
Ethical and legal issues for creating audio-visual interview data

Veerle Van den Eynden and Scott Summers

UK Data Service

University of Essex

Managing and Sharing Digital Data Series

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UK Data Service



Research data services team

- Supporting researchers to make research data shareable
- UK Data Service helps materialise Data Policy for the Economic and Social Research Council (ESRC)
 - Data management planning advice & guidance
 - [Data management guidance & training](#), esp. on confidentiality, security, ethics
 - Research data available for re-use to maximum extent possible, via:
 - ReShare repository
 - <http://discover.dataservice.ac.uk>



Warm-up

- What do you see as pros and cons of sharing data in research with people?
(2 groups, post-it notes, 10 minutes)



Drivers for sharing data

- Increasing drive for openness and sharing – value and transparency
- Technological advances - easier for digital data to be discoverable and accessible
- Sharing data - fundamental in collaborative and multi-stakeholder projects

Enable optimal data sharing through the research lifecycle

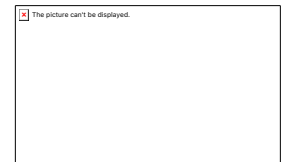
Open where possible, closed when necessary



Too difficult to share data widely?

Ethical, legal and research integrity challenges

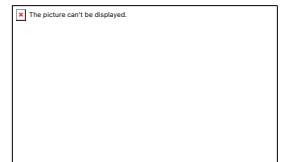
- Personal, confidential or sensitive information
- Linkage of data in multi-disciplinary projects
 - social with geo-located data or biomedical data
 - difficult to conceal identity of participants
/fieldwork locations
- Lack of trust in others mis-using data
- Efforts and funding compete with ‘the science’



Ethical research

.....

“do no harm”



Scenario

- Research on asylum seekers and refugees' experiences of forced labour, using interviews. These participants can be considered vulnerable
- We want to use the collected research data (interviews) for analysis and share afterwards with other researchers
- Interviews are likely to contain personal information
- Is it ethical to share the research data? What are pros and cons?
- How should we protect participant's anonymity?
- Read about this [case study](#)



What the researchers did

- Address ethical issues before the research started
- Discuss principles of 'doing no harm', anonymity and informed consent iteratively in the team as issues arose throughout the project
- Stress independence of research from authority
- Provide written consent at the end of the interviews, so interviewee knew and could reflect on what they had shared
- Hold interviews in places convenient for interviewees
- Include interviewee in interpreter selection
- Collect biographical data after interview
- Not record any official identifying data (e.g. Home Office numbers)
- Let interviewee choose a pseudonym



Ethical arguments *for* sharing 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)
- Avoid social and personal harm
- Uphold scientific standards
- Comply with relevant laws
- Data repositories such as UK Data Service 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



Key principles of research ethics

- Research should aim to **maximise benefit for individuals and society** and **minimise risk and harm**
- The rights and dignity of individuals and groups should be respected
- Wherever possible, participation should be voluntary and appropriately informed
- Research should be conducted with integrity and **transparency**
- Lines of responsibility and accountability should be clearly defined
- Independence of research should be maintained and conflicts of interest cannot made explicit

[ESRC Framework for Research Ethics](#)

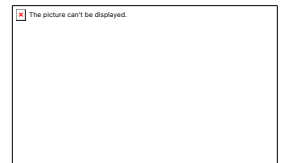


Strategy for managing and sharing research data obtained from people

1. Obtain **informed consent**, also for data sharing and preservation or curation
2. **Protect identities** e.g. anonymisation, not collecting personal data
3. **Regulate access** where needed (all or part of data) e.g. by group, use or time period



Consent



Consent is 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.

[UKDS template consent form](#)



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
- **across the research lifecycle** e.g. for each new data collection in a longitudinal study
- Examples:
 - in a multi-modal study, allow the participant to **consent (or not) separately** to data sharing for various data collection events, e.g. survey, clinical assessment,...
 - in a qualitative study, allow the participant to **consent (or not) separately** to data sharing of anonymised transcripts, non-anonymised audio recordings, photographs,...



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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)

Managing access to data

Open

- available for download/online access under open licence without any registration

Safeguarded

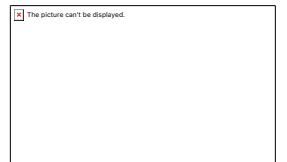
- available for download / online access to logged-in users who have registered and agreed to an End User Licence (*e.g. not identify any potentially identifiable individuals*)
- special agreements (depositor permission; approved researcher)
- embargo for fixed time period

Controlled

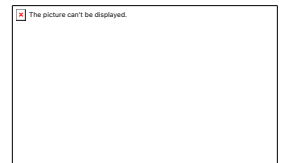
- available for remote or safe room access to authorised and authenticated users whose research proposal has been and who have received training

Exercise: consent

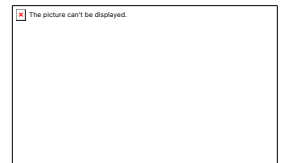
- Evaluate example consent forms
- Which strategies and wording can you use to discuss consent for data sharing with participants in the field and stakeholders?



Legal Compliance



(1) Duty of Confidence

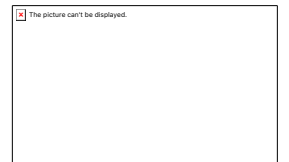


Duty of confidentiality and data sharing

- Duty of confidentiality exists in UK common law and may apply to research data
- Information given in circumstances where it is expected that a duty of confidence applies, cannot normally be disclosed without the information provider's consent
- Disclosure of confidential information is lawful when:
 - The individual to whom the information relates has consented – **consent for data sharing**
 - 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



(2) The General Data Protection Regulation



The General Data Protection Regulation (GDPR)

- New EU-wide data protection regulation
- Came into force 25 May 2018
- The GDPR gives data subjects greater control over their personal data, whilst modernising and unifying European data protection rules
- Clarity, transparency and accountability
- Data Protection Act 2018



The General Data Protection Regulation (GDPR)

- Personal data is defined as ‘any information relating to an identified or identifiable natural person’ (‘data subject’).
- Living persons
- Though there may still be ethical reasons for wanting to protect this information
- Anonymised data is NOT personal data so the GDPR does NOT apply
- Applies to:
 - any EU researcher (data controller) who collects personal data about a citizen of any country, anywhere in the world
 - A data controller or data processor based outside the EU but collecting personal data on EU citizens



The GDPR principles for processing personal data

1. Process **lawfully, fair** and **transparent**

Inform participant of what will be done with the data, process accordingly

2. Keep to the **original purpose**

Collect data for specified, explicit and legitimate purposes

Do not process further in a manner incompatible with those purposes

3. **Minimise** data size

Personal data collected should be adequate, relevant and limited to what is necessary

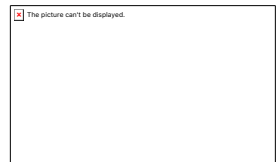
4. Uphold **accuracy**

Personal data should be accurate and kept up to date

5. **Remove** data which aren't used

6. Ensure **data integrity and confidentiality**

Protection against unauthorised or unlawful processing, accidental loss, destruction or damage, using appropriate technical or organisational measures



Data subject rights

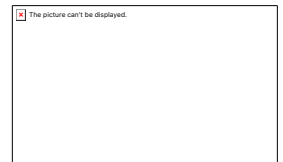
- The right to be **informed**
- The right of **access**
- The right to **rectification** (correction)
- The right to **erasure** (right to be forgotten)
- The right to **restrict processing**
- The right to data **portability**
- The right to **object**
- Rights in relation to automated individual decision-making and profiling



Grounds for processing personal data

One of these must be present to process a data subject's personal data:

- **Consent** of the data subject
- Necessary for the performance of a **contract**
- **Legal obligation** placed upon controller
- Necessary to **protect vital interests** of the data subject
- Carried out in the **public interest** or is in the exercise of official authority
- **Legitimate interest** pursued by controller



The GDPR research exemption

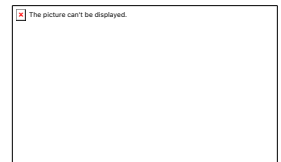
Further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes is not considered to be incompatible with the initial purposes

Appropriate safeguards, e.g.

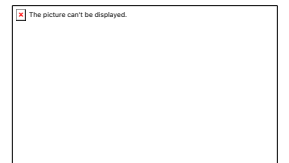
- data minimisation
- pseudonymisation

Principles 2 and 5 less strict:

- Purpose: further processing of personal data allowed (2)
- Personal data may be stored for longer periods (5)



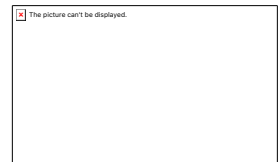
(3) Copyright



Copyright



- Copyright is internationally recognised form of intellectual property right, which arises automatically as a result of original work such as research
- Copyrighted output from research could include spreadsheets (and other forms of originally selected and organised data), publications, reports and computer programs
- Copyright will not cover the underlying facts, ideas or concepts, but only the particular way in which they have been expressed
- The right will lie with the author of the work, or with their relevant institution—different universities will have different policies on intellectual property
- A copyrighted work cannot usually be published, reproduced, adapted or translated without the owner's permission



Copyright – key considerations



- Questions 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?
- Key considerations
 - Joint ownership
 - Datasets created by multiple researchers
 - Derived datasets
 - Database rights
 - Provision in a contract
 - Repository copyright rules



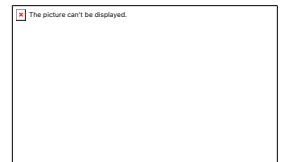
Copyright scenarios exercise (1)

Case Study 1 – Copyright of Archived Data

A researcher uses International Social Survey Programme (ISSP) data obtained from ZACAT / GESIS - Leibniz Institute for the Social Sciences in Germany. These data are freely available to registered users. The researcher incorporates some of the ISSP data within a database containing his own research data. Can this database be deposited with another archive?

Case Study 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. Articles or excerpts are copied into a database and coded according to various criteria for content analysis. (i) Can the researcher use such public data without breaching copyright? (ii) Can the database be archived and shared with other researchers?



Copyright scenarios exercise (2)

Case Study 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

Case Study 4 – Copyright of Interviews with Stay-at-Home Parents

A researcher interviews various stay-at-home parents about their careers and produces audio recordings and near verbatim transcripts herself. The researcher analyses this material and offers it to a data archive. The researcher did not get signed copyright transfers for the interviewees' words. What are the rights issues surrounding this offer of data



Questions

Collections Development
and Data Publishing:
Research Data Services

ukdataservice.ac.uk/help/get-in-touch

