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# Ethical issues in using HR data

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UK Data Service

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# 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



Data lifecycle

Plan to share

• Legal and ethical

Obligations

Consent for sharing

Anonymisation

Access control

Resources

Copyright

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## Legal and ethical issues

"Research data can be shared legally and ethically"



SHARE ↗

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

<b>Use of the information I provide beyond this project</b>		
I agree for the data I provide to be archived at the UK Data Archive. <sup>2</sup>	<input type="checkbox"/>	<input type="checkbox"/>
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.	<input type="checkbox"/>	<input type="checkbox"/>
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.	<input type="checkbox"/>	<input type="checkbox"/>

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

Comment [v1]: Replace: Ken

Comment [v2]: delete

Comment [v3]: delete

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.

Comment [v4]: Replace: Ken

Comment [v5]: Replace: Ken

Comment [v6]: Replace: Ken

**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 consent 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/>





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"backup" Earth

Can We Expect Ethical  
Behavior from  
Government and

## What is Ethics?

## Decision Making

Making an Ethical Decision

Tomando una decisión ética

A Framework for Ethical Decision Making

Thinking Ethically

How to Identify an Ethical Issue

Making Decisions About Right and Wrong

## The Utilitarian Approach

Calculating Consequences

How to Use the Utility Principle

## The Rights Approach

Rights

How to Use the Rights Test

How to Use the Exceptions Test

How to Use the Choices Test

## The Fairness Approach

Justice and Fairness

How to Use the Justice or Fairness Test

## The Common Good Approach

Common good

How to Use the Common Good Test

## The Virtue Approach

Ethics and Virtue

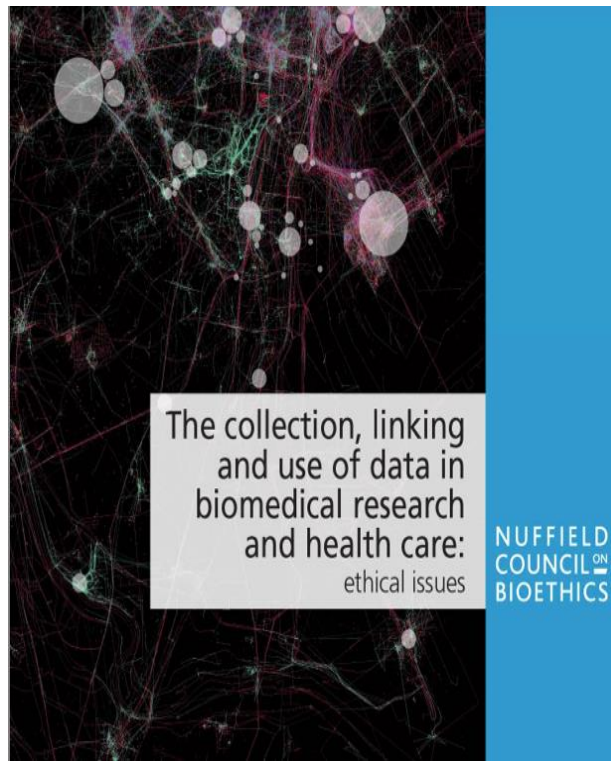
How to Use the Virtue and Character Test

## How to Compare Conclusions From the Different Approaches

<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



Nuffield Council on Bioethics







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# References

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# Contact

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