

The legal framework for accessing data



The legal framework for using administrative data for research purposes

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1 Introduction

ADR UK (Administrative Data Research UK) uses a range of legal gateways to access data for research purposes depending on the type of data being used. UK Government broadly sets the legal framework, however there are some differences between nations due to devolved government powers.

2 The legal framework for administrative data

Across ADR UK, the main category of data accessed for research is administrative data. This is data collected by administrative systems across civil and public services. Although not originally collected for research purposes, it can be extremely valuable for research because it has such broad coverage of the population.

In the UK, data protection legislation is set out in the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. These two pieces of legislation cover the UK's implementation of the General Data Protection Regulation (GDPR) and determine how and when organisations can process personal data.

The Digital Economy Act 2017 (DEA) is a permissive legal gateway that facilitates the linking and sharing of de-identified data by public authorities for accredited research purposes. It is fully compliant with GDPR legislation and supports valuable new research insights about UK society and the economy. The UK Statistics Authority is the statutory accrediting body responsible for the accreditation of processors, researchers and their projects. The Office for National Statistics (ONS), which reports to the UK Statistics Authority, is the major data infrastructure partner of ADR UK, with ADR UK funding the expansion and improvement of the ONS Secure Research Service.

The DEA is the preferred legal gateway to link and share administrative data, however, other legal gateways may be used. The DEA cannot be used as a legal gateway to access data held by other types of organisations (for example, commercial and third sector organisations), as these are not in scope of this legislation.

Under the DEA, before data can be shared for research purposes, it must be processed by an accredited processor so that the data is 'de-identified'. All four of the [ADR UK trusted research environments](#) are DEA-accredited processors. Once the data has been de-identified it can be made available to an accredited researcher in a secure environment. The processor must ensure that any data (or any analysis based on the data) retained or published by the researcher, is 'disclosure controlled'. This means it is checked thoroughly to minimise the risk of individuals in the data being re-identified or other misuses of the data.

For further information about the legal gateways that support research access to public sector data, visit the [UK Statistics Authority](#).

3 The legal framework for health data

Health data has a different legal framework than other public sector administrative data described above.

3.1 Defining health data

GDPR legislation defines 'data concerning health' as: *"Personal data relating to the physical or mental health of an individual, including the provision of health care services, which reveals information about their health status"*.

In practice, this includes all data that relates to a person's health status and comes from any part of the healthcare service (including GPs and hospitals). This includes data such as:

- cancer registration data
- Hospital Episode Statistics data
- GP Extraction Service data
- congenital anomaly registration data.

In addition to health data from healthcare services, there are other sources of data that relate to a person's health that are not collected directly from healthcare sources. The [General Register Office](#) for example, and the equivalent organisations in Scotland and Northern Ireland, collect information on the registration of:

- births (including date of birth, the parents of the baby and birthweight)
- deaths (including the underlying cause of death and conditions that contributed to the death)
- stillbirths.

Other public services may also be a source of some health data, such as health data collected by prisons, police or educational institutions.

3.2 Health data is special category data

Regardless of the source, data concerning health is 'special category' data under data protection laws and is subject to additional rules.

In addition to data protection laws, health data is also generally subject to a common law duty of confidentiality. This means that before health data can be used for research purposes, either the patient must consent, or another legal gateway is needed to disclose the data.

3.3 Accessing health data for research purposes

The DEA currently excludes access to [Data] “relating to the provision of health services or adult social care”. Data outside the scope of the DEA can be shared under different legal gateways, and additional approvals may be required. For example, health data may be shared:

- where there is a legal obligation to disclose it such as:
 - disclosures to NHS Digital mandated by the Health and Social Care Act 2012
 - notification of infectious disease (Health Protection Regulations 2010)
 - a direction from the Secretary of State for Health and Social Care under section 3(4) of Control of Patient Information 2002
- where there is permission to disclose the information under The Health Service (Control of Patient Information) Regulations 2002.

For more information, please see the [guidance published by the Information Commissioner's Office](#).

4 Legal frameworks in the ADR UK national partnerships

4.1 ADR England

The [ONS Secure Research Service](#) is the primary trusted research environment in England and is an accredited processor of administrative data under the DEA. The ONS supports access to ADR England administrative data for accredited research based on the legal framework described above.

4.2 ADR Northern Ireland

In Northern Ireland, projects accessing administrative and/or statistical data are handled by the Northern Ireland Statistics and Research Agency (NISRA). As outlined above, sharing of personal data is legally allowable under Article 6 of the GDPR where there is an exemption for processing of personal data for statistics and research purposes. De-identified data can be accessed via the NISRA Secure Environment under processes laid out in the DEA which facilitates the linking and sharing of datasets held by public authorities for research purposes.

In instances where a research project wants to use health and social care data, access is granted using different or additional legal gateways. For example, the Northern Ireland Longitudinal Study (also accessed via the NISRA Secure Environment) supports health and social care related research involving Census data linked to health card registration data and General Register Office information. It is a mixture of health, statistical and administrative data and is made available for research under the Census Act (NI) 1969 Section 5.

For access to NHS data for research purposes, projects proceed under the [Honest Broker Service](#) which facilitates the provision of anonymised data from the Regional Data Warehouse for accredited health and social care related research, operating under the 'Five Safes' framework and within the requirements of the GDPR.

4.3 ADR Scotland

The [National Safe Haven](#) is a trusted research environment in Scotland accredited to process and share data with approved researchers under the DEA and GDPR. Access to data held in the Scottish National Safe Haven is managed by the Public Health Scotland electronic Data Research and Innovation Service (eDRIS).

Researchers wanting to use administrative data can apply to do so using the lawful basis provided by the Data Protection Act 2018. In addition, researchers in Scotland have to work with their research organisation to identify a legal gateway for their research. This legal gateway is decided based on the legal gateway the research organisation uses for processing administrative data, the research project and the intended use of the data. The proposed legal gateway is then assessed by the data owner for suitability. An example of a legal gateway used by a researcher is Section 7 of the Universities (Scotland) Act 1898 (as amended by Section 8 of the Universities (Scotland) Act 1966). eDRIS can assist researchers with their applications to access data.

To access health data, researchers may need to find an additional legal gateway appropriate to the research, such as the National Health Service (Scotland) Act 1978 or the Public Health (Scotland) Act 2008.

4.4 ADR Wales

The SAIL Databank is an accredited processor under the DEA and works under the general principles and legislation outlined above in respect of the GDPR, the Data Protection Act 2018 and the DEA. SAIL Databank complies with all good practice guidelines concerning data sharing, including the UK Information Commissioner's [code of practice on information sharing](#).

SAIL Databank receives anonymised data in accordance with the UK Information Commissioner's Office [code of practice on anonymisation](#). The legal grounds most commonly used for processing identifiable data to render it anonymous under the UK GDPR and the Data Protection Act 2018 is Article 6(1)(e). This article relates to the performance of a task carried out in the public interest and in respect of special category, where use is for scientific research under Article 9(2)(j).

Occasionally, data owners will rely on legal gateways related to the statutory framework underpinning their function. (E.g., the Criminal Justice and Court Services Act 2000 or the Statistics and Registration Service Act 2007.) These will vary according to the relevant data provider.

The Welsh Government has provided for the processing of health data through the Digital Government (Welsh Bodies) Regulations 2018. These regulations provide for data generated by specific health bodies to be included within the DEA provisions that allow for lawful processing. To process health data, SAIL Databank works with Digital Health and Care Wales, a special health authority which provides important NHS data flows for anonymisation in conjunction with appropriate agreements with relevant local health boards.

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