



Facilitate Open Science Training for European Research

**SEMINAR:
Preparing research data for open access**

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MANAGING AND SHARING RESEARCH DATA: CONSENT, CONFIDENTIALITY AND DISCLOSURE

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UK Data Service



Overview

- Open access to data in research with people as participants
- Obligations: legal, ethical
- Consent
- Anonymisation
- Access regulation

Research with people as participants

- Research data may contain personal data - data that allows living individuals to be identified
 - Legal: data protection / privacy legislation (data about living individuals)
 - Inform participants how personal data will be used, stored,....
 - Store securely, avoid disclosure
 - Need consent from participant to share such data
- Research data may contain confidential information - information given in confidence, agreed to be kept confidential (secret) between two parties
 - E.g. information on business, income, health, political opinion,...
 - Legal: duty of confidentiality
 - Ethical: do no harm
 - Need consent from participant to share such data

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 ADP, 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

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 people
- Extend voices of participants
- Provide greater research transparency
- Enable fullest ethical use of rich data

Options for sharing research data that may contain confidential information

- Obtain informed consent, also for data sharing and 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

Consent across the data life cycle

- Engagement in the research process
- 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



When to ask for consent

	Pros	Cons
One-off	<ul style="list-style-type: none">• Simple• Least hassle for participant	<ul style="list-style-type: none">• Research outputs not known in advance• Participants will not know all content they will contribute
Process	<ul style="list-style-type: none">• Most complete for assuring active consent	<ul style="list-style-type: none">• Might not get consent needed before losing contact• Repetitive, can annoy participant

Right to withdraw from research

- Key feature of consent
- What about already collected data?
 - removing data not usually allowed, at least in most surveys
- What if project is longitudinal?
 - permit withdrawal
 - explain to participants the cost to the project of data that would be lost



Format for consent

Written

- more solid legal ground
- often required by ethics committees
- offers more protection for researcher
- not possible for some cases: infirm, illegal activities

Verbal - with or without recording (interviews)

- can be difficult to make all issues clear verbally
- possibly greater risks for researcher
- best if recorded

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 anonymizing (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

Informed consent for unknown future uses ?

- Provide as much information as possible about potential reuse
 - who can access the research data
 - purposes - research, teaching,...
 - confidentiality protection, e.g. conditions for future users
 - general consent - similar to consent with emergent research topics
- Medical research and biobank models - enduring, broad, open consent
 - no time limits
 - unspecified hypotheses and procedures
 - 99% consent rate (2500+ patients) - Wales Cancer Bank

Do participants consent to share data with other researchers in future ?

- Foot and mouth disease in N. Cumbria
 - sensitive community information
 - 40/54 interviews; 42/54 diaries; audio restricted
- Finnish research on consent
 - re-contact participants: life stories, gender, etc.
 - 165/169 (98%) agreed to sharing
- Timescapes
 - longitudinal data on personal relationships
 - > 95 % consent rate to share data

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	Y	N
I agree for the data I provide to be archived at the UK Data Archive. ²	<input type="checkbox"/>	<input type="checkbox"/>
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.	<input type="checkbox"/>	<input type="checkbox"/>
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.	<input type="checkbox"/>	<input type="checkbox"/>

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.

UK Data Archive model consent form

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 about 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: I'd like to start with your career history really. Perhaps you can start from when you finished school?

RES: First of all I'd 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.

Managing data access

- UK Data Service: web access to data and metadata
- Data freely available for use; commercial use charges
- Metadata / documentation always open
- Data available under 3 access levels:

OPEN

SAFEGUARDED – End User Licence

(e.g. not identify any potentially identifiable individuals)

- Special agreements: depositor permission; approved researcher
- Embargo for fixed time period

CONTROLLED – only for accredited users

- Access via on-site or virtual secure environment
(secure lab)

Can such research data be open ?

- ESRC research data policy:
 - *Publicly-funded research data are a public good, produced in the public interest, which shall be made openly available and accessible with as few restrictions as possible in a timely and responsible manner that meets a high ethical standard and does not violate privacy or harm intellectual property.*
 - Openly available research data, with as few restrictions as possible, means in the ESRC context that research data will be made available for re-use free of charge, as open data, safeguarded data or controlled data; the access category being selected to minimise the risk of disclosing personal information

Open about data with restricted access

Publish:

- Which data exist
- Where data are kept, e.g. which repository
- Who can access them
- For which purpose can they be used
- Under which conditions

In practice: data with access conditions

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.

- Interviews (audio + transcript) and written diaries with 54 people
- 40 interview and diary transcripts are archived and available for re-use by registered users
- 3 interviews and 5 diaries are embargoed until 2015
- audio files archived and only available by permission from researchers

discover.ukdataservice.ac.uk/catalogue/?sn=5407

doc.ukdataservice.ac.uk/doc/5407/mrdoc/pdf/q5407userguide.pdf

In practice: access conditions ReShare

Global Uncertainties: Security In an Africa of Networked, Multi-Level Governance

Leonard, David 2014. Global Uncertainties: Security In an Africa of Networked, Multi-Level Governance. [Data Collection]. Colchester, Essex: Economic and Social Research Council. <http://reshare.ukdataservice.ac.uk/id/eprint/851233>

The programme of research centres on how the various institutions responsible for the production of security and the management of conflict in Sub-Saharan African societies do, could and should evolve in response to the presence of violent conflict. These institutions include: the armed forces, police, courts (civil as well as criminal), 'traditional' institutions of local governance, elections (and other methods of choosing leadership), international organisations (such as the United Nations, African Union, UN High Commission for Refugees, the World Court.), and the community of international donor nations. The programme is built on the observation that all governance (especially in Africa) is multi-leveled and networked - from the village to the international organisation, and well beyond what is specified in formal government structures. Thus the focus will be not only on the ways in which key conflict-management institutions evolve themselves but also on the changing ways in which the networks in which they are embedded actually operate. This leading edge research challenges theories about the state, state formation, and sovereignty as well as the dynamics of violent conflict as presented in the dominant current work on Africa. The primary methods of research will be network analysis and qualitative interviewing.

Creators:	Creator Name	Email	Affiliation	ORCID
	Leonard, David	Unspecified	Institute of Development Studies	Unspecified
Research funders:	Economic and Social Research Council			
Grant reference:	RES-071-27-0048			
Subjects:	Law, crime and legal systems Politics			
Date deposited:	31 Jan 2014 19:00			
Last modified:	22 Oct 2014 19:27			

In practice: access conditions ReShare

— Coverage and Methodology

Collection period:	Date from: 1 April 2009	Date to: 31 March 2013
Country:	Sierra Leone	
Data collection method:	Group interviews in 39 villages and towns in rural Sierra Leone	
Observation unit:	Groups	
Kind of data:	Alpha-numeric, Textual	
Type of data:	Qualitative and mixed methods data	
Resource language:	English	

— Access and Administration

Data sourcing, processing and preparation: Citizen interviews

Copyright holders:	Name	Email	Affiliation	ORCID
	Leonard, David	Unspecified	Institute of Development Studies	Unspecified
	,	Unspecified	Unspecified	Unspecified

Contact:	Name	Email	Affiliation	ORCID
	Leonard, David	leonard@berkeley.edu	Institute of Development Studies	Unspecified

Notes on access: The names of individual respondents have been removed from the data set.

Publisher: Economic and Social Research Council

Last modified: 22 Oct 2014 19:27

In practice: access conditions ReShare

AVAILABLE FILES

Data

- Security_%26_Networks.xlsx
 - Accessible to:** Registered users only (safeguarded data)
 - File or bundle content:** Data
 - File or bundle description:** Security & Networks
 - File format:** application/octet-stream
 - License:** UK Data Service End User Licence
 - File size:** 10Kb
- + Sierra_Leone_Security_%26_Networks__Coded.xls
- + Copy_of_Somalia_SC_peace_initiatives.xlsx

Documentation

- Sierra_Leone_methods.doc
 - Accessible to:** Anyone (open data)
 - File or bundle content:** Documentation
 - File or bundle description:** Sierra Leone methods
 - File format:** application/msword
 - License:** UK Data Service End User Licence
 - File size:** 64Kb

In practice: access conditions ReShare

The Impact of Living Abroad: Stress, Adaptation, and Intergroup Contact

Geeraert, Nicolas 2014. The Impact of Living Abroad: Stress, Adaptation, and Intergroup Contact. [Data Collection]. Colchester, Essex: Economic and Social Research Council. <http://reshare.ukdataservice.ac.uk/id/eprint/850827>

Whether as migrant, expatriate, or overseas student, living abroad has an impact on individuals in terms of well-being, task-oriented functioning, and intergroup behaviour. This research examines the impact of intercultural contact by comparing such sojourners with a matched group of peers. The study will monitor a large cohort of international exchange students (sojourners) before, during and after intercultural contact. The research has four objectives. A first objective is to research the occurrence of acculturative stress, specifically examining when, and why stress occurs, and how it evolves over time. A second objective is to examine cultural learning and adaptation. In particular, the research will explore whether sojourners benefit in terms of improved culture specific knowledge (eg language, customs), general cultural awareness, and personal development (eg self-confidence). A third objective is to study the impact of intercultural contact on intergroup behaviour. The study will appraise whether and how intergroup contact influences perception of ingroup and outgroups. Finally, the study will investigate how differences in cultural distance (ie the extent to which cultures are different) affect these issues of stress, adaptation, and intergroup contact.

Creators:	Creator Name	Email	Affiliation	ORCID
	Geeraert, Nicolas	Unspecified	University of Essex	Unspecified
Research funders:	Economic and Social Research Council			
Grant reference:	RES-062-23-1211			
Subjects:	Psychology			
Date deposited:	04 Apr 2013 13:42			
Last modified:	01 Oct 2014 13:22			

+ Coverage and Methodology

+ Access and Administration

AVAILABLE FILES

Data

- data.csv

Accessible to:	Registered users requesting permission access from depositor until 1 January 2015
File or bundle content:	Data
File or bundle description:	data



Questions ?

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