

Curation after the fact: Practical and ethical challenges of archiving legacy evaluation data

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Children's Research Network for Ireland and Northern Ireland

12th International Digital Curation Conference 20th – 23rd of February 2017. Quincentenary Conference Centre (QCC) at
The Royal College of Surgeons of Edinburgh. Parallel session C6: Ethical Challenges.

The story of the data: how things were (2004 – 2016)

- ❖ The Children's Research Network for Ireland and Northern Ireland
- ❖ The Atlantic Philanthropies (AP): significant investment into Prevention and Early Intervention (PEI) children & youth sector in Republic and Northern Ireland between 2004 – 2016
- ❖ AP funded 52 programmes across range of community organisations providing PEI services - independent evaluation condition of funding
- ❖ University-based research teams from education, economics, sociology, psychology, nursing commissioned to carry out the evaluations
- ❖ End product: a report
- ❖ 2016 spend-down of AP funds – wish to capture their legacy in Ireland

Evaluation data is an extreme example of the sensitivities and tensions in social research data

OUTCOME EVALUATION

HOW THE PROGRAMME PERFORMED

What makes it sensitive:

- Control group v's trial group
- Standardised measures, for example child's cognitive and emotional development or a parent's sense of confidence when parenting
- Demographic info used to explore causal factors in test scores
- Baseline – most risky in term of identification of individuals
- Longitudinal element = characteristics gathered over a number of years

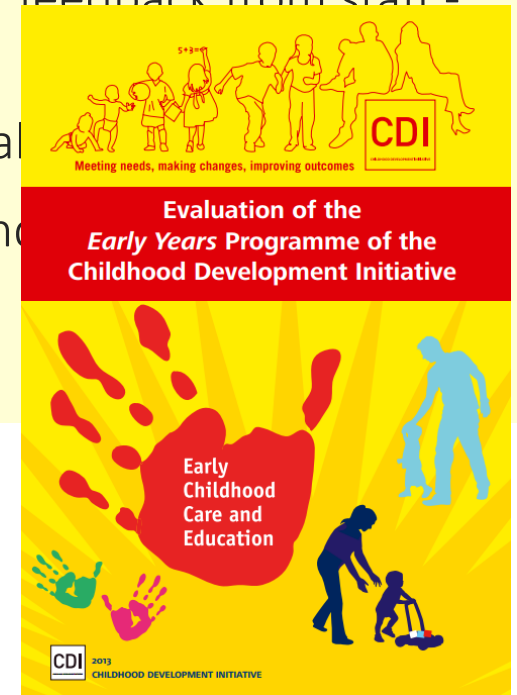
PROCESS EVALUATION

HOW THE PROGRAMME WORKED IN PRACTICE

What makes it sensitive?

- Opinions of participants, or feedback from staff – could be quite critical
- Honest feedback is essential
- Personal stories – these tend to be sensitive for the populations

Culture of publicly sharing and promoting in PEI services = confidentiality issue for the data



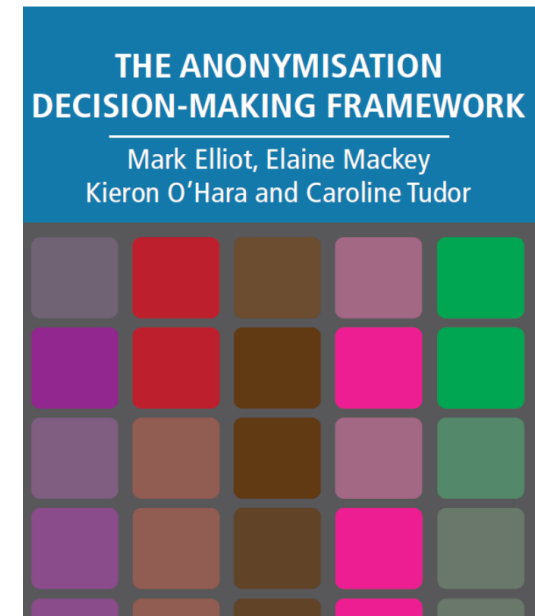
How do we convince ethics boards that such data can be safely and ethically shared amongst academic researchers?

Three-step approach to sharing sensitive data proposed by most social science archives...

“when gaining informed consent, include provision for data sharing; where needed, protect people’s identities by anonymising data; consider controlling access to data” (UKDA *Managing and Sharing Data*, 2011, pg. 23).



<http://ukanon.net/ukan-resources/ukan-decision-making-framework/>



Anonymise
the data

Our use case approach to anonymisation



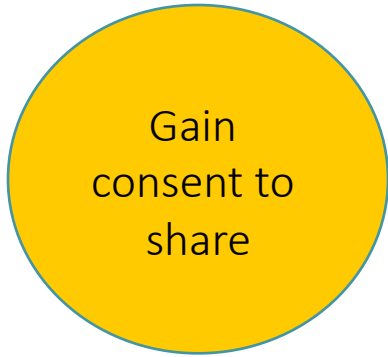
- ❖ In anonymisation there's a “trade-off” between data that is safe to share and useful and worthwhile (Elliot et al., 2016)
- ❖ Use case approach: consideration of who the authentic user will be and what they will most likely want to get from the data
- ❖ We developed use case scenarios by speaking to our Network members
- ❖ Our interpretation: alter demographic variables which run a higher risk of disclosure, while leaving the standardised score variables untouched. Break the primary ID link between archived file and old files (the case ID).



Control
access

Our environment-based approach to anonymisation with End User Licencing

- ❖ “environment-based solution” (Elliot et al., 2016) by controlling
 - *who can access the data (user accreditation)*
 - *how they can use it (End User Licence)*
 - *how and where the data is accessed from (encrypted delivery and storage)*
- ❖ Not a cure-all but limits the risk of data being targeted for ill intent, because it is not easy to get to
- ❖ Unexpected outcome: fostering a culture of safe handling of all research data amongst the research community e.g. encrypted storage of research files



Retrospective consent – small trial study with Maynooth University

- ❖ Ethical question: ‘older’ data that is of great value to the public good but missing informed participant consent
- ❖ Experiment with retrospective consent
 - Researcher is re-contacting 30 participants by letter after 6 years*
 - Following up with phone call to capture their opinions*
 - May provide material for ethics boards*
- ❖ **Caution:** Huge work for the researchers, not viable for quant studies
But an interesting case study none-the-less

Conclusion: How the project has impacted on research culture in Ireland

1. Delivered guidance to researchers on how to archive (with focus on evaluation research)
 - (a) CRN-PEI Guiding Principles outline key legal and ethical obligations
 - (b) CRN-PEI Protocols define the standards for how data is prepared
2. Stimulated community-led capacity building in secondary analysis – real life examples of how to do it
3. Simultaneously raised the question of archiving requirements across multiple university research ethics boards



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PEI Research Initiative project runs until Dec 2017

Thank you for your attention... any questions?