

**Cross currents in genetics and ethics  
around the millennium 1999-2001**

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## 1. Summary

*Key questions* for this project were: How is genetic knowledge affecting policy and practice in perinatal health care services? What challenges and opportunities does the knowledge present, and how do practitioners address these in their daily work, both individually and together? What aims and values guide them, and how can insights from ethics and social science help? How can these insights be shared in more useful ways with busy practitioners? Can multidisciplinary group discussions help staff to discuss and resolve dilemmas?

*Participants and data collection* Seventy people working in or linked to two English hospitals, (one teaching hospital and one district general hospital) and in attached community services, were interviewed individually by the two research sociologists (PA and CW). The semi-structured 'guided conversations' encouraged respondents to give their own accounts and meanings. The interview themes included interviewees' views about genetic developments and moral beliefs and values, and how these affected their daily work. Interviews were supplemented with ethnographic observations. Fifty-six interviewees then took part in eleven small discussion groups led by a health care ethicist (BF); twelve people attended twice, at their request. Their work related directly or indirectly to perinatal care, and participants included: midwives; health visitors; neonatal nurses; genetic counsellors; sonographers; obstetricians; fetal medicine specialists; haematologists; paediatricians; psychologists; chaplains; legal, audit and primary care managers. For approximately two hours each, the groups discussed topics raised during the earlier interviews, and were of mixed disciplines and seniority. With permission, interviews and seminars were taped and transcribed. Participants gave short follow up individual evaluations of the seminars.

*Data analysis* The transcripts were analysed and coded by content for emergent themes. Codes were compared for similarities and differences across the groups, eventually leading to broader themes which made up the overall theoretical framework. The research team met frequently to discuss the data and analysis and to incorporate sociological and philosophical perspectives, in order to add to the richness and validity of the analysis.

***Results of the intervention*** Participants found the in-hospital ethics seminars useful in increasing inter-professional understanding, engaging people from varied backgrounds, covering a wide range of pressing issues coherently, and addressing important though seldom discussed ethical questions. Crucially, the agenda were based on prior in-depth interviews with health staff on their key, local concerns about the social and ethical consequences of advances in genetics and their impact on professional policies and practice. The seminars worked well in contrasting hospitals and specialties. A planned series of seminars would have more effect on policy and practice than single events and could, potentially, contribute usefully to clinical governance.

*Reports* The main outcomes of the project are papers for professional and academic journals based on the transcripts. The papers completed so far, report: participants' evaluations of the in-hospital ethics seminars; the many complications which practitioners experience when trying to provide equitable prenatal services linked to the characteristics of the women they work with and to broader questions of ethnicity, gender and religious belief; the complications of trying to draw

the line' over which fetal conditions should be tested and referred for termination of pregnancy; the dilemmas raised by nuchal translucency ultrasound scans; and whether non-directiveness and informed choice are possible in the context of antenatal screening and testing.

## 2. Background

By the mid to late 1990s, reports in the mass media, and the scientific, medical and ethics press could be taken to assume that genetics was flourishing in medical practice as a regular basis for clinical diagnosis and prognosis, and for understanding the aetiology and progress of disease (ref. 1). During our research project 1999-2001, genetics-linked news was seldom out of the headlines. [See Tables 1-3] **Official expectations of the developments were high. The expert report *The genetics of common diseases* stated:**

'Many of the most important human disease genes are likely to be identified within the next five years....It would be easy to underestimate the impact this is likely to have on the definition and understanding of disease and in turn its impact on health care. We face quantum changes in understanding akin to the changes in the knowledge of infectious diseases that accompanied the microbiological revolution started by Pasteur and Koch....these developments present dramatic new opportunities to improve the health of the nation' (Department of Health 1995).

During our research interviews and seminars, practitioners often mentioned news items related to genetics. A health visitor said:

'When I talked about the [ethics seminar] group to my husband, he's a chemist, he reminded me that a few years ago I used to say [about media reports of scientific innovations] "that'll never happen" but he knew it would happen and he was right. Since the meeting I've seen things in the [news]papers and thought....perhaps it will happen here one day. I'm worried about how some people are over-treated.'

The brief summary in tables 1-3 mentions only a few of the relevant events. There were also growing numbers of related research projects, publications, multi-disciplinary conferences and policy meetings with associated briefing papers and lobbying during this period, besides art exhibitions, such as, 'Paradise Now: Picturing the Genetic Revolution' and 'Artists Mine Genomic Issues: Unnatural Science' both in New York, 2000.

Tables 1-3 The international context of developments in genetics around the millennium

### Abbreviations:

AAAS American Association for the Advancement of Science  
ACGT Advisory Committee on Genetic Testing (UK)  
BMA British Medical Association  
EGE European Group on Ethics in Science and New Technologies, advisory group to European Commission.  
FDA US Food and Drugs Administration  
GM genetically modified

HFEA Human Fertilisation and Embryology Authority (UK)  
HGC Human Genetics Commission (UK)  
HTA Health Technology Assessment, Southampton publishes systematic overviews  
and policy reports.  
NHGRI National Human Genome Research Institute (US)  
RCOG Royal College of Obstetrics and Gynaecology  
WMA World Medical Association

Table 1. 1999

1999 April	
May	Nuffield Council on Bioethics publishes positive report on genetically modified food. Critical reviews illustrate growth of media and public hostility towards GM foods.
June	
July	IVF specialist, Dr Edwards announces 'soon it will be a sin for parents to have a child that carries the heavy burden of genetic disease'. Publicity about using stem cells to grow replacement organs. Gene linked to Alzheimer identified. UK government bans human reproductive cloning and sets up advisory group to consider 'therapeutic' cloning.
August	Cystic Fibrosis Trust Director gives conference lecture 'Why GM Humans are a Good Idea'. Indian government asks doctors to stop providing prenatal sex selection services.
Sept	Jesse Gelsinger dies during US genetic trial. Ovarian tissue is transplanted back into a woman in UK. Prof Sheila McLean (Glasgow) calls for national bioethics council to consider such cases. Conference at the Galton Institute about eugenics is disrupted by protestors. Craig Venter develops blueprint to construct a synthetic bacterium. An ectopic triplet survives to be delivered safely with his sisters at 29 weeks. 'Genius' gene NR2B manipulated in mice at Princeton. Public debates about insurers' rights to use genetic tests.
Oct	Chromos Molecular Systems, British Columbia, announce they have bred mice which inherit their parents' artificially inserted chromosomes. Stock and Campbell argue that artificial chromosomes may offer better gene therapy in humans than viral vectors. New Scientist (1023) leader on benefit and inevitability of genetically modified embryos. BMA supports human reproductive cloning.
Nov	HFEA and ACGT publish consultation document on Preimplantation Genetic Diagnosis. Transplanted fetal cells appear to benefit a patient with Parkinson's.
Dec	US Hudson Institute hosts international meeting on dangers of the future biological arms race; genetics could quickly make Chinese race the most powerful one and opting out of biological race is said to be as dangerous as opting out of nuclear arms race.

Table 2. 2000

2000 January	Icelandic parliament grants US DeCode company exclusive license to genetic database of 270,000 population for 12 years - after DeCode gave large donations to the political parties. Lord Winston's lecture to Royal Society expresses his distress at being unable to use therapeutic cloning. UK NHS receives first royalties bill from US biotech company for using tests to identify a breast cancer gene. RCOG asserts that only two embryos should be implanted after IVF. FDA temporarily put gene therapy experiments on 'clinical hold'.
Feb	UK Government's ACGT, subsumed into the new Human Genetics Commission HGC, publishes report for consultation on Prenatal Genetic Testing. US Asilomar 2 symposium of leading academics and politicians debates self-regulation by geneticists. European Parliament withdraws patent for human cloning after protests. HFEA permits frozen eggs to be implanted. UK government consider setting up a large national DNA data base.
March	Biotechnology Industry Organisation BIO conference, and alongside a large protest Biodevastation conference, in Boston. British Council of disabled People issue a Position Statement and List of demands on Disability and the New Genetics because of their alarm about genetic developments. Berkeley researchers announce first 'bionic chip' part living tissue part machine for potential implants to treat disease such as diabetes. UK government seem to retract on former open enthusiasm for GM food.
April	BBC Radio 4's annual Reith lectures, this year on Respect for the Earth, with much support for biodiversity and criticism of GM agriculture, again reflects public concern about GM animals, crops and food but little interest in GM humans. BMJ publishes article on how genetics 'will transform performance in the health services' and 'education of all health care professionals [is] needed in order to capitalise on the results of genomics research'. 'obesity gene' found in mice.
May	HGC's first public consultation meeting. Publicity scare over 150 Sheffield women given false positives when screened for Down's syndrome. Fluorescent 'labelling' of genes developed in Massachusetts. HTA recommends expansion of haemoglobinopathy screening. WMA plans guidance on data bases, concerned about genetics, confidentiality and international inequalities. Two French babies with Severe Combined Immuno-deficiency respond well to gene therapy.
June	Draft DNA Human Genome Sequence publicised in US and UK, accompanied by numerous media articles about genetics advances. Conflicts between US commercial sequencing (Craig Venter, Director of Celera) and UK non-profit sequencing (largely funded by Wellcome Trust) which opposed patenting.
July	UK <i>Economist</i> has 16 pages on genetic advances and 'tailored' children. s Royal Society international report on the benefits of Transgenic Plants and World



	Agriculture.
August	
Sept	AAAS report Human Inheritable Genetic Modifications reviews dangers of germline engineering but does not call for a ban and instead advises on future regulation. US scientists are granted federal funding for human embryonic stem cell research. UK surveys show public opposition to human cloning and show that experts tend to say they regret that it will inevitably happen. US Hastings Bioethics Centre publishes a Disability Rights Critique of Prenatal Genetic Testing. European Parliament votes to oppose human cloning. British Sociological Association Annual Medical Sociology Meeting has its first genetics 'stream'; far more highly attended than the rooms booked could hold.
Oct	In the US, Mr and Mrs Nash have a son Adam who was selected as an embryo to be a bone marrow donor to his elder sister who has Fanconi's anaemia. A Scottish couple seek to ensure a female embryo is implanted, after their daughter died. Japanese and Dutch governments ban human cloning. The European Patenting Office refuses a human to pig, cow or sheep mixed species cloning patent. The application said that the US company BioTransplant Inc and Stem Cell Sciences Australia had already produced pig-human embryos.
Nov	UNESCO's International Bioethics Committee debates ethical and economic aspects of human genetics in Quito. Lawsuit over Jesse Gelsinger who died in a genetic trial is settled out of court; scientists and funders allowed to resume research. Enquiries reveal other adverse episodes, regulatory violations and financial conflicts of interest in trial. EGE advises against embryo cloning for stem cell research and use. Disabled Peoples International (Europe) position statement on threats to their rights and survival from the new genetics.
Dec	US religious group, the Raelians, fund attempts to clone a dead child. US bioethicists Buchanan, Brock, Daniels, Wikler publish 'From chance to choice', arguing that human genetic engineering is inevitable and maybe desirable to create more just societies. UK and US scientists seek approval for gene transfer in utero trials which would affect fetal germline. UK issues patent for 'designer sperm', developed through research which lies outside HFEA regulation. Japanese scientists grow sperm and aim to reprogramme male cells to produce eggs so that gay men can father and 'mother' children. The technique uses cloning but evades Japanese laws by producing gametes not embryos.

Table 3 2001

2001 Janua	New US President Bush supports voluntary and temporary controls, and only for federally funded research on human
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ry	cloning. First GM (rhesus) monkey, ANDi, reported. British Parliament allows 'therapeutic human cloning'. Cystic Fibrosis Trust, highest spending charity on single-gene research, closes its support network for adults with CF (who criticise the Trust's use of sickly child image to raise research funds.
Feb	Human Genome Sequencing completed at total of 30-40,000 genes. Craig Venter of Celera Genomics (US) claims that the main potential use will be pharmacogenetics and not genetic engineering. Francis Collins NHGRI (US) claims there will be pressure on future scientists to enhance human embryos genetically. HGC consultation document on Personal Genetic Information (on gene banks, genetic discrimination, insurance, personal privacy). House of Commons Science and Technology Committee and Royal Society of Medicine criticise British Government's line on allowing insurance companies to use genetic tests. Johnjoe McFadden (Essex University) warns that 'our genes are doomed'; unless we resort to human GM we will fail to compete internationally.
March	Council of Europe's protocol against human cloning takes effect. US Congress pre-legislation hearing on Human Cloning. Coalition of US organisations opposed to human cloning and inheritable genetic modification. Drs Antinori and Zavos hold workshop in Rome on cloning human beings, despite cross national condemnations.
April	Prof Robert White, neurosurgeon at Cleveland Ohio, reports his research on transplanting monkey heads, arguing that the person is the brain - which may require a new body. Five cloned transgenic piglets born at Roslin Institute.

Main sources: British Medical Journal; Medical Ethics Bulletin (UK); Genetic Crossroads (US); Human Genetics Alert (UK), New Scientist.

Against this background, our qualitative sociological and philosophical research project investigated how health care practitioners and managers were facing practical and ethical issues associated with the 'new genetics' in their daily work. We conducted interviews and group discussions in two hospitals. One aim of the discussions was to 'bring ethical discussions into the hospital'. Knowledge of bioethics amongst health care professionals has expanded rapidly over the past two decades, and although in-house ethics committees which review clinical practice (rather than research) are still rare in Britain, ethicists work closely with practitioners in hospitals in London, Manchester, Oxford, Edinburgh, and other centres.

Links between everyday practice and the formal application of bioethics, however, are usually made personally by individuals who have attended conferences or courses, or read ethics literature. They then face the challenge of applying ethical ideas not only to their own practice, but possibly also to the policies, rules, relationships, routines and resources which structure their work. Attempts to change practices in order to raise ethical standards bring complications and stress and, unsurprisingly, people who return to their department from courses with enthusiasm to

promote new ideas encounter difficulties and may become disillusioned. One possible solution is to bring ethics into the hospital by convening seminars for groups of practitioners who share in reviewing problems and considering changes and practical ways forward. We organised small group seminars chaired by a philosopher within the hospital departments involved with the research.

### **‘The new genetics’**

The new genetics refers to knowledge and techniques arising out of the discovery of recombinant DNA in the 1970s. It involves research into the genetic components of disorders and behaviours, and the clinical application of genetic knowledge to testing, screening, informing and treating affected people. Many social and ethical issues raised by the new genetics are not new. However, the new genetics is associated with geneticisation in the increasing tendencies to reduce explanations for physical, mental and behavioural differences to possible genetic origins. The promotion of a model of genetic disease and medical alleviation can divert attention and resources away from possible social origins and social remedies for health and behavioural problems. The growing influence of genetics in medical practice effects slow changes in attitudes among individuals and society towards future generations, human identity, relationships and reproduction, and towards the prevention and control of disease. (2) Hoedemaekers and Have (3) list six incongruities, which arose from the geneticization of prenatal services in Cyprus since thalassaemia began to be prevented three decades ago. These are:

- the difficulty of promoting free choice in the directive environment of the clinic;
- health care staff are mainly responsible for the framework of prenatal decisions yet they push responsibility for choice making on to prospective parents;
- doctors promote medical methods of prevention, abortion, which go counter to accepted traditions of medical support, treatment and cure for the weak;
- as induced abortion becomes less exceptional it becomes more standard, thus compromising practitioners’ efforts to offer equally balanced choices;
- free individual choice is emphasised but the hidden public pressures are underestimated;
- contrary to the usual public statements, the new diagnostic techniques serve the purposes of country and state.

In relation to these types of concerns, we investigated how staff in the two English hospitals thought about the current and potential advantages and disadvantages as the expanding new genetics affected their work.

### **‘Genetic screening’**

Genetic screening is widely referred to (4), although the term is largely inaccurate. The only Mendelian single-gene conditions screened for in Britain, and then in only a few areas which have ‘high risk’ populations, are sickle cell and thalassaemia. In contrast to genetic tests, ultrasound and maternal serum screening search for phenotypes such as raised hormone levels, or anatomical anomalies (5). Down’s syndrome and spina bifida are not Mendelian conditions so that antenatal staff and prospective parents are much less likely to know people living with the conditions which are detected by serum screening and scanning. Their discussions and decisions may therefore tend to be less informed, with less attention to the range of likely severity and the difficulty and complexity of trying to decide whether the potential life might be worth living, than they would be in genuine genetic screening. Significantly, the haematology staff we spoke with had detailed practical knowledge about these familial conditions through their daily work

with all age groups and their discussions tended to pay more attention to the varied severity of the conditions, including mildly affected cases.

Our research about genetics around the millennium has been much concerned with prenatal screening, for several reasons. A broad definition of screening covers the follow up tests, although chorionic villus sampling and amniocentesis now are used in Britain too selectively with high risk cases to be defined as screening, but some follow up tests check genotypes. At present, the widening gaps between genetic knowledge and clinicians' ability to treat genetic conditions are especially apparent in the prenatal period when the main 'remedy' available is termination of affected pregnancies. Scanning contributes towards closing the gap between genetic testing of selected high risk cases and mass routine screening of healthy populations. Although scans cannot detect the main single gene conditions such as cystic fibrosis or haemoglobinopathies they open the way for genetic knowledge to be introduced rapidly into prenatal diagnostics in the following ways. Increasingly, women are offered nuchal translucency scanning for possible chromosomal conditions earlier in pregnancy (11-2 weeks) as part of their first routine visit to the antenatal clinic, a stage when many consider that a decision to terminate is not as serious and painful a decision to make as it would be later on. The women do not have to elect to visit especially for the scan, as they do for maternal serum screening at about 18 weeks. When tests are offered on this opt-out rather than an opt-in basis, acceptance rates are much higher (Angus ref). 'One-stop clinics' which offer the tests, counselling and option of abortion in one visit are also liable to speed and expand the acceptance of interventions for fetal anomalies among all pregnant women. As new genetic knowledge and techniques, such as the possibility of isolating fetal cells in maternal blood, develop, the practical channels for implementing this knowledge will already be deeply entrenched in routine services; the new knowledge and skill will be able to flow rapidly into care. The staff were however, very concerned that already there is not time to discuss the list of potential problems and options. Discussions about screening and testing revealed professional attitudes and practices which linked to current and potential future work with the gradual expansion of genetic diagnoses and treatments into the health services, and raised many relevant ethical issues which perplexed the staff.

However, we have tried to avoid using the term 'genetics screening', except when quoting health staff who used the term, for these reasons. We have aimed to stand back from the expansion of genetics, and its actual or putative links with the new reproductive technologies, in order to question and examine these links critically, and not to assume that they already exist. Discussion of phenotypes (the expression of genes which merges into nurture and environment) as if they are genotypes becomes part of the uncritical process of geneticisation. Research and policy which assume that 'genetic screening' is already widely implemented may also inadvertently contribute to the genetic expansions which we set out to examine. Before genetic screening is actually introduced across Britain, it would be advantageous if policy makers and the general public debated the costs and benefits of such a decision, instead of using terms which imply that the decisions had already been made.

### **Genetic concerns in hospital practice around the millennium**

Around 2,000 AD, how closely linked, in the view of practitioners, was genetics to clinical practice in Britain? We planned to conduct research in preconceptual, prenatal and neonatal departments. A preconceptual specialist said that genetics was not sufficiently relevant to his work for it to be worthwhile for us to research his department. The neonatal staff took part in

interviews and seminars but said that genetics was of little relevance to their specialty, because genetics conditions were usually referred for termination of pregnancy if they were detected prenatally, or else the conditions, such as cystic fibrosis, sickle cell or muscular dystrophy, tend to present after the neonatal period. The prenatal staff were much concerned with chromosomal and anatomical rather than strictly Mendelian conditions, but the genetics of fetal sex was much discussed in one hospital. The practitioners who expressed most directly concern with Mendelian genetics, at preconceptual, prenatal, childhood and adult stages, were the haematology staff and community paediatricians caring for children with special needs.

### 3. Aims

In this research about how new genetic knowledge affects health services policy and practice around the millenium, the main aims were:

- \* to review the social and ethical consequences, of advances in genetics, and their impact on professional policies and practices in pre and post natal services;
- \* to examine influences and interactions between disciplines with their different aims, methods, knowledge and values in promoting health;
- \* to contribute to greater mutual understanding between disciplines of the opportunities and challenges brought by genetic advances and the means of addressing these collectively;
- \* to build on the very varied expertise of the group members in order to develop academically sound and practical multi-agency ways of addressing dilemmas raised by genetic advances.

The seminar participants were informed that the more detailed aims of the in-hospital ethics seminars were:

- \* to have a multi-disciplinary discussion about ethics in relation to perinatal services and genetics which we hope will be useful to everyone attending;
- \* to see how a visiting ethicist can assist team discussion within the hospital setting;
- \* to begin to see whether this type of small group ethics discussion could be a useful format for other departments and hospitals to develop;
- \* to contribute further data to the Cross Currents in Ethics and Genetics research project for use in reports about the research methods and findings.

The aims are partly complementary and partly conflicting. They combine holding experimental groups, with documenting practitioners' views, and with possibly altering those views through the seminars. The aims include bringing philosophy into the hospital to take account of the local context, and also creating a transferable format useful to other hospitals and specialties. The

groups were intended to be enjoyable, stimulating and useful for people with a range of interests and levels of knowledge about ethics. We hoped that people would think that the groups deepened their thinking. How far the aims were achieved is considered in the conclusion.

#### **4. Methods**

**The research was based at an inner city teaching hospital A, and an outer city district general hospital B. In-depth interviews were conducted with 69 staff in prenatal and neonatal departments and in related clinical, management and community services (by PA and CW) (see table 4 the information leaflet, table 5 the list of interviewees, and table 6 the interview questions and themes). Most of the interviewees later took part in ethics seminars facilitated by the ethicist (BF) (see table 7 information sheet, and table 8 list of seminar participants). We conducted some observations of the staff working in clinics. Both hospitals served very varied communities with many people who had African or Asian origins.**

**Table 4. Information leaflet about the project** (Set out in A5 folded leaflet)

**Cross currents in genetics**  
a study of how staff working in perinatal services in two London Hospitals  
address questions about genetics and ethics which affect their work  
April 1999-March 2001

**Please would you help us with our research?**  
We are asking 32 members of staff at your hospital

- \* to take part, over 14 months, in two interviews
- \* to take part in one two-hour small group discussion, about ethical and legal issues raised by advances in genetic knowledge
- \* to allow us to observe them working with their colleagues
- \* and, if appropriate to observe them working with patients at times to be agreed with them.

**We hope that people who take part in this project  
will find it personally useful to them.**

**Researchers:**  
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This leaflet gives some details about the project.  
If you are interested, we would be pleased to give you more information.

**2.**

**The research questions**

- \* How does new genetic knowledge affect policy and practice in perinatal health care services?
- \* What challenges and opportunities does the knowledge present?
- \* How do health care staff address these in their daily work, individually and together?
- \* What aims and values guide them, and how can insights from ethics and social science help?
- \* How can such insights be shared in more useful ways with busy practitioners?
- \* How can small multi-disciplinary group meetings help staff to discuss and resolve dilemmas?

**Research aim**  
To work with perinatal staff to develop ways to address ethical and legal issues, raised by genetic advances, which help staff who inform and support patients affected by these advances.

**3. Research methods**

- \* Talking with and observing the work of 32 staff from 16 disciplines: medicine, nursing, midwifery, counselling, technicians, clergy, research, administration and management

- \* Eight 2-hour multi-disciplinary taped discussion groups, each for 4-6 staff, led by a philosopher, about ethical and legal issues raised by advances in genetic knowledge.
- \* Over 14 months, 2 audio-taped interviews with the 32 staff, lasting 1 to 2 hours.
- \* Qualitative and quantitative analysis of data, to report in journals for practitioners, policy makers, and medical law and ethics teachers.

**Risks, discomfort**

Some staff might feel anxious about some of the topics we will discuss with them, but our aim is to help them to find supportive ways of tackling dilemmas.

This project mainly concerns the health staff, but some patients will be indirectly involved when we observe the staff during their daily work. If our observations appear to distress patients or staff, or to interfere with professional care, we will withdraw.

4.

**Rights of all staff and patients affected by the research**

We respect your rights:

- \* to take time to decide whether to agree to help us;
- \* to refuse to take part or to be observed,  
without this affecting your work or care;
- \* to sign a consent form if you agree to help us;
- \* to refuse to answer certain questions;
- \* to withdraw from this project at any time;
- \* to have notes and tapes about you kept in a safe lockable place and registered under the 1998 Data Protection Act;
- \* to be kept informed about the research and reports if you wish;
- \* to have your privacy respected,  
by making sure you cannot be identified,  
if we repeat your comments to other people,  
and when we publish reports about the research.

**The project has the approval of :**

--- Hospital Research Ethics Committee 99/119 and of  
Professor ---- Consultant Obstetrician.

**Funder:** The Wellcome Trust

**Heads of Department**

Professor Ann Oakley	Professor Jonathan Glover
Social Science Research Unit	Centre for Medical Law and Ethics
Institute of Education	King's College
University of London	University of London

May 1999

A similar shorter version was prepared for anyone being cared for the staff we were observing.

To protect anonymity, each practitioner is identified in our publications by a number and the hospitals are not identified, although a similar range of views was found in each one. In addition, practitioner titles have been purposely kept broad, so for example, practitioners described as 'midwives' range from junior midwives to senior managers, whilst 'obstetricians' covers research



fellows, specialist registrars and consultants working in obstetrics and fetal medicine.

**Table 6. The interview questions and themes**

**Cross currents in genetics June 1999**

Name; post; time in profession; and at hospital or health district;  
previous experiences in this or other profession; main qualifications/ courses attended.

1. General account of your daily work, main duties, job description, does it have any explicit reference to genetics? Your views on working in or near a leading university and research hospital. Your views on how your work relates to/ fits-in-with colleagues in the same and in the other professions, and in the hospital and/or community team. The supports or pressures you experience.

2. What kinds of opportunities and challenges do genetic advances present in your work?  
(Talk about meanings of “genetic advances”. If the reply is “none”, ask prompts)  
What does ‘genetics’ mean to you? What words does ‘genetics’ bring to mind?  
Will you give one or two detailed examples of how you dealt with related practical questions recently, alone or with colleagues? (Prompts if needed, such as: to introduce a new type of test; to counsel prospective parents; to help a baby with a serious genetic condition to survive? Any changes in routines or attitudes among colleagues over past decade, that might have been influenced by new ideas in genetics? Who benefits? Patients, junior or senior staff, research, the trust, society?) How might the new genetics affect your work in future? (Note active and/or passive, optimistic and/or pessimistic, pragmatic and/or principled replies, confidence or diffidence.)

3) What values and beliefs inform your thinking - ethical, legal, financial, professional, personal? (Such as when considering which conditions are worth screening for and why, or how you inform and support patients/clients, or why you value informed choice or believe it is not achievable.) Do you feel your colleagues share and support your values?  
Do you feel your employers share and support your values? If so, how or how not?  
Can you give examples, such as what you feel others expect or require you to do?  
Do you have formal or informal discussions or negotiations with them, or are expectations implied? Do you think there is general agreement among the staff, or personal or discipline differences? And how are any differences negotiated?

4) How helpful or relevant is, or might be, some formal knowledge of ethics, law and social science (research methods) to you and your colleagues? Any examples, especially in understanding and dealing with the consequences of genetic advances? Any ethical questions, examples, experiences, you have had or heard of that you think it could be useful to discuss in small group? Views on ethics and teaching methods that guide or promote debate or work towards solutions? What would you expect or want from an ethics session? Might our research team be useful to you / your department in sharing in/ promoting discussion? (They may say they have no time and it is unnecessary. They might have ideas on themes or methods for the groups and later interviews, or even on social science research for the future.)

5) Follow up to the interview - discussion groups. Answer any questions about these and check if interviewees are willing to take part. Ask if they have any questions for us.  
We might have too many people for the groups.  
Can we observe you at work?  
Do you have any suggestions of your colleagues we could approach?

**Table 7. Seminar information sheet.**

**Table 8. List of seminar participants.**

T = teaching hospital D = district general hospital

[Clare - the next list got muddled and I cannot remember which col is which and which is the missing heading can you help? Did you have a proper version at any time? Shall I use the lists you presented to the advisory group?]

Group	nos.	consult	managers	men	hours
		Present	-ants		
T1	6	1	1		1 1.5
T2	5	1	3		1 1.5
T3	6	1	2		2 1.5
T4	4	2	1		- 2
T5	9	1	1		1 2
T6	7	3	1		1 2
T7	7	3	3		2 2
sub					
totals		44	12	12.5	
D1	5/6	1	-	1?	- 2
D2	5	2	1	2	1 2
D3	7	-	2	1	- 2
D4	5	-	2	1	1 2
sub					
total	22				2 8
total	66	17	17	13	14 20.5

**Professions;**

**Teaching hospital**

Midwives: 4, managers, 3 ultrasound scanners, 1 in community, 1 in research  
Nurses; 2 NICU sisters;.

Consultants: 2 fetal medicine; 1 obstetrician; 1 paediatrician; 2  
neonatologists; 3 haematologists;

Registrars and research fellows: 7 obstetric/fetal medicine

Genetics counsellors: 2

Psychologists: 2, psychoanalyst: 1; bereavement counsellor: 1;

Haematology scientist: 1; Chaplain: 1; Legal adviser: 1.

43 people were interviewed, 24? Of whom attended one or two groups

3 declined, (chaplain, psychiatrist,)

4 couldn't find suitable date (nurse manger, psychotherapist??, GP)

3 left before the groups met (chaplain, lecturer, midwife)

8 were interviewed for background breadth of ideas

**District Hospital**

21 of 26 interviewed attended a group

3 declined (scanner, lecturer, translator)

1 could not find suitable date (GP)

I cancelled at last minute (chaplain)

Midwives; 4 managers, 3 lecturers, 2 juniors, 1 community, 1 genetic  
counsellor

Consultants: 1 obstetrician, 4 community paediatricians,

2 clinical audit managers; 2 health visitors; 1 psychologist; 1 PCG chief  
executive.

**Preparation for the seminars**

Methods of organising the seminars are recorded in this background report at some length, in order to supplement the brief accounts in our published papers for the benefit of those who would like to organise similar ethics meetings. The earlier sociological interviews were an important

preparation in gathering relevant and timely themes to discuss at the seminars.(6) Interviews lasted from 45 to 120 minutes. Of the interviewees asked to take part in a research seminar; xx refused, xx had to drop out at the last minutes, xx attended twice at their request which we had not expected, and xx joined groups but had not been interviewed.

While we interviewed, our plans gradually changed. We dropped from 120 to 90 minute sessions, in case people were deterred from attending, although after three seminars which seemed too short we returned to 120 minutes and this worked well. We moved from plans to video into audio taping. It was important to be unobtrusive in sessions when people were asked to risk speaking openly. Two researchers (PA and CW) acted as observers and were able to identify speakers later from tapes and notes. We discussed how to balance the good research practice of warning people about an expected agenda, with being flexibly responsive to directions the group might take spontaneously. We debated the numbers of people to invite and moved up from six to inviting eight or more, partly to ensure a good attendance as people often had to drop out at short notice to respond to emergencies. The aim was to balance time for each person to speak fully with having enough contributors for a lively discussion. The average of seven participants worked well.

Convening the groups was a major task (by CW) requiring numerous phone calls to arrange and confirm dates, and remind everyone the day before. This time investment was probably essential to ensure a good attendance. The easiest group to convene was the only single interest one (haematology). They were, however, keen to attend second groups to meet a greater interdisciplinary mix and more 'challenging and conflicting views'. It is possible that a larger single issue group would have been worthwhile and much time was spent in trying to convene an ethics seminar during a large (fertility) unit's weekly meeting but this did not succeed.

Plans for the content also gradually changed. An emphasis on general ethical principles altered into a context specific agenda based on participants' stated concerns during their interviews. From believing that the ethicist should teach and offer 'chunks of expertise' to the group, we came to think that she should mainly be a facilitator, encouraging, clarifying and occasionally extending the discussion. This slightly reduced our anxiety about how the groups would work, by transferring the responsibilities we had assumed were ours (to inform, entertain and enlighten without being patronising or too complex or too superficial) towards a sense of more equally shared responsibility. The quality of group discussion came to depend on everyone present, when it was unhelpful for a few people to work too hard. The main responsibility, however, still rested heavily on the ethicist with the added challenge of responding to participants' initiatives instead of providing a preplanned session. We aimed to 'bring ethics into the hospital', physically by basing seminars within units, and substantively by involving people with similar expressed concerns and concentrating on their themes. The seminars thus differed from the more usual format of the analysis of abstracted cases by generic groups of strangers in ethics centres.

Changes in our plans are illustrated by a) an earlier note, b) the informal agenda decided on the day of the first group, and the following section which reports the actual meetings.

[Delete this and instead just put two of Bobbie's pre-meeting notes of topics?]

a) Plans for possible discussion topics, three weeks before the first group:

- \* informed choice and autonomy
- \* how do they see increases in prenatal screening affecting their work
- \* prevention of disability and aims to increase the healthy birth rate
- \* possible impact on society of shifts in thinking about who should be born
- \* the invisibility of genetics so far in much clinical practice and policy plans
- \* is there is a surprising gap between emphases on genetics in clinical journals and conferences versus daily practice
- \* the being and the becoming of genetics.

And practical themes such as:

- \* working as a team and relationships between departments, cross-currents, interconnections between professions
- \* creating harmonious team work to benefit patient care
- \* managing change and transition - over past few years with development of scanning

And evaluation:

- \* what did you gain from the group
- \* how we might improve the format for future groups.

B) Planned agenda on the day of the first group

(add one or two of Bobbie's short pre-meeting lists here?)

### **On the day**

Participants were given a sheet (table x) when they were invited and again when they arrived. We arrived in plenty of time to arrange the room, put a notice on the door 'research ethics seminar, please do not disturb' remove spare chairs, and arrange chairs for people to be comfortably close but not cramped. We served sandwiches and hot drinks, people chatted as they arrived and waited for late comers. Participants sat on easy chairs around a coffee table. At the one group which met around a large desk level table, people seemed more anxious, less willing to start talking, they avoided eye contact and took notes at first. As the participants said later, it took time to warm up; other groups more quickly established lively and informal interactions.

Sessions began with informal introductions. Then the ethicist spoke quite slowly for a few moments, repeating points on the information sheet described above. She added,

'We all want to talk together and interact, and I will begin with a warning that in a philosophically led discussion it is polite to challenge, and you mustn't feel I'm being aggressive if I say Why? Or, How do you back that up? That's what we're interested in doing, digging out the reasons why you hold your views. Now of course, tell me to get lost if you find I'm digging too deep. But please don't feel uncomfortable, and I think it's quite valid for you to ask each other these sorts of questions, as long as we realise that we've got to expect each other's very different views. I'd like to assure you of the confidentiality, that we have mentioned. You will not be directly discussed or identified when the transcripts are made and reports are written. Does anyone have any procedural questions before we begin? I'm afraid I'll have to rely on you to jump in to the discussion, and please don't feel you are being tested. There are no right or wrong answers, it is your own views that matter. We are every interested in the views and reasons you have.'

The slightly informal language and leisurely pace seemed to encourage most people to speak confidently. They listened carefully and seldom interrupted, they often spoke at some length. No one was asked to speak unless they looked as if they wished to, so that some people spoke much more than others, and a few people hardly spoke, these tended to be non-clinicians.

Within a few days, everyone was telephoned, or occasionally met, (by CW) to ask them for their evaluations of the seminar. The responses are reported in the attached paper: **'Examining ethics in practice: health service professionals' evaluations of in-hospital ethics seminars'**.

#### **Our dilemmas when organising the seminars**

The participants frequently discussed 'where to draw the line' between applying new clinical techniques, or else withholding them as potentially harmful and unethical. They debated how far they should be non-directive and respect patients' decisions non-judgementally or else refuse to support decisions they felt to be unethical, such as termination for sex selection or for a very minor anomaly. They wondered how to provide an equal service for varying kinds of people. Similarly, we were sometimes uncertain where to draw the line between: collecting research evidence while intervening to teach bioethics; documenting people's views and values while also possibly extending and altering these; offering a safe space to encourage free discussion yet ensuring stimulating relevant debate; probing, questioning and sometimes challenging their views without intimidating or silencing people. We also pondered on non-directiveness and how to avoid either preaching ethical standards or appearing to endorse relativist or unethical views if these were expressed. We aimed for equality, setting neither too high nor too low an academic level of discussion between people with widely differing backgrounds.

#### **Data analysis and writing of papers**

With consent, the 70 interviews and 11 seminars were fully transcribed and were analysed with background notes of observations, the relevant literature, press cuttings and other material. Transcripts were coded by the researchers individually using methods of open coding and grounded theory which allow themes and concepts to emerge from the data.(7) The research team met frequently to analyse the data, combining sociological and ethical perspectives to enrich and validate the analysis, and sharing work on planning, structuring and revising each paper. For a list of completed papers see page xx.

#### **Our experiences of multi-disciplinary research**

Besides involving participants from a range of disciplines, the research team combined sociology and philosophy. We found this mix valuable and stimulating and record here a few our experiences. The two sociologists, Clare and Priscilla, had many initial concerns about whether busy practitioners would agree to give us time and, especially, meet for the ethics seminars. The philosopher, Bobbie, was confident that they would be interested in taking part, and was proved

right. At first we were anxious about how to explain the new research approaches to potential participants. We were unsure what to expect ourselves of the seminars, and therefore how to provide adequate information to ensure that the practitioners' consent was reasonably informed. Particularly when inviting people to the first group, it was hard to give them any idea as to what it would be like.

As the convenor, Clare felt very responsible for the groups: firstly, to her colleagues in getting people to attend, because the groups were a key part of the project; secondly, to practitioners themselves. With her background as a health practitioner, Clare wondered whether they would find the groups useful, and whether busy practitioners would be willing or able to give up around two hours of their time, to something that might sound a bit nebulous to them. We wondered whether enough people would attend to make a discussion possible, given that the workload of many practitioners was heavy and often unpredictable. We were uncertain whether sufficient people with nonmedical backgrounds would agree to attend and help to ensure that a range of disciplines was involved.

Clare wondered if Bobbie would be able to make the groups relevant for all participants, given the diversity of their interests. Clare and Priscilla felt nervous as people arrived, trying to remember all their names to be able to introduce them to each other. It was a bit like being a party hostess, something we've never been good at! Another challenge was to make sure that the environment was reasonable - the seminar rooms were either too hot or too cold, one was too noisy, and people came in to use the photocopier despite our 'please do not disturb - ethics research seminar in progress' notice on the door. One room was rather cramped and stuffy, and another too large. Fortunately, participants appeared to become absorbed in the discussions quickly, and to ignore the conditions.

As the project proceeded, we became more aware that we had all gone into the discussions with different agendas and assumptions about what they would and should be like, which we had never really discussed. Priscilla said that she had anticipated more challenging and 'consciousness raising' discussions. Clare and Bobbie felt that it was vital to treat the participants and their views respectfully, and to provide a safe non-judgemental space for them to talk freely and confidently. This approach was also valuable for collecting material on practitioners' frankly expressed views to add to the interview data. Most people only attended one seminar, and for many this was an introduction to ethics, so that establishing mutual trust and respect were crucial tasks for these initial sessions.

The sociologists were very pleased and relieved after the first group, to see how skilled Bobbie was at facilitation, making everyone feel welcomed and included, and making the discussion relevant. Although we had faith in Bobbie, Clare's experience at a recent conference, which was her first meeting *en masse* with ethicists, had left her anxious. Many of them seemed to be not really in touch with the realities of health care and were more keen to score points in terms of how well they argued, rather than thinking about the people represented by the case studies they were discussing with small groups.

Clare found pleasure at doing the follow up interviews, and hearing how much people felt that they'd gained from the groups, and sharing their reports with the research team. She also became interested in the points that Bobbie picked up on, and others that she let go. One of these points - that the value of the fetus for some practitioners becomes the value that the pregnant woman places on it - became the basis of a joint paper.

While working on the end-of-project presentations to give at both the hospitals, we were concerned to make the research reports relevant for all concerned. We expected practitioners to want mainly practical recommendations for improving the services they provide, and we debated

how to present research findings which stress difficulties, complications and ambiguities in their work which do not have easy solutions.

Priscilla found the monthly team meetings, and almost daily discussions while analysing data and writing papers, especially valuable. They helped to draw out ideas which otherwise would have remained much less developed. Writing joint papers was very enjoyable, and it shared out the tasks and burdens. For each paper, the lead writer did most of the drafting, sifting through the data, selecting and editing quotations, and setting out the themes and commentaries. The other two were then able to make major and minor editing suggestions, and could see the paper with a more detached clarity than if they had written the first stage. We usually agreed with one another's suggestions. Clare was meticulous in checking that the transcriptions and the edited quotations were accurate and did justice to the original speakers.

Another useful exercise was when all three of us wrote 'what genetics means to me'. We discussed our very varied replies and this alerted us not to expect standard responses during the interviews and to be aware of how complex and tentative notions about genetics can be.

Generally, we all held feminist views about women's rights to choose to terminate a pregnancy. Clare was particularly interested in unravelling the many difficulties which the women and practitioners faced when trying to ensure informed choice. Bobbie added philosophical theories about respect for women's autonomy and rights, and whether the fetus counts in any sense as a person with rights. The philosophy was woven into the discussions during the seminars and during the data analysis and writing of papers, especially about varying concepts of the value of the fetus. Priscilla started from a position which was trying to combine feminist and philosophical traditions with respect for disabled people, as some disability writers (such as Shakespeare, 1999) advocate. We had challenging discussions which helped Priscilla to complete two papers on screening for Down's syndrome begun during a previous European project (Alderson, in press, a and b). Our views altered during the project, illustrating the benefits of multidisciplinary research, as we were influenced by and developed an appreciation of each others' views, and the backgrounds that we were drawing on. Our understanding of the disability rights perspective is one example, and this especially developed during the co-drafting of papers, commenting on them, and agreeing on the final versions. These were times when differences particularly emerged, new understandings of each others' views were reached, and compromises were made, so that we were all (reasonably) happy with the final version that was submitted.

Bobbie had always wanted to get involved in empirical research, and in the past had been frustrated by the abstract and detached nature of much philosophising. Even applied ethics can seem divorced from reality at times. In all her work Bobbie's aim is to talk to people who have the power to make a difference, not to other philosophers who care only about the elegance of arguments. This project therefore combined two things she values, talking to health care professionals about what they do, and helping them to sort out what they ought to do, and secondly, finding out whether the preoccupations of philosophers in any way reflect the concerns of those involved in health care. She thought that the project allowed her to learn so much about how research is done, and saw it as an apprenticeship which is still ongoing. She felt very much the junior partner, yet felt confident to have a view and have a go. She valued the sociologists' endorsement of her methods of facilitating the groups. At times it was not possible to combine providing a supportive introduction to ethics, with challenging controversial and occasionally discriminatory views expressed by some participants. Encouraging people to speak sometimes involved the risk of seeming implicitly to endorse these views. With many participants, however, we had only one meeting in which to try to achieve aims which sometimes conflicted, and we had to temper our approach in the light of this limitation. Had we had the chance to meet, say, over a

period of six weeks, Bobbie thought that we could have discussed controversies much more deeply, and that participants who stayed the course would have relished the challenge. At the initial meetings we succeeded in being inclusive, safe and gently questioning.

Bobbie considered that we have learnt that co-researchers need to spend more time at the beginning of a project sharing their perspectives, goals and priorities. She valued the discussions we had on respecting the research participants' confidentiality, and in how challenging we should aim to be. If we had discussed and resolved these questions earlier in the research process, we might have avoided some tensions during the group sessions.

Philosophers work in a very different way to sociologists, Bobbie now believes, and speed of response to the data is an example of this. A philosopher is used to the luxury of thinking time and slow reflection, in fact these are the only 'laboratory tools' philosophers require. She will probably be reflecting on this project for several years to come and producing papers borne of it for longer whereas sociologists, because of the way their work is organised, are not allowed this longer gaze, but maybe do not want it.

The project built research capacity by considerably increasing our appreciation of one another's disciplines and of the rewards of working together. We also gained understanding of how combining philosophy and sociology can enrich the gathering, analysis and reporting of the research data, besides the linking of evidence to insights into current and future policy and practice concerning genetics in clinical care.

### **Confidentiality**

We put much time into discussing the issue of confidentiality, and sometimes had to make compromises. In order to include a diverse group of practitioners, we had often only interviewed one or two representatives from each specialty. Some of these were people doing fairly unique jobs, which would make them easy to identify. When writing, we therefore agreed to use umbrella terms, such as 'obstetrician', to represent not only obstetricians, but also those working in fetal medicine, both senior and junior doctors, but to allocate individual numbers to each participant. This caused problems when writing papers, when, for example, those whom we had similarly labelled with the umbrella term midwife, but who were actually senior managers, were quoted. Sometimes it was obvious from the quote that the midwife speaking was a senior manager, and at other times the quote might be more informative for readers if it was known that the remark had been made by a senior manager. However, such senior managers might be recognised, as they are few in number. For this reason, we gave a few easily identifiable participants two numbers and two job titles.

**5. Results (is this the right heading?) Combine with**

**6. Conclusions and implications of the research**

**[To many readers this will be the most important section. Can we discuss on Monday?]**

### **Meeting the research aims**

**According to the participants' evaluations, the seminars met the research aims, noted earlier. Almost everyone found the seminars useful in assisting team discussion by regrouping staff in new ways, drawing on their very varied expertise, and encouraging them to learn from one another and to address crucial but seldom discussed topics. The groups worked well in two different types**



of hospital (teaching and district) and across a range of specialties. The seminars were academically sound, in that people at all levels of knowledge and experience said they were interested and informed, including people qualified in ethics and those new to the subject. The title of 'ethics' warranted wide-ranging discussions from health policies, science and society, to professional practice and relationships, knowledge, thoughts and feelings. As many people mentioned, these were welded into coherent discussions. The sessions appeared to avoid being too obvious, superficial, complicated, theoretical or remote from practice.

The seminars contributed to the larger research project, when the staff were both research subjects and partners, contributing data, gaining and generating new insights through their interactions, and controlling how much they wished to be involved. The sessions offered time and space for sharing seldom talked about concerns, and for expanding people's thinking about ethics. The seminars documented how the health professionals' views about social and ethical consequences of advances in genetics and their impact on professional policies and practice, expressed during earlier individual interviews, were repeated or modified, confirmed, developed or challenged by their colleagues. The groups therefore partly validated the interview data showing where there was broad agreement. The evaluations and other data illustrated interactions between disciplines with different aims, methods and values.

Evidence, analysis and publications (8 April 2001 rough notes for discussion follow here)

Maybe we need a section here about how our papers met the research aims

and I think we need sections on:

Might we summarise main conclusions from each paper, whoever was lead author?

Limits to reviewing social and ethical consequences - though we could summarise quite a bit on this

Practical recommendations for future seminars

\* Preliminary interviews were vital, in order to base the seminars on key local, practical concerns to the staff.

\* It is likely that instead of a visiting ethicist, an in-hospital part-time ethicist who routinely spends time observing and talking with staff, planning sessions with them and following up their concerns would be more useful. A Trust appointment would overcome the problems mentioned about confidentiality.

\* Ethics moved geographically into the hospitals and also substantively into practitioners' daily concerns. It was important to avoid general and abstract ethical discussions.

This, and the way groups attended in-hospital seminars, appears to have stimulated more debate with other colleagues later, and attracted people new to ethics to attend, than when one or two people attend external courses.

\* Care taken in arranging the right number of chairs in a close circle and welcoming people helped to create a pleasant atmosphere. A midwife commented 'The ambiance was good. I liked the way you welcomed everyone personally and had hot drinks and food, it was done in a leisurely way, around a coffee table, I didn't feel pressured at all.'

\* The effects are likely to be more useful and lasting from a series of seminars which develop people's confidence, insights and critical debate. The series should encourage wide-ranging debate but also have specific topics and aims planned with the participants in order to avoid repetition. The place and timing of sessions and the mix across disciplines and hierarchies would require careful discussion.

\* The costs of preparing and organising the meetings, refreshments, the ethicist's and participants' time would need to be covered. A dedicated, patient, persistent and tactful person would be needed to set up the sessions.

Ethics - to consider critical questions or to assist smooth progress?

I think we should emphasise the dangers of rushing into action without due reflection the ethics which helps things to proceed more smoothly or the ethics of holding back, questioning policies and making space to think and rethink them. Also the need for making connections between different professional perspectives, and across hierarchies, such as the experience of daily work with pregnant women linked to local and national policy making awareness of the micro in the macro context the place of academic research to increase insight which practitioners and policy makers can use apply in their work it is not our place to make practical recommendations but to show people (what they often already know) perhaps a little more clearly and illuminated by drawing different insights together which busy practitioners may not have time or opportunity to do.

They have told us their views and experiences we have relied on their knowledge but we have had time to listen at some length to a wide range of people some of whom seldom meet during seminars some participants expressed surprise or relief at learning that others shared their views.

There was a breaking of silence, permission to share seldom expressed concerns. Just as practitioners find they have to little time to discuss the questions with women in prenatal clinics and that the women tend to have to make decisions based

on too little information and a sense of private anxiety and individual responsibility for their dilemmas, so the practitioners appear to feel under informed and privately carrying duties and being potentially culpable instead of being able to recognise that they stem from public and economic policies.

The difficulty of looking below the surface, at what may appear obvious once it is described but which is often missed, especially perhaps in invisible elusive matters of values and ethics, is illustrated by a review of a book by four distinguished ethicists. Noah Efron (who works in an Israeli University and is writing *Golem, God and Man: on biotechnology*) reviewed *From chance to choice: genetics and justice*, by Buchanan A, Brock D, Daniels N, and Wikler D 2000 Cambridge University Press). He praised the power and detail of their arguments but showed that they missed key issues. He summarised the book as considering ethical dilemmas in relations between scientists and society, and between governments and individuals. The four authors argue that these ethical dilemmas concern justice more than freedom, in the fair distribution and sharing out of the benefits of new genetic technologies. They follow Rawls's questioning of how we can create a just society despite the natural differences between people, for example, of ability or opportunity. Like Rawls they conclude that people are willing to accept inequality if goods are shown to benefit the least well off members as much as the most well off ones. They conclude by advocating human genetic modification as a means to increasing equality, fairness and autonomy. But, Efron asks, but how can we ensure equality, fairness and autonomy when these concepts can no longer be fixed or agreed because the genetic technologies alter not just what we have, but who we are and thus our normative concepts and values, identity and relationships. Similarly we have aimed to bring to the surface seldom discussed views and values as well as reviewing present developments in the light of possible futures while seeking to avoid making unfounded predictions.

**Examining the future (still repetitive here)**

Tables 1-3 show how rapidly new genetic knowledge and techniques were advancing, so that social research on these issues can quickly become out of date, a historical record instead of offering means of understanding and addressing social and ethical questions raised by future developments before they quickly become present realities. We asked the health care staff about their views of the past, present and future, how they felt they were, and would be, affected by genetic advances. We traced how, and possibly why, quite tenuous new ideas and under-evaluated technologies can so rapidly pervade the health services over the past three decades, such as genetic counselling, prenatal screening and scanning and the increasing application of genetics in the preconception and paediatric services.

In areas of very rapid change, sociologists are posed with the problem of how to avoid writing history - records and analysis which have been superseded by events before their reports are

published. Our research about contemporary topics suffers the added disadvantage of lacking historical foresight/hindsight. How can our research inform or warn if it is confined to solid evidence which so rapidly becomes defunct? And yet the problems of speculating rationally about likely futures seem equally severe. Barbara Adam's foreword to *Contested futures* (8) notes that 'the techno-science of today creates future presents for our successors' who cannot influence today's decisions. 'It is [therefore] the socio-political task of the present' to research future as well as current needs. She advises that sociologists can explain and render visible present taken-for-granted and often ignored processes, by examining how the future is created, contested and managed; how opportunities are created for some at the expense of others; how uncertainties and contingencies are handled and risks and benefits are balanced. The task is not to predict the future but to identify intricate interactions and the use of language and metaphors which rewrite the present into the future as, for example, in the use of religious terms and imagery.

### **Paving the way to genetics**

The cross currents in genetics and ethics research project 1999-2001 was initially designed to examine the influence of genetics in preconceptual services. The department we approached in 1998, however, felt that genetics was not a relevant enough issue to be worth researching in preconceptual services. In contrast, consultants working in general obstetrics and fetal medicine welcomed and supported the research plans. Currently the main practical impact of genetic knowledge is in prenatal detection of fetal abnormalities in order to offer prospective parents the option of termination of pregnancy. Our research was therefore conducted mainly in the prenatal services, and expanded into neonatal, community paediatrics and haematology services in the two hospitals.

[I've left this bit in because I wonder if we can do something with this idea? Social research therefore risks becoming simply a historical record, instead offering means of understanding and addressing social and ethical questions raised by future genetic developments before they quickly become present realities.

This possible paper would report ideas propounded in our research interviews and seminars, and set them in the context of contemporary research literature and media reports and speculation. The paper covers past, present and future in its aims: (1) to indicate how health care practitioners and managers believed they were being and soon would be influenced by new genetic knowledge and techniques at the millennium; (2) to compare their views with those of researchers, policy makers and journalists; (3) to trace how and possibly why quite tenuous new ideas and under-evaluated techniques can so rapidly penetrate the health services. These innovations, some over the past three decades, others through recent rapid expansion, include genetic counselling, prenatal screening and scanning, and the increasing application of genetics in the preconception and paediatric services.]

### **The language of certainty or of probability**

We examined how medical and genetic information is presented and managed to serve certain aims and interests. One example is the phrase 'Down's syndrome is the commonest form of severe mental retardation', which frequently appears on clinic leaflets and is mentioned by staff. Firstly, 'mental retardation' is now a criticised term in some circles and certain British journals ask authors to replace it with 'severe learning difficulties'. The changes of terminology from fool to idiot to feeble minded to retarded to learning difficulties denotes discomfort not only about the disability itself, but also about the unfortunate history of medical management (ref). 'Learning

difficulties' is the phrase preferred by people who have these difficulties (ref), partly because it indicates an educational rather than a medical problem, one that is treatable and not, as medical authors conclude, untreatable,(ref) and one which everyone shares to some extent across the whole spectrum of humanity. It is a more inclusive term. 'Mental retardation' is likely to sound more alarming to expectant parents. 'Learning difficulties' is also an appropriately contextual term; people have difficulties in some contexts and not in others. Learning difficulties are constructed or exacerbated when people are treated as much less able than they could be, and are excluded from opportunities to learn through self-fulfilling negative expectations.

The second aspect of the phrase which biases the information negatively is in the words 'the commonest form'. 'The commonest diagnosed form' would be more accurate. Approximately one in 100 people have severe learning difficulties (SLD) and approximately one in 600 people have Down's syndrome. Five in 100 people with SLD therefore have some other condition from a wide range of conditions, many of which remain undiagnosed. The third negative complication is in the implicit certainty of the phrase, which glides over controversies about whether IQ, and therefore SLD, can be defined or assessed, and about the social construction of disability (ref). For example, health professionals tend to speak of 'some children with Down's syndrome are able to attend mainstream schools, but very few of them', as if the school attended accurately reflects the assessed IQ of the child. Yet there is little correlation. Instead, choice of school depends on available places and this depends on provision and policies of local education authorities (LEA). Some LEAs admit all local children with Down's syndrome to comprehensive mainstream schools, others send all of them to SLD schools, others have a range of options.

The 'fight' with the LEAs which many parents have over the choice of their child's school illustrates how the choice depends more on beliefs about SLD than on the type of precise medical-psychological IQ assessment which is implied by information in the prenatal clinic. A leaflet given out by the clinic states: 'Down's syndrome is the most common cause of mental handicap and it occurs in about 1 in 700 pregnancies.' The implicit certainty and precision in these few words illustrate how, on a far wider scale, many kinds of tentative, ambiguous concepts are repackaged into authoritative medical certainties. Pressures such as time constraints, health professionals' training, textbook knowledge, and traditional ways of giving information and invoking trust, all undermine efforts to transfer from explaining certainties to explaining probabilities. Yet this transfer is essential if the clinic staff and perspective parents are to be able to have informed discussions about, for example, the probabilities in maternal serum screening results, or the prognosis of a fetal condition.

Although the staff implemented policies which, without the professionals' agency would remain unfulfilled, they tended to deny their own agency and to transfer power onto other agents or structures. Practitioners and also managers frequently alluded to commercial, consumerist and media pressures on them, and their need to manage risk, prevent litigation, and accept economies in their resources. The pressures on the staff to offer an equal standardised service raised three great difficulties for them: equity - to attempt to offer a fair service to all no matter how unequal the patients were in their needs or abilities; sensitivity - to provide a flexible, reasonably tailored and humanely responsive service, within the framework of impersonal, standardised equality; professional ethics - is this a code of binding principles which guide practitioners' and patients' decisions, or should the non-judgmental expert promote health through respecting patients' choices? The paradoxical concept of respect for autonomy, as either a principled imperative or

relativist licence, encapsulates the professionals' dilemma, which we address in our papers for publication.

### **Cross currents in genetics**

Each profession plays varying parts in how they initiate or lead, support, accept or resist innovations. The interviewees tended to assume that their profession must be drawn in to support prenatal screening and testing programmes. The clergy, even a Roman Catholic chaplain, and the various counsellors spoke of supporting distressed parents after termination of pregnancy 'picking up the pieces' helping people to 'go through the grieving process' without blaming them in any way. The counsellors who combined psychological support and listening with giving information would advise, for example, parents to agree to an autopsy in order to gain some relief through knowing about the cause of a stillbirth and to gain some confidence and hope about the informed care during future pregnancies. In these ways they presented genetics as valuable knowledge which answers society's needs. For psychologists and psychiatrists, genetics might provide scientific evidence to support diagnoses of behaviours for which they currently have to rely on symptoms alone, and not on definitive signs such as genotypes. Ethicists and theologians have shown how their specialised knowledge can complement genetic knowledge and research - such as in the ethics of individual autonomy which fits the 'selfish gene' ethos, or in a classical history of gynaecology from Aristotle and Aquinas which removes objections to embryo research.

The midwives, individually and collectively through their Royal College, appear to accept the growing list of risks to discuss with pregnant women, apart from complaining about lack of time and the difficulty of helping women to understand the information. Midwives describe rising aspirations, from delivering a living baby to achieving a 'perfect' baby. These professions-related-to-medicine followed the medical lead and played supportive 'handmaiden' roles, which maintained and strengthened their own positions in multidisciplinary teams. They could be seen as more professional in dealing with scientific, up-to-date genetic knowledge, in some cases at the leading edge of research and innovative practice. [Haematology staff rather different knew it increased complexity and skill.]

Among doctors themselves, the community paediatricians were surrounded by expert parents, psychologists, special teachers and therapists and they cared for children with sometimes undiagnosed and seemingly untreatable, incurable conditions. The team members all spent time advising parents on the daily care of disabled children and in practical matters the doctors did not necessarily have greater knowledge. Genetic knowledge promised to enable the doctors to make new, unique contributions to managing the children's conditions, which would thus distinguish them more clearly from other members of their multi-disciplinary teams. The doctors valued medicine's scientific and moral obligation to clarify, whenever possible, diagnoses, prognoses, decisions about treatment and information to patients and carers

through understanding of the cause and nature of disease. Genomics offers exceptionally clear forms of understanding, rigour and accuracy in diagnosis. It is far less clear on prognosis, and the haematology staff were very aware of these complexities. We are analysing the transcripts which show how the various professions reacted and interacted in their responses to genetic developments.

#### 7. Future research priorities - outstanding questions

Our research has identified great ambivalence, some enthusiasm and some anxiety about established and newer techniques, including prenatal screening and genetic diagnosis, among the health professionals whom we interviewed. Continuing research about their explicitly held views and the underlying structures which influence their daily practice and policy making is needed in order to increase understanding of the effects and efficiency of their work.

Similar qualitative research with parents who use these services, to complement the mainly quantitative psycho-metric research which has been conducted so far, would also provide important missing information.

In view of the profound concerns raised during the in-hospital ethics seminars, and the participants' general views on their value in discussing important but neglected questions, we conclude that the seminars are a useful format for hospital Trusts to develop. These are likely to be especially useful in areas of change, such as is beginning to occur through new genetics knowledge. The groups could also be useful in risk management and clinical governance.

Although this short study of single-event seminars cannot estimate the impact on participants' practice or policy making, it does provide a promising start towards multi-disciplinary ways of addressing dilemmas in everyday health care. The main evidence lies in the interest and need expressed by participants for the seminars, and a few reported effects on practice. It remains to be seen how well the seminars would work with other ethicists and in various clinical specialties. Seminars might fit into routine department meetings. However, professional and public awareness of the relevant ethical questions and how these can serve more informed debate and decision making would be increased through greater use of the ethics seminar format we have developed, complemented by prior sociological interviews to elicit participants' key concerns.

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## 9. Publications from the project

Williams C, Alderson P, Farsides B (in press) **Is non-directiveness possible within the context of antenatal screening and testing?** *Social Science & Medicine*

Williams C, Alderson P, Farsides B (submitted) **Achieving informed choice in prenatal services.**

Williams C, Alderson P, Farsides B (submitted) **Dilemmas encountered by health practitioners offering nuchal translucency screening: a qualitative case study.**

Williams C, Alderson P, Farsides B (submitted) **Health practitioners' discussions about 'drawing the line' in prenatal screening and testing.**

Alderson P, Farsides B, Williams C (submitted) **Examining ethics in practice: health service professionals' evaluations of in-hospital ethics seminars.**

Alderson P, Farsides B, Williams C (submitted) **Practitioners' views about equity within prenatal services**

## 10. Selected conference/seminar presentations

7th April 1999 **Disseminating research and links with the health services. Seminar at the Social Science Research Unit, Institute of Education, University of London (PA).**

4<sup>th</sup> June 1999. *SSRU Open Day*. **Presentation about the Wellcome project aims and objectives. Social Science Research Unit, Institute of Education, University of London (CW)**

8th July 1999 **The contribution of sociology, Conference on Making medical ethics interesting: theory for practice. King's College, University of London. (PA)**