Management & Sharing of Research Data

26 March 2025

Sudipta Saha, *Project Officer*

Research & Innovation Infrastructures Unit

Health Research Board

Research. Evidence. Action.

Management and Sharing of Research Data Policy

- **Effective 01 January 2020**
- Requires **Data Management Plan (DMP)** submission as specified within 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
- Current HRB DMP Template aligned to **Science Europe DMP Template**

Requirements:

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

DMP what is it?

DMPs *state* ***what data*** *will be created and* ***how****, and outline the* ***plans for sharing, storage*** *and* ***preservation****, noting what is appropriate given the nature of the data and any restrictions that may need to be applied"*

DMP help researchers to:

- Make informed decisions
- Avoid duplication, data loss and security breaches
- Develop procedures early on for consistency
- Ensure data are accurate, complete, reliable and secure
- Plan to share data and increase impact

HRB DMP International Review 2024

Purpose

- Previous postal review in 2021 identified very low quality DMPs across awards
- Results fed back + engagement with institutional data stewards/community
- Policy requires DMP submission plus certification from HI Data Steward (Initial draft + final version)
- Re-assess quality of DMPs to influence any necessary updates or changes to our policy

DMP International Panel

Panel Members

- Dr Christiana McMahon, Research Data Support Officer, University College London
- Mr Matt Mahon, Research Information Officer, University of Glasgow
- Dr Gemma Marsden, Open Research Specialist, Cranfield University
- Ms Sarah Stewart, Research Data Manager, St. George's, University of London




DMP Assessment Criteria

1. Data Description & Collection or Re-Use of Existing Data
2. Documentation & Data Quality
3. Storage & Backup During The Research Process
4. Legal & Ethical Requirements, Codes of Conduct
5. Data Sharing & Long-term Preservation
6. Data Management Responsibilities & Resources & Feasibility

DMP Scoring

Scoring Range:
1-Poor, 2-Average, 3-Good, 4-Excellent

- **Score 4** would be 5-6/6 areas marked sufficient, excellent quality; no changes required
- **Score 3** would be 4/6 areas marked sufficient, good quality, some minor areas for improvement
- **Score 2** would be 3/6 areas marked sufficient, average quality and several areas for improvement
- **Score 1** would be 1-2/6 areas marked sufficient, poor quality and significant areas for improvement

Review Summary

Section 1 - Data Description & Collection

Strengths:

✓ Data types & methodology well-described

✓ Clear rationale for data use in some plans

✓ Reuse of existing data mentioned

Areas for Improvement:

❌ Justification for new data collection often unclear

❌ Data format (open/proprietary) not always specified

❌ Level/type of data sometimes vague

Section 2 – Documentation & Data Quality

Strengths:

✓ Strong documentation & version control in some plans

✓ Metadata standards occasionally addressed

Areas for Improvement:

❌ Metadata standards often undefined

❌ Quality control measures lack detail

❌ Long-term data quality maintenance unclears

Review Summary

Section 3 – Storage & Backup

Strengths:

✓ Backup strategies described (e.g., centralized systems)

✓ Some plans highlight secure storage

Areas for Improvement:

❌ Backup processes lack clarity

❌ Risks with personal device storage

❌ Encryption for external drives rarely mentioned

Section 4 – Legal & Ethical Requirements

Strengths:

✓ GDPR compliance frequently addressed

✓ Ethical approval & anonymization noted

Areas for Improvement:

❌ Ethical processes lack practical details

❌ Anonymization methods unclear

❌ Protocol change management vague

Review Summary

Section 5 – Data Sharing & Preservation

Strengths:

✓ Repositories & DOIs mentioned

✓ Some clear preservation plans

Areas for Improvement:

❌ FAIR data principles not fully addressed

❌ Long-term archiving plans vague

Section 6 – Data Management Responsibilities

Strengths:

✓ Roles/responsibilities often defined

✓ Institutional oversight mentioned

Areas for Improvement:

❌ PI's role in management unclear

❌ Costing/resources lack detail

Recommendations

- Panel & HRB recommended no changes to current policy
  -Continue requesting DMPs(initial + final) and signed declaration
- HRB to enhance our DMP template with further guidance
- Continue engaging with HIs/data stewards
- Actively follow-up with grant holders regarding DMPs pending submission
- Conduct another review in the future

HRB DMP Management

RDM Policy

- Applicant follow RDM policy and Call Guidance which specify DMP requirements and answer RDM related questions at application stage
- Mandatory DMP submission at 3-6 months from project start date
- Submit Final/Update version DMP at the end of the Grant

DMP Collection

- DMP submitted to HRB DMP inbox (**DMP@hrb.ie**) **all grants** expect DIFA
- DMP downloaded from email submission
- DMP linked to the grant folder on GEMS

DMP Monitoring & Review

- Not reviewing all DMPs
- Will review a sample as appropriate

Updated HRB DMP template

Based on the Science Europe Template

Section 1
Data Description & Collection or Re-use of Existing Data
Section 2
Documentation & Data Quality
Section 3
Storage & Backup During The Research Process
Section 4
Legal & Ethical Requirements, Codes of Conduct
Section 5
Data Sharing & Long-term Preservation
Section 6
Data Management Responsibilities & Resources

New HRB DMP template

New HRB DMP Guidance

HRB DMP Question	HRB DMP Guidance	Assessment Levels	
General Information		**Sufficiently Addressed**	**Insufficiently Addressed**
Administrative Information	Please provide: 1) Name of Grant Principal Investigator 2) Project Name 3) Grant Reference Number (if applicable) 4)Version of DMP (e.g. first/final)	Contains the minimal information required to identify the grant, grant holder and project	No or limited information provided impacting ability to identify who is responsible for the project, DMP and its implementation, or which grant it relates to
Section 1 Data Description & Collection or Re-use of Existing Data		**Sufficiently Addressed**	**Insufficiently Addressed**
1a How will new data be collected or produced and/or how will existing data be re-used?	Explain which methodologies or software will be used for data collection and/or data analysis	Gives clear details of where the data come from and how new data will be collected or produced. It clearly explains methods and software used	Provides no explanation, or insufficient details to get a clear understanding of where the data come from and what data will be collected or re-used
	State any constraints on re-use of existing data, if applicable	Explains, if existing data are re-used, how these data will be accessed and any constraints on their re-use	If applicable, does not explain sufficient rationale for generating new data
	Explain how data provenance will be documented	Explains clearly, if applicable, why new data must be collected, rather than re-using existing data	
	Briefly state the reasons if the re-use of any existing data sources has been considered but discarded		
1b What data (for example the kind	Give details on the kind of data: for example, numeric (databases, spreadsheets), textual (documents), image, audio, video, and/or mixed media	Clearly describes or lists what data types will be generated (e.g. numeric, textual, audio, video, etc.) and their associated data formats including, if needed, data conversion strategies	Provides no or little details on what data types will be generated and does not provide a valid reason for this omission (for example a statement that no data will be produced or generated)

New HRB DMP template

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DMP General Information

Grant Reference Number:		Principal Investigator/Grant Holder Name:	
DMP Version (e.g. first/final):		Project Title:	
Name of Person Completing DMP:		Role on Project (Person completing DMP):	

Section 1 Data Description & Collection or Re-use of Existing Data

1a How will new data be collected or produced and/or how will existing data be re-used?

Answer:

1b What data (for example the kind, formats, and volumes), will be colle

Note: Information derived from previously existing data sources - namely output, processed, new data under this question.

Answer :

Section 6 Data Management Responsibilities & Resources

6a Who (for example role, position, and institution) will be responsible for data management (i.e. the data steward)?

Answer :

6b What resources (for example financial and time) will be dedicated to data management and ensuring that data will be FAIR (Findable, Accessible, Interoperable, Re-Usable)?

Answer:

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HRB DMP template

New template and DMP declaration form can be found in the HRB website:

https://www.hrb.ie/funding/grant-management/reporting/

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hrb.ie


THANK YOU
ANY QUESTION?

HRB Open Research

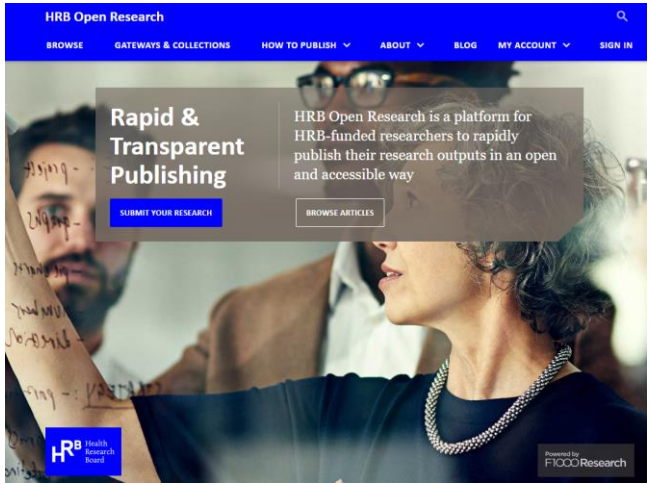
An introduction to the platform

Dr Irene Castellano, Health Research Board Ireland

Health Research Board

Research. Evidence. Action.

What is HRB Open Research?

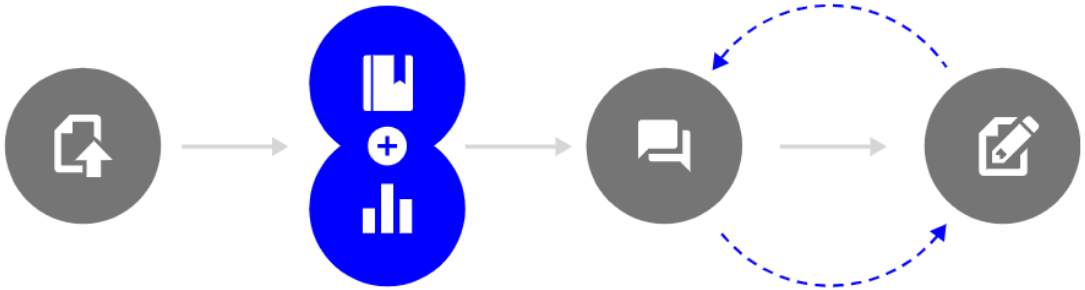


- Publishing platform launched in Feb 2018 for HRB grantholders
- Run by F1000 as service provider using open publishing model: Open access CC-BY; Open data; Open, post-publication peer review
- Focus on publishing all quality research outputs and offering a variety of article types
- **563 publications to-date**
- Number one most popular publishing venue for HRB funded researchers since 2018
- **Diamond model** - service costs and APCs paid centrally by the HRB, zero cost to authors for publication
- Same model as used on other open research funder platforms including Wellcome Open Research and Open Research Europe

http://hrbopenresearch.org

How it works?

Our Publishing Process



Article Submission

Submission is via a single-page submission system. The in-house editorial team carries out a comprehensive set of prepublication checks to ensure that all policies and ethical guidelines are adhered to.

Publication & Data Deposition

Once the authors have finalised the manuscript, the article is published within a week, enabling immediate viewing and citation.

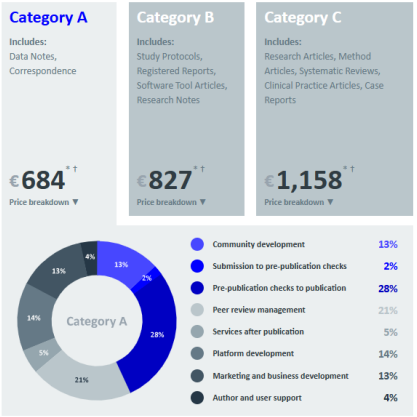
Open Peer Review & User Commenting

Expert reviewers are selected and invited, and their reports and names are published alongside the article, together with the authors' responses and comments from registered users.

Article Revision

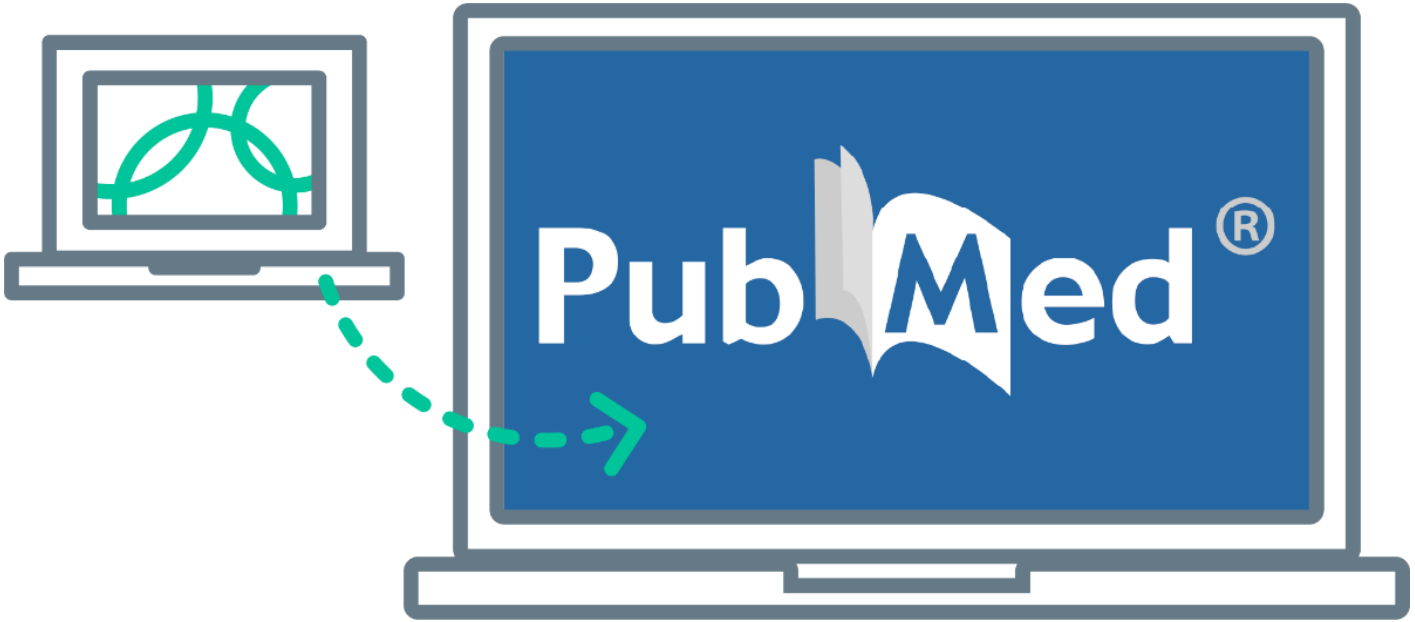
Authors are encouraged to publish revised versions of their article. All versions of an article are linked and independently citable. Articles that pass peer review are indexed in external databases such as PubMed; all published articles are included in Google Scholar, irrespective of peer review status.

Transparent pricing schedule



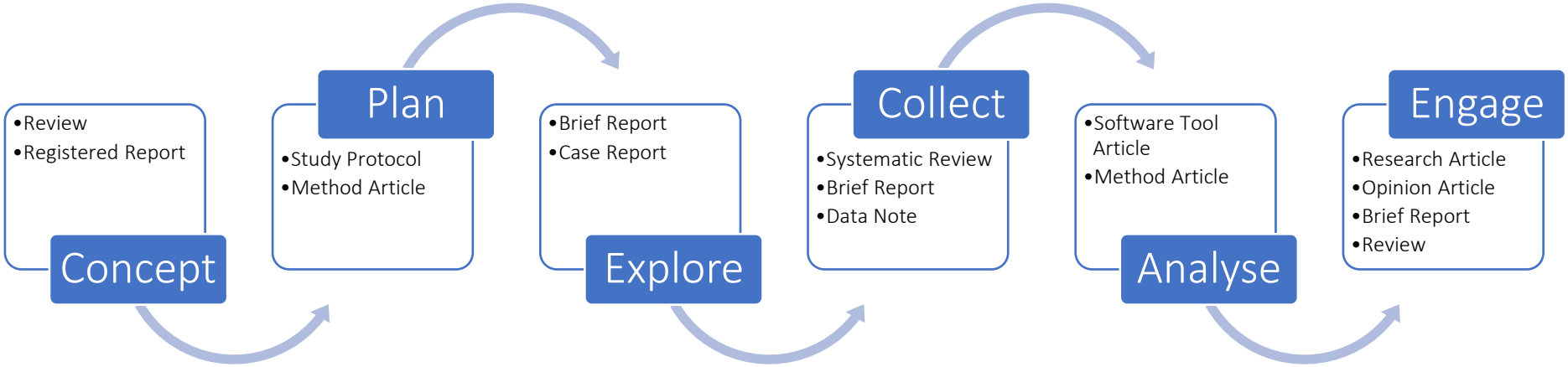
Annual charge
- Platform maintenance
- Monitoring, evaluation and reporting
- Communication and engagement

Indexation



HRB Health Research Board F1000

Wide variety of article types



HRB Health Research Board F1000

Why should HRB researchers publish here?

- **Fast** – articles published within a week once prepublication checks are passed
- **Inclusive** – can publish all your research outputs, including methods, study protocols and null results
- **Open** – fulfils HRB OA requirements
- **Reproducible** – data published alongside article
- **Transparent** – open peer review offers credit for reviewers
- **Easy** – costs are met directly by the HRB

Thank you!

Visit https://hrbopenresearch.org/

For information contact *openaccess@hrb.ie*

or

Emma Smith, Associate Publisher at *HRB Open Research: emma.smith@hrbopenresearch.org*

tilda
Staidéar Fadaimseartha na hÉireann um Dhul in Aois
The Irish Longitudinal Study on Ageing

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

WHO Collaborating Centre for Longitudinal Studies on Ageing and the Life Course

The Irish Longitudinal Study on Ageing (TILDA)

Data Availability & Access

HRB SDAP Seminar – March 2025

Dr Siobhan Scarlett – Senior Data Manager

What is TILDA

Baseline (2009-2011)

8,504 participants

8,175 (50+ years)

62% response rate

1 in 156 adults 50+

Repeat interviews every 2 years

Modes of Assessment

Computer Assisted Personal Interview (CAPI)

Face to face interview in the home

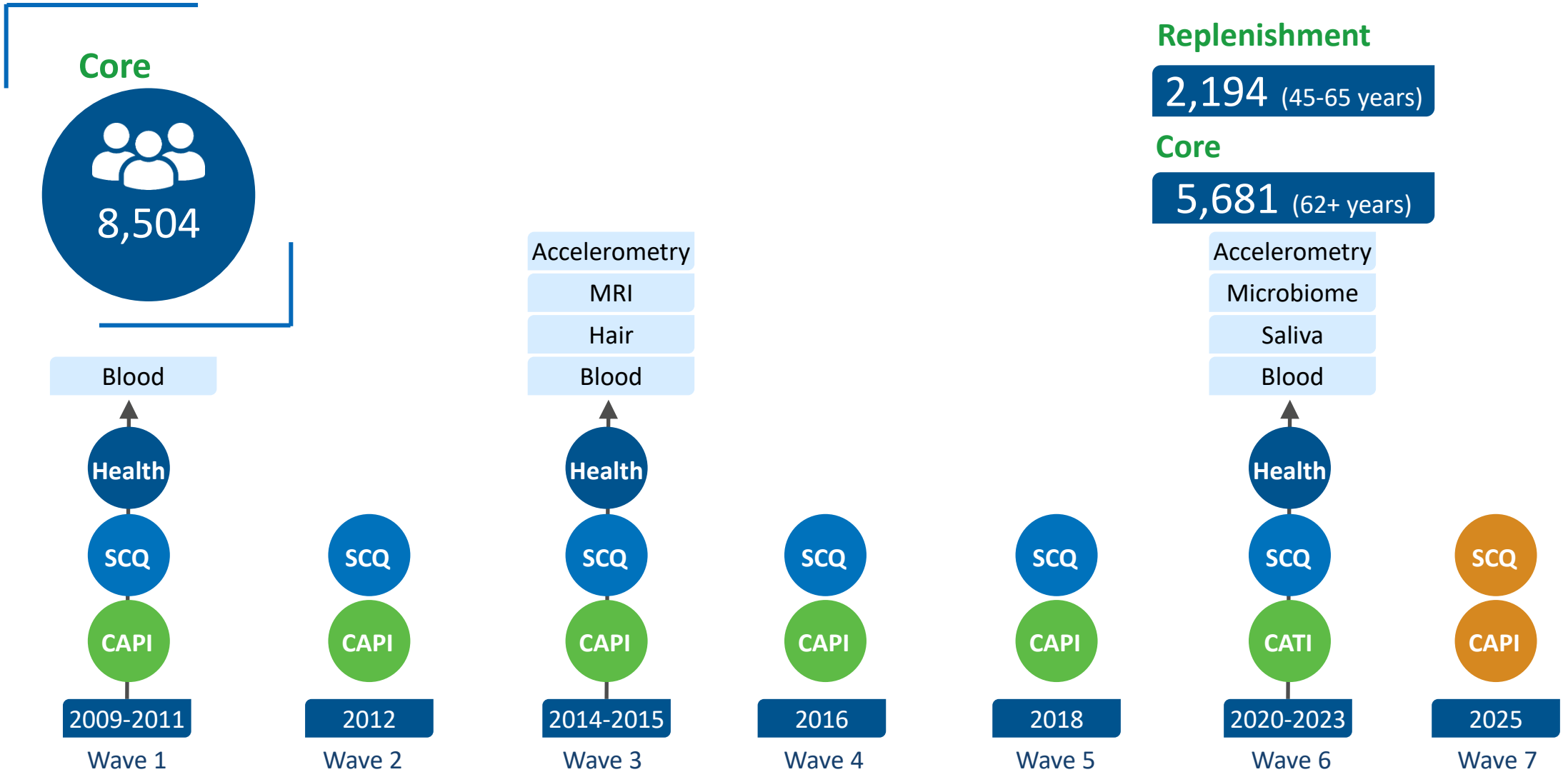
Self Completion Questionnaire (SCQ)

Paper questionnaire completed in own time

Health Assessment

Assessment administered by health practitioner in TILDA Health Assessment Centre

Waves of Data Collection



CAPI: *Computer Aided Personal Interview.* ***CATI:*** *Computer Aided Telephone Interview.* ***SCQ:*** *Self Completion Questionnaire, TILDA Health Assessment.*

TILDA Data

CAPI Content

Social

- Demographics
- Intergenerational Transfers
- Lifelong Learning
- Social Connectedness
- Expectations
- Driving/Travel

Economic

- Employment
- Job History
- Retirement Planning
- Sources of Income
- House Ownership
- Assets

Health

- Physical Health
- Cognitive Health
- Behavioural Health
- Mental Health
- Medications

Self-Completion Questionnaire

tilda

Social Activities	Loneliness	Accommodation Problems	Technology and Internet use
Relationship Quality	Ageing Perceptions	Anxiety	Pet Ownership
Alcohol Use	Quality of Life	Purpose in Life	Sleep Chronotype
Stress	Discrimination	Sexual Activity	Neighbourhood Disorder
Childhood Health Conditions	Creative Activities	Life Satisfaction	Food Frequency

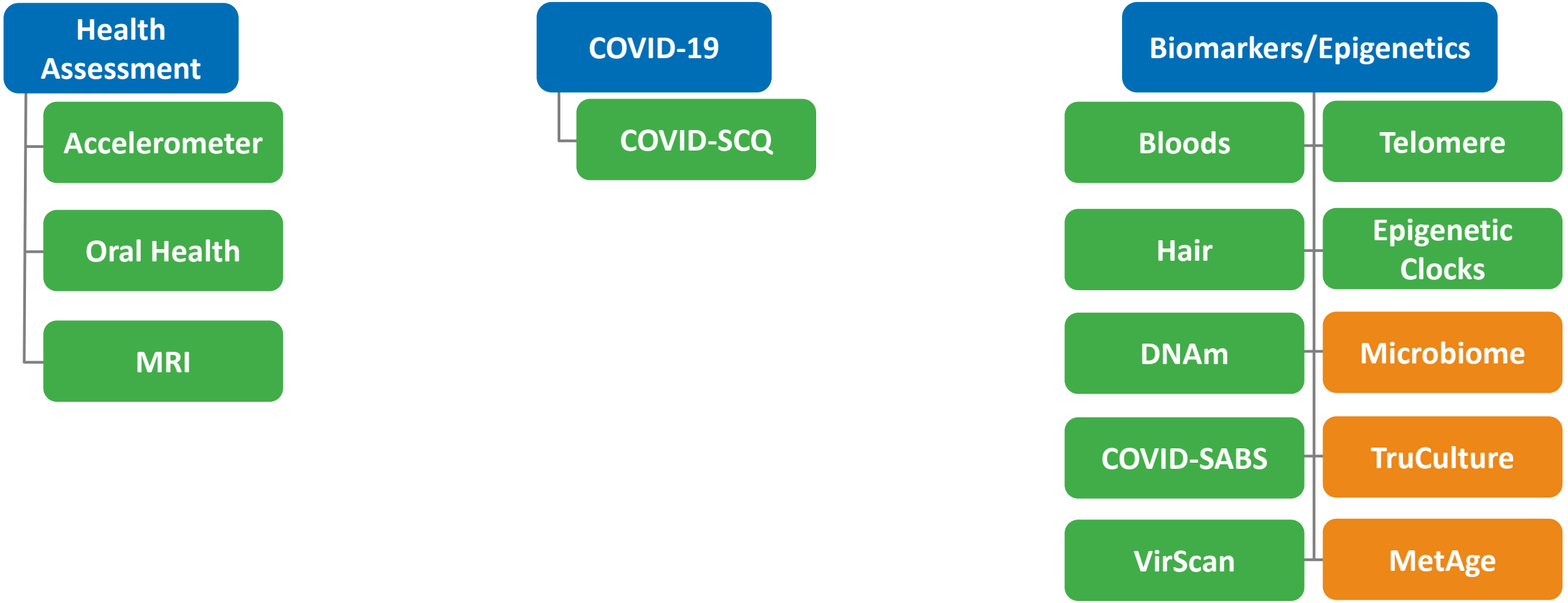
Health Assessment Content

tilda

Cognition	Cardiovascular	Physical Function	Anthropometric / Other	Vision
• MMSE • MoCA • SART • Choice Reaction • Colour Trails	• Blood Pressure • Pulse Wave Velocity • Phasic Blood Pressure • Near Infrared Spectroscopy • Heart rate variability	• Timed-Up and Go • Repeated Chair Stands • GAIT Speed • Heel Bone Ultrasound • Grip Strength	• Waist Circumference • Waist-Hip Ratio • Height • Weight • Blood Samples	• Retinal Image • Contrast Sensitivity • Visual Acuity • Macular Pigment Optical Density

Supplementary Datasets

Substudies



Supplementary Datasets

- GMS medical card scheme
- Medicines and food supplements
- Dosage, strength, cost of drug
- Inappropriate prescribing

88% Consent rate
Wave 1-5 linked (1.9million claims)

- RCSI & ICGP
- Health conditions, medications, vaccines, treatments, visits, emergency visits, healthcare utilisation
- No. of GP and nurse visits
- Medical card introduction

92% Consent rate
Ongoing Linkage (<1% complete)

HSE PCRS

GP Pilot

Data Linkages

Environmental exposure

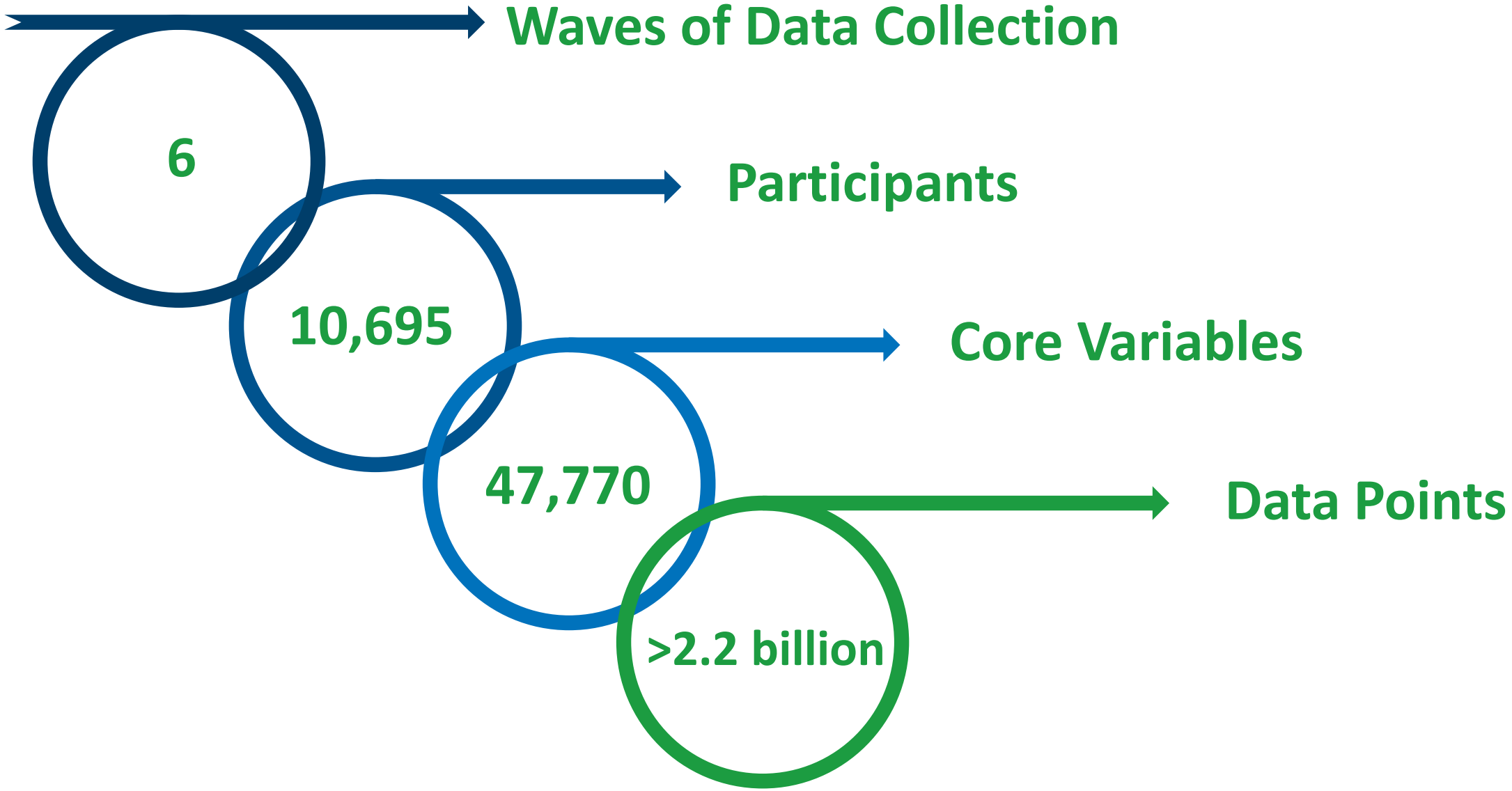
GRO

- GIS, Mapping, CSO, EPA
- Public services
- Environmental: Radon, Air pollution, water fluoridation mapping
- Green & blue space
- Lifetime Exposures

- Cause of death
- Co-morbidities
- Mortality
- End of life care
- Access and costs

89% match rate

TILDA in Numbers



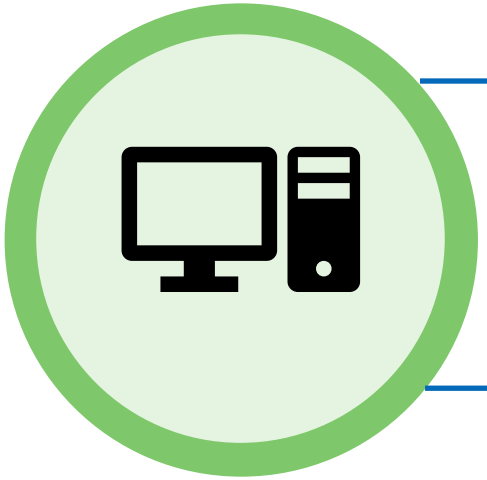
Access & Availability

Public Dataset Access

- TILDA Public Datasets archived with the ISSDA Data Repository.
- Application form available and processed through their website.
- Pseudonymised versions of the TILDA datasets - Waves 1 – 5 + COVID-SCQ. ***Wave 6 (Sep 2025).***
- All variables reviewed for inclusion.
- Datasets updated periodically to include new variables.
- If variable is too identifiable – variable is not included for release, or may undergo anonymisation techniques.
  - Top/bottom coding
  - Categorisation
  - Combination of variables
- Documentation detailing all variables public dataset status available on TILDA website and ISSDA.

Sensitive Dataset Access

https://tilda.tcd.ie/data/accessing-data/hotdesk/



In-Person Hotdesks

Restricted computers in TILDA offices

In-Person Hotdesks

Access sensitive TILDA data

Safe Haven

Restricted use – data cannot be removed

Bespoke datasets

Generate aggregated output

Online booking system

Researchers book in advance.

Access from 10am – 4pm Monday to Friday

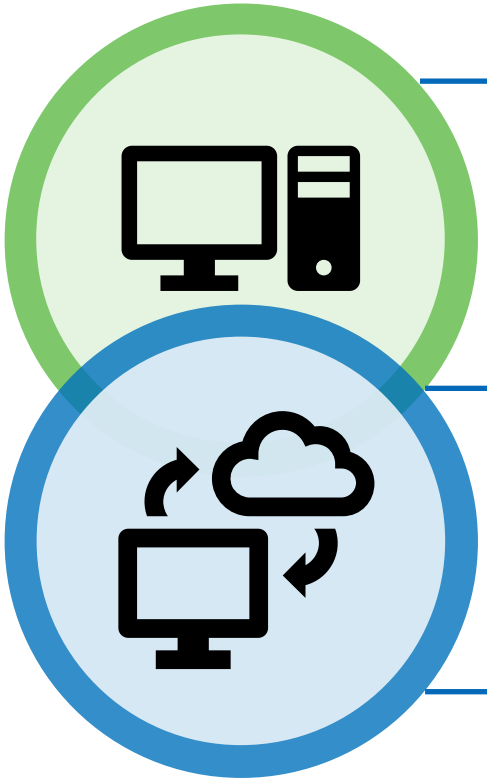
Results sent to users

Generated output reviewed at end of the week

Results emailed to researchers

Sensitive Dataset Access

https://tilda.tcd.ie/data/accessing-data/hotdesk/



In-Person Hotdesks

Restricted computers in TILDA offices

Remote Hotdesks

Cloud Connected Trusted Research Environment
(Available Q2 2025)

Remote Hotdesks: TILDA VISTA

Virtual Infrastructure for Secure TILDA data Access

Cloud Connection

Access from anywhere

Encrypted connections

2-factor authentication logins

Data does not leave host servers

Safe Haven

Restrictions in place

Data cannot be downloaded

Bespoke datasets

Secure analysis of sensitive data

Virtual Environment

Virtual Windows OS machines

Scalable as demand increases

Mixture of standard and high-performance computing power

Wide range of software available

Results Overview

Results must still be reviewed

Only aggregated output

Sensitive Dataset Access

- Hotdesk applications are reviewed every two weeks.

- Researchers are required to provide proof of GDPR training from their own institute, complete TILDA data training, and sign a data use agreement.

Data Availability & Resources

- Datasets must be cleaned and processed before release for analysis.

- New datasets released periodically – check with team re. timelines for access before applications.

- Resources available to help navigate the data-
  - TILDA in-person data workshops (https://tilda.tcd.ie/data-workshop/)
  - TILDA data workshop webinars (https://tilda.tcd.ie/data-workshop/webinar/)
  - TILDA questionnaires & documentation (https://tilda.tcd.ie/data/documentation/)
  - TILDA questions searchable database (https://tilda.tcd.ie/data/questionnaire/QuestionnaireHarmonisation/)

- TILDA team is available to check information such as sub-sample numbers in advance of applications.

Applying for SDAP using TILDA data

Contact TILDA Research & Development Manager first
Dr Ann Hever (hevera@tcd.ie)

Get in touch early in case there are any data queries we need to help with and to confirm availability of the data you are interested in using!

TILDA is supported by

An Roinn Sláinte
Department of Health

HRB
Health Research Board

The ATLANTIC Philanthropies

tilda
Staidéar Fadaimseartha na hÉireann um Dhul in Aois
The Irish Longitudinal Study on Ageing

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

WHO Collaborating Centre for Longitudinal Studies on Ageing and the Life Course

Get in touch:

tilda@tcd.ie
siobhan.scarlett@tcd.ie

Additional Funding

An Phríomh-Oifig Staidrimh
Central Statistics Office

Health Research Data Centre

Anthony Macken, CSO Health RDC – healthrdc@cso.ie

March, 2025

CSO Health RDC – brief history

- 2020 - emergency access to COVID-19 data
- Collaboration under S11, Stats Act between CSO, DoH, HSE, MU, OSi, UCD, ESRI, UL, NUI Galway on statistical reporting
- 2021 - Establishment of RMF access to C19 data in collaboration with the HRB, DoH and the HSE: Covid-19 Data Research Hub
- 2024 – Launch of CSO Health RDC

What is the CSO Health RDC?

- Launched - Q4, 2024
- Safe space for access to safe data collected by the CSO for Health Research purposes
- Operation underpinned by GDPR, Statistics Act, 1993, Data Protection Act, 2018 (Health Research Regulations)
- Further detail in CSO Transparency notice

What makes it safe?

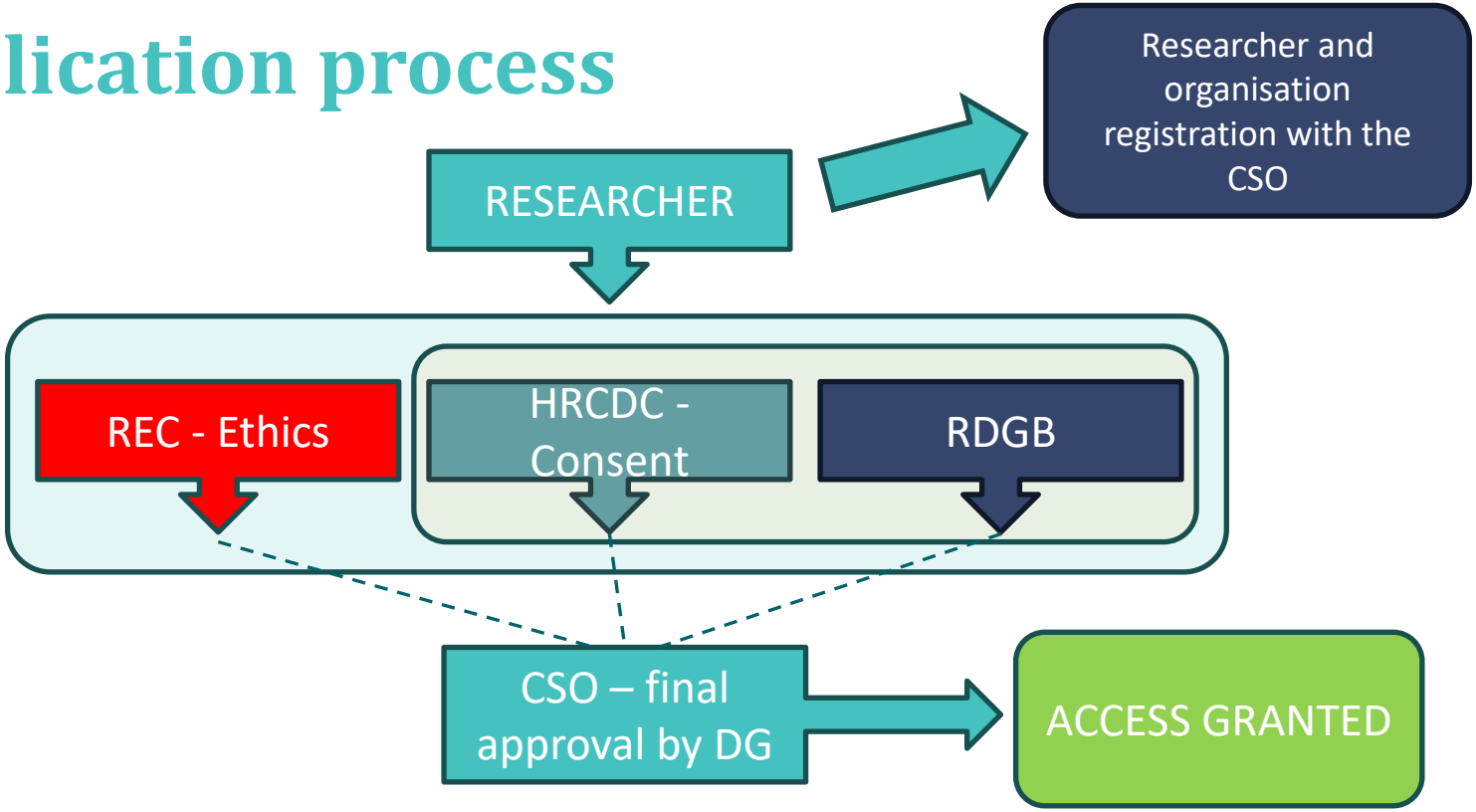
The Health RDC is underpinned by the 5 safes

Health RDC – what data can be accessed?

- IHS
- PCRS
- TILDA tbc
- Vital Statistics
- COVID
- …

- CENSUS
- GUI
- LFS
- SILC
- **Admin data**, e.g. Revenue, Welfare
- …

Application process



Research Data Governance Board (RDGB)

- Additional governance measure
- Main role is to assess the feasibility of the project with available data
- Members - experts in health research
- Monthly meetings

Health Research Consent Declaration Committee

HRCDC

- Explicit consent is a mandatory safeguard under the Health Research Regulations
- HRCDC consent declaration granted when it is satisfied that:
  - all data protection safeguards and technical and organisational measures have been met
  - the public interest in carrying out the health research significantly outweighs the public interest in requiring explicit consent

Health RDC data security - systems

- To access Health RDC microdata, a username, 2FA token and password are required
- CSO Research Data Portal (RDP) is locked down – not possible to export data
- Administration of permissions to access projects is automated via the Researcher Online System for Applications (ROSA)
- Expiry of projects is automated via ROSA.
- All outputs are checked prior to being exported to the researcher

Access to the data

- Secure remote access through CSO's Research Data Portal (RDP)
- Data remains on a CSO server at all times
- Statistical software:

R/R Studio

STATA

SPSS

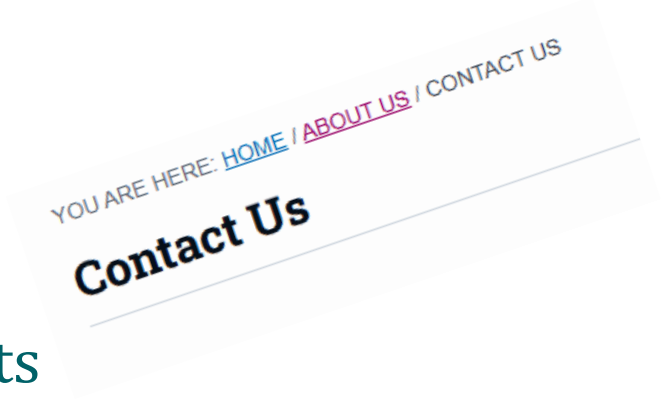
QGIS

Analysis Outputs

- Statistical Disclosure Control (SDC) must be applied
- Researcher has a legal obligation to protect the data confidentiality
- Only aggregated and safe outputs can be released

<< GP Postal Code	3181				
Patient Gender	Female				
Patient Age	31-40				
Number of Children	0	1	2	3	4+
Conditions					
Angina	0	0	0	0	0
High Blood Pressure	0	1	2	0	0
Stroke	1	0	0	0	0
Diabetes	0	2	0	1	0
Heart Attack	3	0	0	0	0

To get started…



- Contact Anthony at healthrdc@cso.ie
- Discuss research project requirements
- Full guidance provided on application process
- Further information on available data and linkage potential
- Where access is approved, guidance available from CSO on using the Researcher Data Portal

An Phríomh-Oifig Staidrimh
Central Statistics Office

Thank you for your attention

Anthony Macken,

CSO Health RDC

Email: healthrdc@cso.ie

March, 2025

National Care Experience Programme

National Care Experience Programme: Datasets and research priorities

Dr Conor Foley, National Care Experience Programme, HIQA

cfoley@hiqa.ie

Improving care experiences together

Health Information and Quality Authority

HSE

An Roinn Sláinte
Department of Health

About HIQA and the NCEP

- The Health Information and Quality Authority is an independent authority established to drive high-quality and safe care for people using our health and social care services in Ireland.
- The National Care Experience Programme is a partnership between HIQA, the HSE and the Department of Health

Mission

- To gather comprehensive feedback from people using services across health and social care services; improving quality, patient experience and outcomes through data-driven insights.

Vision

- To empower service providers with actionable insights that drive continuous improvement, enhance service user experience and ensure optimal care outcomes.

NCEP Strategy 2025-2027

Objective 1: To capture the voice of people using health and social care services

Objective 2: Provide actionable insights to drive improvements in health and social care

Objective 3: Strengthen stakeholder involvement through building a collaborative model

Objective 4: Building a high performing and innovative research offering to provide actionable insights and guidance to health and social care services

Improving care experiences together

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

HSE

An Roinn Sláinte
Department of Health

National Care Experience Programme

Improving care experiences together

Health Information and Quality Authority

HSE

An Roinn Sláinte
Department of Health

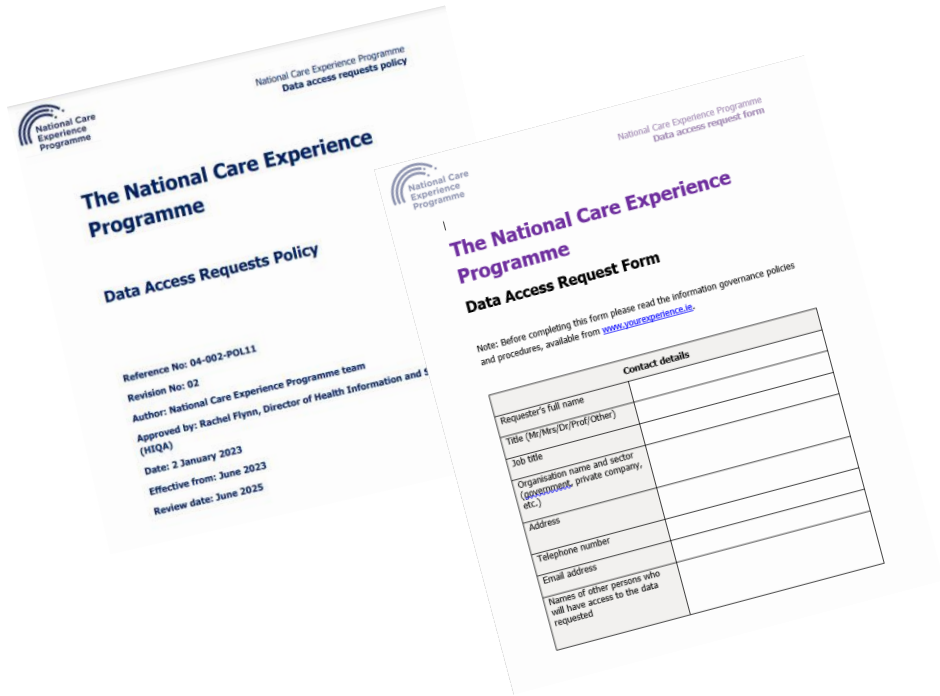
National Care Experience Programme

Each NCEP survey is developed using a defined multistage process and collects closed and open-ended responses

- National Inpatient Experience Survey
  - 6 iterations since 2017, over 70,000 respondents to date
- National Maternity Experience Survey
  - Conducted in 2019 (3,204 respondents), with 2nd iteration to commence in 2025.
- National Maternity Bereavement Experience Survey
  - Conducted in 2022, with 655 women who experienced a loss and 232 partners responding.
- National Nursing Home Experience Survey
  - Conducted in 2022, with 718 residents and 943 family members responding across a selection of 53 nursing homes, reflective of the national profile.
- National End of Life Survey
  - Conducted in 2023, 4,570 bereaved relatives responded, giving feedback on EOL can in nursing homes, at home, in a hospice and in hospital.

Accessing NCEP data

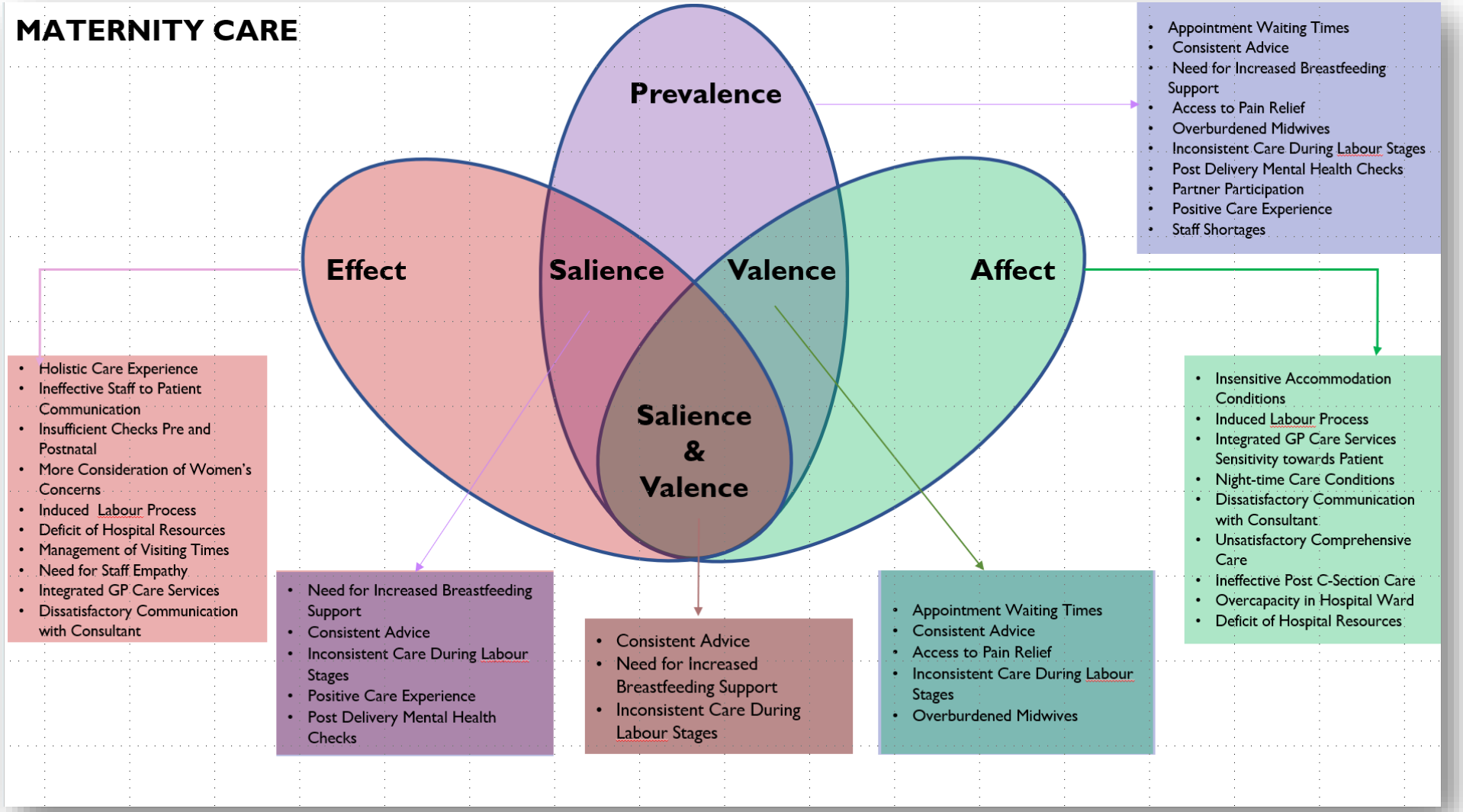
- Data access requests
  - Form accessible via yourexperience.ie
  - 53 access requests fulfilled to date
- Interactive dashboards
  - Tableau and PowerBI for survey results
- Online repositories
  - ISSDA
- Grant-specific arrangements



Successful grants

- 2 x SDAP and 1 x APA as knowledge user co-applicant. Academic partners from Maynooth, Galway and TUD
  - Exploring the demographic and healthcare factors associated with breastfeeding in Ireland; a gap analysis to develop a national infant-feeding survey tool (SDAP-2023-035).
    - Awarded €205,000, due for completion in 2026.
  - No data about us without us: Co-designing the Integration of Health Inequalities into the National Inpatient Experience Survey to Enhance the Participation of and Data about Marginalised Communities (APA-2022-022).
    - Awarded €234,000 (with co-fund), due for completion in 2026.
  - Generating actionable insights from the analysis of free-text comments from the National Care Experience Programme using Qualitative and Computational Text Analytics methods (SDAP-2021-012).
    - Awarded €348,000 (with co-fund), completed in 2024.

HRB-SDAP Maynooth Project Excerpt



Nature of the partnerships

- In all cases, academic PI with all funding going to university. PI led on all dealings with HRB
  - Co-funding provided by HIQA in some cases
  - Creating research agreements to govern working relationship
- Building on existing governance structures, as well as creating project-specific structures
- Time taken to work together to clearly define the problem, linking it to policy objectives
  - Setting clear and feasible objectives with very specific deliverables
  - Clear roles and responsibilities regarding which sections of applications to complete
- Broad range of co-applicants and collaborators
  - Policymakers, healthcare managers, inspectors, international counterparts, advocacy groups
  - NCEP as a stable partnership programme between HSE, HIQA and DOH
- NCEP and HIQA staff with experience of working on grants and funded projects

Example areas of interest for future research

- Triangulation of survey data with data on outcomes, process measures, regulatory compliance, etc?
  - Fitting care experience data into a bigger picture
- Looking across the full suite of surveys – what can we learn?
  - Coordination of care, transitions between services/sites
- Developing a toolkit, creating a community of practice and catalogue to assist providers to respond to survey findings effectively
- Exploring perceived/self-reported patient safety incidents and how they compare to notified patient safety incidents

THANK YOU

QUESTIONS

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www.yourexperience.ie

Improving care experiences together

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

HSE

An Roinn Sláinte
Department of Health

The HRB's national health information systems

SDAP meeting

March 2025

Dr Sarah Craig, Business Lead, NHIS

Health Research Board

Research. Evidence. Action.

Overview

- Overview of our systems
- Successful SDAP collaborations
- Opportunities for NHIS use

Strategic objectives

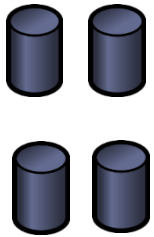
HRB Health Research Board

Research. Evidence. Action.

National Health Information Systems Unit

32 staff

4 systems



4 topic areas

- Mental Health (NPIRS)
- Disability (NASS)
- Drugs and Alcohol (NDRDI and NDTRS)

Overview of the 4 HRB Systems

National In-patient Psychiatric Reporting System (NPIRS)
Established 1963
c. 18,000 admissions & 18,000 discharges
- Database recording admissions to and discharges from psychiatric hospitals

National Ability Supports System (NASS)
Established 2018 (merge of 2 older disability databases)
c. 73,000 records
- Service planning database for HSE funded disability services

National Drug Treatment Reporting System (NDTRS)
Established 1990
c.25,000 cases p.a
- Epidemiological database recording treated drug and alcohol and other behavioural addictions

National Drug-related Deaths Index (NDRDI)
Established 2005
c. 800 p.a
- Census of drug and alcohol related deaths matching 5 sources of data (Coronial files, HIPE, GMR, CTL, PCRS)

Main outputs from the NHIS

Publication of reports/web updates

Data requests, bespoke analysis

Research collaborations

Interactive tables

SDAP projects

Successful SDAP collaborations using NHIS data

Health Research Board

hrb.ie

Successful SDAP collaborations

Year	Applicant	HRB dataset
2021	RCSI	NDTRS and NDRDI
2021	St James Hospital	NDTRS and NDRDI
2023	RCSI	NDTRS and NDRDI

RCSI project NDTRS and NDRDI, 2021

- A multi-indicator analysis of the supply, composition and patterns of use of prescription drugs with potential for misuse and the associated harms and responses in Ireland between 2010-2020
- Anonymised data for 10-year period from **NDTRS and NDRDI**
- Other data sources include HSE-PCRS, State Laboratory, Medical Bureau of Road Safety (MBRS) **National Drugs and Alcohol Survey (NDAS)**, National Self-Harm Registry, Irish Prison Services

ROYAL COLLEGE OF SURGEONS IN IRELAND

RCSI

St James Hospital INCLUDE project 2021

- INCLUDE: Integrating National Repositories for the Cooperation Linkage and Understanding of a Data Driven approach to the needs of Excluded people
- Using NDTRS and NDRDI data
- Other data sources: HIPE, Central Treatment List (CTL), Pathway Accommodation and Support System (PASS), Prison Management Information System, St James's Hospital Inclusion Health Database

RCSI project 2023

- Impact of guidance issued during COVID-19 to expand take-home doses of opioid agonist treatment (OAT) in Ireland: a population-based analysis of prescribing practices and patient outcomes 2018 to 2023
- Anonymised data from **NDTRS and NDRDI 2018-23**
- **Other data sources include** HSE-PCRS

ROYAL COLLEGE OF SURGEONS IN IRELAND

Opportunities in HRB data

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Data points for each NHIS

NPIRS

- Age
- Sex
- Ethnicity
- Employment status
- Legal status
- Homelessness
- Dates of admission and discharge, Admission and discharge diagnosis.

NASS

- Sex
- Date of birth
- Ethnicity
- Residential circumstances
- Specialist disability services used/ required
- Type of disability
- Diagnosis.

Data points for each NHIS ctd

NDTRS

- Sex
- Date of birth
- Sexual orientation
- Educational level
- Ethnicity
- Homelessness
- Dual diagnosis
- Drug use and risk behaviour
- Intervention/treatment, discharge (to & when).

NDRDI

- Sex
- Date of birth
- Ethnicity
- Homelessness
- Mental health
- Problem drug use at time of death
- Risk behaviours
- Drug treatment history
- Toxicology
- Details of death itself.

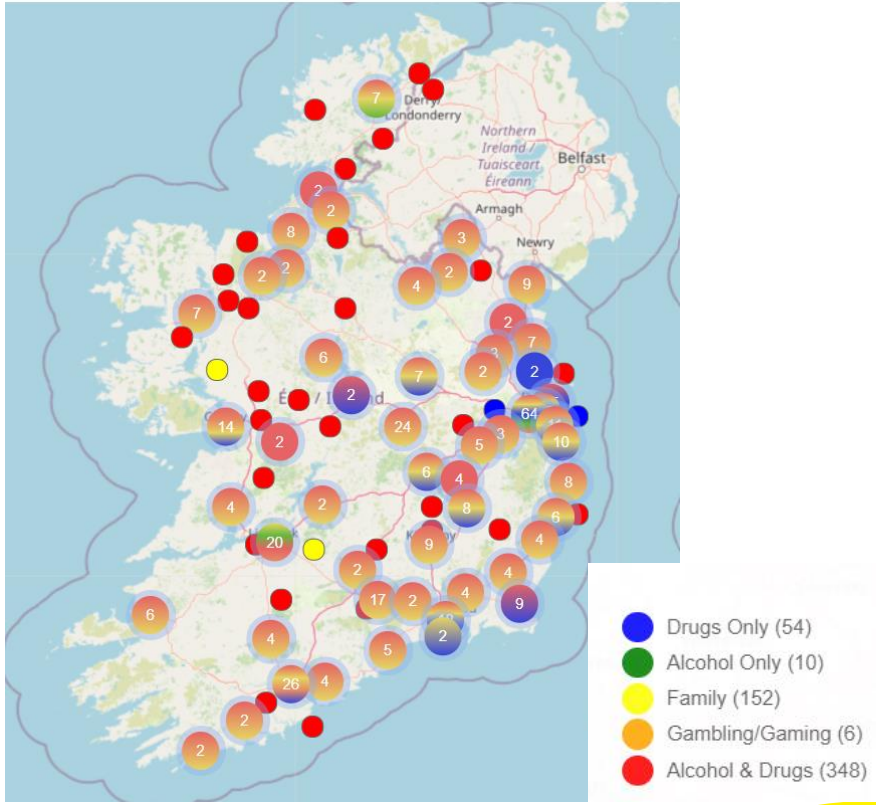
Recent developments

- NDTRS – Engagement with the Gambling Regulator on gambling module
- NDTRS - New modules added on drug related intimidation and dual diagnosis
- NDRDI – resumption of collection of probable suicide deaths for DOH started 2024
- NDRDI – addition of PCRS data so can examine more closely deaths with prescribable drugs implicated

Mapping of data

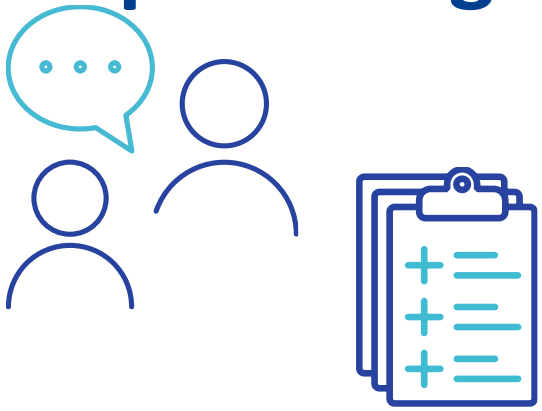
- Recent additions of HRs and IHAs to our systems
- Interactive map to identify location and type of services (partnership HRB/DOH)

https://www.drugsandalcohol.ie/services_map



NHIS requirements when providing data

- Initial engagement on feasibility
- Completion of data request form
- NHIS as collaborator or co-applicant
- Data usage agreement



- Destruction of data when project is complete

Thanks for listening
Any questions?