

# Ethical and legal guidelines in data sharing

Presenter: Dr Hina Zahid

Data Producer Support Lead (ethics)



# Overview

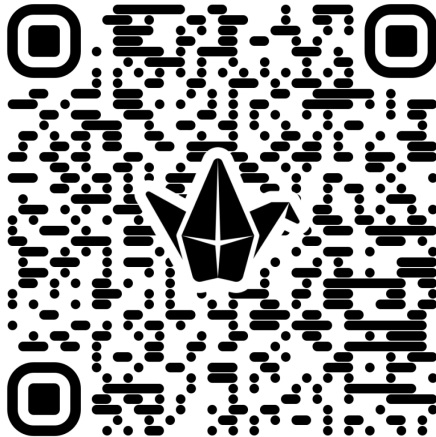
Section 1: Key Principles for Ethical Research.

Section 2: Research Data and Legal Frameworks.

Section 3: Consent in Research.

Section 4: Key Considerations in Secondary Data Use.

Q&A.



# Research data

Primary data	Secondary data
Data collected <b>first-hand</b> for a specific purpose.	Data collected by <b>others</b> for a different purpose.
Methods include surveys, interviews, observations, experiments.	Sources include books, journals, reports, websites, government data.



# Section 1: Key Principles for Ethical Research

# Key principles for ethical research

- Maximising benefits and 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.

# Ethical considerations in data sharing

- Clear guidance designed by the National Statistician's Data Ethics Advisory Committee's (NSDEC).
- Guidance on ethics self-assessment process.
- UKSA Ethics Self-Assessment Tool.

# NSDEC ethics principles

Public Good	Clear benefits for users and serves the public good
Confidentiality/Data Security	The identity of the data subject (individual or organisation) is safeguarded, information is handled confidentially and securely, and consent is properly addressed.
Methods and Quality	The potential risks and limitations of new methods or technologies are evaluated, with adequate human oversight to ensure they meet established standards of integrity and quality.
Legal Compliance	Data and methods are applied in line with legal requirements, including data protection laws, the Human Rights Act 1998, the Statistics and Registration Service Act 2007, the common law duty of confidence, and the Equality Act 2010.
Public Views and Engagement	Public perspectives are considered alongside the data used and the perceived benefits of the research.
Transparency	The way data is accessed, used, and shared is transparent, and communicated clearly and accessibly to the public.

# Data and ethics framework

## [Data and AI Ethics Framework - GOV.UK](#)

Guidance for using data and AI responsibly, ensuring fairness, transparency, and ethical decision-making.

## [Data and AI Ethics Self-Assessment Tool.odt](#)

A checklist-style tool to help teams identify ethical risks and review data/AI projects throughout their lifecycle.

# 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

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

# 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

- [Ethical obligations — UK Data Service](#)
- [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.

# The Data Protection Act and GDPR

## The Data Protection Act and GDPR - UK Data Service

- Rights of the participants
- Principles of processing personal data
- UK GDPR and sharing data

# Lawful basis to process personal data under the UK GDPR

Lawful basis	Example
<b>Consent</b>	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.
<b>Public task</b>	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.
<b>Legitimate interests</b>	Research project funded and undertaken by a private corporation to look at the effects of smoking on car passengers.
<b>Vital interests</b>	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.
<b>Legal obligation</b>	Processing personal data as part of a health and safety report or incident.
<b>Contract</b>	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

<b>Effective anonymisation</b>	<b>Pseudonymisation</b>
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:

[Anonymising qualitative data - UK Data Service](#)

[Anonymising quantitative data - UK Data Service](#)

# 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?

# Key Considerations in Secondary Data Use

# What rights might there be in research data?

- **Copyright (and related database rights):** Control copying.
- **Licensing / reuse rights:** Grant reuse permissions.

## **Further information:**

[Copyright - UK Data Service](#)

[Copyright scenarios - UK Data Service](#)

[Other rights - UK Data Service](#)

[Licensing - UK Data Service](#)

[Resources on rights - UK Data Service](#)

# When is my research data protected by copyright?

## When data is created, shared & reused

**Creation:** Copyright may arise in structure or presentation.

**Sharing:** Controls copying and distribution.

**Reuse:** Defines what others are allowed to do with it.

# 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?

# Copyright scenario

A researcher has used secondary data sources for a research project. He plans to share his data. The sources he used were:

- World Bank open data.
- Microsoft Academics.

# World Bank open data

## Terms of Use for Datasets

*You are encouraged to use the Datasets to benefit yourself and others in creative ways. You may extract, download, and make copies of the data contained in the Datasets, and you may share that data with third parties according to these terms of use.*

# Microsoft Academics

## Microsoft Terms of Use | Microsoft Legal

Unless otherwise specified, the Services are for your personal and non-commercial use. You may not modify, copy, distribute, transmit, display, perform, reproduce, publish, license, create derivative works from, transfer, or sell any information, software, products or services obtained from the Services.

# 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.

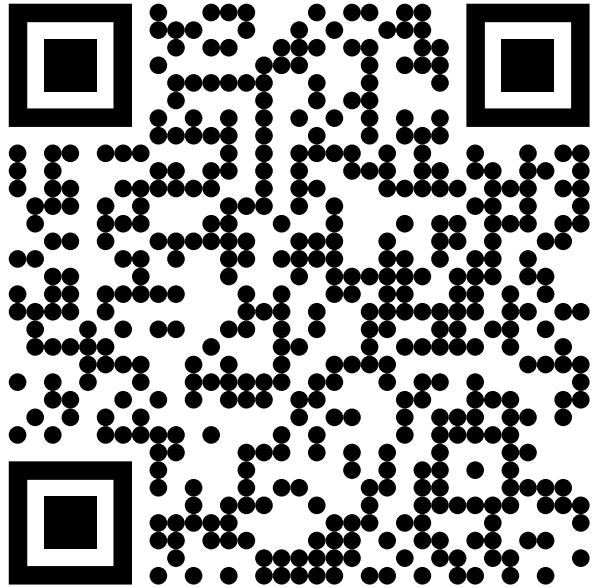
# Best practice for legal compliance

- 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

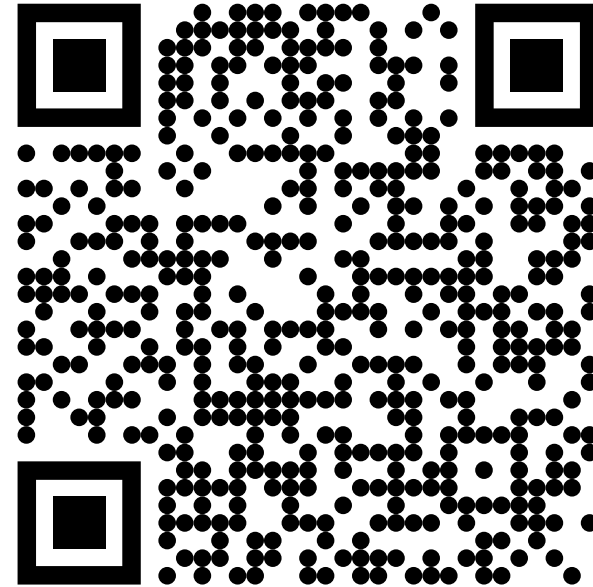
- [UK Data Service](#)
- [UKDS Model Consent Form](#)
- [Example Consent Forms](#)
- [Example Information Sheet](#)
- [Consent for data sharing](#)
- [DARIAH ELDAH Consent Form Wizard | CFW](#)
- [Rights when using secondary data sources](#)
- [Regulating access to data](#)
- [Managing and sharing research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

# Register for the UK Data Service



[UK Data Service › Login](#)

# UK Data Service training and events



[Training and events - UK Data Service](#)



# Thank you.

Dr Hina Zahid

[hzahid@essex.ac.uk](mailto:hzahid@essex.ac.uk)

[datsharing@ukdataservice.ac.uk](mailto:datsharing@ukdataservice.ac.uk)

X: @hinazahid2016

