Consent and anonymisation

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Managing, sharing and archiving social science research data

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UK Data Service



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

	PROS	CONS
One-off	• Simple • Least hassle to participants	• Research outputs not known in advance • Participants will not know all info they will contribute
Process	• Ensures 'active' consent	• May not get all consent needed before losing contact • Repetitive, can annoy participants

Form of consent

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

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

Use of the information I provide beyond this project		
I agree for the data I provide to be archived at the UK Data Archive.[2]	☐	☐
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.	☐	☐
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.	☐	☐

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.

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

Anonymising research data

- Direct identifiers – often not essential research info
- Indirect identifiers

- Remove direct identifiers (or replace with pseudonyms)
  e.g. names, address, institution, photo
- Reduce precision/detail through aggregation
  e.g. birth year vs. date of birth, occupational categories, area rather than village
- Generalise meaning of detailed text
  e.g. occupational expertise
- Restrict upper lower ranges to hide outliers
  e.g. income, age

Anonymising qualitative data

- Remove direct identifiers, or replace with pseudonyms – often not essential research info
- Avoid blanking out; use pseudonyms or replacements
- Identify replacements, e.g. with [brackets]
- Plan or apply editing at time of transcription
- Avoid over-anonymising – removing information in text can distort data, make them unusable, unreliable or misleading; so balance anonymisation with the need to preserve context
- Consistency within research team and throughout project.
- Keep anonymisation log of replacements or removals made – keep separate from anonymised data files

In practice: example anonymisation

Ex 1. Health and Social Consequences of the Foot and Mouth Disease Epidemic in North Cumbria, 2001-2003 (study 5407 in UK Data Archive collection) by M. Mort, Lancaster University, Institute for Health Research.

Date of Interview: 21/02/02

Interview with Lucas Roberts, DEFRA field officer
Date of birth: 2 May 1965
Gender: Male
Occupation: Frontline worker
Location: Plumpton, North Cumbria

Lucas was living at home with his parents, "but I'm hoping to move out soon" so we met at his parents' small neat house. We sat in a very comfortable sitting room with an open fire and Lucas made me coffee and offered shortbread. Although at first Lucas seemed a little nervous, quick to speech and very watchful he seemed to relax as we spoke and to forget abut the tape.

I will just start by asking you to tell me a little bit about yourself and your background.

Well it is an agricultural background. I grew up on the farm where my brother is now. After I left school I did work on the farm but went to college and did exams, did land use recreation, sort of countryside/ environmental management course. So I obviously left agriculture, did the course and came back [to the farm] at weekends.

Comment [v1]: Replace: Ken
Comment [v2]: delete
Comment [v3]: delete
Comment [v4]: Replace: Ken
Comment [v5]: Replace: Ken
Comment [v6]: Replace: Ken

In practice: example anonymisation

Yeah. So is part of your job to look for funding bids and to write funding bits or is that separate?

No. That was what P3 used to do and then it sort of passed down to... really it's with P1 and P4. But I don't actually think there's anything out there at the moment. I think at the moment, because there's all this money saving and things, there's nothing to... there isn't actually anything to access.

M27UK

INT: Id like to start with your career history really. Perhaps you can start from when you finished school?

RES: First of all Id like to say that I do not think that my career is very traditional for someone who comes and works abroad. I graduated from mathematics in 'Country F'. That was equivalent to what is now BSc and MSc and then I did a separate MSc in Computer Science which at that time was called like Specialisation in computer science. And then I started working at the 'Country F' University as a teacher.

INT: Was that in 'City D'?

RES: No, my Specialisation in Computer Science was in 'City D' and my first degree, my mathematics degree was in another university in 'Country F' it is called [Text Cut]

So after I finished in 'City D' my specialisation in computer science I went back to [Text Cut] where I did my first degree and I started working there as an assistant Professor.

Questions

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