

Teaching ethics relating to research with human participants

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Context

- **No set procedure in UK:** Requirement to provide robust ethics review (from university, funders and publishers)
- **NHS research** with staff, patients, social care and groups with impaired capacity to consent use NHS LREC's, clinical trials
- **SSIS (Social Sciences and International Studies)** has 1/3 of staff and students of university, bulk of human participant research, Chair 2 years, disciplinary rep for 4
- **Profile:** 200+ applications a year, high proportion of 'high risk' projects (researcher safety for international students, terrorism studies)
- **Bioscientists/biomedicine** (e.g. in Peninsula Medical School)

Where do we teach research ethics?

- Discipline-specific training usually in research skills modules
e.g. Sabina Leonelli in Biosciences: Bioethics module
 1. Ethical issues in data production
 2. Unethical uses of data and issues in theory-building
 3. Ethical issues in experiments
 4. Authorship/community values and norms
 5. Using ethical theories
- Generic research ethics training (e.g. as part of Graduate Skills programme)
- Target audiences vary enormously in their prior experience of research ethics

The purpose of ethics training?

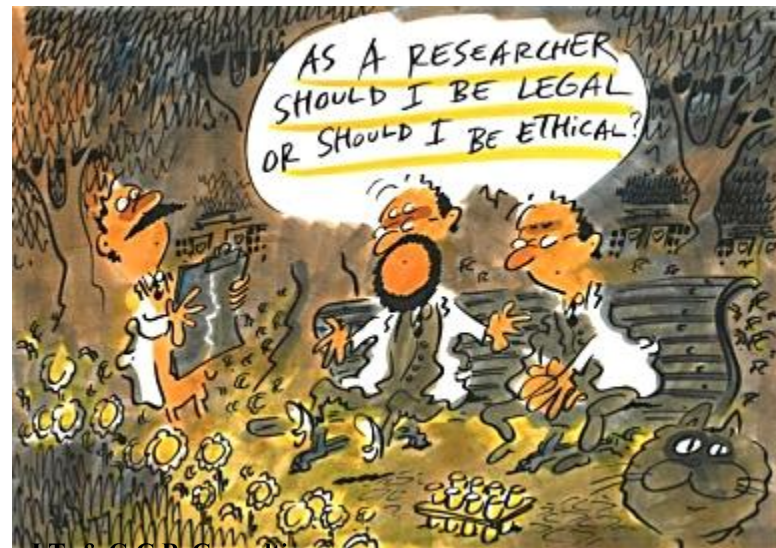
- Develop ethical awareness
- Knowledge of basic ethical principles
- Increase ethical thinking and behaviour in practice
- Ensure compliance with institutional ethics procedures
- Difference between ethics 'in practice' and 'procedural ethics' (Guillemin and Gilliam, 2004)



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Teaching ethical-legal awareness and compliance

- No law on research on human beings in UK, unlike animals
- Emphasis on individual's consent
- Data Protection Act
- Terrorism Acts
- Mental Capacity Act
- CRB (Criminal Records Bureau)
- Human Rights Act
- Freedom of Information Act
- Human Tissue Act
- NHS Act



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Teaching research ethics: the challenges

- Often a compulsory course; not all from same discipline
- Short time to cover ethical principles and infinite circumstances that stem from them
- May be first time students have encountered bioethics/research ethics
- Hostility to ethics procedures amongst some groups (see it as restricting academic freedom/ as university regulation)
- Different generations of researchers with different ethos



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What counts as human participation research?

- **Human participants** involved in research or intervention activities
- ‘**Participants**’, also subjects, interviewees, gatekeepers
- **Secondary analysis** of large anonymized data sets: no
- **Internet research (grey area)**: is it ‘text’ similar to a newspaper for public analysis or should we treat those who produce it as human participants with similar ethical standards?
- **Secondary data with identifiable info** e.g. medical records
- Often asked: ‘**are conversations ‘research’ and do I need ethics approval for them?**’
- **What about students’ ‘practice’ research?** (e.g third year project)

Moving from first principles

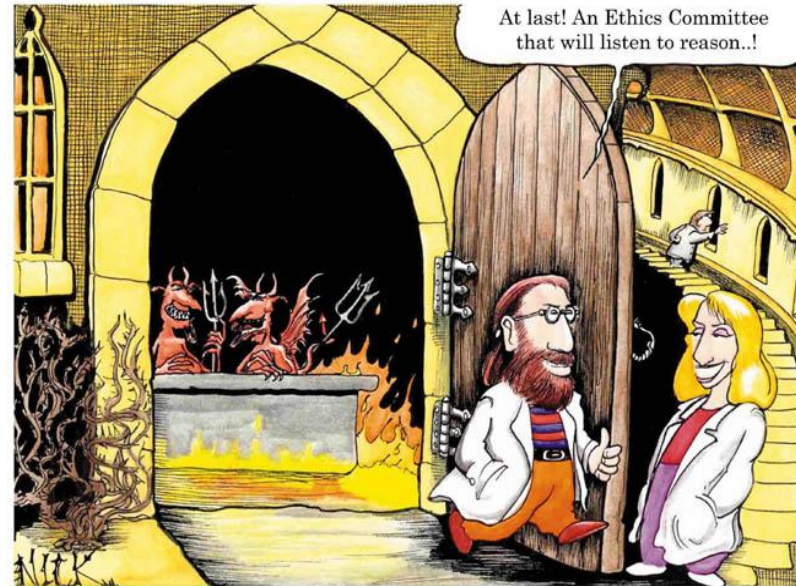
- A quick history of research ethics ‘horror-stories’
 - Nazi ‘experimentation’
 - Stanford Prison experiment
 - Tuskegee syphilis study
 - Yanomami anthropological study
 - Hwang fraud case (embryonic stem cell cloning)
- Most of history is the abuse/mistreatment of human subjects in medical contexts
- Nuremberg, Belmont and other codes to protect the human subject

Key ethical principles for human participation research

- Respect for people (voluntary participation, dignity)
 - Beneficence (do no harm and maximise benefits)
 - Social justice (who benefits?)
 - PAC (privacy, anonymity, confidentiality)
 - Academic freedom and integrity
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- How to move students from these basic principles to ethically evaluating their own work?

Case studies

- Have the students form 'mini ethics committees'
- Effective: research ethics are socially produced, represent consensus and norms in academic group
- Illustrates conflict/dilemmas as group members disagree
- Disadvantages?



Cartoon by Nick (Nicholas) D. Kim: www.LAB-INITIO.com

Informed consent

- Staff/students encouraged to use 'standard' consent/information forms
- Problematic: leads to 'cut and paste' attitude
- Oral vs. Written- justification
- Level of information and tailoring

Encourage questions: What does it mean to 'inform' a participant?
Is a one-off consent procedure ok for ongoing participatory research?

Assessment of possible harm to participants

- Physical (e.g. in situations of violence)
- Emotional/psychological (e.g. distress)
- Commercial/institutional (e.g. compromised reputation, commercial secrets)
- Violation of privacy/confidentiality

Important to assess risk to researcher as well as participants

Students find this difficult to get right: either under or over-estimate harms

Is the harm greater than you might encounter in ordinary life? (e.g. MRI scan, blood tests, being scared, getting upset)

Societal ethical implications

- Societal level of evaluation of biomedical and bioscience potentially missing
- E.g. novel forms of non-invasive prenatal testing, often viewed in terms of individualized decision-making (both on behalf of scientists/clinicians involved in producing technologies and their potential users) but has potential social level consequences



Don't frighten the horses

- Danger of 'ethics hypervigilance'
- Creating awareness without over-hyping risks or creating a risk-averse generation of bioscientists and social scientists
- Specify the 'benefits' clearly as well as the risks, including the social benefit of an engaged active research population

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Improving research ethics teaching

- Encourage students to be participants themselves; to experience being studied, observed, experimented on
- Pod casts/new media; as way of transmitting basic information
- Creating a research ethics culture: part of research process, not 'bolt-on' (and identifying how can institutions help this)
- Opportunity to 'talk ethics' (e.g. in workshops, with supervisors, ethics officers)

Workshop questions

- What the advantages and disadvantages of using mini-ethics committees/case studies when teaching research ethics?
- More generally, how could research ethics training be improved?

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