



Research ethics – one size fits all?

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Research ethics in difficulty?

- Biomedical researchers encumbered with over complex, bureaucratic, inconsistent and slow ethical and governance requirements (Rawlins Report 2011)
- Social scientists ‘angry and frustrated’ when forced into biomedical frameworks or at best ‘fearful’ of being coerced into a parallel system with similar problems and *censorship*
- Interdisciplinary research?!

Should we be concerned?

- ‘We’ as:
 - beneficiaries of scientific/biomedical/social research as members of the public
 - participants, students, researchers and academics
- Most research benefits us individually and collectively – worth encouraging!
- Some research can be harmful – worth preventing!
- The challenge of getting the balance right for *all*

My involvement in applied ethics

- Almost 25 years researching and developing ethical policy and guidance for counselling and talking therapies:
 - Resolving tribal differences between professional groups
 - HIV/AIDS counselling research at a time of moral panic
 - Leading a profession from rules to principles
- 15 years teaching research design and methodologies
- 6 years as Research Ethics Officer for Faculty of Social Sciences and Law at University of Bristol

Principles of research ethics

- Safeguard well-being of research participants
- Facilitate high quality research
- Be proportionate, efficient and foster meaningful dialogue between stakeholders and researchers
- Build confidence in research through independence, transparency, accountability, and consistency

🌟 The challenge of 'one size fits all'

- Differences between types of research
- Differences between ethical approaches
- Absence of moral consensus in contemporary society – contemporary social challenges of inclusivity and relational integrity across difference

Outline of lecture

- Experiment of putting myself in the research participant's position
- Finding the appropriate ethics – five archetypes
- Strategies for enabling research ethics to develop



🔥 4x participant

- *Participant's well-being paramount*

Studies

- 'Monitoring use of web-browser' UoB
- 'Learning, identity and life-story' USA – doctoral student
- 'Future of Education Departments in UK Universities' – senior UK academic for book
- 'Fracture Healing Study' international drugs trial from Paris –participant at BRI

'Web browser monitoring'

- Notified when it would occur and that it would be non-attributable/anonymous with reminder
- Brief realisation at time
- Blurred boundaries between audit, service monitoring, research, journalism and security
- We live with high levels of scrutiny that it is difficult to escape but with limited direct impact
- Irony that reality TV can repeat controversial experiments that would be unlikely to get ethical approval as research

'Learning, identity and life-story'

- Doctoral student exercise in USA
- IRB approval and formal consent
- Friendly and respectful semi-structured interview on personally sensitive issues
- When researchers re-assemble to discuss experience ...
- Respect beyond the face2face encounter?

✶ 'Future of Education Departments¹¹ in UK Universities'

- Interviewed as Head of School
- Research, purpose and opportunity to comment on personally identifiable material to be used in any publication
- Interview taped and consent given orally – declined to sign form as unnecessary
- Professional role and public accountability/ researching personal and private issues



✶ 'Future of Education Departments¹² in UK Universities' *continued*

- How transferable are practices of clinic and laboratory to everyday life in society?
 - Private/public
 - Protected as sensitive/expect accountability/wider communication expected
- Useful test:
 - Is the research participant being exposed to greater risks than encountered in everyday life?

'Fracture Healing Study'

- Promise that I will be treated with respect
- Every effort will be made to avoid harm
- Participation requires consent and right to withdraw at any time
- RCT: selection, inclusion and participation
- Dietary supplements 2x day – additional hospital monitoring

✶ 'Fracture Healing Study'

continued

- Biggest challenge finding 4 hours without food in unpredictable daily routine
- Additional X-rays, BP readings and blood tests?
- Crossing over from consent as promoting the respect and well-being of the participant and legal protection for research bodies?
- Limits of consent? Can I *trust* the researchers to be *respectful* and watch for my *well-being*?

Finding the appropriate ethics

- Archetypes – an idealised pattern or model from which copies are made – symbolic representations of good or evil from the collective unconscious or culture
- Five ethical archetypes

🔥 Archetype: Demonic researchers



🔥Nuremberg – statement for prosecution

- “a thinking chemist could have solved it ... in a few hours ... by the use of nothing more gruesome than ... jelly, ... semi-permeable membrane and a salt solution”
- Instead, “vast armies of disenfranchised slaves were at the beck and call of this sinister assembly ... rendered rightless by a criminal state [in pursuit of] Nazi pseudo science”

🌟 Archetype: researchers for the greater good?



Tuskegee Syphilis Study

- Ethical issues
 - Actively withholding treatments: salvarsa (organic arsenic), stopped treatment when subjects conscripted, deterred treatment by local Drs; withheld penicillin when available as an effective treatment in 1940s
 - Studying vulnerable and powerless subjects for benefit of others
 - Deception – monitoring and data gathering misrepresented as treatment



Consequences

- Belmont Report in USA
- Legislation
- Mandatory institutional review boards
- Dominance of bio-medical research ethics
- Globalization as Americanization

Archetype: respectful scientific researcher

- Attentive to showing respect
- Works within individual explicit consent
- Watches for and protects research participants from harm
- Ensures quality of research
- Appropriate knowledge claims, dissemination and impact

✶ End of story for research ethics?

- Entrenched by atrocity avoidance and ‘peppermill’ tendencies in rule-based ethics/governance
- Problems with encompassing all social sciences research – especially ethnography
- Archetypes too restrictive – unduly favour individualism and masculine ways of knowing and being
- Alternative ethical archetypes generated within social science



Sources of other metaphors and archetypes

- Gendered alternatives – the wise and ethical mother/parent
- Interactions between people – ethic of trust



Archetype: Caring mother/parent

- Empathy, nurturing, and caring for the well-being of those around them
- Multiple dependencies and responds according to capability for independence and needs within the group (fairness)
- Evil/harm involves 3 conditions: pain, separation and helplessness
- Good is both relational and relativist

🔥 Example of ethic of care in research

- Educational research: Head teacher grants access; parents' consent sought
- Research into friendship based on series of classroom activities and discussions
- Parents refuse consent
- Pupil desperately wants to take part and stays with group of friends
- What should researcher do?

Ethic of trust/being trustworthy

- Cassandra
- Striving to be *trustworthy*
- May be to multiple others
- Attentive to a number of dimensions in face to face interactions



Being trustworthy

Creating a relationship between researcher and participant(s) of sufficient quality and resilience to withstand the challenges of:

- *Difference* e.g. individual/collective
- *Inequality* e.g. expertise/less knowledge
- *Risk* e.g. who carries the risk?
- *Uncertainty* e.g. researching what is not yet known – the basis of careful listening

🌟 Examples of ethic of trust in research

- Obtaining consent in rural India
- Some research requires opposite of objective detachment
- Longitudinal in-depth observation or interviewing 'No intimacy without reciprocity'
- 'Ethics and psychotherapy' Bond, 2007

✶ Enabling research ethics to move to 'one size fits all'

- Rebalance the fear of atrocity with the hope of benefits from research for *all*
- Recognise the gendered legacy and dynamics encoded in the 'respectful scientist' archetype
- Create ethics that are portable between natural and social sciences
- Downplay rules in favour of principles to guide judgement in all aspects of research, especially across diverse cultures and contexts

✶ Enabling research ethics to move to 'one size fits all'

- Avoid overloading ethical review in advance – especially in 'real world' or open-ended research
- How can researchers demonstrate that they are 'fit and proper' persons to be ethically mindful?
- Regard all 'human subjects' as 'participants' – humanise how we talk about research
- Strengthen accountability to participants to counteract inequalities with researcher
- Be proportionate to risk – take account of opportunity cost.