

Management and Sharing of Health Research Data

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Strategic objective 3. Trusted data

Promote and enable the use of data to shape health policy, enhance healthcare delivery, and drive broader research and innovation initiatives

Action 3.1. Play a leading role with other stakeholders to promote and enable the infrastructure and environment for the optimal use of health and social care data and statistical data for research.

Action 3.6. Take a national leadership role in driving the FAIR* data and open research agendas. (*findable, accessible, interoperable and reusable)



RAII – Data and Personalised Medicine

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Sharon Kappala - Programme Officer

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Cross-Organisational Data Group

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HEALTH DATA PROJECTS

Data Access,
Sharing, Storage,
Linkage Model
(DASSL)

Joint Action
Towards European
Health Data Space
(TEHDAS)

HRB Secondary
Data Analysis
Projects (SDAPs)

COVID-19 Data
Research Hub

HRB Data
Management
Plans-Collection
and Management

Genomic Data
Infrastructure
Ireland

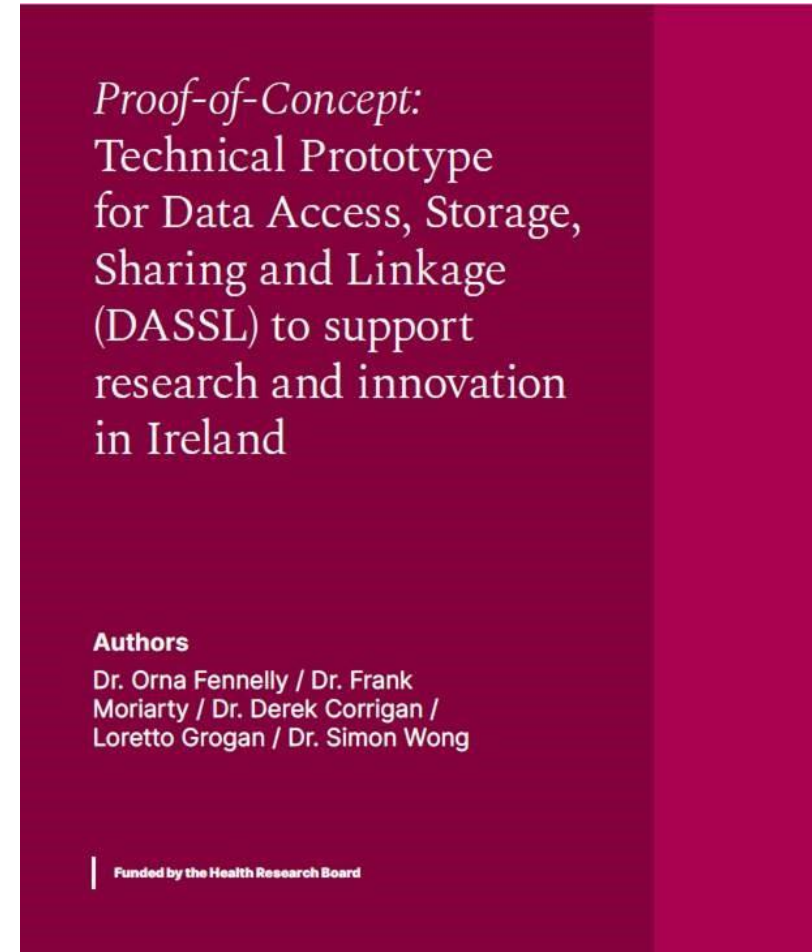
National Irish
COVID-19 Biobank

Data Access, Sharing, Storage, Linkage (DASSL) Award

- To progress the national conversation on the need for technical infrastructure in Ireland for data access, sharing, storage and linkage.
- Outcomes and Recommendations from the project relevant to the Health Data Access bodies (HDABs) in the upcoming EHDS and the need for secure trusted environments for data sharing and linkage.

Report now available on HRB Webpages

<https://www.hrb.ie/funding/approved-awards/dassl/>



HRB Secondary Data Analysis Projects (SDAP)

Aim of the Grant Scheme:

Overall aim of the scheme is to optimise the use of existing health and social care data sources to deliver high-quality, high-impact evidence for policy and/or practice.

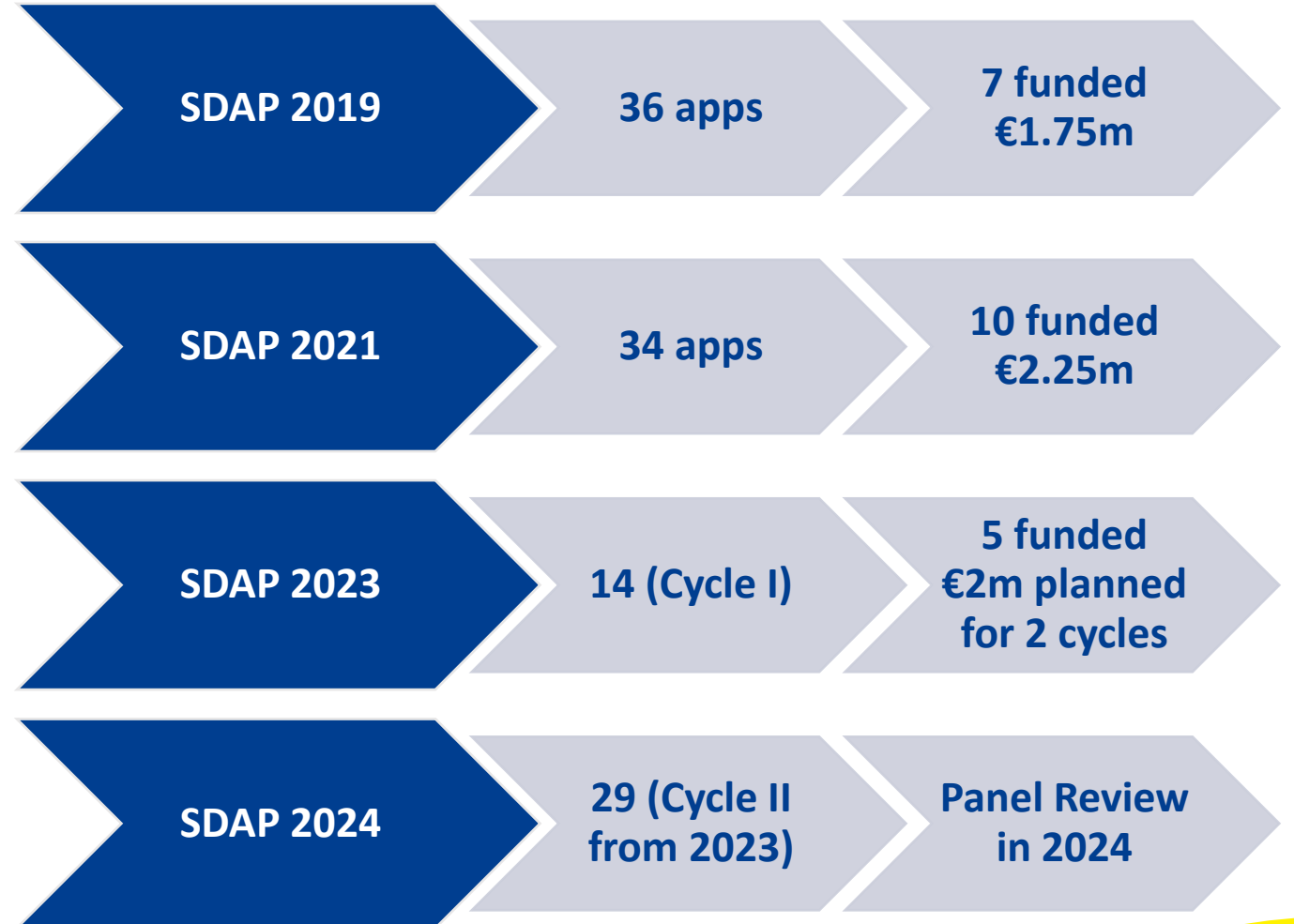
Objectives:

- i. To answer policy and/or practice-relevant questions using secondary data.
- ii. To develop and strengthen partnerships between researchers, data controllers and knowledge users in the area of secondary data analysis.
- iii. To enhance capacity for further research of this nature in Ireland through upskilling, training and education of team members where possible.



HRB funding of Secondary Data Analysis Projects

- SDAP is the dedicated funding stream established under HRB strategy 2016-2020 for individual projects.
- We planned to run three rounds under the current HRB Strategy 2021-2025.
- Collecting and building on learnings, in line with latest developments, revise the new call for 2025 (launch in Q4 2024).



Learnings to Date:

- Interesting to note breadth of proposals including varied datasets and populations.
- Examples of most accessed datasets via SDAPs
 - The Irish Longitudinal study on Ageing (TILDA)
 - Primary Care Reimbursement Service (PCRS)
 - Hospital Inpatient Enquiry (HIPE)
 - Growing Up in Ireland (GUI)
 - Maternal & Newborn Clinical Management System (MN-CMS)
 - National Cancer Registry datasets (NCRI)
 - International datasets included the **UK biobank, Finnish Care Register for Health Care, and the English Longitudinal Study of Aging.**

Learnings to Date:

- Timing of the projects vary-some take longer to access required datasets.
- Time consuming to recruit relevant expert staff – scarcity of statisticians, data analysts, epidemiologists and PPI compared to the demand.
- Gaps in research design and methodology expertise.
- Challenges in using data resources - Lack of skillsets, expertise and incentives.
- Several requests for No-Cost Extensions due to COVID related delays.

COVID-19 Data Research Hub

- HRB in partnership with the Central Statistics Office and the Department of Health (2021-2023) developed a mechanism to provide **access to Irish COVID-19 data for research purposes.**
- The purpose is to make individual level administrative COVID-19 datasets available to researchers via the CSO Researcher Microdata Files (RMF) process under Section 20(c) of The Statistics Act, 1993.
- Research Data Governance Board (RDGB) acts as a central point for application receipt, screening, review and prioritisation of data requests and HRB is the secretariat.



COVID-19 Data Research Hub

Main data flows available for researchers

- HSE coronavirus assessments, test referrals and facilities data (a2I_src)
- COVID cases in hospitals for the previous 24 Hours (C19HospitalCases_src)
- C19 Covid Care Tracker Application Data Source Tier (CCT_src)
- HSE Computerised Infectious Disease Reporting System (CIDR_src)
- Hospital Inpatient Discharge Data (HIPE_src)
- National Office of Clinical Audit Intensive Care Unit Data (NOCA_src)
- COVID-19 Vaccine Data (In progress).

Lessons Learnt

Learnings applicable to HDABs regarding data access application management process.

Appetite for secondary use of data in research community

PPS identifiers and Eircode huge potential to enable research related to health inequalities e.g. social deprivation, health care utilisation

Limitations: Lack of access to specific data, funding for projects, potential to link, quality and “fit for purpose” of collected data.

Critical value of RDGB committee expertise

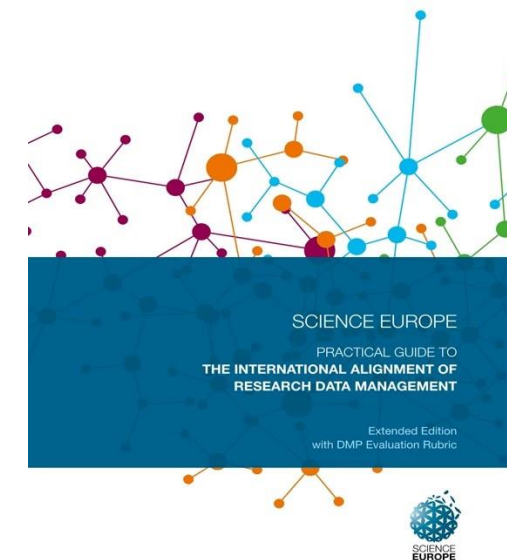
Potential to expand the available datasets beyond COVID-19.

HRB Policy on Management and Sharing of Research Data

- Came into effect from 01 January 2020.
- Requires a **Data Management Plan (DMP)** supplemental to all approved grant proposals where DMP requirements are specified within the award call guidance.
- The DMP will outline how the data for a specific project will be collected, organised, stored, backed-up, preserved, shared, archived and disposed-
- HRB DMP Template is closely aligned to **Science Europe DMP Template.**

Considerations :

- Host Institutions must sign a declaration that DMPs for research projects have been completed in partnership with an Institutional data steward or equivalent.
- The completed DMP and signed declaration must be submitted to the HRB as a first deliverable of all HRB Funded projects.
- A final updated version of the DMP must be submitted with the final report.



Next Steps

- Continue to review the Research Data Management Policy Landscape and Implementation of best practices.
- Research Data Management (RDM) Training Opportunities.
- Proposed HRB RDM Policy review and refresh in 2024, including consideration of FAIR agenda, and liaising with ZonMw on data management and FAIRification for data intensive investments
- As a funder, we are focussed on identifying gaps in the system and raise awareness of international RDM best practices.
- Continue to work closely with National Open Research Forum and Data Stewards across Host Institutions.



The Future

- Focusing on research opportunities via SDAPs.
- Reviewing SDAP Grant Scheme and introducing revisions needed.
- To offer improved opportunities for secondary use of health data nationally for research and innovation via SDAP and data hub.
- Continuing to work with NORF and Data Steward community to progress the Research Data Management Agenda.
- To develop partnerships with government organisations/stakeholders for optimising use of health data at national and international levels.

THANK YOU!

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