

Research Data – A Rising National Priority

Research data is a valuable national asset, and the management and sharing of research data are among the most pressing challenges facing the higher education and research sectors. The acceptance of data as an important strategic asset in responding to Covid-19 is accompanied by greater awareness of the gaps and outstanding issues. The opportunity for transformation needs to be matched with a strategic choice for investment.

Research data is a valuable national asset, and the management and sharing of research data are among the most pressing challenges facing the higher education and research sectors. In order to unlock the full value of existing and future research data, it is essential that data be stored, managed, accessed, and shared within a robust governance framework that also protects privacy and confidentiality.

Many countries have begun to implement national policies for data produced through publicly funded research.¹ Ireland does not yet have a national policy, but best-practice initiatives are emerging which can inform a coordinated Irish agenda.

Partnerships and practices – a funder approach

One of the most significant drivers to improve research data management and sharing comes from research funders. The Health Research Board (HRB) is developing a supportive and efficient environment for research data by leveraging the expertise of international partners, implementing practical actions, developing policy for health research data, and driving a national discussion.

The HRB has partnered with the International GoFAIR Office to develop common FAIR data stewardship skills and networking among key support staff in Irish research institutions.² (FAIR = Findable, Accessible, Interoperable and Reusable.) In September 2020 the HRB hosted an international panel to discuss the data management plans (DMPs) prepared with the support of these trained data stewards, alongside institutional reports on research data management. Issues arising for further clarifications include the defining of budget costs, appropriate use of metadata and citations, data licences choice, data storage processes, and decisions on IP protection versus data sharing.



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The HRB has also partnered with F1000 to develop HRB Open Research,³ an open publishing platform with integrated support for health researchers to implement open data policies alongside published articles. From 2021 this platform will also include the option to publish machine-readable DMPs that are aligned to the FAIR data principles.⁴ This will serve to promote best-practice learning and to credit data stewards and authors, and will enable the mapping and tracking of research outputs that link articles and data.

2019 was a particularly busy year. Following a dedicated funding call on secondary analysis of data, the HRB made seven awards at a total cost of €1.75m.⁵ The HRB also funded a proof-of-concept technical infrastructure project to demonstrate how researchers can be given secure and controlled access to anonymous and linked health and social case datasets in Ireland.

This work builds on an earlier published discussion document,⁶ which presented a Data Access, Storage, Sharing and Linkage (DASSL) model showing types of infrastructure and services required to unlock the significant value of currently underexploited data for the public good. It is being led by the Irish Centre for High-End Computing (ICHEC) at NUI Galway working with researchers at the Royal College of Surgeons in Ireland, Trinity College Dublin, and the Health Service Executive (HSE). Further discussion and investment are required to scale up this model to serve national research requirements.

In 2019 the HRB published a new policy on the management and sharing of research.⁷ In line with best international practice,^{8,9} HRB-funded researchers are now required to develop DMPs to consider how data is collected, stored, managed, and shared throughout the lifecycle of their research projects. A HRB digital DMP template, based on Science Europe's 'Practical Guide to the International Alignment of Research Data Management', has been prepared for this purpose.¹⁰

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The HRB is also learning from excellent resources such as the EU FAIRsFAIR project, which is providing a clear actionable agenda for numerous research data issues.¹¹ It is using expertise from partnerships and initiatives across Europe to help turn the European Open Science Cloud (EOSC) into a functioning infrastructure.¹² FAIRsFAIR leaves no doubt on the requirements of different research stakeholders to harmonise mechanisms, strategies, and policy approaches over a sustained period.

Combined, these developments of services, infrastructure, and other resources to support research data management needs and the reuse of secondary data provide a rich picture of the breadth and fast pace of change in a single organisation.

Covid-19 and research data

In Ireland and beyond, the need for more efficient access and processing of data has been brought into sharp focus by the Covid-19 pandemic. Data sharing has reached unprecedented levels, allowing research to make swift progress. Our health system and our society have also adapted to changing conditions, using digital infrastructure and data sharing to provide remote

consultations, to monitor people with Covid-19 continuously at home, and to use mobile applications for contact tracing.

Data collection and management are accepted as fundamental to Ireland's efforts to tackle Covid-19. In September 2020 the government launched its Plan for Living with COVID-19,¹³ which will guide Ireland's response over the next six months. The plan recognises the crucial role of research in informing and shaping our immediate public health and policy response to Covid-19 and the vital importance of data in supporting the research process.

The Central Statistics Office (CSO), Department of Health, HSE, and others continue to support the collection, collation, and statistical analysis of Covid-19-related data. These include routinely collected health service data, census, and administrative data, and data from research cohorts. The HRB and the CSO are now establishing a mechanism to facilitate secure and controlled access to these data for research purposes.

A rising national priority

Short-term emergency responses to address Covid-19 need to be aligned with long-term agendas. The acceptance of data as an important strategic asset in responding to Covid-19 is accompanied by a greater awareness of the gaps and outstanding issues in research data management and sharing. The OECD refers to the need to ensure 'adequate data governance models, interoperable standards, data sharing agreement involving public sector, private sector and civil society incentives for researchers, sustainable infrastructures, human and institutional capabilities and mechanisms for access to data across borders'.¹⁴

“ The European Commission strategy has long promoted digital transformation in health and care.

Already in 2020, the HRB and others have committed to participate in two new EU initiatives, an European infrastructure project to handle population data on Covid-19¹⁵ and a Joint Action on EU Health Data Space that will focus on governance, data quality, and infrastructure of health data in Europe.¹⁶ The European Commission strategy has long promoted digital transformation in health and care. In October 2020 the member states prioritised the creation of a common health data space by the end of 2021.¹⁷

Is the timing right for Ireland to develop a national approach to research data? This will require leadership, a systems approach, a compelling vision, engagement with multiple stakeholders, and a focused pathway to implementation.

In July 2019 the government published a national framework on the transition to an open research environment.¹⁸ A national coordinator is now in place to help deliver a national planning exercise that involves representatives from key organisations discussing priorities for enabling FAIR research outputs, access to research infrastructures, capacity building for key support staff, implementing incentives and rewards for researchers, and open access publication.

The newly established Department of Further and Higher Education, Research, Innovation and Science, combined with the data-focused agenda from the Department of Health, could provide the answer. The opportunity for transformation needs to be matched with a strategic choice for investment.

ENDNOTES

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2. GO FAIR International Support and Coordination Office. <https://www.go-fair.org/>.
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