

Ethical Issues in Data Management

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Introductions

- Who is here?
- What brought you here?
- What would you hope to get from today?



Data management and ethics: Issues evident in research

- **Prospective data collection** generally involves explicit consent process
 - Need to be aware of the type of data you are gathering
 - Need to store data securely
 - Consider archiving and re-use of data
- **Retrospective/existing data analysis** raises a number of issues
 - Research using existing organisational data
 - Individual knowledge of use of data



Common ethical queries by RECs

- Generally participants must be fully informed as to the nature of the study and the way in which data are going to be used/managed
 - What data are going to be used?
 - Who is going to have access to the data?
 - In what format will it be accessed?
 - What data protection rights apply (e.g. withdrawal of data)?
 - Explaining these issues to minors/vulnerable groups is NB
- Data must be stored securely
 - PG students - until the examination process is completed
 - All researchers - until publication
 - Information that could lead to identification is stored separately



Understanding your data: HREC Form

15. Please indicate the form in which the data will be collected and provide brief details:	
a) Identified	
b) Potentially Identifiable	
c) De-Identified	
16. Please indicate the form in which the data will be stored and/or accessed and provide brief details:	
a) Identified	
b) Potentially Identifiable	
c) De-Identified	
17. Describe the measures that will be taken to protect the confidentiality of the data which will be collected:	
a) Who will have control of the data generated by the research?	
b) Please confirm where the data will be stored and that it complies with the guidelines.	
c) In what format will the data be stored?	
d) For how long will the data be stored?	



Understanding data - Some definitions

- What is the nature of the data:
 - Identifiable - Documents with names, video of observations
 - Potentially identifiable- Student numbers, code numbers linked to names (ID key), recordings of interviews
 - De-identified - all information is removed, e.g. transcribed interviews that have been anonymised and cannot be re-established!
 - Anonymous - no information that could identify participant is collected (even researcher not aware of who is taking part)
- **Has different implications for storage of data and issues such as withdrawal of data by participants**



Protecting data: Key principles & new challenges

- Be aware of data protection legislation
- Only collect what is necessary
- More secure storage for more sensitive/identifiable data (encryption vs password protection)
- Be aware of security standards for online/cloud data collection and storage
- What happens when data travel?
- What happens if a journal requests your data?



Questions so far?



Research using existing (organisational) data

- Debate regarding access to data
- Ethical to maximise learning from existing data
- Data protection issues around use of data for reasons other than the reasons it was collected for
- Conference on 'Promoting Health Research & Protecting Patient Rights'
 - 29th November 2006, Killenard, Co. Laois.
 - http://www.dataprotection.ie/docs/07/12/06_Copies_of_Presentations_from_Health_Research_Semina/367.htm



Definitive Guidance

**An Coimisinéir
Cosanta Sonraí**



**Data Protection
Commissioner**

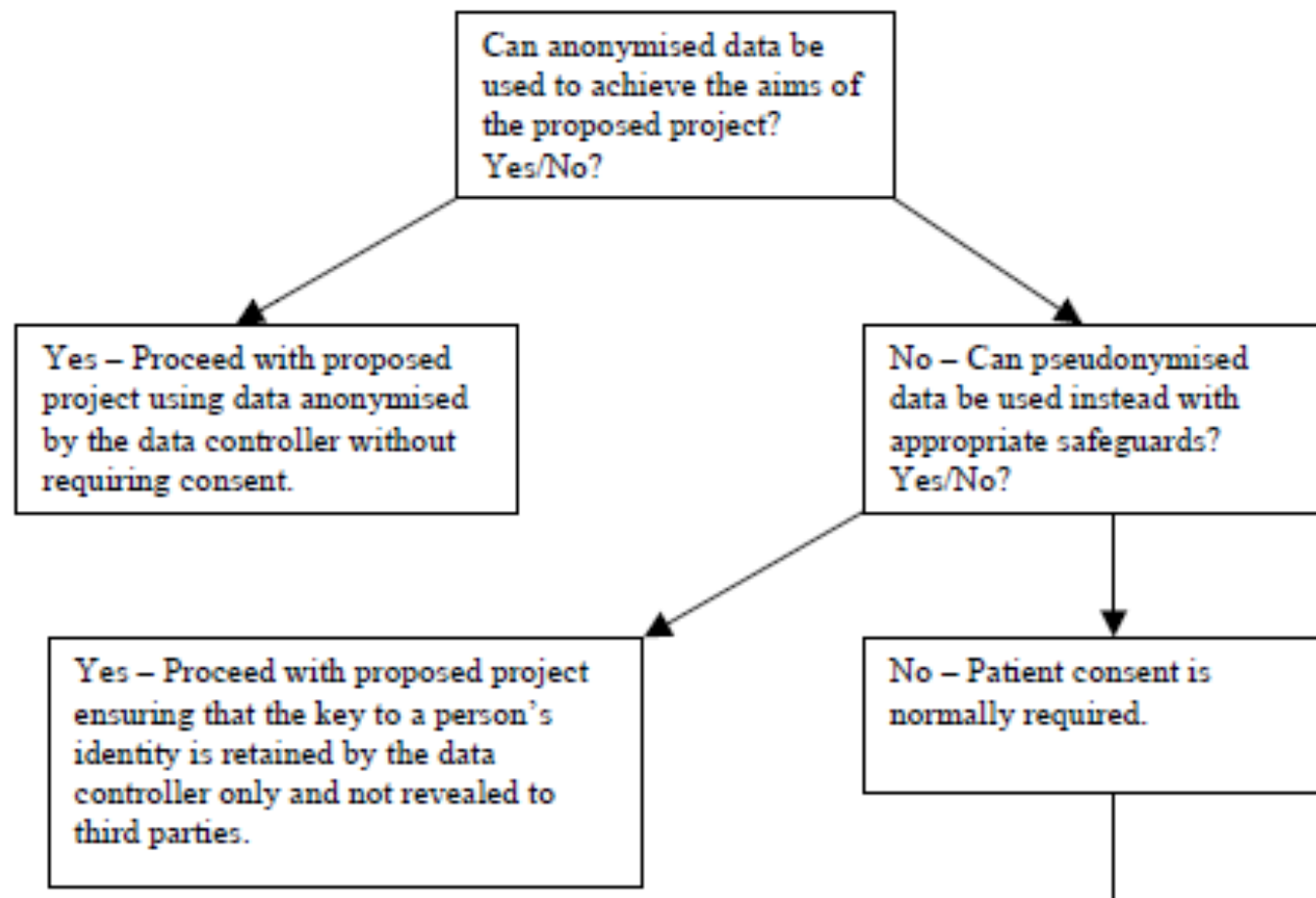


**Data Protection Guidelines on research in
the Health Sector**

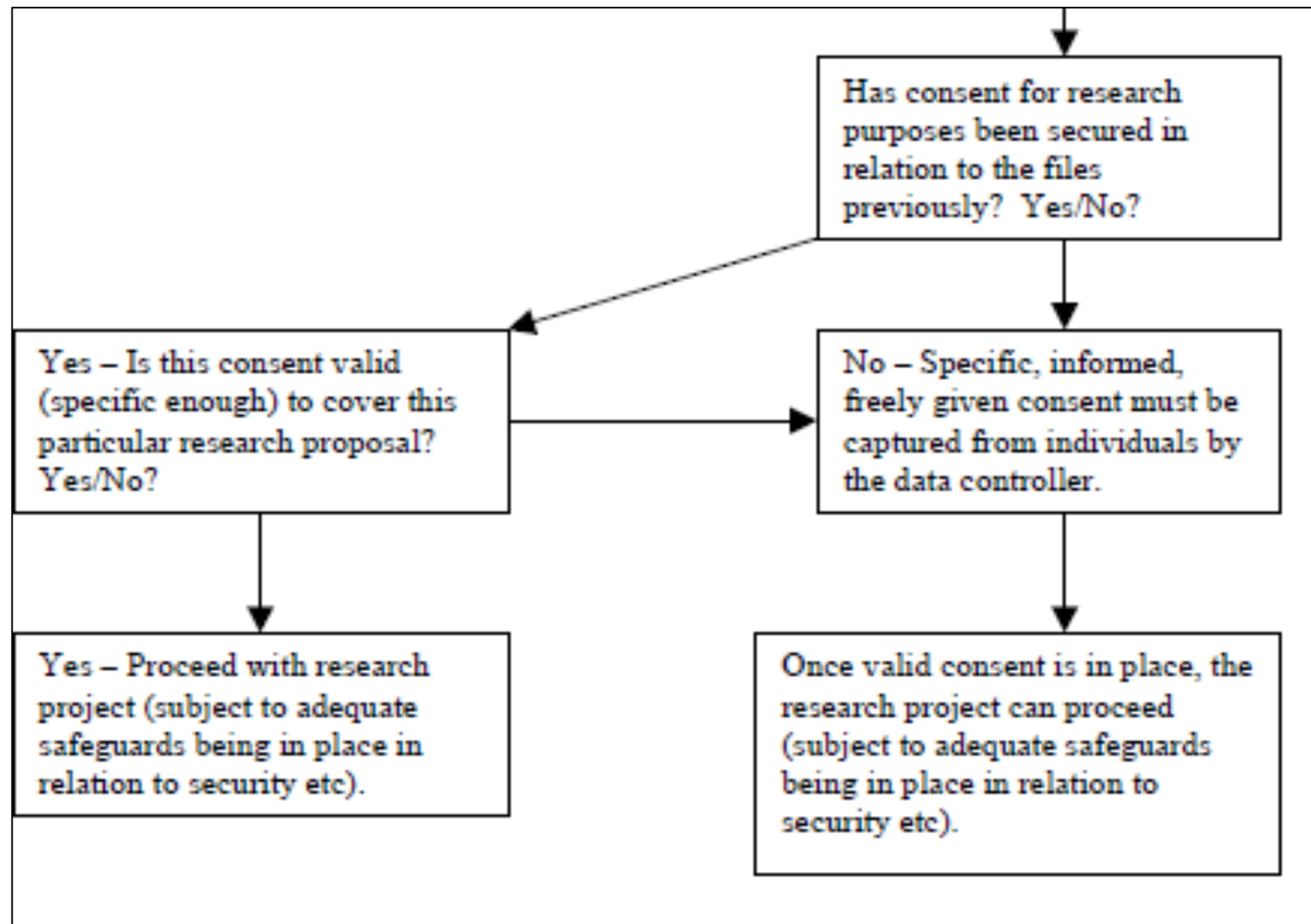
Available at http://www.dataprotection.ie/documents/guidance/Health_research.pdf

Decision Tree (Part 1)

Best Practice Approach to Undertaking Research Projects using Personal Data:



Decision Tree (Part 2)



Questions so far?



Maximising Contribution: Archiving data

- Archiving data for secondary analysis
- Seen as ethical practice
 - Ability to validate and refine or refute published findings using publically available data (Albright & Lyle, 2010).
 - May ensure greater transparency of data (Arrison et al., 2009; Carusi & Jirotko, 2009).
 - Reduces burden of repeat data collection on participants (Corti et al., 2000).



Ongoing debate regarding archiving qualitative data ...

Arch Sci (2007) 7:37–54
DOI 10.1007/s10502-006-9038-y

ORIGINAL PAPER

Re-using archived qualitative data – where, how, why?

Louise Corti

Whose Data Are They Anyway? Practical, Legal and Ethical Issues in Archiving Qualitative Research Data

- **Odette Parry**
University of Wales, NEWI
- **Natasha S. Mauthner**
University of Aberdeen

Qualitative Data Archiving: Rewards and Challenges

Colin Elman, *Syracuse University*
Diana Kapiszewski, *University of California, Irvine*
Lorena Vinuela, *Syracuse University*

Less debate in the literature regarding quantitative archiving

- “Preparing and preserving all data for sharing is perhaps even more wasteful of scientific and social resources as destroying all data after their first use. The ethical dilemma, then, is to discover the most intelligent course through a thicket of ever-shifting circumstances surrounding the preparation, storage, and ultimate secondary usefulness of data” (Sieber, 2005, p.165).



Key ethical issues in archiving

- Legislation such as data protection provides part of the ethical framework
- Disciplinary practice also key
- Issue of acceptable vs best practice



Consent

- ***Voluntary informed consent*** is central to ethical research
- Must ensure that this is extended (as much as possible) to archiving
- Central to addressing data protection issues
- But archiving involves consenting to use without full information
- Importance of 'educated consent'
 - Do participants understand practices?



Respecting Privacy

- Quantitative data assumed to be less identifiable
- Albright and Lyle (2010)
 - Concerns regarding impact of technology on the potential to identify participants in quantitative research
 - Masking of potentially identifiable data though
 - Data swapping,
 - Microaggregation,
 - Adding random observations



Awareness

- Are researchers aware of the benefits and challenges of archiving data?
- Relatively recent phenomenon for many disciplines
- Good vs best practice?
- Changing legislative framework



Issues ...

- When is an archive not an archive?
 - Distinction between formal managed archives and researchers holding data for personal use.
 - Ethical issues in personal archives (who manages them)
- Must ensure data quality
 - “Each set of data an investigator obtains is a slice of reality that may or may not be valid or reliable” (Sieber, 2005, p.166)



General Discussion

