

Gaining consent for sharing your research data

Veerle Van den Eynden

UK Data Service

University of Essex

Newcomers

10 January 2018

UK Data Service



What is the UK Data Service?

- Funded by the ESRC
- Single point of access to a wide range of secondary social science data
- We provide support and training for data creators with accessing, managing, sharing and using data
- Delivered by staff based at universities across the UK (Essex, Manchester, Leeds, Southampton, Edinburgh & UCL)
- UK Data Archive – manages the UK Data Service and curates the data



Have you published or shared your research data?

Can you share data obtained from research participants?

What about ethical and legal requirements, e.g. Data Protection

When sharing data obtained from people

- 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**
- **Data use** in research outputs: presentations, publications, the web
- Data **sharing** and archiving for future uses of data

Keep in mind that not all research data can be fully anonymised, e.g. qualitative interviews may contain personal information

General Data Protection Regulation (GDPR)

- Consent needs to be **freely given, informed, unambiguous, specific** and by a **clear affirmative** action that signifies agreement to the processing of personal data
- Consent must be documented



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



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) |



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

UK Data Service



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/datamanage-ment/confidentiality/conf-language.html>

UK Data Service



Aspects to consider

- Different forms of consent for different materials, e.g. audio recordings, transcripts, photos,...
- 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, teaching, 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



Discussion

- How easy / difficult is consent for data sharing in your research ?
- Which wording would you use?



Questions

Veerle Van den Eynden

veerle@essex.ac.uk

