

23 April 2024

Unlocking data for research that improves health, wellbeing and care

Roger Halliday



Sir Gregor Smith and Sir Ian Diamond

“I do think sharing data or being able to link data together has the potential to provide evidence to improve the lives of all our fellow citizens in a way that almost nothing else does, and that requires easy, ethical, privacy-enhanced data sharing”



“Having linked data available for research at pace was vital for our understanding of the factors underpinning the impact and risks associated with COVID-19, the effectiveness and safety of vaccines, as well as the wider societal and economic impact of the pandemic.”



Strategic Context

COMMISSION ON THE FUTURE DELIVERY OF PUBLIC SERVICES



A **Scotland** where everybody **thrives**
Public Health Scotland's strategic plan 2020-23



FAIRER SCOTLAND ACTION PLAN
FAIRER FOR ALL
ENDING CHILD POVERTY
YOUNG PEOPLE'S LIFE CHANCES
FAIRER WORKING LIVES
THRIVING THIRD AGE

How data helps public finances

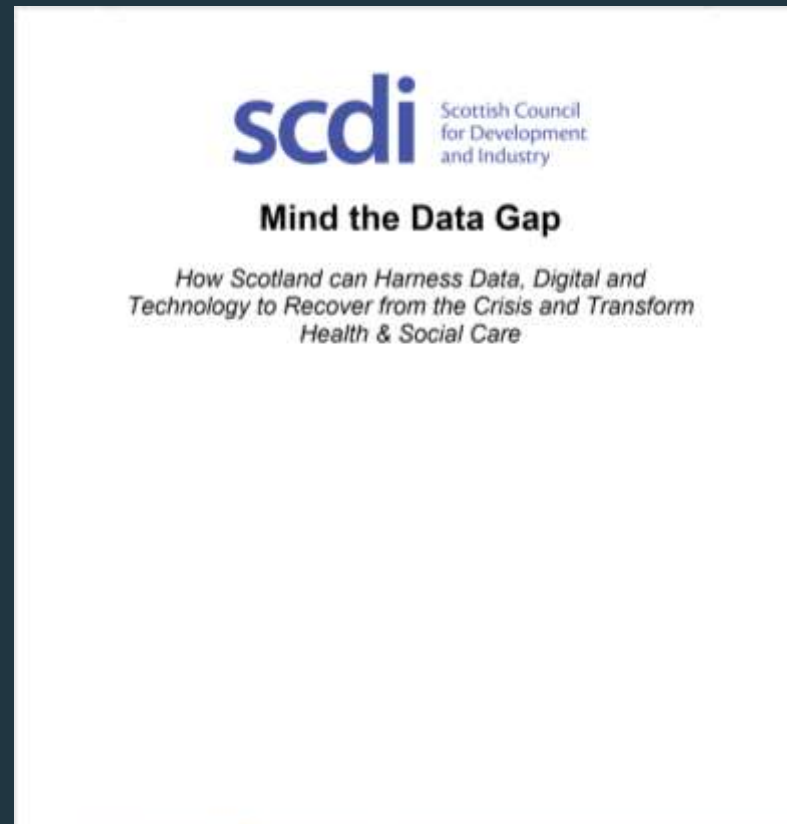
£20 bn to Scottish economy

£1 bn savings for public sector

High pay jobs in data science

Data and life sciences

Life Sciences Industry Leadership Group



Health and social care: data strategy

Supporting research and innovation

- Accelerate data access approvals
- Launch Research Access Service
- Develop industry data access approaches
- Industry representation in strategic data governance
- Data-enabled research study approaches
- Widening data available through Safe Havens
- Supporting international data-driven research



Health and homelessness

Saving time,
money and lives

Preventive intervention
trialled in NHS Scotland

Prediction using
linked data

Prediction using linked data

Linking data
across boundaries

Homeless people access to
healthcare barriers

Organising our
own data

400,000 (8% population)
homeless in last 20 years

About Research Data Scotland

We aim to help researchers make the most of existing data about people, places and businesses in Scotland.

- RDS does **not** generate or collect new data
- We simplify and speed up the use of excellent data that **already exists**
- Our focus is on sensitive **case-level data**, not aggregated data



Scottish integrated data infrastructure



Where we're heading

- Demonstrate trustworthiness
- Speed up data access
- Reduce complexity
- Widen range of datasets
- Connect data

Five Safes framework



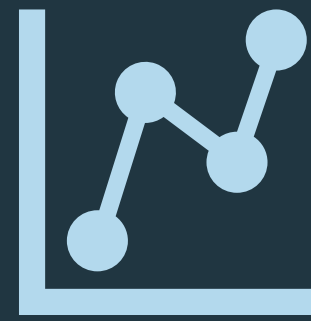
People



Projects



Settings



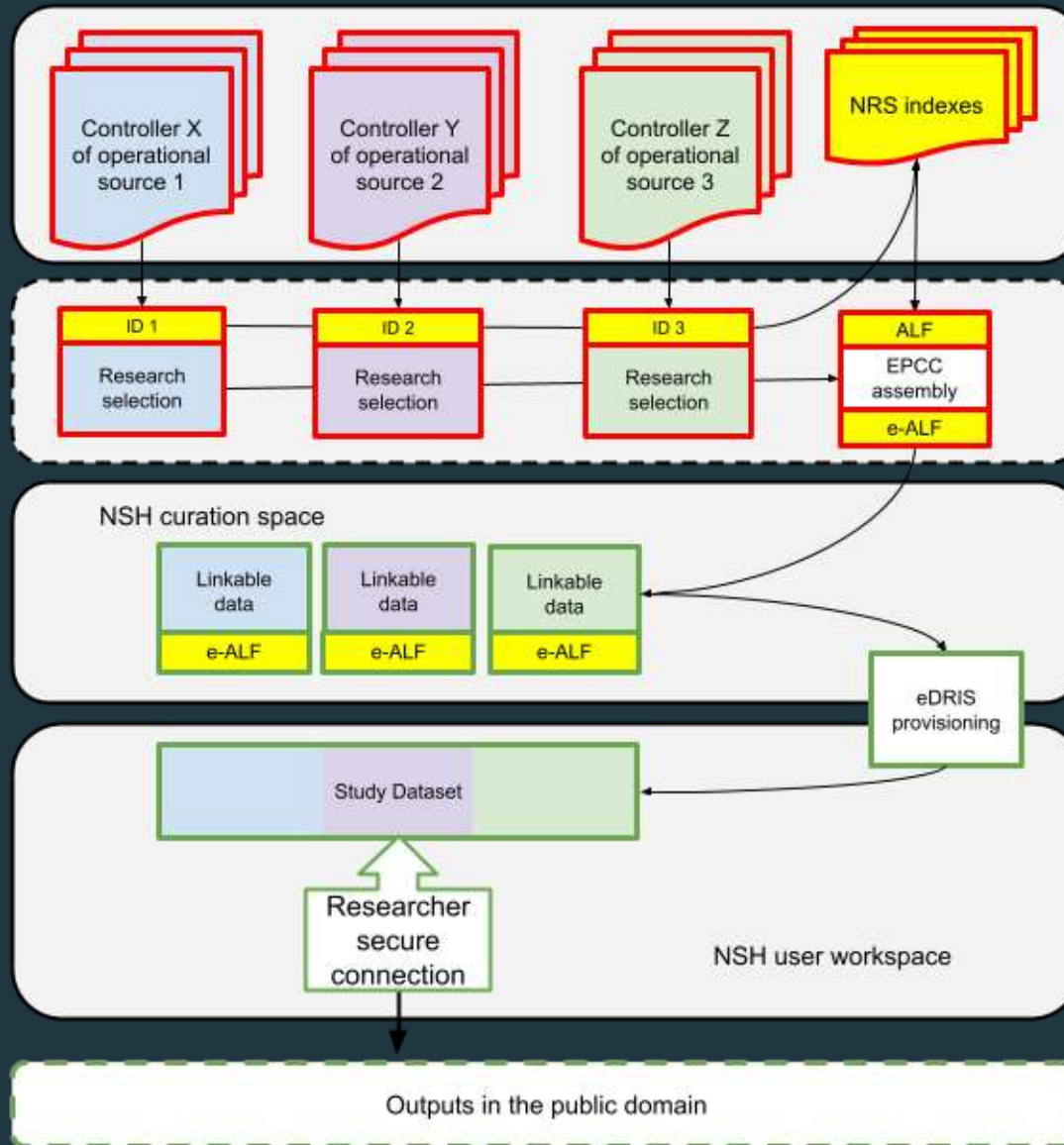
Data



Outputs

Functional anonymisation

Data process flow



Governance flow



Working with the public

We are committed to embedding public engagement as a vital part of the research we enable.

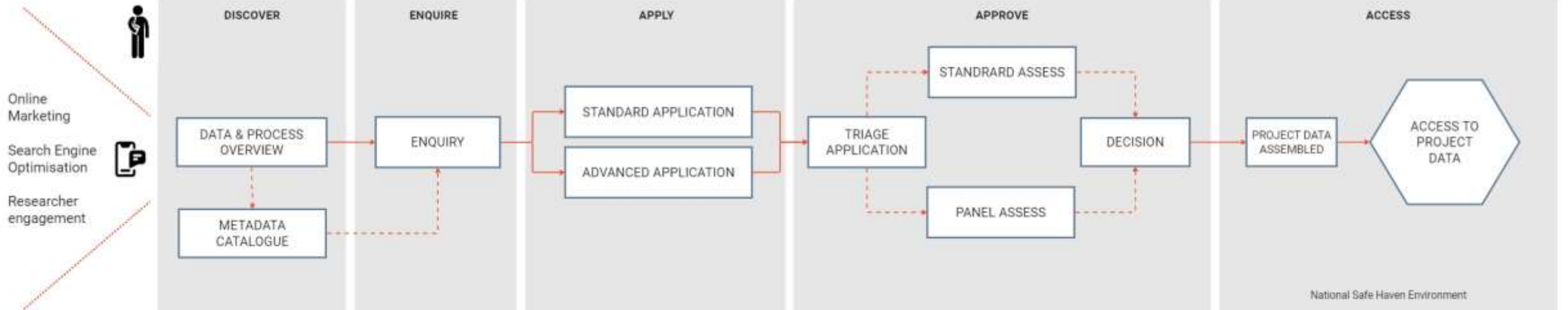
The public is broadly supportive of the use of data for research as long as three core conditions are met:

- Public interest
- Privacy and security
- Transparency and trust



Researcher Access Service

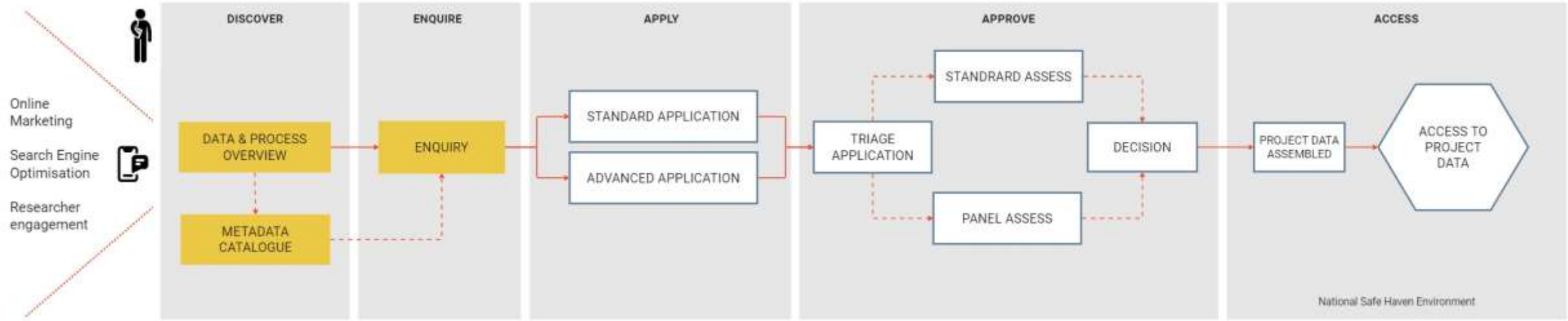
APPLICATION AND APPROVALS



Researcher Access Service

2023

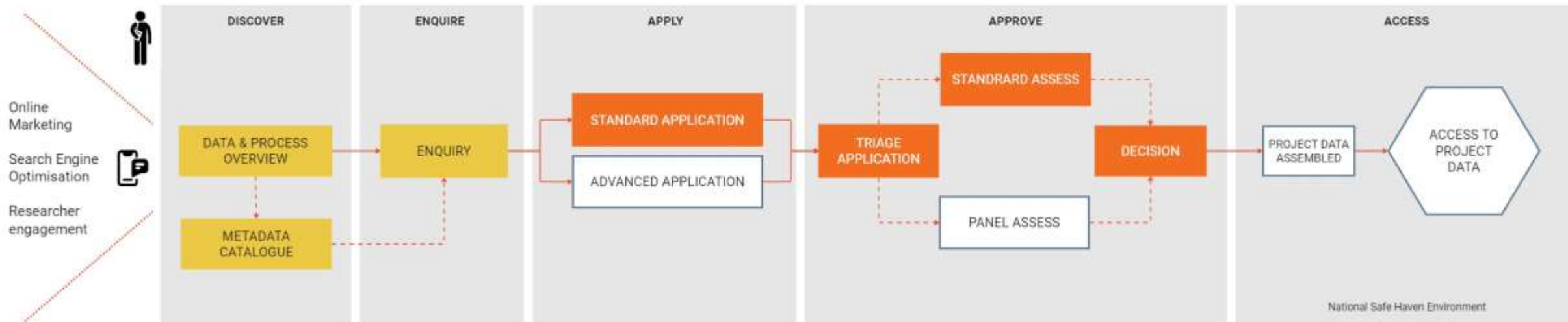
APPLICATION AND APPROVALS



Researcher Access Service

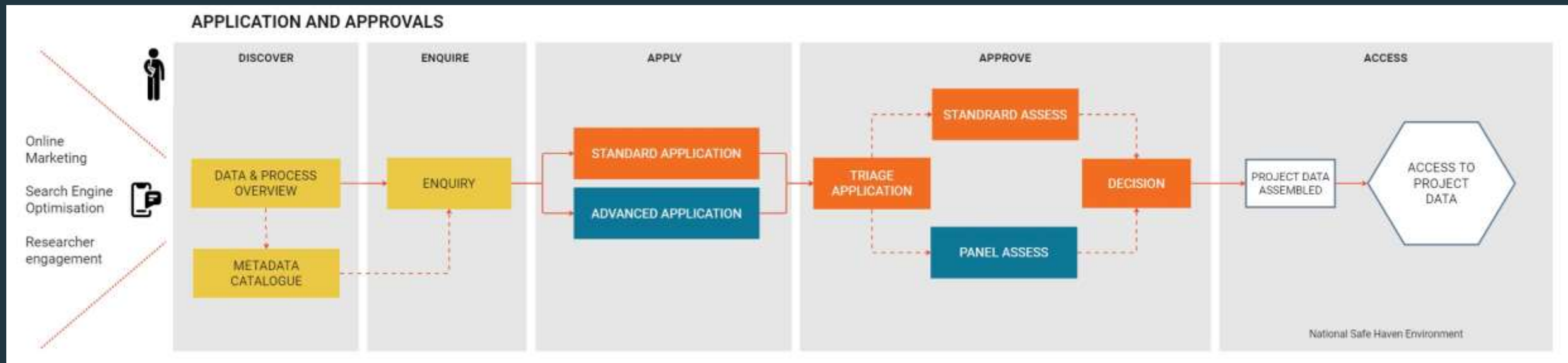
Early 2024

APPLICATION AND APPROVALS



Researcher Access Service

2024/25

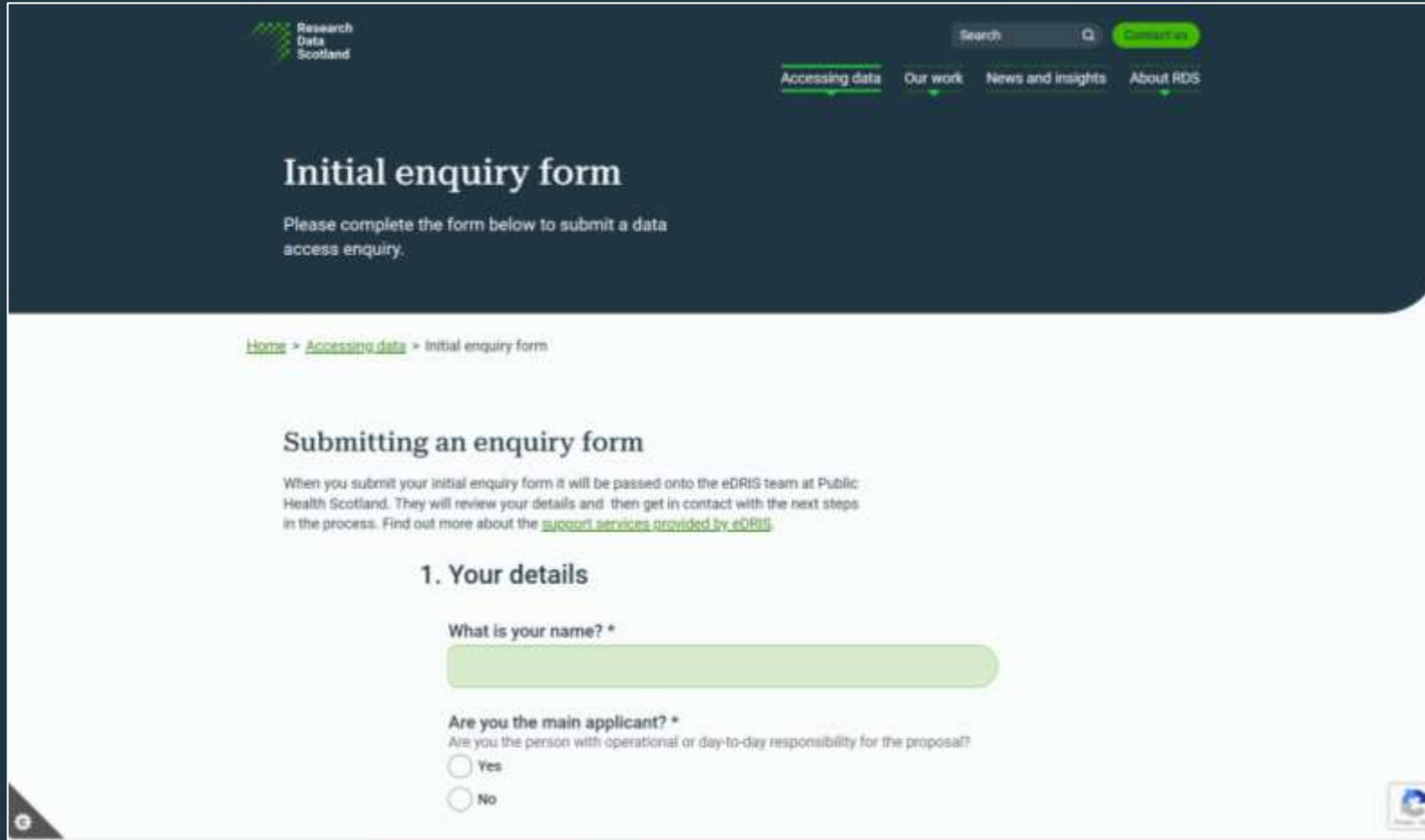


Applications and approvals

The 9 datasets available via this first release will be:

- SMR00 Outpatient (1997 onwards)
- SMR01 Inpatients and day cases (1981 onwards)
- SMR02 Maternity (1981 onwards)
- SMR04 Mental health inpatient and day cases (1981 onwards)
- SMR06 Cancer registrations (1981 onwards)
- PIS Prescribing Information System (2009 onwards)
- A&E (2011 onwards)
- Births (1981 onwards)
- Deaths (1981 onwards)

Getting a project started



The screenshot shows the 'Initial enquiry form' page on the Research Data Scotland website. The page has a dark blue header with the Research Data Scotland logo on the left, a search bar, and a 'Contact us' button on the right. Below the header, there are navigation links for 'Accessing data', 'Our work', 'News and insights', and 'About RDS'. The main content area is white and contains the following text:

Initial enquiry form

Please complete the form below to submit a data access enquiry.

[Home](#) > [Accessing data](#) > Initial enquiry form

Submitting an enquiry form

When you submit your initial enquiry form it will be passed onto the eDRIS team at Public Health Scotland. They will review your details and then get in contact with the next steps in the process. Find out more about the [support services provided by eDRIS](#)

1. Your details

What is your name? *

Are you the main applicant? *

Are you the person with operational or day-to-day responsibility for the proposal?

Yes

No

The page also features a Creative Commons license icon in the bottom left corner and a small logo in the bottom right corner.

<https://www.researchdata.scot/accessing-data/initial-enquiry-form/>

Is there a cost?

Academia and charities

Study type	2024/25 (£)
Small study	6,344
Medium study	15,860
Large study	23,790
Compute/disclose	1,087
Indexing support	3,172

Systems improvement project



Making data linkage faster and more efficient.

RDS led a group of technical colleagues from partner organisations to develop proposals for improvements to the National Safe Haven.

We will now work with partners to implement the recommended process changes, aiming to reduce waiting times for researchers to access data.



Scottish Data for Research Alliance



Synthetic data



'A new copy of a data set that is **generated at random** but made to follow the **structure** and some of the **patterns** of the original data set.' [1]



Synthetic data fund

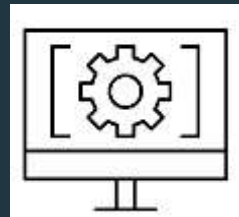


Synthpop



[1] Accelerating public policy research with synthetic data: a report from the Behavioural Insights Team: Dr. Paul Calcraft, Dr. Iorwerth Thomas, Martina Maglicic, Dr. Alex Sutherland (ADR UK)

Scottish Medical Imaging



Developed a
Minimum
Viable Service



Programme
management
approach
introduced
August 2021



Full launch of
SMI in April 2022
and completion
of SMI Service
Strategy

New modalities

2019

Created a
Minimum
Viable
Product



Beta service
launched
November
2020 with 3
years of
MRI, CT and
PET



SMI development
programme
started. New
governance
arrangements



Updated data

2022

2024

Dataset availability

Datasets from:



Available

In development

Future plans

Health

NRS births & deaths	GP demographics	
COVID health datasets	Medical imaging	
GP prescribing	Outpatients	NHS 24
Hospital inpatients	Other PHS datasets	
A&E data		

GP data
Hospital prescribing
Home care prescribing

Genomics

Education

Pupil census*	School leavers*
Looked after children*	Child protection*
Attendance/absence and exclusions*	
SQA National Qualifications*	

Child health/wellbeing census*	
PISA*	Growing up in Scotland*
Curriculum for Excellence levels*	
LEO: Earnings/welfare*	

University & college students*
Other qualifications*

Other

Farm structure survey*

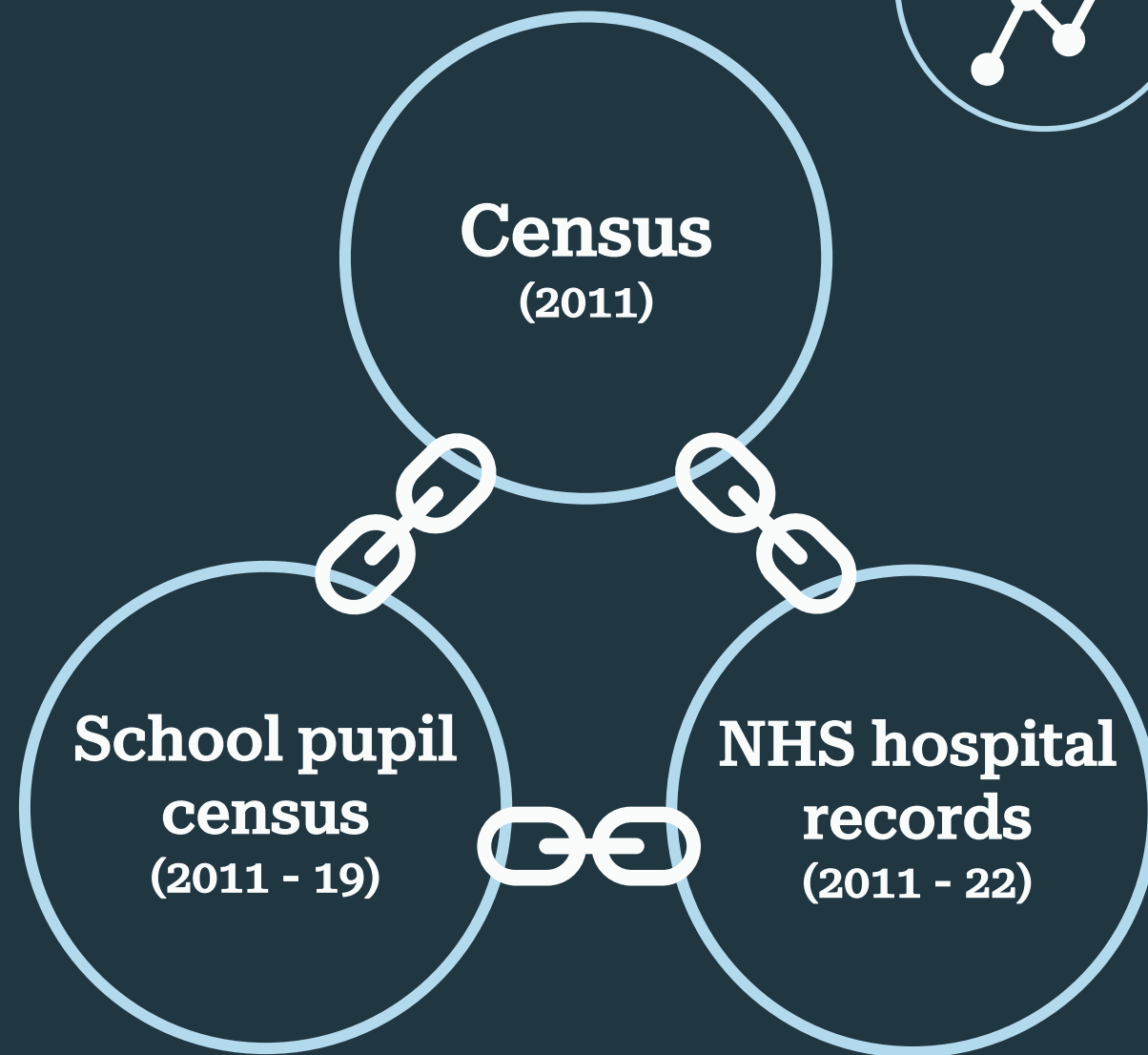
Veterans*
Prisoners*
Council tax
Offenders index*

Children's hearings	Household surveys*
Property transactions	Homelessness
Scottish Social Security	2022 census
Problematic substance use*	Geospatial*
Adult social care	Non-domestic rates
Home energy efficiency	Non-personal data

Equalities Protected Characteristics Dataset project



Data held by public bodies on protected characteristics is **patchy**, of **poor quality**, and often **missing**.



Collaboration with:



THE UNIVERSITY
of EDINBURGH

Scottish Safe Havens Steering Group



Developing the potential for federalised data held by national and regional safe havens

Areas of activity:

- A forum to discuss cross-safe haven collaboration
- Improvement opportunities including information governance
- Will be undertaking a Review of the Safe Havens Charter
- Commercial access to public sector data
- RDS Systems Development Fund
- Other funding opportunities
- PPIE / Public Engagement and Communications

Members include:



Grampian Data Safe Haven
University of Aberdeen • NHS Grampian



Connecting data held in multiple places



- Common policies – 5 safes
- A common place to find data
- A common way of indexing data
- A common application process



- Who prepares the data
- Delegated approvals
- How to link data from secure settings
- Where does the data sit



Private Sector data access for public good



Problem: No consistent arrangements in Scotland.

Aim: Enable appropriate use of data by industry.

RDS Role: Broker cross-sector alignment.

Deliverables:

- 2023 Q4 Draft operational policy to deliver on Scottish Government's forthcoming framework
- 2024 Q1 Cross-sector engagement plan and activities

Working with:



Scottish Government
Riaghaltas na h-Alba
gov.scot

Scottish Safe Havens



Greater Data Safe Haven
Greater Data Safe Haven



Health Informatics
Centre



Greater Glasgow
and Clyde



Public, Research Institute and Private Sector engagement



Innovative
healthcare
Delivery
Programme
Sector

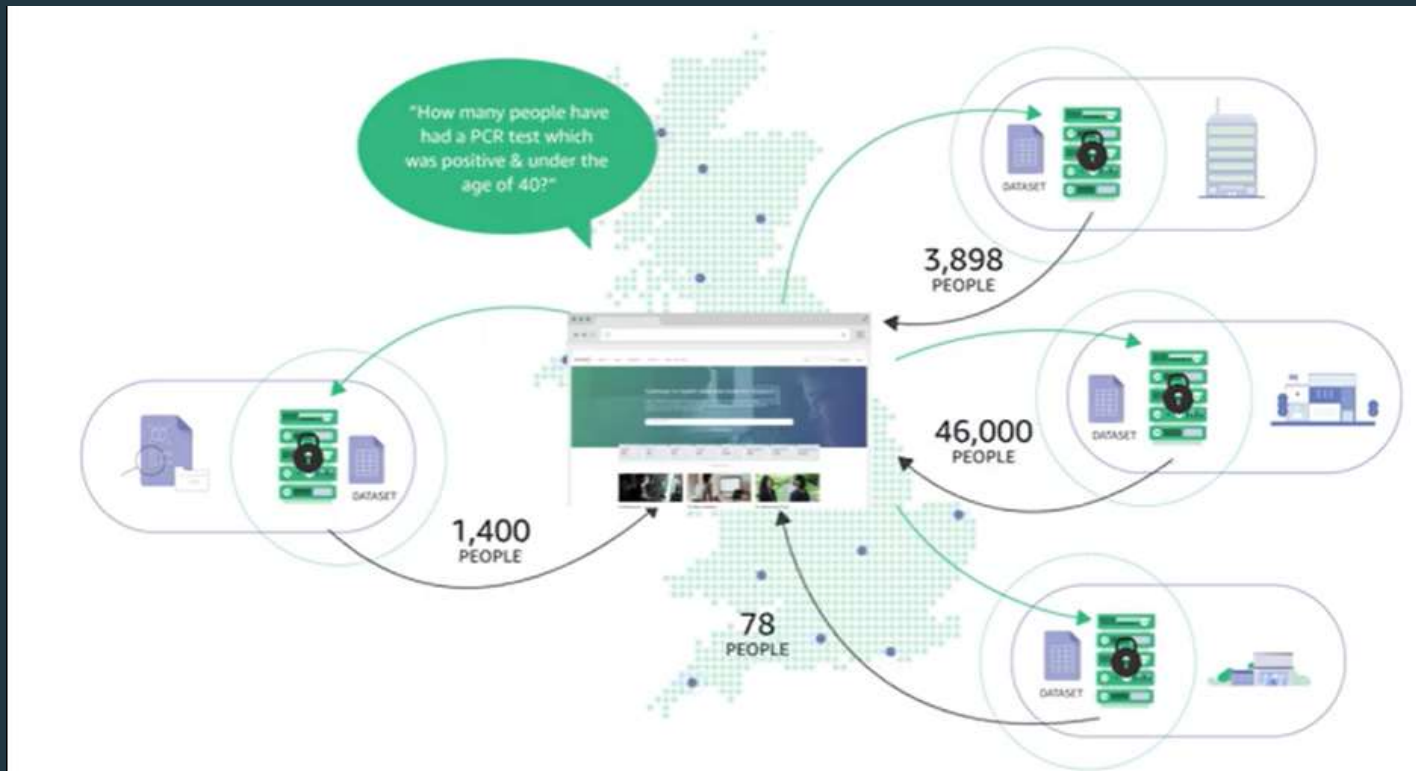


Review of data approvals

How might we maintain public confidence and trust with their data, while removing friction in the data request access application process?

Review findings	Recommendations	Next steps
<p>Frustrations from researchers and panel members</p> <p>Public view</p> <ul style="list-style-type: none">• Reasonableness test• Transparency key• Ethics review• include public/experts	<p>Aim</p> <p>Speed up decision making without losing robustness</p> <p>Changes</p> <ul style="list-style-type: none">• Simplify & digitise• Applicant training• Panel = public + expert• Transparency	<p>Support for changes</p> <p>Governance and resource to implement</p> <p>Priority</p> <ul style="list-style-type: none">• Simplify and digitise application

Cohort discovery tool



- Aim – quick federated size of cohort queries
- Technology HDR-UK led
- Mapping Scottish data
- Timeline autumn 2024

Where we're heading

Aligning approaches

- Refresh Safe Haven Charter
- Single point of access service model
- Industry data access policy
- Scotland Talks Data
- Build 3rd party indexing service

Shaping researcher services

- Run first Researcher Access Service
- Develop full service
- Support data approval improvement
- eDRIS & SMI business development
- National Safe Haven changes

**Faster, more
efficient access
to data for
research in the
public good**

Unlocking data

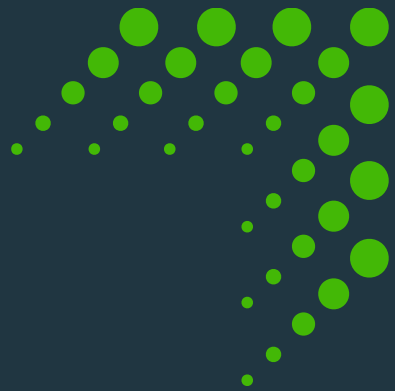
- Data sourcing & curation service
- Data curation/flow transformation
- Access to new datasets
- Set up ONS data share
- Synthetic data service

A sustainable system

- Secure IRO status for RDS
- Build capability to win funding calls
- Agreements with all RDS partners
- New business case to Scot Gov
- Offer for international investors

Questions for discussion

- What are your key research data gaps?
- How could we best make researchers aware?
- Are there people in your teams who would use?
 - And feed back to help us deliver service they need?



Research Data Scotland

 www.researchdata.scot

 [@RDS_Scotland](https://twitter.com/RDS_Scotland)

 [Research Data Scotland](https://www.linkedin.com/company/research-data-scotland)