Minister for Health enables secure access to COVID-19 Data Research Hub

From Department of Health

Published on 3 March 2021

Last updated on 3 March 2021

Today, Minister for Health Stephen Donnelly TD, has launched an initiative to facilitate safe and secure access to COVID-19 data for valid health research purposes.

The Central Statistics Office (CSO) has been maintaining a COVID-19 Data Research Hub since April 2020. To date this data has been used solely by a sub-group* of the National Public Health Emergency Team to conduct statistical analysis on healthcare data.

Now, in partnership with the CSO and the Health Research Board (HRB), an application process has been put in place to enable registered researchers to apply to access the data for research purposes. A series of safeguards have been put in place to protect patient privacy under stringent and transparent rules while advancing our understanding of COVID-19 for the benefit of people's health, patient care as well as health care policy and planning. Following a rigorous approval process, successful researchers will only have access to data from which all identifiers such as names and addresses will be removed.

The Minister said:

"COVID-19 research plays an essential role in tackling the pandemic, identifying areas for targeted intervention and ongoing planning and evaluation of requirements; in addition to other public policy decisions.

"Modelled on best international practice, the mechanism we have in place with the CSO and the HRB will ensure that patient privacy and confidentiality is central when managing our approach to supporting valid research of this data. A key part of this will be the establishment a Research Data Governance Board to review applications to access the data for valid COVID-19 related research purposes."

An example of how research on this data could be used in practice would be to create a greater understanding of variation in COVID-19 risk in people with underlying conditions to tailor health promotion and protection measures.

Safeguards in place when researchers access data for research purposes

• the Minister has established a new Research Data Governance Board (RDGB) which will consider applications to use the data for valid research purposes

- only registered researchers, in registered Institutions in Ireland, can apply for valid research purposes. Access by approved researchers to the data is for a limited, agreed period
- the RDGB will only recommend applications to the CSO for data access if they have been approved by a Research Ethics Committee and the Health Research Consent Declaration Committee
- following CSO approval to access data, researchers will be subject to robust protocols and safeguards implemented by the CSO in line with its Data Management Policy. The researcher will be required to sign a Declaration of Secrecy and will then be appointed an Officers of Statistics for the purpose of their research project

In order to ensure the highest data protection standards, the CSO has finalised a Data Protection Impact Assessment in advance of starting the project and shared this with the Data Protection Commissioner.

Paul Morrin, Assistant Director General, CSO said:

"The datasets in the CSO hosted COVID-19 Data Research Hub can now be accessed by approved researchers to support statistical analyses that forms part of valid research projects. These projects will advance medical treatments, health service delivery, inform policy and planning across Government and wider society.

"Selected researchers will be permitted to apply for access to pseudonymised, individual level data relating to COVID-19 cases, testing, individual information regarding those treated in hospital for the virus and those that have been identified as being a close contact of a confirmed case. At all times the CSO will protect the security and confidentiality of individual data, as it is required to do so under the Statistics Act, 1993, and this data sharing initiative complies fully with data privacy regulations."

Dr Teresa Maguire, Director of Research Strategy and Funding at the HRB said:

"It is essential that the public are aware of and understand the importance of use and re-use of health and social care data for research purposes and the benefits that this can deliver to the people of Ireland. A key principle for all partners in this initiative has been to ensure that everything we do is secure, transparent and supports research in the public interest.

"This is critical in the immediate context of tackling COVID-19, but also more broadly to optimise data and evidence-informed decision-making to transform how health care is delivered and indeed how we manage our own health."

Notes

*Only named members of the Epidemiological Modelling Advisory Group (IEMAG) of NPHET had access to this data before.

Read more about the COVID-19 Data Research Hub.

Data protection

Researchers will only have access to pseudonymised data which means all direct identifiers such as name, contact details, date of birth and address will be removed.

Research Data Governance Board (RDGB)

The RDGB is an independent body established jointly by the HRB and the CSO, in close collaboration with the Department of Health. The RDGB act as a central point for application receipt, screening, review and prioritisation of data requests prior to accessing the CSO service.

RDGB membership

The membership draws a wide range of expertise in secondary data analysis, COVID-19 research, CSO protocols and safeguards and existing governance, safeguards and best practices for research. Read more about members of the group.