

PEALS ANNUAL REVIEW 2006



foreword

Erica Haimes
Executive Director

Whether in research or teaching, co-inquiry or policy impact, PEALS has had a tremendous year. Thanks to the many people who have been prepared to show faith in us and in our track record, we have managed to overcome numerous potential obstacles to make 2006 arguably our most successful year yet. We have secured the long-term appointments of our core senior staff: myself as Executive Director, Janice McLaughlin as Director of Research, Simon Woods as Director of Teaching and Learning, and Tom Wakeford as Director of Co-Inquiry and Public Engagement.



Professor Erica Haimes with visitors from Seoul National University, Korea

We have several people and organisations to thank for new and renewed investment: first of all, the William Leech Charitable Trust and the Northern Rock Foundation for awarding us two further major grants to ensure the rigorous ethical scrutiny of developments in the life sciences through the processes of co-inquiry and public engagement; second, Newcastle University for underpinning the senior academic appointments listed above; third, Durham University and the Centre for Life (CfL) for assisting us with running costs. None of our success would be possible without these contributions and we thank our colleagues and partners for continuing to support us in this and in many other ways.

Such support and investment is valuable not just for the individual posts created but also for the development of PEALS as a whole. Most crucially the investment in these posts gives us the time to think more widely and imaginatively about our goals and ambitions. We have made an immediate start on this, drafting five year strategies for each of our main strands of work (Research, Teaching and Learning, and Co-Inquiry). These strategies and detailed implementation plans for the first year of each were approved by our Advisory Board in October 2006 so we now have frameworks within which to develop our goals, to prioritise the many opportunities that come our way, and to retain flexibility to develop as new possibilities arise.

As many of our readers will know, success often brings its own challenges and we have had to deal with some of these over the past year as well. Probably the most important has been the need to find new accommodation as we had outgrown our current space in the CfL. There was understandable concern

that we might lose something distinctive in changing location but we have moved only 5 minutes walk away from CfL and we are very confident that our personal and professional links are strong enough to withstand that degree of separation (just as we sustain working relationships with colleagues across Europe, India, the USA and Australia). An additional benefit of these challenges is that our three partner institutions (Durham and Newcastle Universities and the CfL) have all reaffirmed their commitment to the partnership: indeed that partnership has been reinvigorated as we seek new ways of working together and new ways of adding value to each of our individual portfolios.

Last but not least, I am very pleased to be able to greet several new (and in some cases, returning) colleagues: Janice McLaughlin joined us in January 2006 as our Director of Research; Tom Martin joined us in May to take up a new secretarial post; Jackie Leach Scully both left us and rejoined us as she was appointed to Senior Lecturer in Sociology at Newcastle University in September; Lisa Matthews rejoined us in October to conduct a public engagement programme around stem cell research; and Michael Barr, having taken up a post at the London School of Economics several years ago, will return to us in January 2007, being appointed to our new RCUK Fellowship to work on biosecurity issues. We warmly welcome all our new and returning colleagues, while also celebrating the contributions of those with whom we have parted company. We also warmly thank all our funders and other colleagues for their continued support.

research and co-inquiry

Over the last year we have redoubled our efforts to increase the research activities made possible through our status as a partnership between Durham University, Newcastle University and the Centre for Life. We have also strengthened our international links via ongoing projects and new collaborations. We have used research away days to bring together PEALS colleagues with our partners, in order to debate the ways forward and identify new possibilities.

Over this past year we have paid particular attention to exploring interlinks between research and co-inquiry, facilitated by two key appointments; Janice McLaughlin as our Director of Research and Tom Wakeford as Director of Co-Inquiry and Public Engagement. Both Tom and Janice have a strong commitment to designing projects that involve citizens as active collaborators in the research process. Co-operative inquiry (or co-inquiry for short) is a way of working with people who share similar concerns and interests in order to understand our world, make sense of our lives and develop new and creative learning processes. It is also a framework that allows specialists and non-specialists to work together to learn how to act to achieve change on those issues that they may want to see change and find out how to do things better. Attempts to challenge this separation between analyst and subject often encounter major obstacles – cultural, methodological and financial. Tom and Janice are committed to addressing these challenges. In so doing they will add new dimensions to the research and public engagement programmes already well established in PEALS. We are committed to ensuring that all our work adds to the understanding of practitioners and policymakers and assist those parties in the exercising of their responsibilities: involving people from diverse backgrounds can only make such processes more robust and effective.

The beginning and end of life

Ethical dilemmas relating to new technologies and medical treatments can be scattered throughout people's lives. In the last year PEALS has continued to research those areas at or near the moment when an egg is fertilised at one end of this spectrum, and in the last years of life at the other.

Sex selection

Amniocentesis and ultrasound are well established technologies, used routinely to detect genetic abnormalities in the foetus. In areas where boys are apparently valued more highly than girls, these same techniques have led to widespread female foeticide. Research quoted by The Guardian newspaper suggested that in India alone 930,000 female foetuses are aborted every year. "Sex selection, ethics and public engagement", written by Jasber Singh and Simon Woods for the Life Genetics Knowledge Park has looked at how a new application of genetics – pre-implantation genetic diagnostics (whereby embryos resulting from in vitro fertilisation (IVF) procedures can be selected according to specified criteria before implantation) – can allow for embryos being chosen or discarded according to their sex. Whilst in some countries this may be used for family balancing (which in itself raises ethical questions), in others there are reports in the media that new biotechnologies are already making it easier to stop female embryos even being implanted in the womb. We are currently looking at how we can undertake research and co-inquiry to address these clinical and social practices.



Jasber Singh with Adam, the son of Janet Davies from the Blackburn citizens' jury



Rana Rafiqun Nessa describes her experience as a DIY citizens' jury member to the Network of European Foundations, Brussels

Talking with potential embryo donors

Women undergoing IVF may choose to donate embryos that are not implanted into the womb for stem cell and other types of research. Erica Haimes and Susan Dowdle have entered the final year of a Wellcome Trust study exploring this area. Dr Jacquelyne Luce left the project in April 2006 to take up a senior research post in Germany, though she retains a link with the project. Interviews with people going through IVF treatment, who have been asked to donate un-transferred embryos, have been completed and are now undergoing systematic analysis. Susan has also been compiling a comprehensive literature database covering publications in the social, legal and ethical aspects of this complex field. Both Susan and Erica have attended a number of meetings over the year to ensure that the project analysis takes into account, and is embedded within, the major national and international research and debates. Of particular importance is the collaboration between this project and a parallel study being conducted by colleagues Christoph Rehmann-Sutter, Jackie Leach Scully and Rouven Porz in Basel, Switzerland.

In 2007 Erica will be working closely with our Basel colleagues, as both teams refine their analyses and conduct a systematic comparison between the two projects. This collaboration is made easier by the fact that Jackie is now a Senior Lecturer in Sociology at Newcastle University. PEALS also now has a 'stem cell group' as we are involved in a number of projects around stem cell research including work with the Northeast England Stem Cell Institute (NESCI), a programme of co-inquiry activities around stem cell research, ethics review exercises with scientists and clinicians working in this area, as well as this current project.

The ethics of taking tissue from foetuses

A project funded by the European Union 6th Framework Programme is looking at the organisational structures, ethical framework, and technologies relating to studies of gene expression in early human development. This research involves

the analysis of key developmental and disease-related genes taken from foetal tissue, including the potential construction of an electronic atlas of the developing brain. The Developmental Gene Expression Map (DGEMap) project began in 2005 and will continue until 2008. During 2006 Simon Woods and Ken Taylor led a substantial review of the scientific, social and ethical literature on the use of human developmental tissue and ascertained the legal position on the use of this tissue in a number of EU member states. They also engaged in dissemination activities for the project, presenting papers and posters at a number of UK and international conferences and workshops.

Dilemmas around health problems in the foetus

An emerging theme in our work at PEALS, one that complements research we are already conducting around the social and ethical aspects of disability, is that of difficulties at or around the time of birth. Erica Haimes has acted as a consultant on a project, funded by Newcastle Healthcare Charity, which explored parents' and professionals' experiences of deciding whether to use feticide, following the discovery of the most serious health problems in the foetus. This project was completed and reported on during 2006. The same research team, led by Newcastle University's Steve Robson and Ruth Graham, has now started a new study on the withdrawal of treatment for seriously ill newborn babies; Erica is also a consultant on this Tiny Lives Charity funded project. Both projects are providing much needed empirical data on these extremely sensitive areas; such evidence is vital if parent support groups, professionals and policymakers are to provide the most effective support, care, and resources. Both projects are also excellent examples of the sorts of collaborations with which PEALS can assist, and of the interplay between the research and policy aspects of our work, as they have contributed to, and benefited from, Erica's membership of the Nuffield Council on Bioethics Working Party on **Critical Care Decisions in Foetal and Neo-natal Medicine: Ethical Issues**



Rannveig Traustadóttir speaking at the May 2006 workshop



Members of Right to be Heard talking to Kohji Ishihara from Japan

Negotiating care for disabled children

A project co-managed by Janice McLaughlin came to an end this year, after three and a half years of research funded by the Economic and Social Research Council. The project, completed in collaboration with Dan Goodley at the University of Sheffield and three research associates (Emma Clavering, Pamela Fisher and Claire Tregaskis), explored the experiences of parents with disabled young children as they received support from different formal and informal care providers. The research aimed to examine and identify responsive care that enabled the disabled child to find a place in the parents' and family's lives with positive articulations for future development; to explore how 'impairment' and 'disability' were negotiated between parents and professionals; and to evaluate how these meanings impacted on the provision of care, perceptions of the disabled baby and the resultant understandings of parenting and professional practice. In doing so the research explored with parents what was meaningful to them as they live with, care for and love a child or children with a disability. The research team wanted to explore how parents' understandings of themselves and the world around them changed over time, what transitions occurred within their lives and how they expressed those changes and responded to them.

The project led to a one day event in May 2006 where the research team worked with parents, practitioners, professionals and voluntary sector groups to explore the difficulties faced by parents and their children and what areas of good practice and challenge participants could identify via their experiences and expertise. Details of the findings are available on the PEALS website.

Ageing and Death

At the other end of our lifespan, Simon Woods has now completed a book project that explores end-of-life issues and reflects on the nature of a good death and how this may be achieved. Entitled **Death's Dominion** (published by Open University Press), the book draws upon a philosophical framework to consider whether it is permissible or desirable to influence the quality of dying. Questions addressed by the book include: What constitutes a good death? Is it possible to arrange a good death? Is killing compatible with caring?

David Clarke, Director of the International Observatory on End of Life Care, says in his foreword:

"This is a philosophical book written by one with experience at the clinical coal-face. It adds significantly to the wider debates about ethics and morals at the end of life. I commend it to all practitioners, ethicists and social scientists who are concerned with the unfolding moral landscape of hospice and palliative care."

A right to be heard – at any age

Older people from grassroots based organisations in Tyneside were pioneers in designing their own citizens' jury in 2002, via the Rowntree Trust funded DIY Citizens' Jury project. This focussed on the lack of resources and vision in our region associated with the prevention, assessment, and treatment of falls. During 2006, many of these older people came together to review the impact of their jury and formed a group, together with Tom Wakeford and Jasber Singh, called Right to be Heard, which is described in more detail below.

Studying the genetics of healthy ageing

PEALS also has a key role in a major European project involving over 20 European partners, examining the Genetics of Healthy Ageing. Erica Haimes chairs the Ethics Steering Group and is a member of the overall Steering Committee. During 2006 the research geneticists and epidemiologists recruited nonagenarians to this project, paying careful attention to the criteria for establishing informed consent. The Ethics group has also responded to queries raised by researchers, such as how to handle requests for feedback from people donating samples and whether the consent given covers usage of samples for other purposes. Whilst these sorts of issues are often more complex than the scientific researchers sometimes realise, they are nonetheless very familiar considerations for those researching more widely on genetic databases; there is a growing literature suggesting how such matters should be handled. As well as acting in this responsive mode, the Ethics Steering Group is also actively monitoring the ethical compliance of the project's partners through an annual ethics survey.



Members of the Nanojury reflect on their conclusions

Living at the nano-scale

An increasing number of projects in PEALS deal with research and its potential applications at the nano-scale, particularly medical nanotechnologies.

During the last year the policy climate in the UK and some international institutions turned decisively towards commissioning public engagement initiatives that focussed on nanotechnologies. PEALS is playing a central part in these activities, in particular through the work of the UK Nanojury it helped set up and facilitate, along with the Inter-disciplinary Research Centre in Nanoscience, Cambridge University, Greenpeace UK and The Guardian. 2006 saw the release of the Jury's preliminary report. Compared to conventional citizens' juries it contained a much stronger element of bottom-up framing, an approach pioneered by PEALS in recent years, in collaboration with the Joseph Rowntree Charitable Trust.

Jasber Singh and Tom Wakeford, the two PEALS co-inquirers involved in the process, have now published **Polluted waters: The UK Nanojury as upstream public engagement**, reflecting on the Nanojury process. It suggests that so-called "upstream" engagement on science-related topics should allow people greater opportunity to contextualise their discussions in their everyday life experiences and concerns. Jasber and Tom's analysis and interviews with the jurors has formed part of a broadcast by Japan's University of the Airwaves. You can read full details of the Nanojury on the PEALS website.

The Lowest Common Denominator?

Matthias Wienroth, a PEALS-based researcher in the second year of his PhD, is currently conducting a range of interviews in Newcastle as the main part of his fieldwork. Drawing partly on Science and Technology Studies, his research aims to analyse the development and different understandings of nanoscale-oriented science and technology (NST). Whilst a large number of social scientific and ethical studies have been conducted on ethical, legal and social aspects of potential nanotechnologies –

and a lively debate in these fields is part of attempts to define NST – only a very small number of projects actually explore scientists' and engineers' understanding of NST and how this might affect the development of that particular research area. Matthias' project, entitled: "The Lowest Common Denominator? A Newcastle case study on the interdisciplinary nature of collaboration in nano(bio)technology", explores three interlinked dimensions of research – disciplinarity, collaboration and identity of researchers – by interviewing scientists and engineers in the area of NST. The project is funded by PEALS and supervised by Erica Haimes and Simon Woods.



Nano researcher Matthias Wienroth

Nano2Life

Erica Haimes is a member of the Ethical Legal and Social Advisory (ELSA) Board on a European-funded network of excellence in nano-biotechnology, Nano2Life, which also provided a small grant to the Nanojury. With PEALS now involved in four nano-related areas of work, we have set up a PEALS Nano Group to share knowledge, ideas and contacts. This group is exploring collaboration opportunities with a similar group in Switzerland. Matthias was granted funds from the Nano2Life Mobility Programme to enable him to travel to interview Erica's colleagues on the ELSA Board as part of his PhD fieldwork on the nature of collaboration in nanoscience. We have no doubt that both the research and co-inquiry dimensions of nanotechnologies will continue to play a large role in our activities at PEALS.



Facilitator of How Gay are Your Genes?, Lisa Matthews



Dr Ian Gibson MP, a participant in the East Anglia Community X-change, facilitated by PEALS

learning and dialogue

Genes, environment and justice

At the heart of PEALS research and co-inquiry has always been a concern for the aspects of the life sciences that affect justice and also the influence of our environmental context on our development, compared with what is “in the genes”: the so-called nature-nurture debate.

How Gay are Your Genes?, which finished in 2006, was the first major project to engage non-specialists in discussions about the biology of being gay, lesbian, bisexual or transgender (LGBT). The Royal Society and the Wellcome Trust provided funding. LGBT people often seem to have been effectively excluded from engagement in issues related to science. Initiatives to reach these and other marginalised groups take considerable work and care. We were lucky to have Lisa Matthews as the co-designer and facilitator of this project as she is a leading writer and organiser of a LGBT literature festival, **Proud Words**. Lisa created a sense of trust and shared ownership with the communities with whom she worked.

One of the highlights of the project was an exhibition in Newcastle city centre by artist Predrag Pajdic, which raised questions about genes and sexuality and explored how biological research affects a particular social group. The exhibition was attended by seven thousand people in its first month. A range of public discussions, including with the LGBT communities, led to calls for the social and political dimensions of the project to be carried forward with these communities.

Forensic DNA Databasing

Whilst our DNA may, or may not, include genes influencing our sexuality, it certainly contains a uniqueness in each individual that has made it a major forensic tool of the twenty first century. PEALS colleagues at Durham University, led by Robin Williams, examine the ways in which the growing authority of the life sciences and biotechnology is used to validate, infer and interrogate the identity of individuals by governments and other control agencies. Its current work pursues this interest by looking in detail at the use of forensic genetics to support criminal investigations and also by considering other applications of bio information – from a reliance on biometrics for counter-terrorism to the use of polygraphy to determine the truthfulness of personal accounts.

The **Forensic DNA Databasing: a European Perspective** project, funded by the Wellcome Trust’s biomedical ethics programme, began in June 2004 and is due to be completed in September 2007. The research explores the ethical and social consequences of the increased use of genetic information by the police in support of criminal investigations across the European Union (EU). It focuses particular attention on: the scientific, technical, legislative and social contexts of the current growth of national forensic DNA databases; the nature and implications of increased trans-national forensic DNA data sharing and genetic information exchange between criminal jurisdictions; and emerging global trends in new forensic uses of DNA analysis. It is the first academic study of the development of these powerful and consequential forensic resources and of the global genetic economy which engenders and is supported by them. In addition, Robin has assisted Tom Wakeford in helping the Human Genetics Commission design a citizens’ inquiry on forensic DNA databases.

The Community X-change

Also on the co-inquiry theme, PEALS and Right to be Heard have helped design a three year project in association with the British Association for the Advancement of Science. Funded by the UK government’s Sciencewise programme, these Community X-changes began in 2006 and will run until 2008. The aims are to improve practices of dialogue, particularly those that allow currently excluded voices to influence policy, provide opportunities for scientists and the public to develop common language through discussion and dialogue, and develop the capacity of our elected representatives, policy makers and the media to engage with participatory processes.

Each Community X-change is a series of workshops where members of the public, scientists and policy makers meet to discuss issues involving science. Participants will meet to explore such issues and to discuss their thoughts, feelings and ideas for possible actions. The approach takes elements from a number of different initiatives including citizens’ juries and common language projects to provide time and space for citizens to discuss issues of local as well as national concern. Community x-changes have taken place in East Anglia in 2006, and are planned in Yorkshire and Liverpool. The discussions will help to shape major science events taking place in these cities as well as developing a programme of events to be rolled out across the UK.

Following the success of our teaching and learning projects during 2005–06, PEALS is now recognised as one of the main providers of continuing and professional development to the research ethics community in the region. We have also maintained our status as a hub of numerous processes of dialogue between diverse specialist and non-specialist communities.

Working closely with the Central Office of Research Ethics Committees (COREC), PEALS has provided ongoing professional and educational development. Between Autumn 2005 and the end of 2006 we have run two 3-day induction programmes for members of ethics committees. The aim of these induction programmes is to provide a common baseline to the multidisciplinary members of research ethics committees (REC). The programme includes research methodology, the review process and the legal and ethical aspects of research. The particular strength of this programme is that it brings together experienced researchers, experienced REC members and new members with different expertise in a programme that allows time for debate and discussion.

In addition we have run **Complex Cases**, a series of intensive workshops providing an opportunity for members of research ethics committees to work intensively on a complex application, with facilitated discussion and an opportunity to benefit from peer support and expertise. These are particularly valued by experienced and new members alike as they offer an opportunity to reflect on the review process, to benefit from colleagues’ expertise and experience and to extend knowledge of new and challenging areas of research.

MSc Genetics

PEALS has collaborated with the Institute of Human Genetics in running the MSc in Genetics. This has grown from an initial cohort of nine students in October 2005 to nineteen students in October 2006. The two taught modules addressing the ethical and social aspects of genetics have proved very popular with students. Most of the students on this programme are well into their careers as scientists yet many of them have noted that this is their first exposure to ethics. They readily agree that ethics is a necessary component of the course and many recognise that they need to be prepared to deal with the multiple public and policy debates that go hand in hand with genetic research. Students have led a dynamic “Genes in the News” seminar programme and have written pieces examining the ethical and social issues involved in the range of genetic treatments and technologies they are being taught in the MSc. In particular they are asked to consider how they can respond to such issues in their future working lives within genetics research and clinical application. The MSc is unique in its integration of such concerns within its curriculum.

policy, practice and global connections



Stephen Macdonald with his examiners and supervisors, including PEALS' Tom Shakespeare



PEALS PhD student Alice Elliot



PhD Student Alex Henderson

Professional Training

There is a specific demand for professionals involved in health care and the life sciences to receive professional training in the social, ethical and legal aspects of their work. PEALS has responded to this demand in a number of ways.

- A Marie Curie Research Training Network (TRANSNET) for the training of clinical and non-clinical scientists led by Anne Dickinson, Professor of Bone Marrow Transplant Biology. PEALS has provided workshops exploring the social and ethical aspects of this work.
- Workshops for clinical ethics committees
- A series of professional ethics seminars to the Newcastle Fertility Centre.
- Contributions to NHS Specialist Registrar training.

PEALS and the Life Knowledge Park

PEALS has continued its close collaboration with the Life Knowledge Park (LKP), one of the six Genetic Knowledge Parks (GKPs) funded by the Department of Trade and Industry and Department of Health. Although the central funding for the GKPs will end in April 2007 the LKP will continue to exist as a vehicle for networking and we hope this will enable further teaching, learning and public engagement activities. Its work is detailed at www.lifeknowledgepark.org.uk.



Café Scientifique speaker on Living Machines, Richard Evans

Café Culture

Alongside our co-inquiry work, described elsewhere, PEALS seeks to encourage more traditional forms of engagement and dialogue with people in our region, as exemplified by our continuing involvement in Café Culture. Growing from the tradition of Café Scientifique, initiated by PEALS in 2000, Café Culture events have grown into a popular and accessible space for intelligent debate not only on science, but also on aspects of culture and politics that are able to give the often packed audiences an interesting evening. Speakers in the 2005-2006 season included Mary Midgley, called Britain's greatest living philosopher by The Guardian, science fiction writer Richard Evans and a double bill with novelist Stephen Webster and biologist Anya Hurlbert asking the question: **What can science learn from art?**

The reputation PEALS and its individual members have built over the last few years means that we are the first port of call for many policy-makers and advisers on a wide range of policy issues, both in the UK and abroad. Two of our senior staff have been heavily involved with the Nuffield Council on Bioethics in two areas.

Bioinformation

Robin Williams accepted an invitation to be a member of the Nuffield Council's current working group which is preparing a report on **Forensic Uses of Bioinformation**. The group is currently collecting information on the use of forensic bioinformation in the United Kingdom, with particular reference to DNA profiling and databasing. It is considering the scientific principles that underlie this technology, as well as the ethical and social ramifications of its use by legal authorities. A public consultation is underway and the Nuffield Council is hoping to publish a report of this work in September 2007.

Neonatal Medicine

Erica Haimes has had the privilege of being a member of the **Critical Care Decisions in Foetal and Neonatal Medicine** working party, which was trying to tackle one of the most difficult aspects of contemporary medicine. The working party met between October 2004 and November 2006 and its membership included neonatologists, an obstetrician, a children's nurse, ethicists, social scientists, lawyers, a health economist and a representative of parents' support groups. It also took evidence from a wider written consultation, and fact-finding meetings with neonatal units, health care managers, representatives of faith communities and parents who had experienced the difficulties associated with having very premature babies. The Nuffield Council Working Party reported its recommendations in November 2006 to considerable international and national media interest.

Children as research subjects

Also on the theme of children, in April 2006 Simon Woods organised, with support from Fionagh Thomson and Janice McLaughlin, the annual PEALS/ Life Knowledge Park Spring Symposium on the theme of children taking part in genetic research. Participants included nationally and internationally known clinicians, clinical researchers, academic lawyers, philosophers and social scientists, in particular those with specialist knowledge of the social, ethical, legal and scientific aspects of genetic epidemiological research. All of them not only promote and support high quality research but also encourage a critical and constructive discussion of the difficult issues in this area. The main focus of the symposium concerned the consent and participation of children in genetic "biobanks" but also looked at issues of research governance and more broadly, public engagement and participation with research of this kind. There were three themes dealt with in three sessions with short keynote papers followed by discussion.



Tom Shakespeare speaking at a British Council event



Researcher Fionagh Thomson



Young members of the Today Programme jury present their recommendations to Hazel Blears MP



Former citizens' jury member, Patrick O'Reilly analyses participatory processes at a R2BH meeting in Edinburgh

Disability

Tom Shakespeare continues to take a leading role in disability debates nationally and internationally. He was keynote speaker at the 2006 UK Disability Studies Association conference, where he launched his new book *Disability Rights and Wrongs* (Routledge). He has been appointed to the editorial board of the World Health Organisation's World Report on Disability and Rehabilitation. He was a keynote speaker at Hokkaido University, Japan, in March 2006, promoting the PEALS model of public engagement on science, particularly *Café Scientifique*.

Human biological samples

Erica Haimes and Robin Williams were commissioned by the Wellcome Trust to review the findings of the research funded by the Trust on the socio-ethical aspects of human biological sample collections. Their task was, first, to review the results of the projects and report to the Trust on the key themes (and differences therein) common to these projects, and second, to advise on whether there are any major dissemination targets or messages, for the Trust and others, with a view to developments in the field since the completion of the various projects considered. This review is another example of the interplay of the various strands of PEALS as it was based on a collaboration between Newcastle (Erica) and Durham (Robin) universities. It also shows the influence of our own research projects on helping to set future research agendas (both Robin and Erica were Principal Investigators of Wellcome funded projects on human sample collections). Furthermore it indicates the potential impact of one piece of our work on other activities and developments (for example, this report was formally presented to the UK Biobank Ethics and Governance Council and will also be used in the PEALS 2007 symposium on the governance of human sample collections).

Beyond the gene

PEALS has developed new expertise in discussing issues around illegal drugs, alcohol use, crime associated with such substances, young people and ageism. This is in addition to the capacity to conduct participatory processes on issues traditionally seen as coming under the broad remit of science

and social science, such as nanotechnologies, and rural development. This is because our co-inquiry and engagement work uses bottom-up framing, allowing participants to join funders in setting the agenda that is to be discussed.

During 2005-06, Tom Wakeford served on the President's Advisory Group of the British Association for the Advancement of Science, the Joseph Rowntree Foundation advisory group on community cohesion among Muslim communities, a methodological planning group for the European Citizens Panel initiative and was an invited expert to a workshop organised by the European Commission's Joint Research Centre (JRC) in Ispra, Italy. The JRC is a research-based policy support organisation working for EU policy-makers.

World Bioethics Congress

In August 2006 Simon Woods and Ken Taylor participated in the International Association of Bioethics eighth world congress in Beijing. This event attracted bioethicists and philosophers from around the world and covered a diverse range of issues, from World War Two era bio-warfare experiments to twenty-first century nanotechnologies. Since the event was organised by the Chinese Medical Association, there were a number of sessions devoted to bioethics issues in China and her neighbours; a frequent topic for discussion was the Hwang stem cell scandal in Korea.

Simon presented a paper "*Philosophy as a resource for medicine: bioethicists alongside scientists in multi-partner research projects*" in which he discussed the relationship between philosophy and medical science through the lens of two collaborative projects with which he is involved, DGEMap and SmartHealth. A poster by Ken Taylor, Simon Woods and Professor Susan Lindsay, of Newcastle University's Institute of Human Genetics, was also presented at the congress. Entitled "*Ethical and Social Issues facing a European Centre for Human Developmental Gene Expression Research*", the poster explored ethical concerns related to the project, including tissues required for the scientific programme being obtained from women undergoing elective termination of pregnancy.

Juries on the airwaves

By the beginning of 2006, PEALS was coming to the end of a highly successful collaboration with the BBC's Today Programme. During 2005, a team of PEALS-based facilitators, led by Bano Murtuja and Tom Wakeford, had formed a partnership with Today to use the DIY jury technique. It was the first citizens' jury process to be pod-cast, in its entirety, by a national broadcaster. Today also broadcast eleven separate items on the jury process on BBC Radio 4, including an interview with Tom on the day the jury presented its conclusions to the then Home Office Minister, Hazel Blears, MP. Tom Wakeford and Simon Woods have also discussed bioethical issues on Radio 4's *Material World* and BBC Radio Scotland's *Values Added* respectively.



Jasmine and Darren ask questions during the Today Programme Jury

Helping the birth of a new network

PEALS has also facilitated the formation of Right to be Heard (R2BH), a group of people from a variety of backgrounds who have taken part in processes of participatory democracy since 2001. Most, but not all, of its founding members have worked with PEALS in the past. R2BH particularly includes people from those communities who often experience oppression in society and are excluded from decision-making. Its core membership consists of around fifty people from the UK, other European countries and India who are keen to work in solidarity with each other and others marginalised from power.

At two initial meetings of the network in Cumbria (February 2006) and Edinburgh (June 2006), funded by the Economic and Social Research Council, participants agreed on two initial aims for R2BH: first, to provide opportunities for participants in processes, such as citizens' juries, to work on an equal footing with facilitators to achieve greater social justice by improving the accountability of decision-makers; and second, to foster alternative principles of participation from those that currently dominate professional practice.

other PEALS News

RCUK Fellowship on biosecurity

PEALS was pleased to be awarded a prestigious RCUK Fellowship in 2006. Based on a proposal drafted by Robin Williams, Janice McLaughlin and Erica Haimes, the Fellowship provides partial funding for a post-doctoral Fellow for five years, with a view to the Fellow gaining a permanent academic post. Such Fellowships are particularly apt for PEALS since the terms of the award require the Fellow to combine research and lecturing with outreach in schools. We are pleased that we were able to appoint Michael Barr, previously a Research Assistant in PEALS who then worked in BIOS at the London School of Economics. Michael will work collaboratively with Robin Williams (PEALS-Durham) to develop a programme of research on bio-security, building upon Robin's current work on forensic uses of DNA.

Durham-Newcastle links

During 2006 Janice McLaughlin and Robin Williams began a series of 'PEALS roadshows' in academic departments at Durham University. The aim is to discuss our work with potential collaborators and develop further PEALS activity within Durham University. Presentations were held in Sociology and Medical Anthropology, with further meetings scheduled in 2007. These meetings sit alongside the ongoing work and connections with the Wolfson Research Unit in Durham, in particular Janice's role leading the development of the Wolfson research theme: Risk, Safety and Technology.

Stephen Macdonald

Having successfully defended his PhD thesis on dyslexia, class and the education system, Stephen has been appointed Senior Lecturer at the University of Sunderland's School of Health, Natural & Social Sciences. Everyone at PEALS wishes him congratulations and good luck.

Ethics of participation in genetic research

Alex Henderson is now in the third year of his PhD at PEALS. He is continuing to analyse interviews undertaken with parents of boys with Duchenne muscular dystrophy, who are contemplating research participation in projects that will involve new genetic technologies. The project explores the concepts of consent, the expectations of the different parties involved and decision making processes. Alex continues to be co-supervised by Simon Woods, Tom Shakespeare and Kate Bushby from Newcastle University.

Restricted growth project

The data collection for this Big Lottery funded project, led by Tom Shakespeare and Sue Thompson, and described in detail in last year's Annual Review, is now complete. Sue recruited 92 respondents for the quantitative survey, and has conducted more than 50 qualitative interviews with restricted growth people from the North of England. This is the largest and most representative research project ever conducted with restricted growth people, providing information about both social and medical aspects of skeletal dysplasias. Preliminary findings were shared with the Restricted Growth Association, which manages the project, at their October 2006 convention. Early findings show how public reaction – staring, mockery and even violence – structure the identities of people with restricted growth. There is also important new evidence about the impact of health complications such as sleep apnoea and spinal stenosis.

Women and diabetes

PEALS PhD student Alice Elliott is undertaking a research project exploring the empowerment of women who use diabetes healthcare services in the North East of England. Her project, which forms the basis of her PhD, is being funded by the Economic and Social Research Council and Newcastle Primary Healthcare Trust. Supervision of the project is being undertaken by Janice McLaughlin and Catherine Exley from Newcastle University, and Gillian Hawthorne from the Newcastle Diabetes Centre.

Policy, Ethics and Life Sciences (PEALS) Research Centre, Citygate, St James Boulevard, Newcastle upon Tyne, NE1 4JH
Tel: +44 (0)191 243 0780
Fax: +44 (0)191 243 0814
Email: peals@ncl.ac.uk
Web: www.peals.ncl.ac.uk

The PEALS Team

Erica Haimes
Janice McLaughlin
Tom Wakeford
Simon Woods
Robin Williams

Executive Director
Director of Research
Director of Co-Inquiry
Director of Teaching and Learning
Durham Convenor of PEALS

erica.haimes@ncl.ac.uk
janice.mclaughlin@ncl.ac.uk
tom.wakeford@ncl.ac.uk
simon.woods@ncl.ac.uk
robin.williams@dur.ac.uk

Michael Barr
Emma Clavering
Anne Galbraith
Tom Martin
Lisa Matthews
Tom Shakespeare
Kenneth Taylor
Sue Thompson
Fionagh Thomson

RCUK Academic Fellow
Research Associate
PEALS Office Manager
PEALS Secretary
Research Associate
Research Fellow
Research Associate
Research Associate
Research Associate

m.t.barr@ncl.ac.uk
e.k.clavering@ncl.ac.uk
anne.galbraith@ncl.ac.uk
tom.martin@ncl.ac.uk
lisa.matthews@ncl.ac.uk
t.w.shakespeare@ncl.ac.uk
kenneth.taylor@ncl.ac.uk
sue.thompson@ncl.ac.uk
fionagh.thomson@ncl.ac.uk