



IDRN Human Tissue Training Day

Ethical Issues Related to the Use of Human Tissue in Research

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1. Consent

- Idea of ‘informed consent’
 - Competence
 - Information
 - Lack of coercion
- Problems with information provision
- Problems with information reception



But why is consent needed at all?

- Autonomy
- Ensure lack of coercion
- Ownership



What about cases where consent is impossible?

- Person has died
- Children
- Incompetent adults



2. Confidentiality

- A means to protect privacy?
- An absolute principle?
- Is there anything special about tissue?



Coding/Anonymity

- Is this the answer?
- Problem: why privilege anonymity over tracing?



3. Property rights

- Different types of tissue: donated; surplus; biopsy; stored sample
- Does the donor retain rights of ownership?
- If so – when (if ever) are they lost?



IP

- Suppose some commercial product is developed from the tissue – does the original donor have any claim to a share of the benefits?



4. Standing up for the common good

- Most regulations and bioethics – focuses on individuals
- However, much research on infectious disease is seeking to bring benefit to populations
- Why is there such reluctance to use common good arguments?



SARS

- Opportunities for research into infectious diseases such as SARS have been missed due to concerns about consent etc.
- Why think consent is always more important?



5. What is it to be an ethical researcher?

- Two contrasting forms of regulation:
 - 1) External
 - 2) Internal



(a) External Model

- Codes, policies, rules, legislation etc.
- Formal, written, “law-like”
- Often result of ‘scandal’ or extreme case

- Individuals held accountable according to conformity with regulations
- Assumption: get rules right – rest will follow



Problems

- Interpretation – when does a rule apply?
- Inflexible – ignores details of cases?
- Encourages poor behaviour – e.g. box ticking



(b) Internal Model

- Not about obeying rules – nor just about action – but about acceptance of responsibility
- Link to idea of being a professional
- Professional autonomy and responsibility



IM.(cont)

- About type of person you are
- Depends on professional education and training, culture, politics, social structures and activities



Conclusions

- A range of ethical issues in relation to the use of human tissue
- Are the ethical principles appealed to in regulations the relevant ones?