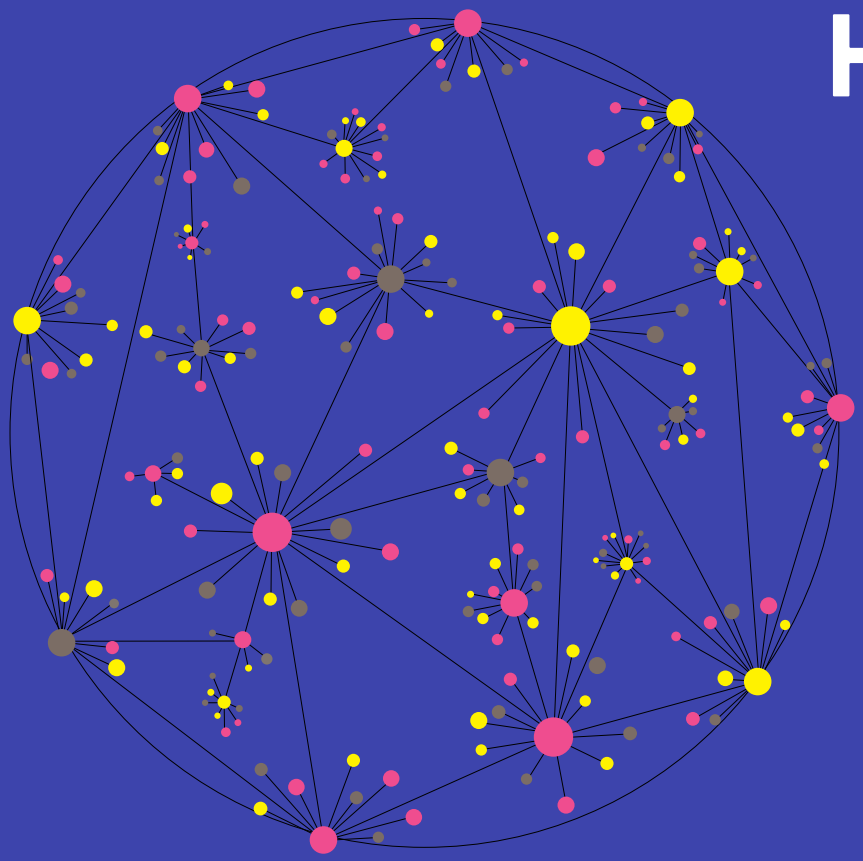
Health Research Board

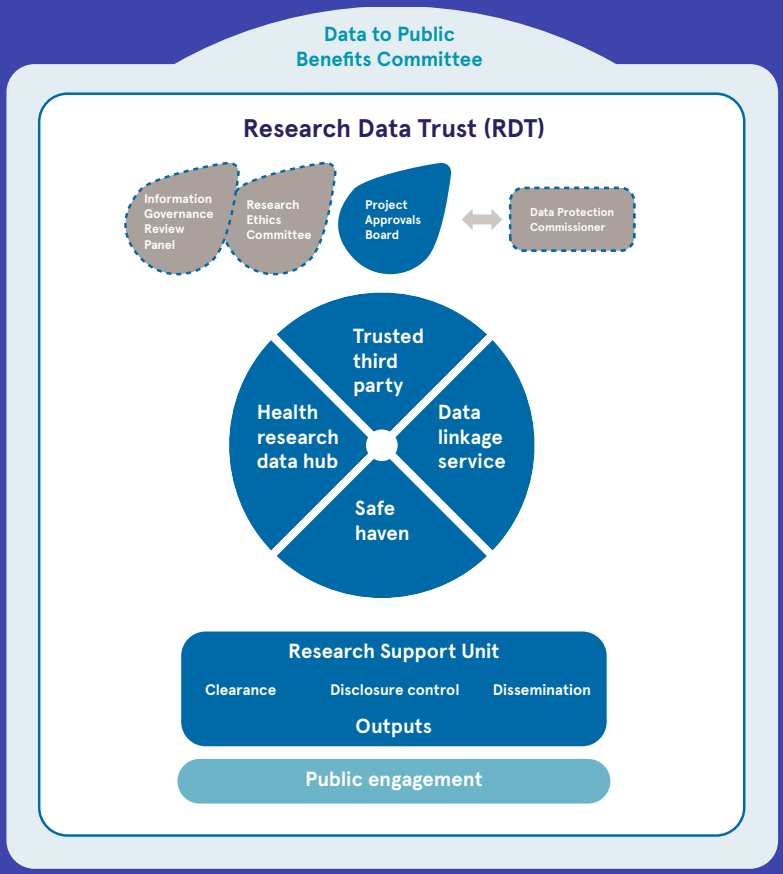


Proposals for an Enabling Data Environment for Health and Related Research in Ireland

Summary

The DASSL model

The key elements of the DASSL model are outlined here.
Their configuration requires further discussion and agreement.



The 'HRB Data Project' looks at the opportunity to improve people's health and healthcare delivery by creating safe access to health data and developing ways to link and share existing data effectively and responsibly.

The challenges

There are currently a number of challenges in relation to safely accessing data, sharing it with others and linking different datasets.

The HRB Data Project reveals that a range of complex cultural, social, technical and governance issues are the source of many concerns among data users. These include concerns around data protection and good governance, and poor skills in preparing data so that it is suitable for sharing.

Many questions with potential to inform policy and practice are not attempted, or are abandoned or inordinately delayed because data cannot be accessed in a timely manner.

Sometimes, data has to be collected all over again. This leads to duplication of effort, increased costs and delays in securing research results that would benefit people's health or the delivery of health and social care.

Patient confidentiality in the sharing of health data must be paramount. However, in line with the Caldicott Principles for using data, 'the duty to share information can be as important as the duty to protect patient confidentiality'.

So, ultimately, what we need to do is strike a solid balance between individual privacy and public benefit.

The potential

Ireland has considerable data resources in a number of fields which could be harnessed to advance medical treatments, enhance health service delivery and inform policy and planning across government and civic society.

These include:

- Routinely collected health services data (e.g. see ***Catalogue of National Health Information Sources in Ireland,*** 2014)
- Disease registers (e.g. Cancer Registry)
- Survey data and cohorts (e.g. Growing Up In Ireland)
- Census and administrative data

The fundamental question is - how can researchers and policy makers avail of one of our most valuable national assets i.e. existing data, and use such data in a safe, secure manner, protecting the privacy and confidentiality of the data subjects, and in accordance with existing legislation?

The purpose of the HRB Data Project is to explore these issues, identify the key players and their concerns, and formulate a way to address infrastructural deficits within the Republic of Ireland.

The proposals

The DASSL (Data Access, Storage, Sharing and Linkage) model which we have developed (see overleaf), following inputs from a wide range of stakeholders, and with reference to international experience, outlines the key elements required to create a robust data sharing environment in Ireland.

The model addresses the requirements for data access, sharing and linkage experienced by Irish researchers and identifies the infrastructure and services that need to be developed as part of the Irish data and statistical infrastructure going forward.

This model enables:
- Safe projects (valid research purpose)
- Safe people (trusted researchers)
- Safe data and data governance (people's data protected)
- Safe setting (security controls and secure environments)
- Safe outputs (disclosure control of outputs)

The main aim of this report is to stimulate a national conversation towards implementing the key elements of the model which will:
- maximise the use of our national data assets
- enable the health research community, as well as the broader science, technology and innovation ecosystem, to use it to deliver benefits for the Irish people and to enhance delivery of our health and social care services.

The future

If we want to have a safe and modern infrastructure that will enable researchers to unlock the significant value of currently underexploited data for public benefit, then the DASSL model, or a similar one, needs to be implemented. This will facilitate health research and other data analysis that serves national economic and social agendas.

The work undertaken by the HRB enables us to identify the most important pieces of infrastructure and data services needed in order to meet the data access, sharing, storage and linkage needs of both the health research community and the broader data community in Ireland.

The HRB believes that the DASSL model and the discussion document will stimulate much-needed debate and action towards establishing the data infrastructure and services required to improve people's health, enhance approaches to healthcare and support world-class research and innovation in Ireland.

A copy of the full report, *Proposals for an Enabling Data Environment for Health and Related Research in Ireland* by Rosalyn Moran, is available from the Health Research Board or online at www.hrb.ie/publications

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