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

Ruth Geraghty
Data Curator on the PEI Research Initiative project at the Children’s Research Network for Ireland and Northern Ireland

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

<table>
<thead>
<tr>
<th>OUTCOME EVALUATION</th>
<th>PROCESS EVALUATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>HOW THE PROGRAMME PERFORMED</td>
<td>HOW THE PROGRAMME WORKED IN PRACTICE</td>
</tr>
<tr>
<td>What makes it sensitive:</td>
<td>What makes it sensitive?</td>
</tr>
<tr>
<td>• Control group v’s trial group</td>
<td>• Opinions of participants, or feedback from staff - could be quite critical</td>
</tr>
<tr>
<td>• Standardised measures, for example child’s cognitive and emotional development or a parent’s sense of confidence when parenting</td>
<td>• Honest feedback is essential</td>
</tr>
<tr>
<td>• Demographic info used to explore causal factors in test scores</td>
<td>• Personal stories – these tend to be vulnerable populations</td>
</tr>
<tr>
<td>• Baseline – most risky in term of identification of individuals</td>
<td>Culture of publicly sharing and promoting in PEI services = confidentiality issue for the data</td>
</tr>
<tr>
<td>• Longitudinal element = characteristics gathered over a number of years</td>
<td></td>
</tr>
</tbody>
</table>
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).

Gain consent to share

Anonymise the data

Control access

http://ukanon.net/ukan-resources/ukan-decision-making-framework/
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).
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
Contact: r.geraghty.crm@effectiveservices.org
PEI Research Initiative project runs until Dec 2017

Thank you for your attention... any questions?