

## Notes on Problems with Bioethics and Contributions from Social Science

### Priscilla Alderson PhD

Professor of Childhood Studies

Social Science Research Unit Institute of Education University of London

### Stages of bioethics

1. Paternalism, beneficence and complacency (Hippocrates up to 1940/90s)
2. Scandal, alarm, concern (*Nuremberg Code* 1947 after Nazi research in world war II, *Declaration of Helsinki* 1964 after Thalidomide 1963, US President's Commission 1970s after Beecher and Pappworth books on research scandals, new UK government led research governance 2001-4, after Bristol and Alder Hey Inquiries 2001 into inadequacies in research and treatment concerning children.
3. Development of guidance and governance: US President's Commission from 1970s (*Belmont Report*) involved multidisciplinary and 'lay' voices, women and ethnic minorities (bioethics linked to civil rights?). Challenging debate between disciplines medicine, law, philosophy, theology, with gradual overcoming of doctors' resistance. Massive growth of bioethics courses, conferences, journals, research ethics committees (RECs/IRBs) and of support and funding from pharma industry. Growth of medical confidence in formal regulation to protect subjects, researchers and good name of research.
4. Possibly now over-regulation (?) and fraud linked to over-funding (see numerous recent debates in medical journals).

### Stages of social research ethics

1. Paternalism – suggest many social scientists still at stage 1.
2. Lack of impetus of scandal - social and education research does not visibly kill or maim (though as discussed at meeting, social research can result in extremely serious harm to individuals and to whole groups and societies through misleading reports and misuse of reports)
3. Governance, being rapidly imposed, with much resistance given lack of stage 2 experiences, gradual learning, funding and incentives, that bioethics has had.
4. Fraud – not such a problem given lack of pharma funding, but fraud in covert deceptive research still permitted, such as in psychology (BPS), sociology (BSA) and education (BERA) guidance, and widely taught and practised.

### Paradox:

Medical research ethics guidance and review tend to be collective and political (regional, national, international networks and enforced standards), multi-disciplinary + 'lay' voices involved.

Social research ethics tends to be individual and private (BSA guidance), guidance and RECs (if any) tend to be single-disciplinary, and single-voiced when guidance until recently written mainly by one person.

Paradox that 'lay' members and chairs of bioethics RECs are assumed to understand complex biochemistry or genetics whereas social researchers argue that 'lay' people cannot understand social issues. If so, ethical research following informed consent would be impossible.

## **Contribution of social research ethics?**

This paper reviews four contributions that social research does/could contribute to research ethics.

1. Critical analysis (for example, of agency, risk–benefit)
2. Emotional insights
3. Understanding ethics in practicalities, and in early and later stages of projects rather than over-concentrating on mid-stages of data collection and analysis.
4. Politics - impact of research

These notes also raise questions for discussion, for example, how does the illusion of detached impersonal scientific objectivity collude with bioethical ideals of Kantian detachment? (Seidler V, 1986 *Kant, respect and injustice*. London: Routledge).

## **1. Critical analysis of functionalist bioethics**

Some bioethics concepts to unravel

### 1a) Transferring agency

*The Nuremberg Code* (1947) emphasised ‘1. The voluntary consent of the human subject is absolutely essential.’

By 1986, Faden R and Beauchamp T (*A History and Theory of informed Consent*, Oxford University Press) wrote:

Because of the ‘many confusing associations surrounding the term “voluntariness”’ it should be replaced by the term ‘non-control that does not have the history and connotation that burdens [*sic*] the terms “freedom”, “voluntariness” and “independence”.’ They appear to assume the position of practitioners/researchers and not of patients/subjects/participants in attributing all agency to practitioners, and none to the patients’ ‘free power of choice’ (Nuremberg) in which voluntary consent is control by the subjects over their consent/refusal. Also perhaps here an implicit mistrust of emotions/motivations and literally movements and drive beyond pure reasoning, which disenfranchises emotional fraught patients from ability to give informed reasoned consent.

1bi) ‘Children cannot refuse’ – children can of course refuse, no law can stop them from saying ‘no’. Question is whether doctors can accept children’s refusal or have to override them. Bioethics guidance advises researchers to respect young children’s refusal.

1bii) ‘Children cannot consent’ – Research shows how young children can have the intellectual and moral capacity to consent to treatment (Alderson P 1993 *Children’s consent to surgery*, Open UP). In English and Scottish law doctors can respect children’s consent to treatment, which can override parents’ refusal. Consent to research is more questionable in law, and so empirical research could contribute here.

### 1c) Other loaded phrases in bioethics

\* ‘Healthy volunteers and patients’ - as if patients are not also volunteers

\* ‘Risk benefit’ – as if risk is uncertain and benefit assured ‘hoped-for benefit’ would be more accurate

\* ‘Therapeutic research’ (deleted from *Helsinki* 2000) -

‘Research’ is systematic investigation, the acts of collection and analysis of data, which cannot offer direct benefit to subjects/participants – they benefit the researchers  
‘Therapy’ is intervention intended to benefit

Research may or may not examine interventions intended to benefit and report on their relative effectiveness, but the topics of research need to be distinguished from the basic acts of research if researchers are not to have delusions about their aims and role and effects on subjects, and are not to exert undue pressure on potential subjects to consent.

In the above definition, all research is 'non-therapeutic' and therefore medical and social research acts are on equal level,

People in control groups or who are having placebos are mis-described as being in 'therapeutic' research with accepted higher risk levels.

\* 'Therapeutic research/cloning' mixes time, the hope of possible future treatment that might benefit, with the present reality of experiment, which would be the more accurate term.

1d) More on risk benefit analysis

The equation involves apples and oranges – present risk to subjects/participants versus hoped for benefits to future patients/clients, possibly years later after peer reviewed publication and slow processes of altered practice. Any indirect incidental benefits of research (being fortunate enough to be in the most effective arm in a trial, possibly enjoying and gaining personally from being interviewed) cannot be intended or assured. If the treatment being researched is known to be the most effective the research would be unnecessary and unethical.

1e) Health care research is pre-defined and designed, social research may be open-ended. Yet RCTs in their processes, blinding and effects may last for many years. Funded research, including anthropological has to be pre-designed enough to satisfy funders, and the open-ended parts and revisions can be explained to subjects/participants – and may be designed and negotiated with them. Brief reports can explain changes to RECs, and 4-6 member advisory groups (as Rowntree projects have) can review practical ethical problems with the researchers as they arise.

1f) Risk assessment - Incidence of risk can be measured, but not severity which is subjective and unpredictably personal (Jan Pahl later contrasted her high risk sensitive research on domestic violence when women seemed happy to talk, with seemingly low risk research on meals in geriatric wards when old people were extremely upset by the apparently innocuous question: How long have you been here?)

## **2. Emotions or Impersonal Objectivity**

Social research ethics could increase bioethics understanding of moral emotions.

- Researchers' awareness of their feelings as sources of moral insight: hopes, fears and anxieties about mistakes, lack of time and resources, stress, uncertainty and failure, pity and empathy (MacIntyre A, 1966 *A short history of ethics* on how Kantian detachment and lack of empathy underlay Nazi research)
- Researchers' practical learning from and acting on these feelings
- Rapport and sociability, vital aspects of research with sensitive responses to participants' reluctance, distress or anger
- Exploiting or defusing power discrepancies between researchers, and between researchers and participants – skills that are partly informed by emotional 'literacy' awareness.

Note: There was not time to discuss this at the meeting and I hope the webpage debates could apply, for example, on Bendelow and Williams's work here.

### **3. Practicalities Throughout Research and Beyond the Data Collection Stages**

Social researchers could increase, for all researchers, their awareness and empirical understandings of and debates about many details, such as:

- \* Choice of research topics and questions – stigmatising?
- \* Is the research worth doing? In whose interests?
- \* How can it be justified to IRBs/RECs and to participants?
- \* Do methods fit questions?
- \* Selection and inclusion, such as silencing and excluding of children's voices until recently?
- \* Access and confidentiality? As well as all the usual ethical questions.
- \* Ethical funding and contracts?
- \* Are people treated as research objects, subjects, participants or co-researchers?
- \* Unkind designs?
- \* Complaints, revisions, accountability? Do people know whom to complain to, and are their structures from responding seriously to complaints?
- \* Information leaflets? Bioethics and RECs lead the way in expecting clear information leaflets and writing these can help to clarify researchers' understanding of their work.

There are examples of information leaflets on

[http://eppi.ioe.ac.uk/ssru\\_docs/DiabetesReportFinal.pdf](http://eppi.ioe.ac.uk/ssru_docs/DiabetesReportFinal.pdf)) and

<http://www.ioe.ac.uk/ssru/reports/foretellingfutures.pdf>

- \* Consent, refusal, withdrawal, pausing, selecting questions? Do participants know they have these rights? (Some research give children red and green circles to use as traffic lights, and hold up when they wish to stop or restart.)

The numerous detailed problems that arise through research projects raise many ethical questions. See Hallowell N, Lawton J, Gregory S, (eds) 2005 *Reflecting upon research: the perils, pitfalls and pleasures of doing social science research*, Open University Press.

Alderson P, Morrow V 2004 *Ethics, social research and consulting with children and young people. Barkingside: Barnardo's* reviews questions that arise through ten stages of research from inception to implementation.

### **4. Politics, ethics and the social context of research**

Practical social research can explore how bioethics principles of respect, justice, avoiding harm, trying to benefit pervade all aspects of research.

Philosophers debate whether ethics concerns abstracting key issues from 'household rubbish' or else seeing how the 'rubbish' constitutes ethical problems (Grimshaw J 1986 *Feminism and Philosophy*. Brighton: Wheatsheaf. Social researchers can explore:

- \* effects of class, gender, age, ethnicity, poverty, inequalities and current policies, as much more than variable, on the research processes and therefore outcomes?
- \* dissemination to diverse groups including users of the services researched?
- \* implementation? Moving beyond the academic journal paper into practitioners' and users' journals and conferences, helping to bridge the chasm between research analysis/findings and practical change and implementation.

\* Impact of research findings on related social groups? Children could drink in pubs until the 1908 Act excluded them. This is one of countless examples of how children and young people have been excluded from mainstream and now 'adult' society, in ways that have benefited but also harmed them. Childhood is now a state of social exclusion in Western countries, partly following research over 19<sup>th</sup> and 20<sup>th</sup> centuries about child development theory and needy, dependent, incompetent and deficient children – theories and prejudices that are slowly being refuted by current research. The exclusions are leading to extremely serious imbalances between older and younger generations, economic, ecological, political that need to be central concerns of ethical research.

\* Are research conclusions and recommendations drawn from the evidence, or based on researchers' prior assumptions and prejudices and interests?

\* Use of positive images, avoiding stigmatising terms?

\* Reporting participants' views?

\* Attempt to balance impartial research with respect for participants' worth and dignity?

### **Finally – a National Social REC?**

2005 is a vital time in social research ethics. Research sponsors, agencies and professions are revising their guidance and governance. The ESRC has commissioned two reviews and refuses to publish both of these. The government in imposing onerous governance procedures on social researchers working through health and social services – and this is likely to spread to education and other areas soon. I suggest that the many individuals and groups concerned with social research should be more proactive and start by convening a national REC for social research. This could:

- \* cover all main disciplines and professions in social research
- involve reps from relevant funders, commissioners, associations and agencies
- have 'lay' members and 'lay' chair
- invite experts in law and ethics
- devise ways to collaborate between bioethics and social research
- approve which kinds of research go to social or bioethics RECs
- ensure adequate but not surplus funding and staffing
- plan and revise national guidance through wide consultation
- promote courses, conferences and debates on research ethics
- promote efficient networks of LRECs
- advise on hard questions that LRECs cannot resolve alone (when to accept children's consent, confidentiality and family genomics research)
- work with national funders, policy makers, mass media on linking research to policy, practice and public debate.