic.

People who experienced disrupted access to healthcare were more likely to have experienced avoidable or potentially preventable hospitalisations. Disrupted access to appointments (e.g., visiting their GP or an outpatient department) and procedures (e.g., surgery, cancer treatment) were key pathways for explaining increased risk of an avoidable hospitalisations.

Action is needed to remedy these inequalities, and efforts to ensure continuity of care during pandemic-related disruptions may need to be more clearly targeted to those most in need of care.

Policy Implications: Action is needed to tackle backlogs in postponed or cancelled care, including targeted support to people who experienced disrupted access to care

Serology

The Serology team has been studying SARS-CoV-2 antibody levels in the LPS to assess immune responses following natural infection or vaccination.

We found that individuals with the lowest 20% of anti-Spike antibody levels had a 3-fold greater risk of SARS-CoV-2 infection compared to the top 20%.

Individuals at increased risk of COVID-19 complications had consistently greater odds of having low antibody levels.

Third vaccination increased absolute antibody levels for almost all individuals and reduced relative disparities compared with earlier vaccinations.

The LPS are also playing a key role in the Immunology NCS, where cohorts are charting the immune response to infection in the real world, longitudinally and in great detail.

Policy Implications: These findings support a policy of triple vaccination

Vaccination

OpenSAFELY has played a key role in several parts of COVID-19 vaccine delivery in the UK, specifically in prioritisation, delivery, and measurement of safety and effectiveness.

The early COVID mortality risk stratification work was a critical part of creating the prioritisation groups, with the UK Joint Committee on Vaccination and Immunisation (JCVI) requesting that OpenSAFELY present data on several occasions.

The findings helped in creating prioritization groups based on COVID mortality risk stratification, and highlighted disparities in vaccination rates between different demographic groups.

We analyzed the COVID vaccine uptake in different ethnic groups and found that some groups, particularly Black or Black British people, Pakistani and Bangladeshi groups, are more hesitant to take the vaccine due to concerns over future unknown effects, lack of trust in vaccines, and possible side effects.

We also carefully defined methods to describe the comparative effectiveness of initial vaccines, how that effectiveness has changed over time, and effectiveness of booster vaccination.

Policy Implications: OpenSAFELY played an important role in the COVID-19 vaccine delivery and can be deployed to answer real-time policy questions in the future.

Treatment

Following the emergence of new treatments for COVID-19, the team were quickly able to link data on who received such treatments into OpenSAFELY.

We initially described which patient groups were being given the treatments, finding large regional variation, with particularly low administration in socioeconomically deprived areas and care homes.

We then described the real world effectiveness of these treatments, initially comparing two of the first used treatments, molnupiravir and sotrovimab.

We have demonstrated that data about roll out of new treatments can be rapidly linked to primary care and other data, to monitor drug coverage and effects in near-real time and produce unbiased estimates of drug effectiveness.

This data has been used to inform NICE, NHSE prescribing guidance and WHO as part of their review of the recent guidance.

Policy Implications: This work shows that better use of linked data to conduct or emulate low-cost, rapid RCTs – particularly when drug effectiveness is likely to be changing rapidly.

Long COVID

Results from LH&W have improved the precision of long COVID diagnosis for research purposes and informed strategies for care provision.

Triangulation of LPS and EHR data has identified risk factors for long COVID, such as age, gender, ethnicity, pre-pandemic health, overweight/obesity, and asthma.

Symptoms of long COVID include fatigue, shortness of breath, muscle pain or aches, difficulty concentrating, and chest tightness.

We also found that GP coding for long COVID is inconsistent and lower than other estimates of long COVID prevalence.

People with long COVID also faced challenges in accessing healthcare services, with ethnic minority participants facing mistrust and fear of services deterring them from seeking support. Healthcare professionals also discussed systemic barriers to delivering services.

These findings have been passed onto the Cabinet Office, SAGE, NICE and NHSE/I Long COVID Taskforce to help improve care and support for people with long COVID

Policy Implications: People with long COVID need more support. The results played a role in the NICE living guideline and led to an NHS Specification to increase GP coding for long COVID.

UK LLC

As part of the LH&W NCS, the UK LLC has established a new national trusted research environment (TRE) for longitudinal research.

For the first time, a considerable proportion of the interdisciplinary UK longitudinal community have committed to a new-way-of-working based on a centralised TRE: UK LLC. The UK LLC is now acting as a 'pathfinder' Trusted Research Environment for the UK.

Work using the UK LLC includes the disruption of healthcare provision due to pandemic mitigation measures. The UK LLC has allowed linkage of individual reports of experience of disrupted healthcare to health outcomes in the EHRs of the same individuals across several large cohort studies, enabling the identification of the risks associated with disrupted care.

It has also enabled individual level quantification of long COVID GP coding which shows a striking discrepancy between long COVID as perceived and reported by participants in LPS and evidence recorded in their EHRs. This could reflect substantial unmet clinical need, in keeping with patient reports of difficulties accessing healthcare and sub-optimal recognition of, and response to, their illness when they do.

Policy Implications: Certain policy relevant questions can only be answered appropriately using this important new resource. The UK LLC has made significant and tangible differences to how major UK Governments are engaging with requests from LPSs to link data.