

# Secondary Data Analysis Projects (SDAP) 2025 Seminar Summary 26 March 2025

## **❖** Session 1 SDAP 2025 Scheme & SDAP Grant holders' Experience

#### SDAP 2025 Scheme

Session 1 commenced with attendees being welcomed to the HRB by Mr. Gavin Lawler, Programme Manager for the SDAP Scheme.

He highlighted the HRB's existing commitments and increased investment to support enabling secondary data analysis to occur under the HRB Strategy and presented an overview of the 2025 SDAP Scheme.

The 2025 call requires applications to be made on behalf of a consortium team of researchers, data controllers, and knowledge users and include effective public and patient involvement (PPI). Datasets must align with HIQA data quality standards and primary data collection is excluded from scope. There will be two cycles for 2025, to enable those unsuccessful in Cycle 1, to amend their application based on feedback and re-submit to Cycle 2. Applicants may apply to either cycle independently alternatively. Each cycle will have a two-stage assessment review process evaluating the scientific merit, knowledge translation, and PPI components. Applications recommended for funding should score highly across all assessment criteria.

#### **Key changes for 2025 include:**

- Budget: Increased from €250,000 to €350,000 per project
- **Duration**: Increased from 24 months to 36 months with an additional 6 months permissible (up to 42 months maximum in the development of a tool)
- Deadlines: Cycle 1 30 May 2025

Cycle 2 opens in **September** and closes **9 January 2026.** 

For further information including the Guidance Notes please see: <u>HRB Secondary Data Analysis</u> Projects 2025.

 Informing Youth Suicide Prevention and Mental Health Promotion through Secondary Analysis of the Planet Youth Datasets (Inform - YSP)

Speaker: Dr Bernadine Brady, Co-PI, UNESCO Child & Family Research Centre, University of Galway

Dr. Brady shared her SDAP experience via a project focused on analysing Planet Youth datasets involving 15,129 secondary school students.

## **Key findings:**

- Four patterns of adversity linked to self-harm and suicidality
- Declining mental health trends over time
- The critical role of community and individual protective factors

The challenges involve balancing academic rigor with policy needs to ensure research meets scientific standards while remaining actionable for policymakers. Additionally, maintaining strong HRB engagement and reporting structures is beneficial for facilitating impactful research translation. The project delivered academic outputs, policy engagement, and a youth advisory panel, contributing to Ireland's national suicide prevention strategy, Connecting for Life. Additionally, this work underscores the importance of data-driven approaches in addressing youth mental health crises.

 Disparities in Heath Outcomes of Chronic Kidney Disease Between Men & Women in the Irish Health System

Speaker: Prof Austin Stack, School of Medicine, University of Limerick

Prof Stack presented findings from his HRB SDAP analysing sex disparities in chronic kidney disease (CKD) outcomes in Ireland.

The research, involving 125,890 patients, revealed:

- Higher CKD prevalence in women
- Lower hospitalization rates for women compared to men
- Similar mortality rates between sexes

#### **Key Challenges:**

- Fragmented health data systems complicating comprehensive analysis
- Governance issues in data access and integration

Despite these hurdles, the study has significantly influenced both national and global policies. It has led to invitations to national strategy and policy events, contributed evidence for the Department of Health's Reform 2023, and informed the United States CDC surveillance of CKD for 2023-2024, including the National Kidney Disease Surveillance System. Prof Stack stressed the urgent need for integrated data infrastructure to improve CKD management and reduce care inequities. The HRB's support was pivotal to enable the project's success.

The DXA (Dual-energy X-ray Absorptiometry) Management Application Project (MAP): A
 Personalised Patient-centred Tool for Osteoporosis Screening & Fracture Prediction

**Speaker:** Prof John Carey, University of Galway

Prof. Carey presented on the Dual-energy X-ray Absorptiometry (DXA-MAP) Project, a HRB SDAP focused on improving osteoporosis screening and fracture risk assessment. By analysing existing Dexa scans, the team developed a personalized risk model for Irish adults, exposing gaps in current tools.

## Findings revealed:

- 300,000–500,000 Irish adults over 50 have osteoporosis
- High potential for post-fracture complications and suboptimal care

The project validated clinical tools and proposed a national osteoporosis program

#### **Key challenges:**

- Data access barriers
- Healthcare system inefficiencies
- Need for policy reform

Emphasizing value-based care, the DXA-MAP Project aims to transform osteoporosis management. They initiated a policy document to gain traction for a national osteoporosis programme. It outlines how to evaluate, treat, and manage individuals at risk, based on established standards and best practices.

**Learn more:** DXA-MAP Project

# Session 2 HRB Data Management Policy and Datasets

#### HRB Policy on Management & Sharing of Research Data

**Speaker:** Mr Sudipta Saha, Project Officer, Health Research Board, Ireland.

Mr Saha presented an overview of the HRB policy on Management and Sharing of Research Data, which has mandated Data Management Plans (DMPs) are required for funded projects since 2020. In 2024, an international review of submitted DMPs identified strengths (e.g., GDPR compliance) and areas for improvement (e.g., unclear metadata standards). The HRB has developed an updated HRB DMP template to assist grant holders to improve DMP standards which is aligned with the Science Europe template. The HRB will maintain current policy with enhanced guidance and institutional engagement to support grant holders.

## Key highlights:

- No changes to current policy-initial and final DMP must be submitted to HRB with host institution DMP declaration form certified
- HRB actively monitoring submissions for quality and will conduct further reviews
- DMPs should be submitted to <u>DMP@hrb.ie</u> (expect DIFA)
- Enhanced DMP template with further guidance available on HRB website

Resources: HRB DMP templates and Declaration form for HI

#### HRB Open Research Publishing Platform

Speaker: Dr Irene Castellano, Project Officer, Health Research Board, Ireland.

Dr. Castellano's presented an overview of HRB Open Research, an innovative open-access platform launched in 2018 to support HRB-funded researchers to publish their work transparently. F1000 manages the platform, which operates on a diamond model, eliminating author fees and supporting diverse outputs like protocols, data notes etc.

## Impact & Reach:

• 563 studies published since 2018, emphasizing reproducibility (via data sharing) and inclusivity for all research types.

#### **Researcher Benefits:**

 Provides a streamlined publishing pathway for HRB-funded researchers and is indexed in PubMed and other major databases.

**Explore more at:** HRB Open Research

## • The Irish Longitudinal Study on Ageing (TILDA)

Speaker: Dr Siobhan Scarlett, Senior Data Manager, TILDA

Dr. Scarlett presented The Irish Longitudinal Study on Ageing (TILDA), a comprehensive study tracking over 10,695 participants aged 50+ since 2009. Data is collected through interviews, health assessments, and linked datasets (e.g., GP records, biomarkers), covering social, economic, and health metrics.

#### **Key Updates & Requirements:**

- Data Access: Available via public datasets (ISSDA) or sensitive datasets through inperson/remote "hot-desks" (e.g., TILDA VISTA, launching Q2 2025).
   The introduction of the remote hot desk is a significant development, providing SDAP applicants with enhanced access options.
- Compliance: Researchers must complete GDPR training and sign data agreements.
- Support: TILDA offers workshops and documentation for applications.
- Recommendation: Early contact with TILDA's team is advised for SDAP projects.

**Learn more: TILDA** 

#### CSO Health Research Data Centre

**Speaker:** Mr Anthony Macken, Assistant Principal, Researcher Coordination Unit, Central Statistics Office

Mr Macken introduced the CSO Health Research Data Centre (CSO HRDC), a secure platform launched in Q1 2025 for accessing health research data. Governed by GDPR and the Statistics Act, the HRDC follows the "Five Safes" framework (safe people, projects, settings, data, outputs). It offers datasets such as Irish Health Survey, Primary Care Reimbursement Service, COVID-19 data, and census records through a secure remote portal with analytical tools like R and STATA.

#### **Key Updates & Requirements:**

- Launch: Q1 2025 follow-up to pilot HRB CSO Covid-19 Data Hub which operated during pandemic for access to Covid-19 data
- Approval Process: Requires clearance from the HRDC Research Data Governance Board (RDGB) and Health Research Consent Declaration Committee (HRCDC)/REC
- Confidentiality: Researchers must adhere to strict rules for aggregated outputs

Contact: healthrdc@cso.ie

#### • National Care Experience Programme

Speaker: Dr Conor Foley, Senior Analyst, HIQA

Dr. Foley introduced attendees to the National Care Experience Programme (NCEP), highlighting its collaborative foundation between HIQA, the HSE, and the Department of Health. NCEP collects patient feedback through surveys, including inpatient, maternity, nursing home, and end-of-life care experiences, with over 70,000 respondents to date.

## **Key Updates and Requirements:**

- Data Access: Available via interactive dashboards, ISSDA, and grant-specific arrangements.
- HRB-Funded Projects: Supported three studies including SDAP focused on breastfeeding, health inequalities, and text analytics.
- Future Research: Aims to link survey data with outcomes and enhance care coordination.
- Collaboration Focus: Emphasizes partnerships with policymakers and service providers.
- The program continues to prioritize patient-centred insights to drive healthcare improvements.

Learn more: yourexperience.ie

#### HRB National Health Information Systems (NHIS)

**Speaker:** Dr Sarah Craig, Head of National Health Information Systems

Dr. Craig showcased how the HRB's National Health Information Systems (NHIS) curate and maintain four essential health datasets:

- NPIRS (National Psychiatric Inpatient Reporting System)
- NDTRS (National Drug Treatment Reporting System)
- NASS (National Ability Supports System)
- NDRDI (National Drug-Related Deaths Index).

These systems support research through reports, data requests, and collaborations, including three SDAP-funded projects analysing NDTRS/NDRDI data on prescription drug misuse and opioid treatment outcomes.

#### **Key Updates and Requirements:**

• NHIS main outputs: Reports, web updates, data requests, bespoke analysis, research collaborations, interactive tables.

- Recent Developments: Engagement with the Gambling Regulator, resumption of probable suicide death collection, new modules on drug-related intimidation and dual diagnosis.
- Data Provision Requirements: Feasibility engagement, data request form, NHIS as collaborator/co-applicant, data usage agreement, data destruction post-project.

NHIS also offers an interactive <u>service map</u>

**Learn more:** NHIS