Ethical and legal guidelines in data sharing

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Overview

Section 1: Key Principles for Ethical Research.

Section 2: Research Data and Legal Frameworks.

Section 3: Consent in Research.

Section 4: Key Considerations in Secondary Data Use.

Q&A Session.

Research data

Primary data

Secondary data

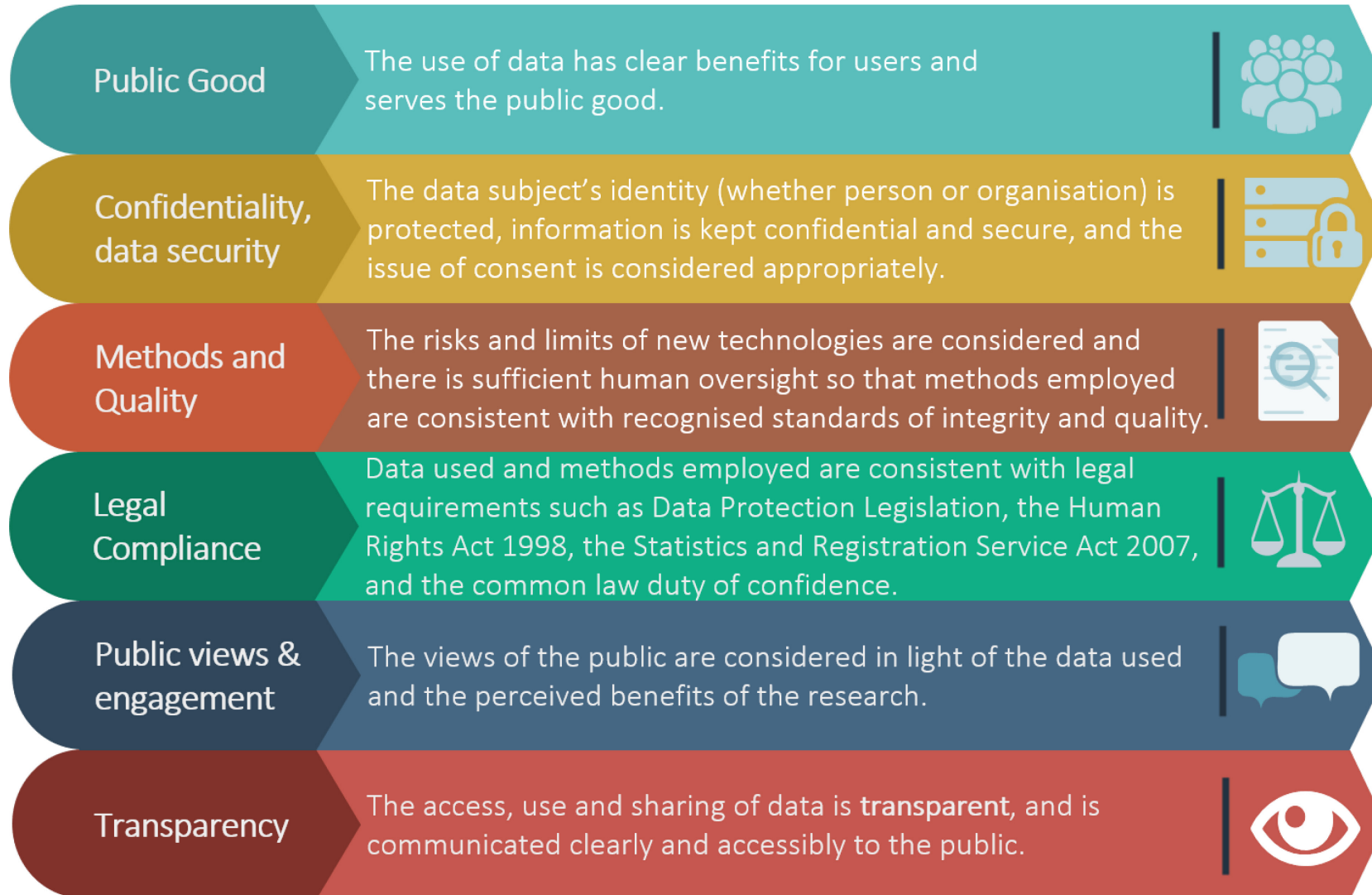# Section 1: Key Principles for Ethical Research

Key principles for ethical research

- Maximising benefits & minimising risk and harm.
- Respecting the rights and dignity of participants.
- Voluntary and appropriately informed participation.
- Integrity and transparency in conducting research.
- Clearly defined lines of responsibility and accountability.
- Avoiding conflicts of interest.
- Providing information about the collection, use, and archiving of their data.

Ethical considerations in data sharing

- Clear guidance designed by the National Statistician's Data Ethics Advisory Committee's (NSDEC).

- UKSA [Ethics Self-Assessment Tool](#).

NSDEC ethics principles

Public Good
The use of data has clear benefits for users and serves the public good.

Confidentiality, data security
The data subject's identity (whether person or organisation) is protected, information is kept confidential and secure, and the issue of consent is considered appropriately.

Methods and Quality
The risks and limits of new technologies are considered and there is sufficient human oversight so that methods employed are consistent with recognised standards of integrity and quality.

Legal Compliance
Data used and methods employed are consistent with legal requirements such as Data Protection Legislation, the Human Rights Act 1998, the Statistics and Registration Service Act 2007, and the common law duty of confidence.

Public views & engagement
The views of the public are considered in light of the data used and the perceived benefits of the research.

Transparency
The access, use and sharing of data is **transparent**, and is communicated clearly and accessibly to the public.

Data Ethics Framework

Best practices for ethical sharing of research data

- Ethical obligations should be considered throughout the research lifecycle.
- Be knowledgeable about policies of relevant research organisations.
- Comply with relevant laws.
- Avoid social and personal harm.
- Contact data repositories to seek guidance.
- Consent should be in place for the future uses of the data.

Section 2: Research Data and Legal Frameworks

Research data and legal frameworks

Types of data
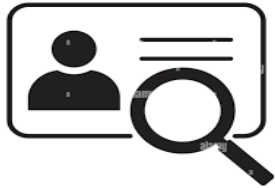
1. Data that relates to identified or identifiable individuals.

2. Anonymous data that no longer relates to identified or identifiable individuals.

3. Synthetic data.

Personal information

- Any information relating to an identified or identifiable natural person.

- Includes special categories of personal data (e.g. ethnicity, political/religious beliefs, health, genetic and biometric data).

- Data protection regulations apply when

  personal information is collected.

Research Data 1: Data that relates to identified or identifiable individuals

- The common law duty of confidentiality.

- Data protection legislation (the UK General Data Protection Regulation (UK GDPR) within the Data Protection Act (DPA) 2018).

Duty of confidentiality and data sharing

- Exists in UK common law and may apply to research data.
- Disclosure of confidential information is lawful when:
  - the individual to whom the information relates has consented.
  - disclosure is necessary to safeguard the individual, or others, or is in the public interest.
  - there is a legal duty to do so, for example a court order.
- Best practice is to avoid very specific promises in consent forms.

Data protection considerations

- If personal information about people is collected or used in research data protection regulations apply.

- EU GDPR (2018) & country specific laws: A researcher based in a country from the European Union (country that adheres to EU GDPR) collects personal data about people living in a country from the European Union.

DPA (2018) & the UK GDPR
- a researcher based in the UK collects personal data about people anywhere in the world
- a researcher outside the UK collects personal data on UK citizens

DPA (2018), EU GDPR (2018) & the UK GDPR
- a researcher based in the UK collects personal data about people across Europe

Data subjects rights

- The right to be **informed.**
- The right of **access.**
- The right to **rectification** (correction).
- The right to **erasure** (right to be forgotten).
- The right to **restrict processing.**
- The right to data **portability.**
- The right to **object.**

Principles of data processing

All data must be:

- be processed lawfully, fairly and transparently.

- be kept to the original purpose.

- be minimised (only the personal data that is necessary is collected).

- be removed if not necessary.

- have the accuracy upheld.

- be kept confidential and integrity maintained.

Lawful basis to process personal data under the UK GDPR

Lawful basis	Example
Consent	Survey to capture public opinion, whereby email addresses are collected to contact respondents at a later stage. Qualitative study on a sensitive topic, e.g. violence against women, where respondents may be identifiable from the collected information.
Public task	Longitudinal study of people living with dementia and their carers, to identify how people would like to be supported. Findings inform and support the caring strategy and public advocacy
Legitimate interests	Research project funded and undertaken by a private corporation to look at the effects of smoking on car passengers.
Vital interests	Hospital treating a patient after a serious road accident can search for his/her ID to find previous medical history or to contact his next of kin.
Legal obligation	Processing personal data as part of a health and safety report or incident.
Contract	Processing personal data as part of an employment contract.

Lawful basis to process personal data

- Research conducted in the UK:

  - **Task in public interest** (for all public bodies (NHS / HSC, Universities, UKRI, etc).

  - **Legitimate interest** (for all non-public bodies (charities, commercial companies, etc).

- If you are processing special category data::

  - Lawful basis.

  - Additional condition .

  - Data protection impact assessment (DPIA) for any type of processing which is likely to be high risk.

GDPR and research

- Principles.

- Rights of data subjects.

- Processing grounds for processing personal data.

- Emphasis on transparency, clear information, clear documentation.

- Reuse for research allowed with safeguards.

Research Data 2: Anonymous data that no longer relates to identified or identifiable individuals

Effective anonymization	Pseudomisation
Application of one or more anonymisation techniques to personal information. When done effectively, the anonymised information cannot be used by the recipient to identify the data subject either directly or indirectly	Processing of personal data in such a manner that it can no longer be attributed to a specific data subject without the use of additional information, provided that such additional information is kept separately and is subject to technical and organisational measures
Not subject to the UK GDPR	Subject to the UK GDPR

Further information:
- UKDS guidance on How to anonymise quantitative and qualitative data
- ICO guidance on anonymisation, pseudonymisation

Research Data 3: Synthetic Data

- Synthetic data is information that is artificially created (algorithmically) rather than generated by real-world events.

- Not subject to data protection legislation or the common law duty of confidentiality.

Section 3: Consent in Research

Consent in research

Consent is the process by which a researcher discloses appropriate information about the research so that a participant may make a voluntary, informed choice to accept or refuse to cooperate.

Why to seek consent?

- Consent for research ethics.

- Consent for processing of personal data.

How to seek consent?

- Consent can be gained in **written** or **oral** form.

- Format depends on the kind of research.

- Important to document:
  - how it has been gained.
  - what information has been provided to the participants.
  - what they have agreed to.

Three key areas to be addressed

Wording in consent forms and information sheets could be broken down in **three** key areas:

- Taking part in the study.

- Use of the information in the study.

- Future use and reuse of the information by other.

Handling personal data in research

- Will the research project collect personal data or special categories of data?
- Who will be the data controller for the research project?
- Will the research involve collaboration with other partners?
- Who will have access to the personal data collected?
- What ground will be used for processing the personal data in a project?
- What information needs to be communicated to participants?
- How and where will the personal data be stored?

Strategies for managing and sharing research data obtained from people

- Protection of identities when promised (e.g. anonymization).

- Processing ground for personal data (e.g. public task, consent).

- Regulated access where needed (open, safe guarded, controlled).

Managing access to data

Open
- Available for download/online access under open licence without any registration.

Safeguarded
- Available for download / online access to logged-in users who have registered and agreed to an End User Licence (e.g. not identify any potentially identifiable individuals).

Controlled
- Available for remote or safe room access to authorised and authenticated users whose research proposal has been approved and who have received training.

Key Considerations in Secondary Data Use

What rights might there be in research data?

Copyright

Database rights

Further information on rights in research data and different scenarios

Rights in research data

- Right granted to creators and owners of works that are the result of human intellectual creativity.

- Assigned automatically to the creator.

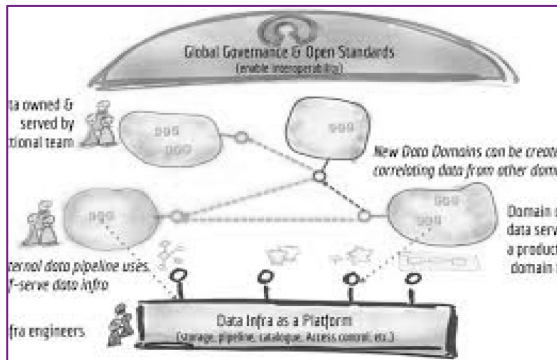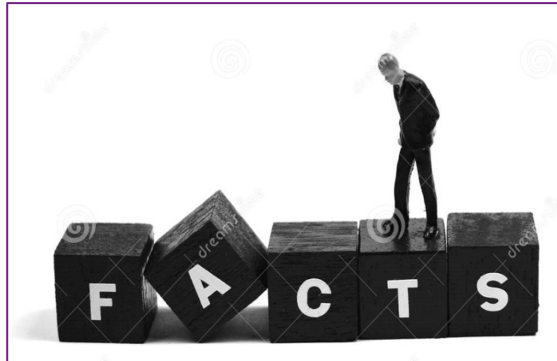- When data is shared, original owner is the right holder.

Further information on rights in research data and different scenarios

When will my research data be protected by copyright?

When data is created, shared & reused

When will my research data be protected by copyright?

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Month	T_a (°C)	GHI (W/m²)	DHI (W/m²)
January	6.8	116	67
February	11.5	182	106
March	13.1	212	127
April	19.4	285	182
May	19.9	302	214
June	25.5	349	269
July	25.1	344	265
August	24.9	299	227
September	22.3	262	194
October	20.2	196	135
November	14.2	150	99
December	7.5	109	68

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Scenario

A researcher studies how health issues around obesity are reported in the media in the last 10 years. Freely available newspaper websites and library sources are used to obtain articles on this topic. Data includes articles and excerpts.

- Can the researcher use such public data without breaching copyright?
- Can the data be archived and shared with other researchers?

Best practices when using secondary data

Questions to ask:
- Who the copyright holder of the datasets is?
- Are you allowed to use them and in what way?
- Are you allowed to archive and publish them in a data repository?

- If not, you may need to seek for further permission to distribute material you do not own - copyright clearance.

- If permission is not granted, need to remove copyrighted variables/material before publishing or sharing.

Best practice for legal compliance

- Investigate early which laws apply to your data, including cross-country collaborative working.

- Do not collect or keep personal or sensitive data if not

  essential to your research.

- Plan early on; seek advice from your research office.

- Ensure that you check participants know how this data will

  be used.

- Remember: not all research data are personal (e.g. anonymised data are not personal).

Further resources

- [UK Data Service](#)
- [UKDS Model Consent Form](#)
- [Example Consent Forms](#)
- [Example Information Sheet](#)
- [Consent for data sharing](#)
- [DARIAH ELDAH Consent Form Wizard | CFW](#)
- [Rights when using secondary data sources](#)
- [Regulating access to data](#)
- [Managing and sharing research data: A guide to good practice](#)

Register for the UK Data Service
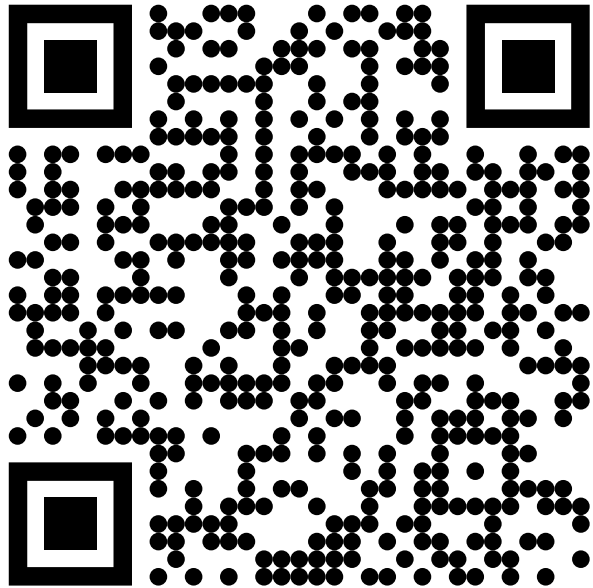
UK Data Service training and events

https://beta.ukdataservice.ac.uk/myaccount/login

https://ukdataservice.ac.uk/training-events/
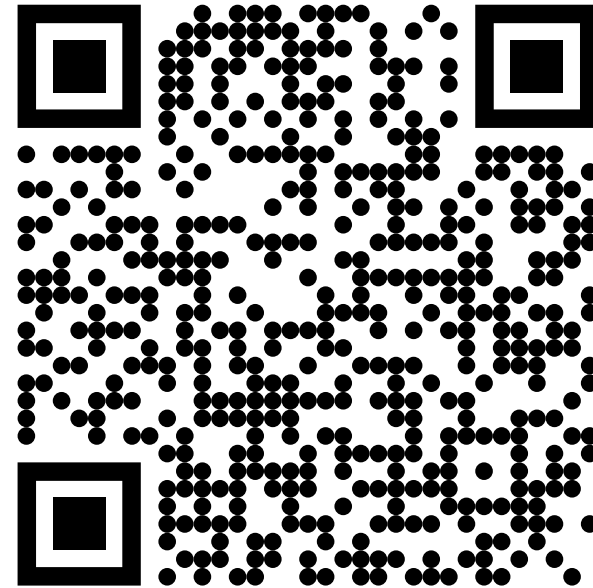
Thank you.

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