Ethical issues in using HR data

Libby Bishop
Research Data Management Team
UK Data Service – University of Essex

Supporting HR organisations to deliver insights from data
University of Essex
29-30 October 2015
Your ethics issues

1. Dilemmas – great benefits of data sharing, but real risks (small to severe) of harm to clients or HR organisations
   - Improve services, meet reporting requirements, but…
   - Real risks: loss of trust, breach confidentiality, harm, violence
   - Tension: “objective” research vs. data for advocacy
   - Uses of representations: can be inaccurate, exploitative

1. Anonymisation
   - Lack of clarity about legal requirements
   - Tools being used – in-house and external systems

2. Consent
   - Uncertain if required – if not legally, then ethically
   - Challenging groups – children, images, those lacking capacity
Five Safes

- Safe People
- Safe Projects
- Safe Settings
- Safe Outputs
- Safe Data

Legal and ethical issues

"Research data can be shared legally and ethically"

Much research data - even sensitive data - can be shared ethically and legally if researchers employ strategies of informed consent, anonymisation and controlling access to data.

Legal issues

Researchers obtaining data from people are expected to maintain high ethical standards and comply with relevant legislation. Ethical guidance is provided by professional bodies, host institutions and funding organisations.

Consent for data sharing

Informed consent is an ethical requirement for most research. It must be considered and implemented throughout the research lifecycle, from planning to publication, and should include making provisions for sharing and future use of data.

Anonymisation
Informed consent – information sheets and forms

- Meet requirements of Data Protection laws:
  - purpose of the research
  - what is involved in participation
  - benefits and risks
  - mechanism of withdrawal
  - usage of data – for primary research and sharing
  - strategies to ensure confidentiality of data, where relevant

- Complete for all purposes: use, publishing, sharing
- Simple and avoiding excessive warnings
In practice: wording in consent form / information sheet

<table>
<thead>
<tr>
<th>Use of the information I provide beyond this project</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I agree for the data I provide to be archived at the UK Data Archive.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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).
Anonymising data

- Plan or apply editing at time of transcription except: longitudinal studies - (linkages)

- Consistency within research team and throughout project

- Avoid over-anonymising - removing/aggregating information distort data, make them unusable, unreliable or misleading
  - ex. image data

Controlling access a better option than over-anonymising
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.
Emerging models - consent

- Dynamic consent – maintain contact, seek content for any new use “substantially” different from original
- Broad or enduring consent – Genome Project, biobanks. Accepted in UK, but not across Europe (e.g., Germany)
- Alternative legitimate basis (in data protection laws)
  - Administrative Data Research Network – consultation and citizen panels
  - Access review committees – medical, Understanding Society
  - Citizen panels
Many guides – making choices

- Privacy Impact Assessment (ICO recommends)
- ICO’s Data sharing code of practice
- UK Anonymisation Network (UKAN)
- There IS an app for that…

http://www.scu.edu/ethics/practicing/decision/
Ethical Decision Making

Download your ethical decision-making assistant!

http://www.scu.edu/ethics/practicing/decision/
4. A set of morally reasonable expectations about the governance and use of data should be determined in accordance with four principles:

- the principle of respect for persons
- the principle of respect for established human rights
- the principle of participation of those with morally relevant interests
- the principle of accounting for decisions
References


- Chessell, M. (2014) Ethics of Big Data and Analytics,


- ICO. Big data and data protection.
Contact

Collections Development and Producer Relations team
UK Data Service
University of Essex
ukdataservice.ac.uk/help/get-in-touch.aspx