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 Departments 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 Departments 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: salvarsan (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 ‘pepper-mill’ 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.