
Informed consent for data sharing and reuse

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Creating Shareable Research Data: Managing and Archiving Social Science Research Data

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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.

Consent and data sharing

The best way to achieve informed consent for data sharing is to **identify** and **explain** the **possible future uses of their data** and offer the participant the option to consent on a **granular level**

For example, in a qualitative study, this may involve allowing the participant to consent (or not) separately to data sharing of anonymised transcripts, non-anonymised audio recordings, photographs,...

Consent in practice

- Consent needs to be freely given, informed, unambiguous, specific and by a clear affirmative action that signifies agreement to the processing of personal data.
- Inform participants about the purpose of the research
- Discuss what will happen to their contribution (including the future archiving and sharing of their data)
- Indicate the steps that will be taken to safeguard anonymity and confidentiality
- Outline the right to withdraw from the research
- Need to balance
 - as simple as possible
 - complete for all purposes: use, publishing and sharing
 - avoid excessive warnings

UK Data Archive model consent form

<http://www.data-archive.ac.uk/media/210661/ukdamodelconsent.doc>

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Timing and form of consent

	Advantage	Disadvantage
One-off consent: participant is asked to consent to taking part in the research project only once.	Simple Least hassle to participants	Research outputs not known in advance Participants will not know all info they will contribute
Process consent : participant's consent is requested continuously throughout the research project	Ensures 'active' consent	May not get all consent needed before losing contact Repetitive, can annoy participants

	Advantage	Disadvantage
Written consent	More solid legal ground, e.g. participant has agreed to disclose confidential info Often required by Ethics Committees Offers more protection for researcher (as they have written documentation of consent)	Not possible for some cases: infirm, illegal activities May scare people from participating (or have them think that they cannot withdraw their consent)
Verbal consent	Best if recorded	Can be difficult to make all issues clear verbally Possibly greater risks for researcher (in regards to adequately proving participant consent)



Right to withdraw

- Right to withdraw – one of key features of consent
- What about already collected data?
 - not usually allowed, at least in most surveys
- What if project is longitudinal?
 - permit withdrawal



In practice: wording in consent form / information sheet – interviews, photos

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 – focus group

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

We ask you to consider the following points before agreeing to participate.


- Your contribution to the research will take the form of a focus group participant. This will be digitally video recorded and transcribed.
- Your name and any information which may directly or indirectly identify you will be altered to protect your anonymity.
- Any recordings of the discussions will be kept securely, and only authorised to other researchers on the condition they preserve your anonymity.
- The transcriptions (*excluding* names and other identifying details) will be retained by the researcher and analysed as part of the study. They will also be deposited with the UK Data Archive which has strict regulations about accessing data for research and protecting participant confidentiality.

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

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In practice: wording in introductory letter– survey

 UK • DATA
ARCHIVE

UK Data Archive, June 2015

Dear,

[Introduction explaining the research]

Thank you very much for agreeing to participate in this survey.

The information provided by you in this questionnaire will be used for research purposes. It will not be used in a manner which would allow identification of your individual responses.

Anonymised research data will be archived at the UK Data Archive in order to make them available to other researchers in line with current data sharing practices.

Yours,
|
[Name, institution and contact details of researcher]

<http://www.icpsr.umich.edu/icpsrweb/content/datamanagement/confidentiality/conf-language.html>

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