IDRN Human Tissue Training Day

Ethical Issues Related to the Use of Human Tissue in Research

Angus Dawson
Centre for Professional Ethics,
Keele University, UK

a.j.dawson@keele.ac.uk
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?
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?