



Policy, Ethics and Life Sciences Research Institute

Annual Report 2000-1

Policy, Ethics and Life Sciences Research Institute

Second Annual Report 2000-2001

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PREFACE

Developments in the science of genetics, reproductive technologies and the life sciences more generally need to be accompanied by an additional perspective, equipped to explore the social, political, legal and ethical aspects of these initiatives. However, when academics from the Universities of Durham and Newcastle met through the autumn/spring of 1998-9 to discuss how we might establish a group to take on this responsibility in the North East, little did we expect that, two and a half years later, we would have such a success story on which to report. In this, our second annual report, we show that PEALS has been immensely successful in establishing not only that social and ethical considerations should have a seat at the table of science, but also that they have a legitimate role in shaping the agenda of that science.

We have achieved this in a very short space of time. Much of this is due to the tremendous hard work of Dr. Tom Shakespeare, hitherto our one full-time member of staff. However, Tom's work would not have been possible without core funding for his salary for two years from the William Leech Charitable Trust, for which we are immensely grateful. Thanks are also due to our Chair, Professor Sir Kenneth Calman (University of Durham), Professor Christopher Edwards (VC, University of Newcastle) and Alastair Balls (CEO, International Centre for Life), who have provided much needed financial, intellectual and moral support to the project.

We were initially funded for two years to see if we could establish a role for ourselves. We have clearly done that and, in consolidating our work regionally, nationally and internationally, we have also been successful in securing longer-term core funding for Tom's post, again from the William Leech Charitable Trust. In addition, we have been very successful in securing other grants and therefore further staff. As well as thanking Carol Clewlow, who worked with us through 2001, we are pleased to welcome Dr. Tom Wakeford and Michael Whong-Barr, researchers, and Anne Galbraith, our part-time secretary, to the PEALS team. These new members of staff represent the future of PEALS. They will be the means by which we fulfil our ambition to research and inform policymaking, professional practice and public participation in the debates around the life sciences. The work has just begun!

Professor Erica Haines

Deputy-Chair, PEALS

Professor of Sociology, University of Newcastle

INTRODUCTION

The second year of the Policy, Ethics and Life Sciences Research Institute has been marked by a success in achieving funding for research and outreach projects, a consequential increase in our activities, and a move into modern and congenial office space. The move came at the end of the year, and will bring the benefit of increasing collaboration with our colleagues in the Institute of Human Genetics. For example, we will be developing research projects in the social and ethical aspects of clinical genetics; we will be developing postgraduate and vocational training; and we will be developing tools for delivering better information to antenatal patients and promoting informed consent.

Thanks to our achievements since foundation in October 1999, the William Leech Charitable Trust has renewed their initial funding of my post for a further five years: my job title has changed from Research Development Officer to Director of Outreach to reflect my specific interests and broader responsibilities. An application to the Northern Rock Foundation has been successful in winning a grant to employ a Director of Research for a five year period from 2002. The post-holder will have a background in the social sciences, philosophy or theology and will help us win more funding for our research activities.

The year also brought developing recognition for our growing expertise in public engagement on bioethics. This was epitomised by the decision of the Human Genetics Commission to hold their first meeting outside London at the International Centre for Life, and their satisfaction with the quality of the dialogue they experienced with 400 local people. It is also underlined by our invitation to participate in regional ethics forums - such as the Newcastle Hospitals Trust Clinical Ethics Committee - as well as national ethical bodies such as the Nuffield Council on Bioethics, and international events.

These developments show PEALS playing its part in the genetics campus at the International Centre for Life. This collaboration was rewarded by the visit of Rt Hon Alan Milburn MP in April 2001. His choice of Newcastle as the location for a major announcement on government genetics policy shows that Newcastle is becoming recognised as a centre of national and international debates on genetics. PEALS' successful collaboration with other University and ICFL partners in the bid to form a regional Genetics Knowledge Park is another illustration of the synergies we are beginning to achieve.

The report is organised under the two main headings of research activities and outreach activities. The appendix lists the events PEALS has organised, and the grants we have won, as well as the relevant research outputs of our participating colleagues from the two universities.

The diverse activities reported in the following pages show PEALS continuing to deliver research and debate on the social and ethical aspects of genetics and other life sciences. PEALS aims to affect professional practice, inform public opinion and influence government policy on science. We use both traditional and innovative methods to achieve these goals. We are proud of the fact that we are not a conventional research establishment. We want to facilitate the public to engage with science and medicine as both consumers and citizens. We wish to thank the funders, collaborators and policy-makers who have supported our work.

Dr Tom Shakespeare
Director of Outreach

Stem cell research: an example of the PEALS model

Stem cell research is an exciting area of potential in science and medicine which has been the subject of intense media and public interest over the last few years. Following the cloning of Dolly the sheep by the Roslin team, the possibility of therapeutic cloning and reproductive cloning have generated many column inches and much scientific interest. Less spectacular, but ultimately more promising, is the ongoing work to derive tissue from stem cells. However, ethical controversy surrounds the derivation of stem cells from donated or cloned embryos, and this has been the focus of political debate worldwide.

PEALS has played a significant part in the British debate on stem cell research through its Durham and Newcastle colleagues. Professor John Burn was a member of the Chief Medical Officer's Expert Group on Therapeutic Cloning, and joined Professor Liam Donaldson to give the presentation of their report to the joint meeting of the House of Lords and House of Commons. Both Professor Burn and Dr Tom Shakespeare contributed to media debates on stem cell and therapeutic cloning. Dr Tom Shakespeare gave a presentation on arguments against stem cell research at the Royal Society meeting in June 2001. Subsequently Professor Sir Kenneth Calman convened a multi-disciplinary group from Newcastle and Durham Universities with regional NHS colleagues to prepare an expert submission to the House of Lords Select Committee on Science and Technology. In September 2001, PEALS hosted a public meeting on the science and ethics of stem cell research which was addressed by Professor Peter Andrews (Sheffield) and Dr Michael Antoniou (Kings, London). In November 2001, members of the House of Lords Select Committee visited Durham to meet with the PEALS expert group to discuss the scientific, ethical, social and theological dimensions of stem cell research.

Newcastle is one of only three centres to have a license to use blastocysts donated from patients in in-vitro fertilisation programmes in stem cell research: the proximity of the Centre for Reproductive Medicine and the Institute of Human Genetics has facilitated this research collaboration. PEALS will be working with colleagues in both organisations to develop a research bid to investigate the social and ethical dimensions of this research through research with the patients who are directly affected during 2002.

The issue of stem cell research, therefore, illustrates the partnerships, synergies and expertise that exist in the wider PEALS network. On this subject and others, PEALS aspires to play a leading role in the national and international debate, and to generate high quality research which will illuminate the technical and conceptual questions involved.

FUNDED RESEARCH ACTIVITIES

I The Goals of Ageing Research Symposium

In 2001 Professor Tom Kirkwood, Professor of Gerontology at the University of Newcastle, gave the BBC Radio 4 Reith Lectures on The End of Age: one of the lectures was recorded at the International Centre for Life. To coincide with this event, PEALS and the Institute for Ageing and Health, University of Newcastle, organised a research symposium on the Goals of Ageing Research, funded by the Wellcome Trust. The event brought together 25 scientists, clinicians, social scientists, philosophers and lay older people to discuss the social and ethical aspects of ageing science.

The following papers were presented and discussed under the following headings:

1. The science of ageing

Dr Thomas von Zglinicki, Institute for Ageing and Health.

Dr Gordon Lithgow, School of Biological Sciences, University of Manchester.

2. Implications for healthcare

Professor Gary Ford, Department of Pharmacological Sciences, Wolfson Unit of Clinical

Pharmacology, University of Newcastle.

Dr Julian Hughes, Consultant in Old Age Psychiatry, Centre for the Health of the Elderly, Newcastle General Hospital.

3. Priorities and quality of life

Mrs Mary Midgley, retired philosopher, Newcastle.

Dr Harry Lesser, retired philosopher, Manchester.

4. Social policy

Professor Carl May, Centre for Health Services Research, University of Newcastle,

Dr Kate Davidson, Centre for Research on Ageing and Gender, University of Surrey

5. Justice and diversity

Professor Solomon Benatar, Professor of Medicine and Director of the Bioethics Centre, University of Cape Town.

Professor Astrid Fletcher, Department of Epidemiology & Population Sciences, London School of Hygiene & Tropical Medicine

The following summary of the symposium was prepared by Dr Julian Hughes of the IAH, who organised the event together with Dr Tom Shakespeare and Lyn Patterson (IAH Administrator).

- 1) Biological research into ageing suggests that lifespan is not a fixed quantity; ageing is not unavoidable; new knowledge might help us better to predict the requirements of an ageing population and understand the biological changes a person experiences when growing old.
- 2) Although it does not seem appropriate to call ageing a disease, at a genetic and cellular level there are connections between the control of ageing and the manifestations of disease. One benefit of ageing research, therefore, will be that the burden of major age-related diseases might be reduced.
- 3) Health care can be measured in terms of efficiency and effectiveness. But there is also a moral imperative to health care that involves caring about older people as much as caring for them. This entails looking at meaning and value in old age.
- 4) Gerontologists and others interested in old age have accepted the need to add life to years over and above years to life. Accordingly, drug intervention trials need to take a long-term view, although this does not always seem practicable to large multi-national drug companies. Those interested in old age need to intervene and negotiate sooner with the drug companies in order to encourage developments to proceed in an ethical direction.
- 5) Most ethical questions are about priorities and choices. Some compromise is needed, but, for this to occur appropriately, conflicting ideals and values must be seen in a wider context. In this context the question generally is: what kind of society would we prefer to live in? Natural science itself, dealing with facts, cannot resolve priorities, which are a matter of values.

- 6) An ethical case can be put for making quality of life a priority in ageing research, rather than immortality or a vastly increased length of life. First, ageing research aimed at the quality of life is more likely to benefit more people. Second, unless life is worthwhile it would not be worthwhile extending it. Third, enhancing life will allow those who benefit to help others. Fourth, there is some likelihood that quality of life improvements can be achieved for many. Finally, a worthwhile life is a desirable end towards which to work.
- 7) Primary health promotion still lags behind secondary intervention procedures when it comes to budget allocation; rationing and discrimination on the grounds of age has been a reality. The issue of retirement needs to be reconsidered, along with the possibilities of lifelong learning. Social policy needs to encourage the inclusion and not the exclusion of older people.
- 8) In the United Kingdom, the National Service Framework for Older People has emphasized the importance of person-centred care. However, although there is broad agreement that this is a good thing, person-centeredness is a complex phenomenon. If taken seriously it means we must understand better how care can be delivered in ways that give older people real influence. The issue is not simply about the organisation and structure of care, but about its ethical basis. There is a need for qualitative and sociological research to understand how professional knowledge is translated into good practice.
- 9) Health inequalities continue into old age. They need a higher profile. Health and social care have an important role in improving quality of life and in alleviating health inequalities. It is not known, however, whether disadvantaged older people have equitable provision and equitable access according to their needs. Ageism has most impact on those with little influence, resource or representation. For instance, the recommendations in the National Service Framework for Older People concerning diet, physical activity and oral health take no account of the barriers to their adoption in older people with lower incomes and reduced opportunities.
- 10) The world is characterised by major inequalities in wealth and therefore in health and longevity. Longevity has improved dramatically world-wide, but this trend has been reversed in the poorest countries. The world shows huge inequities in its distribution of health care resources. Privileged people live in a world in which billions are marginalized and neglected. Will the era of biotechnology improve the lives of the poor? Will advances in genetics or ageing research bring them any benefits? Rationality requires honest answers to such questions.
- Full copies of the papers, and bullet points from the ensuing discussion, are available online at www.peals.ncl.ac.uk/ageing or in paper form from PEALS on request. PEALS will be developing further collaborations with the Institute on Ageing and Health in future, as well as contributing to the Medical Ethics in Gerontology Group's programme.



(photo: Sharon Bailey)

A study of the present and future capacity of youth work services to engage in discussions about the social and ethical implications of genetics and neuroscience

This research project was commissioned by the Wellcome Trust's Medicine in Society Programme in February 2001, and was led by Dr Sarah Banks (University of Durham) in association with Tom Shakespeare at PEALS. Paul Burlison was the research assistant, with contributions from Claire Dodd and Sarah McCluskey, Education Officers of Life Interactive World. The aim was to assess current levels of youth work activity around science and biomedicine and the capacity of statutory and voluntary youth work services to promote discussion and debate on the social and ethical implications of recent advances in genetics and neuroscience.

The research comprised a literature review, a mapping of current activities via a survey of workers, agencies, managers and training agencies, and focus group discussions with youth workers and young people at Life Interactive World.

While the research found little evidence of current activity on biomedicine, genetics or neuroscience, issues such as mental health, use of drugs, cloning, inherited disease and animal testing arose in conversations youth workers had with young people. The majority of respondents felt that there was scope for developing work in this area, and that they would be likely or quite likely to introduce sessions, if support was available. Young people in the focus groups showed that they were able to engage with some of the issues, and regarded them as important.

However, most youth workers had low levels of knowledge of science, and expressed feelings of lack of competence and confidence to initiate debates on science and ethics. There is no recognised science knowledge base to training in youth work, and biomedical issues come up incidentally, if at all. However, issue-based and citizenship-related work is a feature of contemporary youth work practice and training, as is work on moral choices and ethical dilemmas, so there is potential for future developments in these areas. Youth groups run by the voluntary sector, including church-based work, may have more scope to develop this work.



(cartoon: Suzy Varty)

Recommendations from the report include provision of further research, possibly with an action research approach, and pilot projects to explore the potential of engagement. Many of the bioethics and public understanding of science activities currently offered to schools could be adapted for youth groups, for example, touring theatre. Training events for youth workers could increase their confidence in this area, and development of resource materials would also be beneficial.

As well as the report for the Wellcome Trust, the research generated an article for *Youth People Now* magazine and a website feature on youthinformation.com, as well as a forthcoming publication in *Youth and Policy* journal. PEALS has subsequently made an application to COPUS to employ a youth and community worker to do more work with young people and other socially excluded groups. We are also developing further research bids to research young people's awareness of and attitudes to the new genetics.

III

A comparative study of participation and non-participation in the North Cumbria Community Genetics Project

Professor Erica Haines and Michael Whong-Barr have been funded by the Wellcome Trust Biomedical Ethics division to investigate the views of those who have been asked to donate tissue samples to the North Cumbria Community Genetics Project (NCCGP). The NCCGP is a research collaboration between Westlakes Research Institute and the University of Newcastle. Based primarily in Whitehaven, the NCCGP collects blood and tissue samples from the umbilical cord of newborn babies and information about health and lifestyles via questionnaires completed by mothers. The aim of the NCCGP is to assist the identification of gene-disease associations, and the impact of environmental factors on those associations.

However, genetic databases raise a number of ethical issues about the purpose and use of DNA samples and personal medical information. These issues include: the reliability of safeguards to protect confidentiality; the possible misuse of personal information by researchers, employers, insurance companies, police, pharmaceutical and commercial enterprises; the rights of donors to receive feedback on their samples, and whether consent could be truly informed when the future use of samples remains uncertain. These issues are particularly pertinent given the proposal by the Medical Research Council and the Wellcome Trust to establish the UK Population Biomedical Collection.

Our study is guided by the fact that little is known about the views of those who have actually been asked to participate in a genetic database. To assist future discussions on the ethical implications of genetic databases, there is a need to know the views and values of such people and, in particular, their reasons for either participating, or refusing to participate, in such a collection. For example, the extent to which non-participation is attributable to primarily local

factors or to other, more widely held, concerns, and the extent to which non-participation represents a distinct stance to that of participation, are matters for empirical investigation. The NCCGP provides a rare opportunity to study such a population.

We shall conduct a prospective, interview-based, qualitative study. Analysis will be directed towards answering the key research question, what is the repertoire of perceptions, concerns, views, and understandings, that women who have been asked to donate tissue samples to the NCCGP consider, as part of the process of deciding whether to participate or not? Attention will be given to see if there are any differences between participants and non-participants. A brief telephone survey will help to compare and contextualise those recruited to the in depth interview with the broader NCCGP population.

The study will last sixteen months and aims to provide:

- (I) feedback to the NCCGP on the effectiveness and public perception of its procedures and purpose;
- (II) evidence to inform debates on potential donors' attitudes to genetic databases;
- (III) empirical insight into lay uses and understandings of key ethical concepts such as 'informed consent' and 'trust';
- (IV) identification of those issues that are specific to lay perceptions of particular genetic databases and those that are shared across a number of such projects.

IV

Empowering citizens to debate science

A key aim of PEALS work is to enable diverse publics to understand and debate the new genetics. The starting point in any discussion about a dialogue between science and the public is that it should be a two-way process. Every citizen, whatever their educational or professional background, comes with their own knowledge and experience. Scientists wishing to promote the public understanding of science are most likely to succeed if they attempt a mutually educative dialogue with non-scientists. As well as our outreach meetings and talks, 2001 saw the appointment of Dr Tom Wakeford on a two-year project for the Joseph Rowntree Charitable Trust on Do-it-yourself Citizens Juries, which we describe below.

The DIY Citizens Juries project, funded by the Joseph Rowntree Charitable Trust aims to work with communities in the North East with the aim of holding a citizens jury that ordinary people, rather than experts, have designed and co-ordinated.

to interrogate them, and a facilitator who ensures balanced debate.

The right for a citizen accused of a crime to be tried by twelve of his or her fellow citizens was laid down in the Magna Carta. The symbolism of a jury handing out a verdict on an issue of public importance seems to have been widespread since before the Industrial Revolution, especially during the food riots of late 18th century England and the Luddite movement of the 1810s. However, it was not until the 1970s that the method of formally picking 12 or so people at random and asking them to discuss issues of public policy began to be used. By the 1990s however, the use of citizens' juries and associated methods such as consensus conferences and scenario workshops were becoming widespread. The procedure is similar to a legal jury except without a judge, lawyers or an accused person. Having heard evidence from various

Past citizens' juries

- Institute for Public Policy Research & Health Authorities
A series of juries was organised in the Midlands to discuss decisions that have to be made in hospitals regarding policy issues for local health authorities such as what treatments get priority for funding.
- Lancashire County Council - Waste Strategy
This was to allow Lancashire citizens to discuss the waste management strategy for the county, including landfill and recycling policies
- Consumers' Association - Food & Agriculture
This asked jurors in Brighton to interrogate food experts about the way our food is grown, distributed, labelled and sold, including a special focus on GM food, and the role of supermarkets.

A citizens' jury is a means of providing concerned citizens with information that allows them to develop arguments to influence those with power over their lives. They are based on the conviction that non-specialists can make informed and important recommendations on issues that concern the current and future well-being of their fellow citizens. All that is required for people to be able to make those recommendations is: clearly presented information from a number of people and perspectives, an opportunity

different perspectives, and requesting additional evidence if necessary, the jury draw up a set of conclusions rather than a guilty / not-guilty verdict.

In contrast to focus groups and questionnaires, citizens' juries are meant to empower citizens to reach their own conclusions based on a range of evidence, and influence decision makers to change policies for the common good. Most citizens' juries in the past have been relatively top-down affairs, with the

sponsoring organisation deciding on the subject of the jury, the witnesses who will be heard, and what will be done with the conclusions. The unique feature of the PEALS project is that citizens themselves decide all these things, enabling them to have much more control of the process and ownership of the outcome. This is why we call it a DIY citizens' jury, because it aims to show that anyone, not just councils, companies or development workers, can organise one of these processes.

The project only began in September 2001, but we have already talked to many local groups about the project, and received a lot of useful feedback and ideas for policy issues on which to focus. We are now at the stage of narrowing down these ideas into a couple of possible candidates for juries, and assembling a group of local organisations that would help co-ordinate the process.

The pilot DIY jury is intended to act as a catalyst for communities throughout the UK and abroad. The key to making DIY juries more widespread will be the development of a video (developed with Swingbridge Film and Video), and a handbook. This would involve jury members and community groups describing their experiences, so that other groups feel they were able to set up their own DIY jury. Watch this space!



*Dr Tom Wakeford
(photo: Simon Veit-Wilson)*

V

Weekend Away for a Bigger Voice

“Townies to debate farming’s future: Residents of inner city council estates are to contribute to a debate about the future of farming, to the bemusement of farmers.”

Financial Times, Aug 27, 2001

Immediately on appointment, Tom was part of a team that carried out another piece of research for the National Consumer Council in collaboration with PEALS. The *Weekend Away for a Bigger Voice* workshops were held in both Tyneside and in the South West of England. Following a series of crises in British farming and given the health and safety scares relating to food over the past few years, the Government had announced in August 2001 the setting up a Commission to look at how food and farming should be reformed. The ministry now responsible for food and farming (formerly MAFF, now DEFRA), along with the Food Standards Agency (FSA), allocated a small budget to find out what people think, especially those whose views are normally ignored. The work was coordinated by the National Consumer Council, who put the project out to tender, from which a collaboration between PEALS and the citizen empowerment consultancy The Core Group emerged as the successful bid.

In each workshop of a day and a half, our aim was to allow people to express their views on a wide range of issues related to food and farming. The issues covered partly depended on the concerns voiced by the workshop participants, and touched on areas such as:

- What do we want to see happen in terms of the food we eat, how much we pay, where we get it from and how it is produced?
- Food safety, quality, health, environmental and animal welfare issues.
- Money and the cost of food.
- Access and transport issues.

We were asked to draw mainly on the views of those whose income is less than half the average national wage. But the amount of money people have is not the only way in which they can be excluded from getting the food they want. People’s mobility, access to information, proximity to food outlets and ability to choose the food they want are all factors influencing how much control people have over their own food. Our aim was to include people who otherwise would not have had a say.

We were not expecting people to be “experts” on food or farming - all that was required was that they were happy to think about their own experience of buying and eating food. No special skills were needed in debating or public speaking. We used a variety of ways of enabling people to analyse their own experience and formulate their views, including maps and other visual methods. By the end of the workshop, we hoped that participants would have had the chance to get to know each other and the facilitators, feel comfortable about talking about their views to the rest of the group, and put together a list of recommendations for policy makers.

The participatory process involved in the *Weekend Away for a Bigger Voice Workshops on the Future of Food and Farming* was just as important as the policy recommendations on the future of food and farming reached by the participants. Many people arrived not knowing whether they had anything useful to say and went away having acknowledged that they had important contributions to make, either through the workshop, via their local community groups, or as individuals.

The sophisticated analysis of complex issues undertaken by most participants demonstrates that they are capable of far more than mere responses to questions from market researchers. In many ways, the depth of engagement and insight they achieved went beyond that possible using opinion polls, questionnaires, public meetings, internet consultations and most focus groups. The process achieved its aim of being not only participatory but empowering to the citizens it involved. It did not merely gather people’s views, but allowed people to recognise their democratic right and innate capacity to participate in decisions.

There was a significant diversity of opinion among participants. However this did not divide along the urban/rural axis that is commonly portrayed. People living in both areas wished to understand more about the situation of those living in the other area. A mutually educative dialogue was possible during the workshop and led to the rich analysis and wide-ranging conclusions contained in the project report, which is available from the National Consumer Council or from PEALS.

OUTREACH ACTIVITIES

Over 2000-1, PEALS continued to organise events to enable the public to contribute to bioethical debates and policy development.

Human Genetics Commission visit



*Baroness Helena Kennedy QC and Professor Alexander McCall-Smith
(photo courtesy of Human Genetics Commission)*

In November 2000, we hosted the visit of the Human Genetics Commission, in association with the International Centre for Life. This was part of the HGC's work to promote its consultation document on genetic information, entitled *Whose Hands On Your Genes?*. It was the organisation's first public meeting outside London. Following a press conference to launch the document, the Commissioners together with 200 local secondary school pupils toured the Life Interactive World exhibition, and took part in a series of discussions hosted by Professor John Burn. In the evening, 200 members of the public came to meet the Commission and to discuss genetic information and genetic privacy. The event kicked off with a light hearted introductory debate between Professor Burn and Dr Tom Shakespeare, and followed with small

group discussion, ending with a panel. Feedback from participants, and the HGC team, was very positive. The initial report from the consultation is now available on the HGC website at www.hgc.gov.uk

Rethinking Age

In April 2001, to coincide with the Goals of Ageing Research symposium and Professor Kirkwood's Reith Lecture, PEALS coordinated a related series of outreach events under the banner of *Rethinking Age*. These included 'All our days', an exhibition of photographs and words by Sharon Bailey and Pascale Konyn; a performance of Julia Darling's play *Venetia Love Goes Netting* by the actor Madeleine Moffat, and a day conference organised by Better Government for Older People and the Centre for Care of Older People at the University of Northumbria.

Frontiers of Science

During 2001 we organised three meetings under the headline of *Frontiers of Science* in collaboration with the University of Newcastle Public Lectures team:

- In June, we held an event on the science and ethics of behavioural genetics, addressed by Professor Steven Rose (Open University) and Dr Thalia Eley (Institute of Psychiatry, London). This meeting coincided with the Nuffield Council on Bioethics consultation on behavioural genetics, and attendees were given a copy of



*Professors Alan Holland, Erica Haines and John Burn
(photo: Simon Veit-Wilson)*

the document so that they could submit their views.

- In September, we held an event on the science and ethics of stem cell research, addressed by Professor Peter Andrews (University of Sheffield) and Dr Michael Antoniou (Kings, London). This coincided with the House of Lords Select Committee on Science and Technology investigation of embryonic stem cell research.
- In October, we held an event on the science and ethics of mouse genetics, addressed by Professor John Burn and Professor Alan Holland (Lancaster University). This coincided with the opening of the new Institute of Human Genetics, which has been granted £2 million by the William Leech Charitable Trust to develop mouse genetic research.

Other talks

As well as these flagship PEALS activities, we contributed speakers to many other organisations. For example, in July, the local branch of the British Association for the Advancement of Science held their

engagement network coordinated by Dr David Knight, of Newcastle University's Centre for Lifelong Learning.

Throughout the year, we have given presentations to diverse groups in the region, including schools and colleges, University of the Third Age branches, Soroptomist International, Women's Institutes. Presentations to national and international scientific and professional conferences are listed in the appendix.

Working with faith communities

In October 2000, PEALS held a day conference entitled *Assisted Creation?*, which brought together both clergy and laity from the main Christian denominations in the region. The event was a response to the increasing need for pastoral workers to be aware of the clinical aspects of genetics and reproductive technology. Keynote addresses were provided by the ethicists Professor Alastair Campbell (Bristol) and Agneta Sutton, and the clinicians Dr Judith Goodship (Genetics) and Dr Jane Stewart (Reproductive Medicine). Dr Robert Song (Theology, Durham) and Dr Tom Shakespeare led small group discussions and a panel debate. The closing address was given by Bishop Ambrose Griffiths OSB.



*Dr Tom Shakespeare talking with students
(photo: Simon Veit-Wilson)*

annual public symposium. Together with local scientists Dr Kirsten Wolff and Dr Helen Hooper, Professor John Burn and Dr Tom Shakespeare contributed to the debates about plant genetics, animal genetics and stem cell research. The Curtis Auditorium was packed with local sixth formers and members of the public to hear these presentations and take part in discussion. Our collaboration with the British Association will continue in 2002, as we participate in the science

Several projects resulted from this initial event:

In summer 2001, Reverend Andrew Palmer, a Methodist Minister from Cramlington, spent three months on a sabbatical placement with PEALS. As well as participating in PEALS events, Andrew developed a website on genetics and ethics for use by church members and others wanting to explore the issues.

In June 2001, Dr Tom Shakespeare ran a day training event for the local college of healthcare chaplains on genetics and disability, in South Shields. This enabled participants to discuss the social and ethical dilemmas of genetic screening, gene therapy and genetic information, as well as new ways of thinking about disabled people and the social relations of care.

In autumn 2001, PEALS writer in residence Carol Clewlow conducted a series of writing workshops with members of the congregation at St Nicholas' Cathedral in Newcastle. This has also led her into further work using creative writing with the Church of England.

Using creative writing in science and medicine

Our writer in residence scheme was funded by the Royal Literary Fund for three years. Carol Clewlow was appointed to the first 18-month residency in September 2000; in February 2002, the second writer will take over. The PEALS writer in residence spends half her time working with PEALS and the International Centre for Life, and half her time working with staff and students at the Newcastle University Medical School.



*Carol Clewlow at Walker Technology College
(photo: Simon Veit-Wilson)*

PEALS work concentrated in its first phase on imaginative writing workshops, day schools and projects, with a full diary of events in schools, at writers groups and for other organisations such as the Women's Institute, all using themes from genetics. Such workshops have not only covered the region geographically (from Wooler in the north to Teesside in the south) but have also ranged between a class of six-year olds and members of writing groups in their eighties. During the workshops, participants have been introduced to the major themes in the genetics debate, the work of PEALS, using both a background of current popular scientific writing and everything from William Shakespeare to Lewis Carroll. A large amount of writing produced by participants has now been collected and it is hoped that a selection will be published, either in an anthology or via the website. An example of a poem produced by a workshop participant is included below.

Initially workshops and day schools were run on a one-off basis. However for the second phase it has been decided to concentrate on two longer projects, one of these at Walker Technology College in Newcastle where eight first year AS level biology students are

taking part in an after-school imaginative writing project, the other in conjunction with the Newcastle Diocese, involving both clergy and lay people, at Newcastle Cathedral.

A further project established this autumn is that of a Science Fact and Fiction Club designed to bring published writers and scientists together, to explore ways that science is represented in different media, ranging from journalism to popular science to novels.

The first event, featuring novelist Andrew Crumey (author of *Mr Mee*) and Theoretical Physicist Professor Milan Jaros (University of Newcastle) in conversation was held at the Literary and Philosophical Society in Newcastle in October 2001.

Medical School activities have concentrated in two areas, both student selected study modules. The first, Imaginative Writing, was initiated by Carol Clewlow as a first for the Medical School. The second, the Novels, Poetry and Medicine module, was initiated by Richard Thomson, Professor of Public Health, and is in its third year. The response in both areas, from staff and students alike, has been enthusiastic.

The Imaginative Writing module featured two weekly workshops and weekly one-to-one sessions resulting in some serious high quality writing being produced and given a public reading. Three students opted to present formal assessments on the subject of medical humanities using their experience on the course. The Novels, Poetry and Medicine module featured a dozen sessions by the writer-in-residence, including those on the set text, and a series of sessions on a range of literary topics from the writer's perspective. As a result of the residency, a successful monthly lunch-time reading group has also been formed at the medical school.

Last, but certainly not least, is a new project called Operating Theatre, which has already received funding from Northern Arts, and in which the writer in residence is involved. The project is designed to bring practitioners in the arts and health care professionals together in a series of workshops which will produce work both of dramatic integrity and illuminating in terms of medical practice. Six weekly workshops will be held at Live Theatre and it is hoped that the work produced will be subject to public performance, for an invited audience of medical professionals, as a result of weekend long workshop in New Year 2002.

Who Am I?

Chromosome and cell and gene
Recombination - what does that mean?
I was made with all of these
Though could somebody tell me please
If I am purely DNA
Why I look forward to watching a play
Or eating lunch out with a friend
And hoping the day will never end?

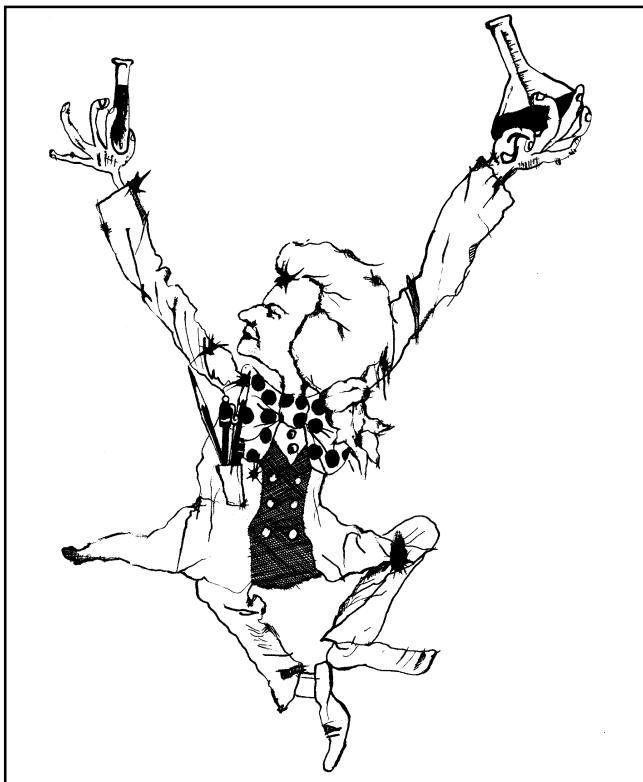
If my genes are the Code of Codes
Why do I like frogs and toads?
And visiting Scotland, Edinburgh, Fife?
Surely that's not the Secret of Life

I am all these things and more
Though I've no way of knowing what came before
If my Life is one big Book
I wish that I had had a look.
That literature I would have read
(No use reading it once I'm dead)
And so I state categorically
That I'm not just DNA, I'm ME!

Nova-Jane Acres, Guide Post, Northumberland.

Sci-art collaborations

After discussion with the staff of Northern Sinfonia and North Music Trust, PEALS and the Northern Sinfonia promoted a pilot collaboration called *Mozart in a Labcoat* at the International Centre for Life. Dr Tom Shakespeare and Andrew Scott, education manager of North Music Trust, held a mock debate about science versus music, using it as an opportunity to explore ideas about the benefits of music in learning (the 'Mozart effect') and whether musical talent was innate or learned. Following discussion with the audience, the evening concluded with a performance of the Mozart Wind Serenade by members of the Northern Sinfonia. This co-promotion was a good way of informing Northern Sinfonia audiences about PEALS work, and PEALS audiences about Northern Sinfonia. The two organisations will collaborate again during 2002.



(cartoon: Peter McGlynn)

Locus+ is a curatorial team who are involved in installations and other public art regionally, nationally and internationally. During 2000 they presented ECHO, an artwork by Wendy Kirkup which explores the ultrasound technology. This event took the form of projection of edited ultrasound footage on a large screen at the International Centre for Life, simultaneously with an identical projection at the Hunterian

Museum, Glasgow, where Wendy had spent a residency. Dr Tom Shakespeare was involved with the interpretative side of this project, contributing an essay on diagnostic ultrasound to the ECHO catalogue, and interviewing Wendy for a video about the artwork. Copies of both are available from PEALS for schools or others with an interest in sci-art.

REPRO: a sci-art project

Our first major sci-art project was a collaboration with Northern Print Studio and Newcastle's Hatton Gallery, culminating in an exhibition in April/May 2001. Thanks to funding from the Wellcome Trust, COPUS and the Regional Arts Lottery, we were able to appoint four artists - Catherine Bertola, Sarah Don, Antoinette Hachler and James Hutchinson - to make new print-based work responding to genetics and reproductive technology.

The participants were briefed in the scientific and ethical aspects by Dr Tom Shakespeare, Dr Duncan Borthwick (Applied Imaging International) and other colleagues. Visual imagery was supplied by the Wellcome Trust Medical Photographic Library and Applied Imaging International. Popular science books were made available. All the artists were positive about their involvement with the project and the subsequent opportunities which opened up for them, as well as by the project's influence on their work. For example, Catherine Bertola said: "the project forced me to look at the subject in a very different way which resulted in work that is completely new in direction - I've learned a great deal both professionally and personally about my work." Hachler was inspired to apply for a Wellcome Trust artist-in-residence award.

Four schools were involved in the project. Each was paired with an artist, who spent time working with pupils. School groups also visited the Northern Print Studio for workshops. Dr Tom Shakespeare gave introductory talks to the school pupils on the Human Genome Project and the social and ethical dilemmas of genetic information. A teachers' pack about the artistic and scientific aspects of the project was developed and circulated to teachers. Feedback from participating schools was excellent. For example, teacher Christine Houghton from St Mary's commented: "All students have raised their grade at GCSE significantly by being included in the project."

The gallery exhibition comprised three elements: work by the artists, work by the school pupils, and a slide presentation of images from the Wellcome Trust Medical Photographic Library and other sources, supplemented by text about genetics and reproductive technology. The launch event for the exhibition was outstandingly successful with 400 members of the public attending, many of them scientists and teachers new to the gallery. Dr Matt Ridley and Dr Tom Shakespeare made presentations about the Human Genome Project and Sci-Art. During the duration of the exhibition there were workshops for schools (see opposite) and a lunchtime talk by Dr Tom

Shakespeare, which was attended by about 50 members of the general public. Acting curator Andrew Heard commented that the quality of the exhibition surpassed his expectations and he was very pleased with the result of both the artists and the schools work. 2,566 members of the public visited the REPRO exhibition.

In 2002-3, PEALS will again be collaborating with Northern Print Studio, this time on a project called *Memory and Forgetting*, which will involve similar approaches to REPRO, but over greater time and with enhanced collaboration between artists and scientists.

FUTURE PLANS

This annual report shows the stability which PEALS has achieved, through the assured five year funding package provided by the William Leech Charitable Trust and our three partner organisations, as well as the new Director of Research post funded by the Northern Rock Foundation. Appointing to this post will be the priority in the first months of 2002.

We are one of the partners in the Northern Genetics Knowledge Park bid which is one of six bids being considered by the Department of Health and the Department of Trade and Industry. If successful, this will lead to the appointment of a PEALS Director of Learning, who would be responsible for developing our post-graduate and professional training courses, in association with the Institute of Human Genetics. Our aim is to provide taught MA courses in Bioethics and Law, and in Genetic Counselling. We will be working towards offering these courses from 2003 for the remainder of the current year.

Plans for two other posts at a more junior level are also advanced. A bid to the Committee on Public Understanding of Science to employ a community education worker for 2 years will enable us to engage socially excluded groups in public understanding of science and bioethics. We are talking to arts and cultural agencies about a bid to employ a Sci-Art officer, who would organise our own events, as well as

working with major arts organisations in the North East to promote science-related commissioning and programming. This could contribute to the Newcastle-Gateshead bid for European City of Culture status in 2008.

Research activities and research bids will continue in 2002. We are collaborators on several applications to the Economic and Social Research Council Post-Genomic Research Initiative, and this may lead to research projects at the Universities of Newcastle and Durham. We are making several research bids to the Wellcome Trust's Medicine in Society programme, to conduct projects on stem cell research ethics, and on everyday ethical decision making, which would also result in research associates joining the team. We continue to work with clinical colleagues on bids which may result in short term clinical fellowships or joint research applications.

We had two staff members at the end of our first year, and now have four at the end of our second. We aim to double again by the end of our third, with a commensurate increase in our research and outreach activities, and the addition of a teaching strand to our work. We believe that our unique combination of innovative public engagement projects and high quality social and ethical research will ensure we play a major part in the genetics future of the region and the United Kingdom as a whole.



Reproductive Technologies
(cartoon: Kate Charlesworth)

Appendix One:

PEALS Events during 2000-1

The following seminars and café scientifiques were promoted during the year:

2000

Monday October 16th: café scientifique with George Monbiot, 'The corporate take over of science'. A very well attended event with the impassioned Guardian columnist and author of *The Captive State*.

Monday November 6th: research seminar with Dr Mariam Fraser (Goldsmiths): 'The nature of Prozac'.

Tuesday November 21st: café scientifique with Tom Kirkwood, 'The lure of a longer life'. A fascinating talk about the science of ageing, and a preview of his Reith Lecture series from the University of Newcastle Professor of Gerontology, and author of *Time of Our Lives: the Science of Human Ageing*.

Wednesday November 22nd: research seminar with Professor Mats Hansson (Ethics in Biomedicine, Uppsala) on 'Multidisciplinary approaches in Biomedical Ethics - with a special focus on the issue of biobanking.' Professor Hansson's visit marked a further development in our growing link with his Research Institute.

Wednesday December 6th: research seminar with Professor Erica Haines (Sociology, Newcastle) on 'Families and identities and assisted conception', examining the social and cultural consequences of 'cosmopolitan conceptions', in which the provision of sperm eggs, pregnancy, clinical care and birth are spread over a number of different countries.

2001

Monday January 15th: café scientifique with Ian Fells, 'Clean energy and the greenhouse effect'. Another excellent presentation from Newcastle's Professor of Energy Conversion, who is also a trustee of the International Centre for Life.

Monday February 19th: café scientifique with Anita Quye, 'Dragons' blood and celluloid'. A talk from an Analytical Research Chemist at the National Museums of Scotland, Edinburgh exploring conservation and other matters relating to historical artefacts.

Monday March 12th: research seminar with Dr Tom Ling (Anglia Polytechnic University) on 'Public participation in genetic policy'.

Monday March 19th: café scientifique with Gabriel Dover: 'Evolution: beyond Darwin'. The Professor of Evolutionary Genetics at Leicester University and author of *Dear Mr Darwin* confounded his critics and entertained his friends with a wide-ranging talk.

Monday March 26th: research seminar with Dr Robert Song (Theology, Durham) on 'The necessity of technology? The case of human genetic engineering'.

Monday May 21st: families: café scientifique with Dr Francesca Happé: 'Autism: psychological deficit or psychological style?'. This event was very well attended by of people with autism and others interested in hearing what this world renowned expert from London's Institute of Psychiatry had to say.

Wednesday May 30th: research seminar with Professor Angus Macdonald (Actuarial Statistics, Heriot-Watt University) on 'Genetics and Insurance: Costing Unfairness?'

Thursday June 14th: research seminar with Dr Jackie Leach Scully (University of Basle) on 'Genetic choices and religious values'. Dr Tom Shakespeare and Professor Erica Haines have both given presentations with Dr Scully and her colleague Professor Christoph Rehman-Sutter in Switzerland, and we will develop joint research projects with their team in 2002-3.

Monday June 18th: café scientifique with Tim Birkhead: 'Promiscuity'. Sheffield University's charismatic Professor of Behaviour and Ecology presented a fascinating talk, and the subsequent discussion was enlivened by the participation of evolutionary biologists Matt Ridley and Sarah Hrdy.

Monday June 25th: research seminar with Dr Nina Hallowell (Royal Marsden) on 'Difficult dilemmas: living with the genetic risk of ovarian cancer.'

Monday July 16th: café scientifique with Peter Coles: 'Dark matter and the fate of the Universe'. A wide ranging talk from Nottingham University's Professor of Astrophysics, taking in life, the universe and everything.

Monday September 17th: café scientifique with Kenan Malik: 'Why a mind is not a machine'. Psychologist and neuroscientist turned author and journalist jostled with his audience to challenge mechanistic ideas about minds.

Appendix Two:

New extended funding secured during 2000-2001

Director of Outreach (over five years from Oct 01)	William Leech Charitable Trust	250,000
Director of Research (over five years from 2002)	Northern Rock Foundation	300,000
REPRO Project	Northern Arts Regional Arts Lottery	4350
REPRO Project	Wellcome Trust Sci-Art start-up grant	5000
REPRO Project	Committee on Public Understanding of Science	3000
Cumbria genetic databases (PI: Professor Erica Haines)	Wellcome Trust Medicine in Society	73003
DIY citizens juries (PI: Dr Tom Shakespeare)	Joseph Rowntree Charitable Trust	67384
Youth work (PI: Dr Sarah Banks)	Wellcome Trust	19075
Ethics of ageing research	Wellcome Trust seminar grant	2500
Total funding secured		£724,312

PEALS is also a collaborator on two other Wellcome Trust funded projects:

DEMOCS	with New Economics Foundation and others	67,446
Café Scientifique	with Duncan Dallas	173,700

Appendix Three:

PEALS participants' relevant research and policy outputs 2000-2001

Dr Sarah Banks (Community and Youth Work Studies Unit, Department of Sociology & Social Policy, University of Durham)

Publications

- 2000 'Principles, rules and qualities: an ethical framework for youth work', *International Journal of Youth and Adolescence*, vol. 9. pp. 61-78 [with Umme Imam].
- 2001 A study of the present and future capacity of youth work services to engage with Wellcome Trust's Medicine in Society programme, University of Durham, 2001 [with Paul Burlison and Tom Shakespeare].
- 2001 'Professional values in informal education work' in L Deer Richardson and M. Wolfe (eds), *Informal Education with Young People: Principles and Practice*, London, Routledge.
- 2001 'Etica em Fragmentos' [Ethics in Fragments] in H. Mouro and D. Simies (eds), *Anos de Serviço Social*, Coimbra, Portugal Quarteto, pp. 101-124
- 2001 'Ethical dilemmas for the social professions: work in progress with social education students in Europe', *European Journal of Social Education*, No. 1, pp. 1-16.
- 2001 *Ethics and Values in Social work*, 2nd edition, London, Palgrave.

Presentations

- November 'The European Social Ethics Project: An Overview', FESET (European Social Educator Training) Seminar on 'Ethics and Training', Paris.
- June 'From Oaths to Rulebooks: a critical examination of codes of ethics for the social professions', AIEJI (International Association of Social Educators) World Congress on 'Ethics and quality of socio-educational action' in Barcelona.
- July 'Accountability and professional ethics', ERSC Clinical Governance Seminar, Leeds.

Professor John Burn (Department of Human Genetics, University of Newcastle University)

Member of Chief Medical Officer's Expert Group on Therapeutic Cloning
Member of Human Genetics Commission
Member of Advisory Group for Department of Health Genetics Green Paper
Member of Royal College of Physicians Ethics Committee

Presentations

- October American Society of Human Genetics (Philadelphia)
- November British Paediatric Cardiac Association Annual Meeting
Macmillan Cancer Relief
- February British Fertility Society Ethics Day
- May World Congress on Human Genetics (Vienna)
- June European Federation of Internal Medicine

Professor Sir Kenneth Calman (Vice-chancellor, University of Durham)

Chairs the Nuffield Council on Bioethics Working Party on the ethics of healthcare-related research in developing countries.

Publications

- 2000 Postgraduate specialist training and continuing professional development, *Medical Teacher*, 22, pp448-51.
- 2000 *Storytelling, Humour and Learning in Medicine*, The Eighth Queen Mother Fellowship, London, The Stationery Office.
- 2001 Issues of risk: this unique opportunity, *J Royal Coll Gen Pract.* 51, pp 47-51.
- 2001 The language of risk: a question of trust, *Transfusion*, 41, pp26-28.
- 2001 A study of storytelling, humour and learning in medicine, *Clin. Medicine*, 1, pp 27-29.
- 2001 Works in theory but not in practice? The role of the precautionary principle in public health policy, *Public Administration*, 79, pp 185-204.

Dr Fiona Douglas (Consultant in Clinical Genetics, Northern Genetics Service).

Presentation

- September Consent and Confidentiality: the issues that affect clinical genetics and the achievement of good practice in this context, British Human Genetics Conference, York.

Professor Erica Haines (Department of Sociology, University of Newcastle)

Serves as international referee on Swedish National Programme for Ethical, Legal and Social Aspects of Genetics.

Publications

- 2000 Spallone, P., Wilkie, T., Ettore, E., Haines, E., Shakespeare, T. and Stacey, M. Putting sociology on the bioethics map, in Eldridge, J. et al, eds. *For Sociology*, Basingstoke, BSA/Macmillan
- 2000 Haines, E. and Weiner, K. 'Everyone has a daddy, don't they?' Lesbians' use of donor insemination, *Sociology of Health and Illness*, 22 (4):477-499
- 2000 Haines, E. Locating and dislocating the child. Proceedings of the 'Habitus 2000: a Sense of Place' conference, Perth, Australia

Presentations

- August Access and anonymity: direct and indirect regulation of family formation in reproductive technologies, Regulating Reproductive Technologies Forum, Melbourne.
- September Bringing sociology into bioethics, EURESCO Conference on bioethics, Davos, Switzerland.

Professor Tom Kirkwood (Institute of Ageing and Health)

See full report at www.ncl.ac.uk/gerontology

Dr Janice McLaughlin (Department of Sociology, University of Newcastle)

Publication

2001 EBM and Risk: Discursive resources in healthcare, *Journal of Management in Medicine*, Vol 5, No 4&5: 352-363

Professor Holger Maehle (Department of Philosophy, University of Durham)

Publications

2000 'Assault and Battery, or Legitimate Treatment?' German Legal Debates on the Status of Medical Interventions without Consent, c. 1890-1914', *Gesnerus* 57, pp 206-221.

2001 'Zwischen medizinischem Paternalismus und Patientenautonomie: Albert Molls "Aerztliche Ethik" (1902) im historischen Kontext', in A. Frewer and J. N. Neumann (eds), *Medizingeschichte und Medizinethik*, Frankfurt/Main and New York, Campus, pp. 44-56.

Dr Tom Shakespeare (Department of Sociology, University of Newcastle)

Dr Tom Shakespeare sits on the Nuffield Council on Bioethics Working Party on genetics and human behaviour and the Newcastle Hospitals NHS Trust Clinical Ethics Committee.

Publications

2000 Arguing about disability and genetics, *Interaction*, pp 11- 14

2001 Making the difference: disability, politics, recognition, in G. Albrecht et al, *The Handbook of Disability Studies*, London, Sage. [With N. Watson]

2001 The social model of disability: an outdated ideology? in S. Barnartt and B. Altman, eds, *Exploring Theories and Expanding Methodologies: where are we and where do we need to go?*, Oxford, JAI, [with N. Watson]

Presentations

January Institute of Public Policy, University of Maryland (Washington DC)
School of Public Health, University of Columbia (New York).

February Disability with Attitude Conference, Sydney.
Department of Social Work, University of Queensland, Brisbane.
Murdoch Research Institute, Royal Children's Hospital, Melbourne.
Institute of Disability Studies, Deakin University, Melbourne.

March 'Is Genetic Technology Getting Out of Hand?' Conference, Uniting Church, Sydney
Wenkenhof Dialogue on Disclosure Dilemmas (University of Basle)

April National Gallery, Helsinki, Finland.

May Forum on Learning Disability: Prevention and Disability (Royal Society of Medicine, London)

June Stem cell research Conference (Royal Society, London)

Association of Research Ethics Committees Conference: Children in Research (Newcastle)

July Marie Curie Fellowship Association: The Impact of Genetics on Science and Society (University College Dublin)

July Disability Rights Commission: The Implications of Genetic Developments for Disabled People (London)

Sept Launch day for Gateshead Self-Help Group Network (Disability Gateshead)

Dr Robert Simpson (Department of Anthropology, University of Durham)

Dr Robert Simpson was a tutor on the 2001 Wellcome Trust Genetics and Society summer school at Hinxton Hall.

Publications

- 2000 Imagined genetic communities: ethnicity and essentialism in the twenty-first century, *Anthropology Today*, vol 16 no 3, pp 3-5.
- 2001 Making bad deaths good: the kinship consequences of posthumous conception, *Journal of the Royal Anthropological Society*, vol 7, no 1 pp 1-18.
- 2001 Ethical regulation and the new reproductive technologies in Sri Lanka: perspectives of Ethics Committee members, *Ceylon Medical Journal*, vol. 46, no 2, pp 54-57.

Dr Robert Song (Department of Theology, University of Durham)

Presentations

- March The Necessity of Technology: The Case of Human Genetic Engineering, Centre for the Study of Christianity and Culture, Regent's Park College, Oxford.
- October What Are the Moral Limits of Embryo and Embryonic Stem Cell Research?, Colloquy on Stem Cell Research, Centre for Ethics and Values, Garrett-Evangelical Theological Seminary, Evanston, Illinois.

Revd Bryan Vernon (Department of Primary Care, University of Newcastle Medical School)

Chair of West End Health Resource Centre. Member of Newcastle Hospitals NHS Trust Clinical Ethics Advisory Group.

Presentation

- October 'Helping Newcastle Medical Students to make mistakes better', Winnipeg, [with Lucy Ward]

Dr Tom Wakeford (Department of Sociology, University of Newcastle)

Tom is a columnist for the Guardian Online (<http://education.guardian.co.uk/higher/>).

Publications

- 2001 Bringing Science Down to Earth, *Science and Public Affairs*, October (www.the-ba.net/the-ba/page.asp)
- Citizens juries on GMOs and farming futures in India, *LEISA Magazine*, vol. 17, no 4 27-30 (<http://www.ileia.org/2/17-4/27-30.PDF>)

Presentation

- September Weekend Away for a Bigger Voice on the Future of Food and Farming, Washington, Co. Durham (National Consumer Council - www.ncc.org.uk/pubs/pdf/feeding_in.pdf)