





DAREUK

How is sensitive data made accessible for research?

Webinar, Tuesday 5 July 2022, 12-1pm







DARE UK (Data and Analytics Research Environments UK) aims to design and deliver a national data research infrastructure that is joinedup, demonstrates trustworthiness and supports research at scale for public good.





DARE UK is funded by UK Research and Innovation, the UK's biggest public funder of research and innovation.







Recap: What is a trusted research environment (TRE)?

A trusted research environment (TRE) is a **highly secure digital environment** that provides access to sensitive data for analysis by approved researchers.









Agenda

12:05-12:20: Public good research under the Digital Economy Act *Lily O'Flynn, UK Statistics Authority*

The Secure Research Service

Bill South, Office for National Statistics

12:20-12:30: The SAIL Databank and the ZOE COVID Symptom Study Chris Orton, Swansea University

12:30-12:40: The Administrative Data | Agricultural Research Collection project Nick Webster, Welsh Government

12:40-12:55: Q&A and discussion

12:55-13:00: Closing remarks

Public good research under the Digital Economy Act

Lily O'Flynn, UK Statistics Authority

07 July 2022



ELIZABETH II c. 30



Digital Economy Act 2017

2017 CHAPTER 30

An Act to make provision about electronic communications infrastructure and services; to provide for restricting access to online pornography; to make provision about protection of intellectual property in connection with electronic communications; to make provision about data-sharing; to make provision in connection with section 68 of the Telecommunications Act 1984; to make provision about functions of OFCOM in relation to the BBC; to provide for determination by the BBC of age-related TV licence fee concessions; to make provision about the regulation of direct marketing; to make other provision about OFCOM and its functions; to make provision about internet filters; to make provision about preventing or restricting the use of communication devices in connection with drug dealing offences; to confer power to create an offence of breaching limits on ticket sales; to make provision about the payment of charges to the Information Commissioner; to make provision about payment systems and securities settlement systems; to make provision about qualifications in information technology; and for connected purposes. [27th April 2017]

B E IT ENACTED by the Queen's most Excellent Majesty, by and with the advice and consent of the Lords Spiritual and Temporal, and Commons, in this present Parliament assembled, and by the authority of the same, as follows:—

DEA Research Powers

- 1) Allows **public authorities** to share their data for research purposes, if they wish to.
- 2) Provides a set of principles and rules that must be met in order for the data to be shared safely and securely.
- 3) Names the UK Statistics Authority as the body responsible for implementing and operationalising these rules and principles, in order for secure data sharing to go ahead.

What is the



Our role in research accreditation...

Independent body that operates at arm's length from government

UKSA Strategy: Joined up data

Statutory responsibility set out in the legislation

Accreditation of researchers, processors and research projects

Research Code of Practice and Accreditation Criteria

- Confidentiality
- Transparency
- Ethics and the law
- Public interest
- Proportionality
- Accreditation
- Retention and onward disclosure

33.1 The Act makes it a condition of the disclosure of data that the research for which the data is disclosed is in the public interest. For the purposes of accrediting research projects the Authority interprets public interest in the same way as 'public good', as set out in the Statistics and Registration Service Act 2007. To secure accreditation, the primary purpose of a research project must therefore be to serve the public interest in one or more of the following ways, to:

- · provide an evidence base for public policy decision-making;
- · provide an evidence base for public service delivery;
- provide an evidence base for decisions which are likely to significantly benefit the economy, society or quality of life of people in the UK, UK nationals or people born in the UK now living abroad;
- replicate, validate, challenge or review existing research and proposed research publications, including official statistics;
- significantly extend understanding of social or economic trends or events by improving knowledge or challenging widely accepted analyses; and/or
- improve the quality, coverage or presentation of existing research, including official or National Statistics. [factnote 11]

https://www.gov.uk/government/publications/digital-economy-act-2017-part-5-codes-of-practice/research-code-of-practice-and-accreditation-criteria

Accreditation

Researchers

Trained individuals with proven skills and experience.

Safe people accessing and using the data.

Safe setting to access the data.

Safe data which is processed and de-identified before access.



Processors

Trusted research environments that are periodically audited to demonstrate security and capability.

Research

Defined projects that the UKSA accredits as meeting the standards in the Research CoPs.

Safe project setting out the remit of the data use.

Safe outputs coming out of the environment once the research has taken place.



Processor Accreditation: Trusting Research Environments





UK Statistics Authority > Digital Economy Act: Research and Statistics Powers

- > <u>Digital Economy Act Accredited Processing Environments</u>
- > List of Digital Economy Act Accredited Processing Environments

List of Digital Economy Act Accredited Processing Environments

Digital Economy Act Accredited Processing Environments are accredited for the purposes of processing data, whether that processing be concerned principally with the linkage or de-identification of data, or the storage and provision of secure access to de-identified data.

If your organisation is interested in becoming an Accredited Processing Environment under the Digital Economy Act, please email Research.Accreditation@statistics.gov.uk.

- UKSA responsible for assessing the security and capability of processing environments to award accreditation.
- Transparent framework setting out requirements for accreditation.
- Audits of accredited TREs to ensure maintained compliance as a minimum.
- Emphasis on improving maturity and service provision for researchers and analysts.



Project Accreditation: Approving Access to Data



Research project application worked by researcher with support of accredited TRE. Approvals from data owners sought.

Final research project and ethical approval provided to the UKSA by TRE for accreditation.

UKSA agrees whether the project can be accredited, or whether independent scrutiny is required.

Average timings

Where required, project reviewed by Research Accreditation Panel for independent accreditation decision.

+ 5 days

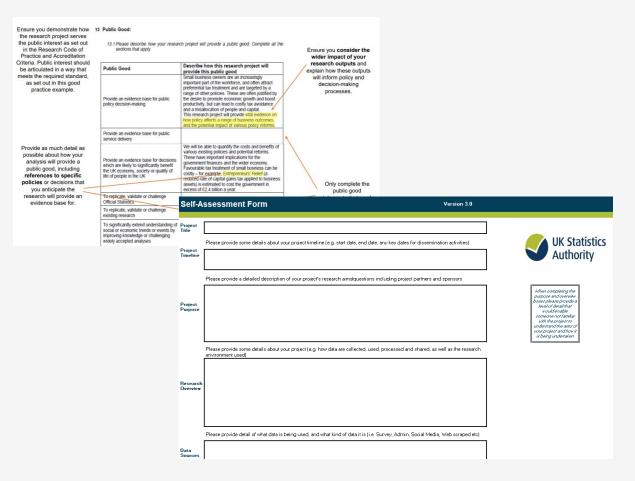
3 days



Accreditation decision passed back to accredited TRE to provide access to data to approved

remit.

Support from the UK Statistics Authority



- Research Project Application
 Guidance
- Ethics Self-Assessment Tool
- TRE training on application standards
- TRE project accreditation tool
- Developing online video guidance

Contact and Support:

Accessing Data via the DEA: https://uksa.statisticsauthority.gov.uk/digitaleconomyact-research-statistics/better-useofdata-for-research-information-for-researchers/

Ethics Self-Assessment Tool: https://uksa.statisticsauthority.gov.uk/the-authority-board/committees/national-statisticians-advisory-committees/ethics-self-assessment-tool/

DEA Accredited Processors: https://uksa.statisticsauthority.gov.uk/digitaleconomyact-research-statistics/better-access-to-data-for-research-information-for-processors/list-of-digital-economy-act-accredited-processing-environments/">https://uksa.statisticsauthority.gov.uk/digitaleconomyact-research-statistics/better-access-to-data-for-research-information-for-processors/list-of-digital-economy-act-accredited-processing-environments/

Email: Research.Accreditation@Statitsics.gov.uk



Secure Research Service Bill South

Secure Research Service

ONS's Secure Research Service gives accredited researchers secure access to deidentified, unpublished data in order to work on research projects for the public good.

The SRS operates under the Five Safes framework to protect data confidentiality. The framework is a set of principles adopted by a range of secure labs, including the ONS.



Circa

5,000 accredited

researchers



Over

600

live

research projects



Approx

125

accessible

datasets

SRS Metadata Catalogue

Easy to search, by all dimensions, including theme, geographic coverage, spatial level, periodicity, data format, data typology (admin, survey etc.)

Full details of variables contained in the dataset, with descriptions, available before research applications are submitted

Viewable in browser, with downloadable extracts functionality

https://ons.metadata.works/domain/index.html



The Five Safes framework



Safe people



Safe projects



Safe settings



Safe data



Safe outputs

Researcher Journey

data

thresholds

Data Owner can specify



determines mode of

access

SAIL Databank ZOE Case Study

Chris Orton
Programme Manager
Population Data Science
Swansea University Medical School







SAIL Databank

- Trusted Research Environment operated by Swansea University, partnered with the NHS
- Database of anonymised data used for health, social care, and administrative (non-health) research (70+ data sources)
- Created in 2007 to pilot the technical, governance, and operating structure needed to make anonymised health data available for research within a remote access infrastructure
- As of early 2022, SAIL has supported over 500 research projects leading to over 500 publications





How it works

- SAIL hosts datasets for research from multiple data providers primarily NHS Wales – but also local and national government, academic institutions, and charities
- Robust anonymisation and governance procedures to ensure fair use and data protection
- Application for data access for research scrutinised by an independent panel of lay people, clinicians, and scientists as to the project's suitability (SAIL Information Governance Review Panel)
- If approved users access project-specific views of the approved datasets via a virtual desktop infrastructure accessed via two-factor authentication



NHS Wales data – an example

- Governance data sharing agreements between NHS Wales and Swansea established to set the sharing rules, legal bases, and data protection obligations
- Technical identifiable data always stays within the NHS. We partner with Digital Health and Care Wales to link and pseudonymise data before sharing it to SAIL, including necessary data suppression and alteration



NHS Wales data – an example

- Technical within SAIL data is DQ/DA assessed, ensuring compliance with anonymisation policies
- Technical patient IDs are always encrypted to ensure database specificity, and encrypted again for project specificity
- Technical data is always accessed as a project-specific view, either restricted by period, scope, or variables, within the SAIL Gateway virtual desktop infrastructure



- Data generated from 'citizen science' during the pandemic, it was a prevalent source of publically generated information on how infection was spreading, in addition to NHS and government data also being generated
- Permitted the tracking of COVID-19 at local and national level before routine testing, track and trace etc. were all fully established
- >4 million participants to date



- SAIL as the BREATHE TRE, partnered with Zoe to make available their anonymised data to the NHS, local authorities, national government agencies, and academic researchers to for ongoing COVID-19 research and tracking
- As with the NHS Wales example, we followed the same path to set up data ingest, with some slight differences to aid the pandemic response



- Governance agree the DSA pre-anonymised data (ZOE ensure this before sharing)
- Technical create automated daily transfer mechanism for millions of rows of data to transfer (including all additions, withdrawals, and schema changes)
- Technical/governance review the data arriving in to SAIL to ensure it conforms to anonymisation policies



- Governance team setup to ensure review of all applications for the ZOE data even before submission to the IGRP (scoping). Emergency response projects identified as any NHS body, local or national authority, etc. needing data for COVID-19 monitoring, strategy and policy purposes – 2/3 day turnaround
- Governance/access users sign data access agreements, send CVs and ensure compliance with safe research
- Access to data via the SAIL Gateway (VDI), using mobile authenticator as rapid 2FA solution to access for this dataset alone



- Technical data provisioned automated to update every few days to ensure it
 - a) did not compromise ongoing work
 - b) ensure data was up to date in content and participant presence
- Governance all outputs subject to SAIL's DEA compliant output checking process, regardless of origin (public sector/academia etc.)

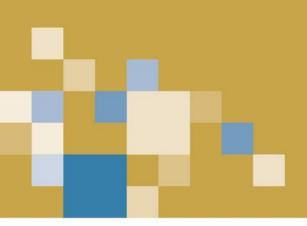






ADIARC

Administrative Data
Agricultural Research Collection



So what is AD ARC?

- The AD|ARC (Administrative Data | Agricultural Research Collection) project aims to integrate the human dimension with data on farming activities.
- AD|ARC brings together experienced data linkage researchers and experts in agricultural affairs with partner organisations.
- Research will investigate relationships between farm households characteristics and recent farming and land use activities with a view to improving the design of future policies.

The data

NI

EU FSS

Rural Payments

Census

IDBR

Passed Feasibility test

Wales

EU FSS

Rural Payments

Census

Health data

IDBR

Education data

Construction of RRD underway



Scotland

EU FSS

Rural Payments

Census

Health data

IDBR

Education data

PBPP forms being finalised

England

EU FSS

Rural Payments

Census

Health data

IDBR

Education data

Waiting for provision of data in SRS

Key

Linkage complete

YDG ADR
CYMRU WALES

Linkage underway

Governance in progress

Issues to be resolved

What are we going to do with the data?

Conduct research that will be relevant to farming households, businesses and policy makers.

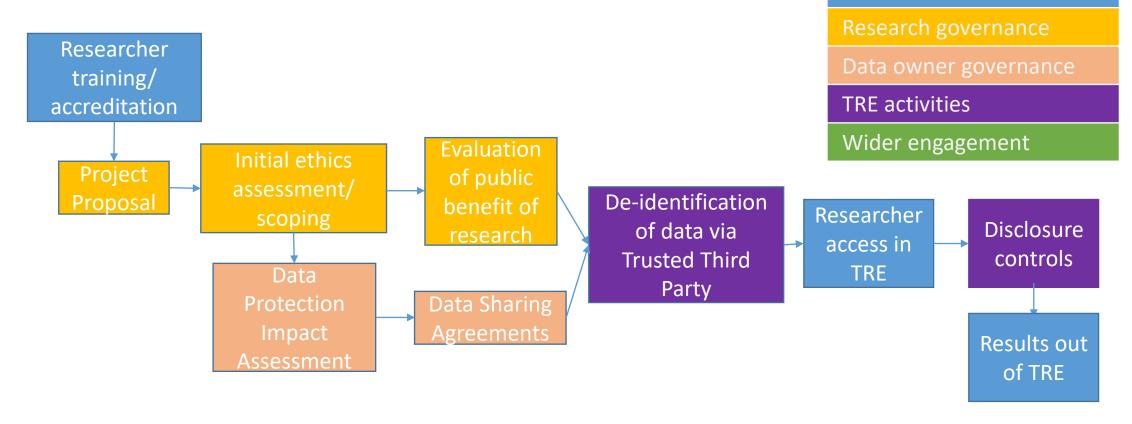
Research work streams:

- Household socio-economic characteristics
- Health and wellbeing
- Prosperity and business resilience
- Environment and place

The different UK Nations

Country	Trusted Research Environment	Trusted Third Party	Application process
England	Secure Research Service	Office for National Statistics	Research Accreditation Panel
		Northern Ireland Statistics and	
NI	Secure Research Service	Research Agengy	Research Accreditation Panel
			Public Benefits and Privacy
Scotland	National Safe Havens	National Records of Scotland	Panel
			Information Governance
Wales	Secure Anonymised Information Linkage	Digital Health and Care Wales	Review Panel

What is required of Researchers



Key

Researcher activities

Consultation with stakeholders, members of the public, government analysts, policy makers and academic experts

Researcher activities

- Researcher accreditation
 - Most TREs now accept central ONS Digital Economy Act Accreditation
 - Takes a couple of weeks to come through
- Researcher access in TREs
 - Metadata patchy
 - SAIL now accessible remotely
 - Some TREs accessible via safe rooms only
- Results out
 - Straightforward

Time taken for AD|ARC: Weeks

Research Governance

- Project proposal
 - Useful exercise in feasibility but varies significantly around the UK
- Ethics assessment
 - Helped by ONS standardisation
 - Varies by institution
- Evaluation of public benefit of research
 - Variable definition of "public good" across the different panels
 - Timescales getting shorter but still Covid backlog
 - If anything challenged, can take a long time

Time taken for AD|ARC: months

Data owner Governance

- Data protection Impact Assessments
 - Different formats between all data owners
 - Have to go through many internal teams with risk averse attitudes
 - Different interpretations of same legislation
- Data sharing agreements
 - Often slowed by legal technicalities
 - Complications of who is responsible for what
 - Often need high level sign off from very busy people

Time taken for AD|ARC: TBC (still not completed but years!)

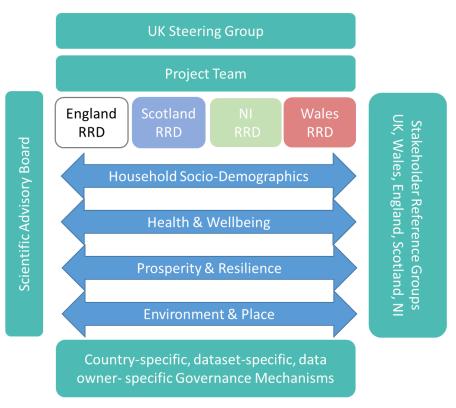
TRE Activities

- De-identification of data
 - Very resource dependent
 - Inconsistent matching techniques across TREs
 - Can be a "black box"
- Disclosure controls
 - Reasonably quick
 - Inconsistent rules
 - Manual process

Time taken by AD|ARC: Months

Wider engagement

AD|ARC Governance Structure



Time taken by AD|ARC: N/A

How DARE can help

- Building common understanding of legislation/policies
- Increase transparency of administrative data research

- Increase consistency across TREs
- Develop technical solutions to work between TREs

Support metadata development







DAREUK

Thank you for listening

www.dareuk.org.uk

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