Copyright, Confidentiality and Openness: Some Irish Experiences

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CES 2012, FSD, Tampere, 4-5 October





Topics

- Background
 - Overview of development of Irish Qualitative Data
 Archive and Digital Repository of Ireland
- Framework for sharing and re-use based on trust
- Challenges to trust
 - Deposit
 - Access
 - Wider institutional challenges
- Future challenges and opportunities



The Irish Qualitative Data Archive: An Introduction

- Established in 2008 as part of the Irish Social Science Platform under PRTLI4
- Evolved as companion service to Irish Social Science Data Archive (<u>www.issda.ie</u>, CESSDA)
- Member of consortium that will develop the Digital Repository of Ireland, funded under PRTLI5
- Our remit:
 - To be the central access point for all qualitative social science data generated in Ireland
 - Promote best practice in data management





Qualitative data



My name is I'm 12 year old

I'm 12 year old

I've in a place called

I've in a place called

I've in a place except for the

construction going on we go shopping in the

village, super quinn of Liftey Valley. I've been

liveng in Lucan 314 year of think it's a

very nice place to live. There are a lot or people

we know who have moved to Lucan. The school

I go to is small because it is temporary

whe are getting a 2 story building next year

but I'll be in secondry chool some of

my priend are going to that school of some

are all ready there. Lucan is far better

that were I lived becore, but the builders

have got to stop diaging up the whole



- What kinds of data do we archive?
 - Interviews (audio, video, transcripts)
 - Focus groups
 - Diaries and documents
 - Field notes
 - Photographs



Data protection system

Agreement on Conditions of Use

This agreement covers the use of data files and all related material (hereafter "data") supplied by the Irish Qualitative Data Archive (IQDA). A signed copy of this agreement must be submitted by all users named on the Data Access Request form.

1. Users of the data

"LEAD USER" is defined as the person who has made an application and been approved to use the data specified in the 'Data Access Request Form'. "OTHER USER" is a person named as "other user" in the 'Data Access Request Form' who has access to the data in addition to the LEAD USER, but under the control of the LEAD USER. LEAD USER and OTHER USERS are collectively defined as the "USERS" and both have responsibilities under this agreement.

2. Purpose of use and disposal of data

USER undertakes to use the data only for the purposes stated in the 'Data Access Request Form,' after which the data will be disposed of. If USER wishes to use the data for other research or teaching purposes, USER will send a new access application to the Archive. Use of the data, and/or results obtained from use of the data, for any purpose other than research or teaching is prohibited.

3. Data security

LEAD USER undertakes that no-one but the USERS will have access to the material. LEAD USER shall be responsible for compliance with the terms and conditions of this agreement and for controlling access to the data. One copy of the data may be held centrally on the LEAD USER's computer systems. Apart from a single copy made by the LEAD USER for the purpose of back-up, no other copy of the data shall be made by any USER. The data may not be copied to local workstations or computers, whether standalone or linked to the LEAD USER's computer system. Security arrangements on the LEAD USER's computer facilities will be established to ensure that access to the data stored centrally is limited to those persons who are permitted under this agreement to access the data.

4. Data protection

USER will ensure that while storing or using the data, and publishing information based on it, the confidentiality of individuals and bodies whose details appear in the data are protected. USER will not attempt to identify, or claim to identify, any individuals or participating bodies in a manner that would breach privacy or data protection laws. USER will not attempt to match, or claim to have matched data relating to individuals or participating bodies to any other data. If, in the course of research, USER recognizes, or suspects he/she might recognize a study participant, USER will

- Consent
- Anonymisation to remove personal or sensitive information
- Rights management framework
 - Depositor and end-user agreements and licenses
 - Access control and user restrictions



Challenges: The RACcER Project

- 'Re-Use and Archiving of Complex Community Evaluation Research'
 - Co-funded by IRCHSS and Tallaght West Childhood Development Inititiavel (2010)
 - Investigators: Jane Gray, Aileen O'Carroll (IQDA) and Tara Murphy (TWCDI)
- Background:
 - Differences between TWCDE data commissioners and researchers on archiving qualitative data
- Key Objectives
 - Document practical and ethical concerns and challenges faced by researchers in relation to archiving
 - Interviews with 30 'stakeholder' respondents
 - Development of archiving strategy for secondary data arising from CDI evaluation
 - Establishment and dissemination of best-practice guidelines for qualitative social science data in Ireland (launched January 2011)



Perceived advantages of archiving

"[The] exercise of archiving...could have a very valuable contribution to make in relation to the management and the use of qualitative data in a way that moves beyond a single project. So replication and all of those kinds of scientific methods issues, which qualitative researchers are often accused of not being prepared to take account of, you could actually get some quite interesting methodological leads, I think anyway, out of the carefully constructed archive."

"So I think information sharing, springboards to revisit places, projects, people who have been archived, and just the whole serendipity I think.... And I think with archiving, if the resource is there and if people surf it, who knows where it might lead, how it might actually set off little thought experiments or ideas for how people might take something further or go off and do something else or whatever."

Researchers

- Comparative and longitudinal research uses
- Historical value
- Potential for improving the status of qualitative research

Data commissioners and funders

- Expanding the evidence base
- Linking data to practice
- Providing baseline information for future projects



Challenges to sharing and re-use

- R1 That's not very appealing as a researcher doing all the hard work.
- R2 Getting the access, building up relationships, all that kind of thing. For somebody else to come along then.
- R1 Who has got the time, when you're out collecting the data, they're doing what you want to be doing with it but you don't have the time.
- R3 While you're out collecting the data... [I]s the added value worth the pain, the time in anonymising?

"[T]he worry...is that it becomes too cumbersome to use and that would really concern me, it would then become this obscure archive which is there but we don't really know who can use it. And people get very angsty about stuff that doesn't seem to be freely available or open and then it is just a bloody white elephant because money has been put aside to do this but it is not something that is transparent. So that is the other side."

Researchers

- Ethical concerns about protection of respondents
- Additional costs associated with anonymisation
- Framed in context of concerns about ownership and intellectual property
- Data commissioners and funders
 - Accessibility
- Both groups
 - Concerns surrounding sustainability and re-use



Outcomes for IQDA



- Refined our understanding of data protection system in practice
- Highlighted extent to which system is based on trust
 - We assume depositors own data and have the right to deposit
- Weaknesses in system of access control
 - We now try to encourage depositors to grant IQDA decision on access at certain point



Emerging issues for license agreement

 Family Rhythms Project (Funded by Irish Research Council)



Family dressed for the weather for V6491

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- Provisions focus on nonidentification, security and exclusive use (individual and project)
- Concern that security provisions out-of-date and not consistent with contemporary research practices
 - Feedback from users and own experience in using data
- We would like to consider
 - Team licenses for research and teaching groups
 - More realistic guidance on best practice relating to security





Digital Repository of Ireland

http://www.dri.ie



Wider institutional issues

- Trust based system that (sometimes!) pretends it's not
- University-based system
 - Advantage that archives are designed and run by researchers but....
 - Universities more oriented towards defending patents and intellectual property than data-sharing
 - Capacity to defend licenses and agreements untested
- Questions remain about degree of commitment to openness and data sharing within Irish research environment
- Absence of secure funding clearly a threat to trust and development of practices of data sharing and re-use in Ireland

