Consent for data sharing

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Lunchtime Data Bites
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How to share data obtained from people in an ethical / legal way?

- Obtain **informed consent**, also for data sharing and long-term preservation / curation
- **Protect identities** e.g. anonymisation, not collecting personal data
- **Regulate access** where needed (all or part of data) e.g. by group, use, time period
- **Securely store** personal or sensitive data (separately)
Consent needed across the data life cycle

- Engagement in the research process
  - decide who approves final versions of transcripts

- Dissemination in presentations, publications, the web
  - decide who approves research outputs

- Data sharing and archiving
  - consider future uses of data

Always dependent on the research context – special cases for covert research, verbal consent, etc.
A good information sheet & consent form

- Meets requirements of data protection laws
  - purpose of the research
  - what is involved in participation
  - benefits and risks
  - mechanism of withdrawal
  - usage of research data – for primary research and sharing
  - strategies to ensure confidentiality of data (anonymisation, access etc.) where this is relevant

- Need to balance
  - as simple as possible
  - complete for all purposes: use, publishing, sharing
  - avoid excessive warnings
## Timing of consent

<table>
<thead>
<tr>
<th></th>
<th>PROS</th>
<th>CONS</th>
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<tbody>
<tr>
<td><strong>One-off</strong></td>
<td>• Simple</td>
<td>• Research outputs not known in advance</td>
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<tr>
<td></td>
<td>• Least hassle to participants</td>
<td>• Participants will not know all info they will contribute</td>
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<tr>
<td><strong>Process</strong></td>
<td>• Ensures ‘active’ consent</td>
<td>• May not get all consent needed before losing contact</td>
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<td>• Repetitive, can annoy participants</td>
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## Form of consent

<table>
<thead>
<tr>
<th>Written</th>
<th>Verbal</th>
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<tbody>
<tr>
<td>• More solid legal ground, e.g. participant has agreed to disclose confidential info</td>
<td></td>
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<tr>
<td>• Often required by IRB</td>
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<tr>
<td>• Offers more protection for researcher</td>
<td></td>
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<tr>
<td>• Not possible for some cases: infirm, illegal activities</td>
<td></td>
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<tr>
<td></td>
<td>• Can be difficult to make all issues clear verbally</td>
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<tr>
<td></td>
<td>• Possibly greater risks for researcher</td>
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<td>• Best if recorded</td>
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Aspects to consider

• Different forms of consent for different materials, e.g. audio recordings vs transcripts

• Right to withdraw – what to do with already collected data?

• Informed consent for ‘unknown future data uses’?

• Provide maximum information about reuse
  • who can access the data – authenticated researchers
  • purposes – research or teaching or both
  • confidentiality protections; agreement by future users
Types of material and consent

Different data sharing consent agreements may be applied to different types of research data, e.g. less sensitive (survey) vs. highly sensitive (medical)

- Text and transcripts
  - can be anonymised
- Images, audio/video recordings
  - data more likely to reveal identities
  - less usable after anonymising (distortion or blurring)
  - anonymising costly

Consent or access control may be better alternatives than anonymisation
Special cases of consent

Children
- own consent (>16) or parent/guardian consent

Employees
- duty of confidentiality to employer, e.g. employment–related research

Vulnerable people, disabilities of any kind
- balance protection from harm with right to participate in research

Internet research, blogs, social media – public vs. private information, can consent be asked?
- ethical decision-making = deliberative process
- nsmnss.blogspot.co.uk/2014/02/new-social-media-new-social-science-and.html
- aoir.org/reports/ethics2.pdf

Retrospective consent, covert research, observational experiments
In practice: wording in consent form / information sheet

We expect to use your contributed information in various outputs, including a report and content for a website. Extracts of interviews and some photographs may both be used. We will get your permission before using a quote from you or a photograph of you. After the project has ended, we intend to archive the interviews at .... Then the interview data can be disseminated for reuse by other researchers, for research and learning purposes.

The interviews will be archived at ....... and disseminated so other researchers can reuse this information for research and learning purposes:
- I agree for the audio recording of my interview to be archived and disseminated for reuse
- I agree for the transcript of my interview to be archived and disseminated for reuse
- I agree for any photographs of me taken during interview to be archived and disseminated for reuse
In practice: wording in consent form / information sheet

<table>
<thead>
<tr>
<th>Use of the information I provide beyond this project</th>
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<tbody>
<tr>
<td>I agree for the data I provide to be archived at the UK Data Archive.²</td>
</tr>
<tr>
<td>I understand that other genuine researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.</td>
</tr>
<tr>
<td>I understand that other genuine researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.</td>
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</table>

As the ESRC is a publicly funded body, it has developed ways to share data among academic researchers (subject to strict conditions). To this end, we hope you will allow your anonymised transcript to be stored as part of the UK Data Archive (a service provider for the Economic and Social Data Service).
In practice: wording in consent form / information sheet

Any personal information that could identify you will be removed or changed before files are shared with other researchers or results are made public.

ukdataservice.ac.uk/manage-data/legal-ethical/consent-data-sharing/consent-forms.aspx
Discussion

• How easy / difficult is consent for data sharing in your research?
• Which wording would you use?
Ethical arguments *for* archiving data

- Not burden over-researched, vulnerable groups
- Make best use of hard-to-obtain data, e.g. elites, socially excluded, over-researched
- Extend voices of participants
- Provide greater research transparency

*In each, ethical duties to participants, peers and public may be present*
Ethical obligations and data sharing

- Research with human participants usually requires ethical review (Research Ethics Committee)
- Ethical conduct in research and protection of safety, rights and well-being of research participants – ‘do no harm’
- Data archives such as UK Data Archive facilitate ethical re-use of research data, protection of participants and safeguarding of personal data
  - data anonymisation
  - regulate data access
  - data sharing is NOT violation of data privacy or research ethics
Questions

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