NIHR | Research Support Service

Specialist Centre for Public Health
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Introduction to good research data management

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Why is good management of research data important?

Good data management is an important part of research integrity and ethical research practice. It also ensures individuals and organisations are fulfilling legal requirements in line with UK legislation.

The UK Concordat to support Research Integrity identifies the following commitments for all research projects. Data management forms an important part of fulfilling each of these commitments:

- **Honesty** (i.e. being honest and realistic about the potential impacts or benefits of the research, in the collection and interpretation of data, in acknowledgement of the work of others and in any conclusions drawn and communicated).
- **Rigour** (i.e. ensuring that all research activities are in line with best practice and standards, that appropriate methods are used, and that any conclusions drawn are accurate and presented appropriately).
- **Transparency and open communication** (i.e. being open about potential conflicts of interest, about the methods used, the data collected and the results – including ensuring that these are widely disseminated regardless of whether positive or negative).
- **Care and respect** (i.e. for participants and other stakeholders, researchers and anyone who might be affected by the research and use of the data).
- **Accountability** (being accountable to participants involved in research and holding individuals and organisations to account when behaviour falls short of these standards).

The UK Data Service has useful information about ethical principles that should be followed when collecting data from human participants. These include:

- Informed consent and voluntary participation (clearly explaining to participants how research data will be used so they can decide if they are happy for their data to be used in this way)
- Protecting privacy and confidentiality
- Transparency (being open about how research data will be used and how data have been collected)
- Minimise harm (ensuring participants are not exposed to physical, psychological or social harm as a result of sharing their data)
- Accuracy and integrity (using reliable methods for data collection and analysis to ensure the data collected is trustworthy)
- Mitigating bias (fairly representing all viewpoints to offer comprehensive understanding of the subject)
- Legal and regulatory compliance (adhering to data protection law and local authority processes)
- Data retention duration (being clear about how long personal and anonymised data will be stored and if it will be reused for future research).

See Ethical obligations - UK Data Service for more information.

Developing a Data Management Plan

A data management plan enables researchers to plan how they will collect, process and store data throughout their research project, including after the project has concluded. It can also help identify roles and responsibilities around data and ensure you are managing data in line with your local authority information management policy.

The following table contains some key questions to consider when developing your approach to data management throughout the life of a research project.

Data Collection	**What data or research materials will you create or re-use as part of your research project?** Your list should include all the physical and digital materials that you plan to create or collect during your project and any secondary data that you plan to re-analyse for research purposes. **How will the new data you are collecting build on or relate to existing data?** Why are new data needed for your project? **What type, format, and volume of data will you create or acquire?** **What methods will you use to capture your data and how will these ensure that your data are high quality (reliable and valid)?** **If you are working with secondary data, do any terms of use or licenses apply (will you need to gain permissions to access the data)?** **Do your existing privacy notices cover the data you wish to collect or use? (See page 6-7 for more information)**
Data Security	**Who will have access to the data? How will you manage access?** **How will you secure your data and protect sensitive information? Will you use passwords, encrypted files etc?** **How will you comply with the Data Protection Act for any personally sensitive data you work with?** **How will you protect your research participants?** Will you obtain informed consent for data retention and sharing? Will you anonymise data to safeguard the privacy of your participants? How will you ensure that individuals are not identifiable if working with small data sets or if

	several data points for an individual are included (which could lead to inadvertent identification)?
Data Storage	**Where will you store your physical and online data?** Will you need additional cloud storage space or physical space to store data? **How will you ensure that your research materials and data are backed up?** **How will you organise your data and research materials? How will you structure and name your files and folders?**
Data Sharing	**Who will you share the data with, and under what conditions?** (see associated resource on sharing data). **Are there any legal or ethical reasons why data should not be released?** **Who will own the copyright and intellectual property for the data you create or re-use?**
Data Preservation	**What data will be preserved after your research project ends?** Will you preserve raw or anonymised data? Will you make your data available to other researchers? *Note: Researchers are increasingly being asked to consider how they can share their research data and materials for future research. The UK Data Service offers excellent guidance on this topic and how you can plan for your data to be shared and re-used by others. See Research data management - UK Data Service for more information.* **Where will it be stored and how long for?** Are there any costs associated with storage? **How will you securely destroy any data that need to be deleted?**

Further resources on data management plans:

- The Health Research Authority has an 'at a glance' checklist for organisations sponsoring (taking overall responsibility for) research projects.
- The Digital Curation Centre has a checklist for a Data Management Plan: http://www.dcc.ac.uk/resources/data-management-plans

Data Protection legislation and lawful bases for processing research data

Under UK legislation, it is important you have identified the lawful basis on which you are using data for research purposes.

There have been recent legislative changes with the introduction of the Data Use and Access Act (DUAA). The DUAA amends, but does not replace, the UK General Data Protection Regulation (UK GDPR), the Data Protection Act 2018 (DPA) and the Privacy and Electronic Communications Regulations (PECR). A summary of the changes is provided here: The Data Use and Access Act 2025 (DUAA) - what does it mean for organisations? | ICO

The Local Government Association have also produced guidance on what the Data (Use and Access) Act means for local authorities: The Data (Use and Access) Act – what it means for local authorities | Local Government Association

Research data in local authorities are processed under the lawful basis 'public task'. This states that 'the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law'.

For more information on lawful bases, see: A guide to lawful basis | ICO

Please note that this is general guidance and you will need to check with your information governance team to clarify the lawful basis for processing data for your project.

Informed consent

UK legislation states that you must be clear, open and honest with people from the start about how you will use their personal data. **You cannot use personal data for purposes you have not explained at the point of collection. This means it is important to think through the different ways you wish to use data before collection and whether this includes reuse of data for research purposes.**

Example:

You are undertaking a survey of all housing tenants to understand experiences of damp and mould to inform routine service delivery. However, you would also like to link to data received with NHS health data to understand the link between poor housing conditions and health problems. If you would like to use these data for research purposes, you must ensure this is clear in the information given to those providing the data.

Local authorities inform individuals how their data will be used at the point of collection – for example asking if data can also be used for research purposes when individuals register for a service. In this instance, they may ask individuals to consent when providing their information and refer to the local authority's privacy notice for full information of how the data could be used.

A privacy notice is a document that gives individuals the right to be informed:

- You must provide individuals with information including: your purposes for processing their personal data, your retention periods for that personal data, and who it will be shared with. We call this 'privacy information'.
- You must provide privacy information to individuals at the time you collect their personal data from them.
- The information you provide to people must be concise, transparent, intelligible, easily accessible, and it must be in clear and plain language.

More information what to include in your privacy notice here: Right to be informed | ICO

Several local authorities and Health Determinants Research Collaborations (HDRCs) have reviewed their privacy notices and added in explicit references to the use of data for research purposes, where these were not already in place.

Consent for use of data for research is also collected when an individual agrees to take part in a research project. This is commonly collected through a form that asks for two different forms of consent:

1. Consent to take part in the research project
2. Consent to use the data collected (now and in the future) in the way outlined in the project information sheet and associated privacy notice.

The consent form should be accompanied by an accessible information sheet that provides potential participants with information about how their data will be used as well as details of what being involved in the study itself means.

Example of data statement from Wirral Council

How will my information be stored and used?
Your information (e.g. notes, photo, audio) will be stored securely by (add name of team or organisation) who adhere to (add name of council) Council's GDPR and Privacy Policy (link). Your information will be used to create case studies and a report that will be shared with XYZ. These may be shared as part of presentations, meetings, or used for future funding applications. They may also be published in the public domain by XYZ. The researchers will give you a Consent Form, where you will consent to how your information is used.

Please note that although consent is essential for ethical reasons, it is not the lawful basis on which data are being processed. Health Research Authority guidance explains this as follows:

Consent to participation in research is not the same as consent as the legal basis for processing under data protection legislation. An example is that a person is asked to consent to participate in research but is told that, if they agree to participate, data about them will be processed for a task in the public interest. The legal basis for data processing is not consent.

Further information on consent to use data

- The UK Data Service provides detailed guidance on documenting consent – see Documenting consent - UK Data Service
- Role of informed consent in ethical data collection, sharing and reuse
- Getting informed consent for user research - Service Manual - GOV.UK

Frequently asked questions

1. Is ethical approval needed for reuse of anonymised data for research purposes, if consent has already been obtained?

For certain activities, independent ethical review by people external to your project or organisation may not be needed. You should always check with any organisations involved to confirm if they have a policy that suggests otherwise.

This is often the case for the following activities:

- Projects using existing data that are completely anonymised (where individuals are not directly or indirectly identifiable).
- Projects using some types of information that are publicly available.

Just because something is publicly available does not mean that there are no ethical considerations for its use in research. For example, there are often ethical considerations when using data from online sources such as social media and therefore need for ethical review may be determined by the type of information, its source and intended use.

2. Do I need to tell people at point of collection of routine data that this might be used for research purposes in the future?

Yes – your privacy notice should contain information on all the ways the data will be used, including future reuse for research purposes.

3. When can I reuse data?

Reusing personal data - you should speak to your information governance team if you wish to use personal data for research as this will constitute a new use of the data and require appropriate checks and approvals to ensure you are acting in line with data protection legislation.

Reusing anonymised data- fully anonymised data can generally be reused for research purposes without separate consent or ethical approval. However, you need to be sure that these data are fully anonymised (cannot be linked back to an individual). If data are potentially identifiable in any way (including pseudonymised) this counts as personal data under legislation.