
Personal, not Painful: Practical and Motivating Experiences in Data Sharing

Louise Corti

Collections Development and
Producer Relations Team

Data Dialogues

University of Cambridge

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UK Data Service



Overview today

- Enable **safe access to data** that meet the needs of **data protection ...** yet fulfil the demands for **open science and transparency**
- Utilise appropriate **policies, licencing and access pathways**
- Examples of 'difficult' quantitative and qualitative data that have been successfully shared
- Helping empower data owners in their decision-making



Tensions in sharing one's research data

- ✓ Want to do good science with integrity
- ✓ See the benefits of sharing and collaboration
- ✓ Need to meet funders policy/contractual mandate
- ⌘ Sharing data 'not possible' - ethical, legal or practical reasons
- ⌘ Unwillingness to share – my IPR, 'they won't understand', no time

Let the counselling begin...

The counselling session



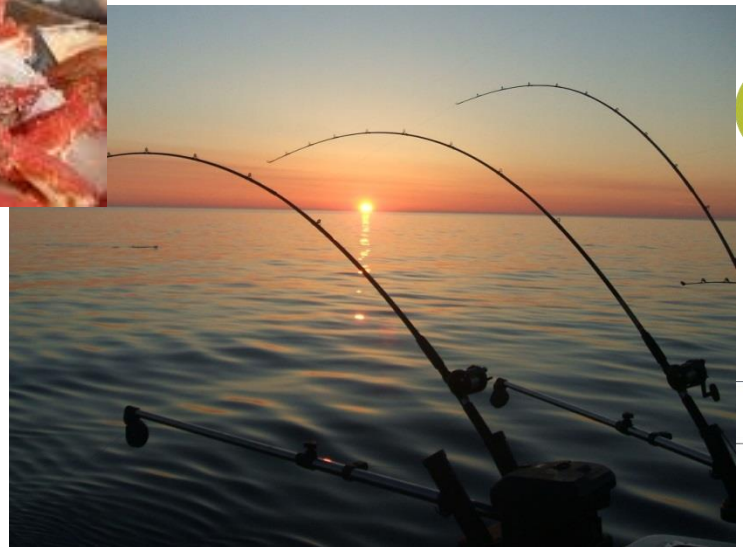
Collections Development work at UKDS



Trawling



Line-catching



The UK Data Service is lucky to build on almost 50 years of practice

7000 data collections across social science spectrum

Supporting the ESRC Data Policy since 1995

Dealing with 1000s of social science data creators using accumulated tried and tested best practice

OUR NETWORK OF TRUST



Data policies

Protocols and templates

Legal agreements/concordats

Negotiation techniques

Incentives for sharing

Key contacts

Expertise and experts

Successful data appraisal

- ✓ Use **Collections Development Policy** – an evolving and living document
- ✓ Use **Appraisal and Selection Criteria** – agreed audit trail, research integrity, ethics and disclosure risk review
- ✓ Use an expert **Data Appraisal Group** with skills across the Service.



Access conditions

Depositor selects, with guidance, the access category most appropriate for the 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

Controlled

- available for remote or safe room access registered users whose research proposal has been approved by an access committee and who have received specialist training

Successful data ingest

- ✓ Standard depositors **licences or data sharing agreements and End User Agreements** – not bespoke
- ✓ Work to an **agreed timetable** for data publishing
- ✓ Use robust and explicit **quality assessment techniques**
- ✓ Use standard **deposit metadata and data description**



Not all data are sensitive

- Common worry about onward sharing of data covering ‘sensitive topics’
- But not ‘sensitive data’ for the DPA
- Deal with personal sensitive data properly
- Discuss consent status and implications
- Offer appropriate (multiple) pathways to access
 - Anonymise and/or control
- Last resort, offer permission to reuse/control access



Negotiation on access – UK cohort studies

- Safeguarded access: most versions
- Special Licence Access: some e.g. [Millennium Cohort Study](#), 2001-2003: Hospital of Birth:—uncoded free-text hospital variable
- Secure access: some e.g. linked Department for Education [educational records](#)

Approved Researchers; 5 Safes framework



Caveats of locking down

- Significant administrative burden:
 - 100s datasets – securing data access owners and committees
 - 1000s users – approved projects, approved researchers, bespoke output checking
- Future proof permission-granting owners moving on:
 - Advocate a Data Access Committee
 - Renegotiate access control level



Health and Social Consequences of the Foot and Mouth Disease Epidemic in North Cumbria, 2001-2003

SN 5407, Maggie Mort, Lancaster University

- Study funded by Department of Health
- Panel of 54 local people in affected area during FM crisis:
 - farmers, agricultural professionals, small businesses, health professionals, vets, residents
- Weekly diaries for 18 months
 - how their life was affected by the crisis
 - process of recovery observed around them (handwritten)
- In-depth interviews and group discussions (audio recordings, transcripts)



Data sharing steps

- ✓ At end of research – desire to archive data
- ✓ Met with UKDS for advice data archiving
- ✓ Sought advice from copyright specialist on archiving
- ✓ Developed separate consent forms for written and audio material, opt in / opt out and an embargo option
- ✓ Piloted discussion on data archiving with panel members :
 - ✓ data anonymisation, confidentiality, copyright, ownership
 - ✓ understanding of archiving and information required
 - ✓ user options of archived data - scholarly / educational purposes
- ✓ Discussed archiving individually with each panel member



Data sharing outcome

- Safeguarded access: 40 interview and diary transcripts were made available for re-use by registered users
- 3 interviews & 5 diaries embargoed until 2015
- 7 panel members declined archiving their data
- Permission only: audio files archived
- [Exemplary user guide and data lists](#)



Managing suffering at the end of life: a study of continuous deep sedation until death

SN 850749, Jane Seymour, University of Nottingham, 2012

- 30 case studies using qualitative methods
- Interviews with staff and relatives closely involved in the care of decedents who received continuous sedation until death at home, in hospital or in hospices
- One of the few studies which seek to take a qualitative perspective on clinical decision-making in this area
- Research talking about delicate and painful issues
- Frameworks for ethical review



Data sharing steps and outcome

- ESRC grant so data sharing mandated
- Negotiation with UKDS
- Discussed anonymisation strategy
- Safeguarded access
- Anonymised transcripts shared

AVAILABLE FILES

Data

— [Data_Transcripts.zip](#)

Accessible to:	Registered users only (safeguarded data)
File or bundle content:	Data
File or bundle description:	Bundle of all data files (Community bases, hospice based and hospital based case studies)
File format:	application/zip
License:	UK Data Service End User Licence
File size:	11Mb

Documentation

— [StudyProtocol.pdf](#)

Accessible to:	Anyone (open access data)
File or bundle content:	Documentation
File or bundle description:	The perspectives of clinical staff and bereaved informal care-givers on the use of continuous sedation until death for cancer patients: The study protocol of the UNBIASED study
File format:	application/pdf
License:	Creative Commons Attribution 4.0 International
File size:	187Kb



Handling queries on self-deposit

- 940 data collections published so far in ReShare
- Some hand-holding for depositors prior to upload
- Full-time repository administrator
 - Junior research level with MA in social science
- 1 in 10 questions relayed up to more senior staff
 - Ethics and disclosure review
 - Some formats and technical issues
- Query tracking system to manage/log/view responses



Sensitive case

- Famous academic anthropologist
- Unwilling to share ESRC data from years in the field
- Life's works over 50 years
- On retirement...

I'm ready now to share that data you asked for...



Data sharing steps

- Ok to say 'No' but helpfully refer
- Take time to sift and weed if you see high value
- Discourage from such physical offers unless you can handle them!
- Be wary that saying no also might have consequences



Key messages from these cases

- Expertise in negotiating and listening
- Understanding of and confidence in discussing the research approach and data
- Appreciation that sensitive topics do not necessarily mean 'sensitive data' (DPA)
- Flexibility in presenting options to PIs, don't offer the most locked down first
- Giving concrete advice and solutions – submit samples of data to assess
- Point to other successful cases
- Be ready to refer on!



LOVE research data



Make it easy to publish and upload data

UK Data Service
ReShare



My data

Logged in as Louise Corti Logout UK Data Service home Help About FAQ Contact

Home Legal Review procedures

Edit collection: [Data Collection #851515](#)

Terms and conditions → Award details → People → Data collection → Upload → Deposit

To deposit a data collection, you must accept the [ReShare Terms and Conditions](#).

- I confirm that I am the owner of the copyright and associated intellectual property rights in the whole Data Collection or am otherwise lawfully entitled to grant this licence on behalf of each and every owner;
- I grant a non-exclusive, royalty-free licence to the UK Data Archive (a department of the University of Essex and not a separate legal entity) of Wivenhoe Park, Colchester, CO4 3SQ (the "University") to hold, make copies of, and disseminate copies of the Data collection, in accordance with the access conditions I will specify when uploading data files: open data accessible to users without registration; or safeguarded data accessible to users registered with the data services provided by the UK Data Archive.

*** I agree to the ReShare data deposit terms and conditions**

☐

Save for later Cancel Next >

Guidance and training resources

- Web-based guidance and FAQ - not read by all..
- Training and capacity building

<div data-bbox="112 632 768 711">Home Legal Review procedures</div> <div data-bbox="112 811 768 868"><h2>ReShare help guidance</h2></div> <div data-bbox="112 939 768 1382"><ol style="list-style-type: none">1. Prepare research data for ReShare2. Deposit data in ReShare<ul style="list-style-type: none">Register and log inTerms and conditionsGrant informationResponsible peopleData collection descriptionsUpload filesDeposit collection3. Further guidance</div>	<div data-bbox="807 582 1570 618">Home Legal Review procedures</div> <div data-bbox="807 689 1570 746"><h2>ReShare data review procedures</h2></div> <div data-bbox="807 789 1570 861"><ol style="list-style-type: none">1. UK Data Service review procedures2. External peer reviewer procedures</div> <div data-bbox="807 889 1570 1382"><h3>UK DATA SERVICE REVIEW PROCEDURES</h3><p>The UK Data Service reviews each data collection submitted to the ReShare repository for disclosure risk, copyright breaches, validity of file formats and level of documentation before publishing the collection. The quality or scientific validity of research data is not evaluated.</p><p>All numerical data files and at least a 10% random sample of textual data files are reviewed.</p><p>Non-English language data files are checked if a staff member of the UK Data Service is familiar with the language.</p><p>Any concerns, changes needing to be made to data files, or requests for additional documentation are communicated to the data depositor for actioning.</p><p>Data review comments and actions taken are noted in the data collection metadata record, as provenance information for the data collection.</p><p>Review procedures</p></div>
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Data review and common issues

- ✓ Overall, a positive experience for most depositors
- ✓ Mostly good quality data and documentation

A few recurring issues after upload:

- ✗ Poor - or complete lack of – documentation/methods
- ✗ Limited descriptive metadata for the catalogue record
- ✗ Poor file names
- ✗ No reason for excluding files, for which fieldwork took place



Remedies

- Relay issues back to depositor - timely
- Accept nothing unless it comes with a clear **ReadMe file** that explains what the collection is about
- Add alerts within the system and common issues to guidance
- Incentives – promote high quality collections



Collection period: **Date from:** **Date to:**
1 October 2008 30 September 2012
Country: United Kingdom
Data collection method: Collection of information from official documentation across several countries
Observation unit: Organisations, Text units
Kind of data: Alpha-numeric
Type of data: Qualitative and mixed methods data
Resource language: English

— Access and Administration

Data sourcing, processing and preparation: Information from various sources, including the International Bureau of Fiscal Documentation

Copyright holders:	Name	Email	Affiliation	ORCID
	Devereux, Michael	Unspecified	University of Oxford	Unspecified
Contact:	Name	Email	Affiliation	ORCID
	Devereux, Michael	michael.devereux@sbs.ox.ac.uk	University of Oxford	Unspecified
Notes on access:	None			
Publisher:	Economic and Social Research Council			
Last modified:	28 Apr 2014 22:42			

AVAILABLE FILES

Data

+ CBT_Tax_database.xlsx

Documentation

+ CBT_Tax_database_description.pdf



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Life at the front end of a Data Service



UK Data Service deposit resources

- UKDS [depositor case studies](#)
- UKDS [webpages](#) and [video](#) on preparing data
- UKDS [webpages](#) on operating the ESRC Data Policy
- UKDS [webpages](#), book and video on RDM issues
- UKDS ReShare guide/checking guidelines
- [Depositing Shareable Survey Data](#) brochure
- UKDS [Collections Development Policy](#)
- UKDS [Selection and Appraisal Criteria](#)
- UKDS [Data Purchase Guidelines](#)
- [Call to action](#): Use of DDI metadata in survey production process




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Prepare and manage data

“Good data habits from the moment you start planning your research”



SHARE

Data created from research are valuable resources that can be used and re-used for future scientific and educational purposes.

Good data management practices are essential in research, to make sure that research data are of high quality, are well organised, documented, preserved and accessible and their validity controlled at all times. This results in efficient and exciting research. Well managed data are easily shared and can thus be used for new research or to duplicate and validate existing research.

Data management needs to be planned early on in research, so that practices can be implemented throughout the research cycle.

Roles and responsibilities of the various players in the research process need to be explicitly established.

LOGIN / REGISTER

DISCOVER UK DATA SERVICE

Data Website

MANAGING AND SHARING RESEARCH DATA

DOWNLOAD OUR DATA GUIDE: Comprehensive best practice guidance for researchers on managing and sharing data

QUICK ACCESS TO

FAQ about managing data

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UK Data Service

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Deposit data

“Valuable resources that can be used and reused”



SHARE

Data created or generated during research or administrative processes are valuable resources that can be used and reused for future scientific and educational purposes. Sharing data can:

- facilitate research beyond the scope of the original research
- encourage scientific enquiry
- avoid duplication of data collection
- provide rich resources for education and training

We proactively acquire data that are suitable for use in research and teaching and that fall within the thematic scope of our Collections Development Policy. We offer different pathways for regular depositors of major survey or other data studies, ESRC award holders and other types of data collections. Please use the appropriate sections to help guide you.

[How to deposit data](#)

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Data Website

DEPOSITING SHAREABLE SURVEY DATA

QUICK ACCESS TO

Guide to preparing data

ReShare self-deposit repository

FAQ on depositing data

Get in touch

Depositing data video




Depositing data

Different steps for different depositors

Home > Deposit data > How to deposit

How to deposit

“Depositing data is straightforward and rewarding”



SHARE

At the UK Data Service we offer different pathways for regular depositors of major survey or other data studies, ESRC award holders and other types of data collections.

New depositors

New depositors, who are not ESRC-funded, can offer their data by sending us a short description of the data collected. We appraise data according to our Collections Development Policy.

Regular depositors

For depositors of large-scale social surveys or government data series we offer guidance on how to prepare data, completing our deposit form and source agreement, information on the checks we carry out on received data, and the ways in which we safeguard data.

ESRC award holders

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DEPOSITING SHAREABLE SURVEY DATA

QUICK ACCESS TO

How to prepare your data

How to deposit data video

ESRC ReShare depositors

UK Data Service

0:58 / 5:57

YouTube

ReShare data review procedures

1. [UK Data Service review procedures](#)
2. [External peer reviewer procedures](#)

UK DATA SERVICE REVIEW PROCEDURES

The UK Data Service reviews each data collection submitted to the ReShare repository for disclosure risk, copyright breaches, validity of file formats and level of documentation before publishing the collection. The quality or scientific validity of research data is not evaluated.

All numerical data files and at least a 10% random sample of textual data files are reviewed.

Non-English language data files are checked if a staff member of the UK Data Service is familiar with the language.

Any concerns, changes needing to be made to data files, or requests for additional documentation are communicated to the data depositor for actioning.

Data review comments and actions taken are noted in the data collection metadata record, as provenance information for the data collection.

Review procedures

1. Generic project-level checks:

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Deposit data collection

UK Data Service



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Contact

corti@essex.ac.uk

Collections Development and Producer Relations team

UK Data Service

University of Essex

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

UK Data Service

