Ethical & legal considerations in data sharing
Overview

Ethical obligations
• Key principles for ethical research
• Ethical research considerations and best practices

Legal compliance
• Duty of confidentiality
• Data protection considerations- GDPR
• Strategies for managing and sharing research data (anonymisation, consent, access controls)
• Copyright considerations
• Best practices for legal compliance

Further resources
A quick question before we begin…

Please go to www.menti.com and use the code

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Key principles for ethical research

• To maximise benefit for individuals and society & minimise risk and harm
• The rights and dignity of individuals and groups should be respected
• Voluntary and appropriately informed participation
• Research should be conducted with integrity and transparency
• Clearly defined lines of responsibility and accountability
• Independence of research should be maintained and where conflicts of interest cannot be avoided they should be made explicit
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

1. **Public Good**: The use of data has clear benefits for users and serves the public good.
2. **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.
3. **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.
4. **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.
5. **Public views & engagement**: The views of the public are considered in light of the data used and the perceived benefits of the research.
6. **Transparency**: The access, use and sharing of data is transparent, and is communicated clearly and accessibly to the public.
Best practices for ethical sharing of research data

• Ethical obligations should be considered throughout the research lifecycle; from planning and research design stage, data collection stage to the future use including publications, archiving, sharing and linking of data.
• Be knowledgeable about relevant research organisations own standards and requirements
• Comply with relevant laws
• Avoid social and personal harm
• Data centres facilitate ethical and legal re-use of research data, protection of participants and safeguarding of personal data
Legal compliance
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
Personal information

**Personal information or data** is any information relating to an identified or identifiable natural person (name, address, postcode)

It also includes **sensitive personal data or special category data** such as ethnicity, political or religious beliefs, biometric data, health
Data protection considerations

• If personal information about people is collected or used in research, then the data protection regulations applies

• Data protection act 2018 (DPA), General data protection regulation 2018 (GDPR) & the UK GDPR 2021

• DPA (2018) & the UK GDPR (2021) applies when
  ✓ 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 (2021) applies when
  ✓ a researcher based in the UK collects personal data about people across Europe
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
Strategies for managing & sharing research data obtained from people

- Protection of identities when promised (anonymisation, de-identification)
- Processing ground for personal data (consent)
- Regulated access where needed (open, safe guarded, controlled)
De-identification & anonymisation

• **De-identification** – refers to a process of removing or masking *direct identifiers* in personal data

• **Anonymisation** - refers to a process of ensuring that the risk of somebody being identified in the data is negligible. This invariably involves doing more than simply de-identifying the data, and often requires that data be further altered or masked. Anonymisation allows data to be shared ethically and legally while preserving confidentiality
What if anonymization is impossible?

- Obtain consent for sharing non-anonymised data
- Regulate or restrict user access
Consent in research

• Consent for research ethics: provide information regarding study purpose, risks, benefits, voluntary participation

• Consent can also be used as a legal basis for the processing of personal data under GDPR
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 and what they have agreed to
Consent documentation: Information sheet

An information sheet should cover the following topics:

- Purpose of the research
- What is involved in participating
- Benefits and risks of participating
- Procedures for withdrawal
- Usage of the data during research, dissemination, storage, publishing and archiving
- Details of the research: funding source, sponsoring institution, name of project, contact details for researchers, how to file a complaint

Cont…
Consent documentation: Consent form

Consent form should:

• Use simple language and free from jargon
• Allow the participant to clearly respond to points such as:
  o The participant has read and understood information about the project
  o The participant has been given the opportunity to ask questions
  o The participant voluntarily agrees to participate in the project
  o The participant understands that they can withdraw at any time without giving reasons and without penalty
  o Future uses (e.g. publications, share and reuse)
  o Signatures and dates of signing for the participant and the researcher

Cont…
cont…Consent documentation

If personal information is collected:
- How personal information will be processed and stored and for how long
- Procedures for maintaining confidentiality
- Procedures for ensuring ethical use of the data

If the GDPR applies:
- The contact details of the data controller (DPO, REO, Researcher)
- Who will receive or have access to the personal data
- A clear statement on the right of the participant (right to access, correction or removal)
# One-off consent or process consent?

<table>
<thead>
<tr>
<th>Consent Type</th>
<th>Advantages</th>
<th>Disadvantages</th>
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<tbody>
<tr>
<td>One-off consent</td>
<td>Simple lease hassle to the participants</td>
<td>Research outputs not known in advance Participants may not know all info they contribute to</td>
</tr>
<tr>
<td>Process consent</td>
<td>Ensures active consent</td>
<td>May not get all consent needed before losing contact, repetitive, may annoy participants</td>
</tr>
</tbody>
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Special considerations when seeking consent

• Medical research
• Internet research
• Twitter
• Consent for linking to administrative data
• Children and young adults
• People with learning difficulties
• Research within organisations or in the workplace
• Crime

Further information [Consent in special cases](#)
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
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*)
- special agreements (depositor permission; approved researcher)
- embargo for fixed time period

Controlled
- available for remote or safe room access to authorised and authenticated users whose research proposal has been and who have received training
Using secondary data

Secondary data is the data that have been already collected by and readily available from other sources.
Sources of secondary data

• Books
• Published sources
• Journals
• Newspapers
• Websites
• Government records
• Blogs
• Diaries
• Social media platforms
• Data available from the data archives/repositories (UKDS)
Using secondary data

Information being in the public domain (e.g. online) does not mean copyright does not apply!

Always remember…

- an intellectual property right assigned automatically to the creator
- Data owner (researcher) has copyright of research data
- Compiled datasets contain original copyright so seek permission to archive when collecting
- Data archives publish data – hold no copyright
- [Cite the data](#)
Best practises when using secondary data

Question 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
Exercise
Exercise

Please share your ideas on the Padlet at:

https://en-gb.padlet.com/hinaz0102/Bookmarks
Scenario 1: Copyright of archived data

A researcher uses COVID data available from the UKDS for research. These data are freely available. He has incorporated this data with some of the data he collected himself to analyse it further. Can he deposit the data he has with another archive?
Scenario 2: Copyright of data in the public domain

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. Can the researcher use such public data without breaching copyright?
Scenario 3: Copyright of survey questions

A researcher wishes to reuse a set of questions from an existing survey questionnaire, to compare results between the newly proposed survey and the original. Can the researcher use the existing survey questionnaires without breaching copyright?
Scenario: Sharing derived data

A researcher has used Heath Survey of England & Wales and created derived variables using height and weight. He wishes to make this data available for reuse. How can he achieve this without breaching copyright?
Scenario: Consent wording

A researcher has used a statement in a consent form “Any information I give will be used for research only and will not be used for any other purpose”
What are your thoughts on it?
Scenario: Consent wording

A researcher has used a statement in a consent form “I understand that only the research team will have access to the data I will provide”

What are your thoughts on it?
Best practise for legal compliance

✓ Obtain informed consent that emphasize data sharing & archiving

✓ Deal with personal sensitive data properly

✓ Investigate early which laws apply to your data

Think ahead, plan for the future!
Further resources

- UK Data Service
- UKDS Model Consent Form
- 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
Future events

- How to anonymise qualitative and quantitative data  (25 April)
- Data management basics: Introduction to data management and sharing  (28 April)
- Data management basics: Ethical and legal issues in data sharing  (29 April)
- Depositing your data with ReShare  (5 May)
- Consent issues in data sharing  (6 May)
- **UK Data Service upcoming events**
Any questions?
Thank you.

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