

Biosciences **Media**  
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# SATSU Annual Review: 2009-2010

September 2010

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## SATSU's Focus

Established in 1988, SATSU is an internationally recognised social science research centre exploring the dynamics, practices, and possibilities of contemporary science and technology. Its principal focus is on the biosciences, health, digital media and social networking including new forms of democratic governance, and the broader regulatory universe within which these are found.

Our approach is to provide both theoretical and empirically-grounded critical analyses of these fields, and to undertake interdisciplinary and policy-relevant research informed by both conventional and novel methodological techniques.

SATSU currently has 16 members and is directed by Professor Andrew Webster.

SATSU welcomes research collaboration and applications for doctoral study in any one of its three main areas of research: the sociology of the biosciences, social informatics/new media, and regulation and governance. Please contact Andrew Webster with inquiries (at [ajw25@york.ac.uk](mailto:ajw25@york.ac.uk)).

# Happy Birthday, SATSU

## Invited Lecture Series

This year saw SATSU celebrating its 21<sup>st</sup> birthday. SATSU also joined forces with the Social Informatics Research Unit (SIRU) (which is based in the Department of Sociology) because of shared research interests, making for a much larger critical mass of researchers here at York working on new technologies, science and culture. We have also marked the occasion with this newly revised Annual review which appears online and is available in hardcopy.

To celebrate these developments we invited two internationally recognised speakers each term who have made major contributions to the three core themes of the unit – the sociology of the biosciences, social informatics/new media, and regulation and governance. These presentations appear as webcasts on the Unit website.

Stephen Graham, our first speaker, who has a personal research Chair in cities and security at Newcastle, linked the digital and regulatory themes, and explored the urban implications of new technologies, the importance of mobility and infrastructure in urban life, the links between cities and surveillance, and the relationships between cities, war and terrorism.

Celia Roberts, from the Department of Sociology at Lancaster, whose research centres on the body, health, reproduction, sexuality and aging (see *Messengers of Sex: hormones, biomedicine and feminism*) provided an historical and current analysis of

the role of hormones in producing sexually differentiated bodies via her intriguingly entitled paper "*It's All Hormonal: Puberty, biomedical technologies and responsibility*"; the lecture also happened to coincide with her own birthday!



Celia Roberts

Our spring term lectures were given by Mike Michael from Goldsmiths and Ann Macintosh from Leeds.

Mike, who is Professor of Sociology of Science and Technology and Director of the Centre for the Study of Invention and Social Process and whose interests include public understanding of science, everyday life and science and technology, and biotechnological and biomedical



Mike Michael

innovation, gave a fascinating paper that examined paper how the animal experimentation controversy is played out through competing versions of 'the public'.

Ann, who is Professor of Digital Governance at the Institute of Communication Studies, is expert in the societal effect of technology on governance processes



Ann Macintosh

and both 'eParticipation' and citizen engagement. She discussed the role of Web 2.0 as a means through which it might be possible to foster Participatory policy development at a national level.

Our final two speakers in the summer term were Donald MacKenzie from the Department of Sociology, Edinburgh and John Abraham from Sussex.

Donald, whose publications have explored the social and historical dynamics of statistics, eugenics, and both computing systems and missile systems gave a fascinating insight into the current financial crisis drawing on his more recent work *Material markets: how economic agents are constructed* (2009), showing how the cultural expectations of risk and technology architecture and network of the banking system co-produced the huge problems we now all face.



Donald Mackenzie

John, who is Co-director of the Centre for Research in Health and Medicine and who has expertise in the development, testing and regulation of drug safety/efficacy/innovation and the sociology and politics of the pharmaceutical industry worldwide, gave a robust and impressive critique of the 'pharmaceuticalisation' of society.



John Abraham

## Visitors to SATSU

During 2009/10, SATSU was fortunate enough to have a number of international visitors

### Francisco Lupiáñez-Villanueva

Francisco joined SATSU in May 2008 for four months in order to share his analysis with academics interested in his area of research, ICTs and healthcare, and collaborate on publications. This collaboration continues; in November 2009, colleagues from SATSU were invited by Francisco to join a workshop at the Open University of Catalonia's Internet Interdisciplinary Institute and Francisco and Mike have recently been published in *International Journal of Medical Informatics* see page 6).



Michael Morrison, Laura Machin and Francisco Lupianez-Villanueva in Barcelona, November 2009

Also see Francisco's blog: [www.ictconsequences.net](http://www.ictconsequences.net)

### Dirk Stemerding

Dirk visited SATSU from September to December 2009 as a visiting research-fellow from the University of Twente. SATSU offered Dirk an environment,

highly relevant to his research focussing on the scientific and societal dimensions of innovation in genomics. In December 2009, Dirk organised a workshop in which a number of researchers from the UK and the Netherlands with a common interest in genomics innovation in human health were brought together. In addition to this collaborative activity, Dirk's stay at SATSU also offered him a highly welcome opportunity to concentrate on writing.



Dirk Stemerding

### Ellen van Oost

Ellen stayed at SATSU for four months between September and December 2009. During her stay she did a literature study on the social aspects of the emerging technology of social



Ellen van Oost

robotics. SATSU provided her with an inspiring intellectual and social environment. Especially in Darren Reed, she found a stimulating discussion partner and they elaborated their ideas in a joint conference paper.

### Lucas Cornips

Lucas came to SATSU between January and May 2010 as a research intern from Weibe Bijker's group at the University of Maastricht, where he was enrolled on the Masters of Cultures of Arts, Science and Technology course.



Lucas enjoying the British winter in York.

Whilst at York, Lucas worked on the REMEDIE and CIT PART projects, looking at the construction of strategic and commercial futures in regenerative medicine and the historic definitions of xenotransplantation.

### Vincenzo Pavone

Vincenzo joined SATSU for five weeks in April 2010 from the Institute of Policy and Public Property in Madrid in order to draw on SATSU's expertise in the social and ethical aspects of biomedicine in his work on pre-implantation genetic diagnosis (PGD) and IVF technologies.

Whilst working in SATSU, Vincenzo gave an interesting presentation on PGD technology in Spain as part of the Brown Bag Seminar Series, which helped him to refine his research in this area. As Vincenzo's visit to SATSU was brief (and delayed by volcanic ash), he will be returning to the Unit in the autumn of 2010.



Vincenzo Pavone

## Funding News

SATSU helped to lead on a successful bid to the European Commission's 'COST' programme with a bid (one of only 3 out of 120 that were funded) relating to the challenges posed by new 'bio-objects'. The bid builds on longstanding links among the proposers who were all members of a Marie Curie Training Site based in SATSU between 2000-5. The members have retained links through annual meetings we have organized. The disciplinary range includes political science, sociology, philosophy, law, economics and bioethics, and all have substantial experience examining the bioscience field.

This research network develops novel interdisciplinary tools that will improve our understanding of bio-objects, their production and governance. The core questions answered through this COST Action are: how are the boundaries between human and animal, organic and non-organic, living and the non-living opened up?; how do bio-objects change social relations?; how does the public-private interface shape the making of bio-objects?; and finally, how does the governance of bio-objects perform at different levels?

## Conferences

In addition to the invited lecture series, there were a number of events that colleagues organised. Here are just a few

### Genomics Workshop, SATSU. 3 December 2009

On the 3th of December 2010 a workshop was held at SATSU, titled *Genomics innovation in human health: a new science, a new society?*

Organisers were Dirk Stemerding, staying at SATSU as a visiting research fellow, and Andrew Webster. The workshop explored the question how future health care and society might be shaped by practices of innovation in genomics. It brought together some 20 scholars in the field of science, technology and innovation studies from The Netherlands and the UK. The programme focussed on the dynamics of innovation in medical genomics, both in the public and private sector, and the way in which innovation in this field is related to emerging practices of personal genome testing.

Presentations were given by Roel Nahuis (University of Twente, The Netherlands), Paul Martin (University of Nottingham, UK), Michael Hopkins (University of Sussex, UK), Lise Bitsch (University of Twente, The Netherlands), and Barbara Prainsack (King's College London, UK)

### Regenerative Medicine in the 21st Century, University of Wisconsin. 9-10 June 2010

The REMEDIÉ project (see page 9) held its second annual conference at the University of Wisconsin Madison in June 2010. The project, co-ordinated by Andrew Webster, received huge support for the meeting from Linda Hogle, based at Wisconsin Madison, and from colleagues in the STS Holtz Centre, especially Daniel Kleinman, and the local World Universities Network (WUN) partner.

The conference provided an opportunity to explore and debate the current state of stem-cells and the wider regenerative medicine and to determine how global shifts will affect both the USA and Europe.

Some of the main points emerging at the meeting include: the need for new, RM-specific regulatory models and procedures that provide for optimal regulation and governance; the advent of clinical trials (CT) for treatment, especially through the development of allogeneic-based therapeutics, requires a rethink about the structure and utility of the conventional CT process; the exploitation and commodification of tissue and women (and their labour) as biological resources which raises quite specific political and bioethical issues relating to property rights and usage; and the existence of diverse models that can be seen in regard to science-based innovation/state/market relations and in particular new innovation models found within China and India.

Mircea Maniu, Smaranda Moldovan and Rodica Mocan from the University of Babeş-Bolyai.

Held on 25-27 June 2010 in the beautiful Romanian city of Cluj in the region of Transylvania, the event was sponsored by the British Council, Institutul Cultural Roman and our own journal *Information, Communication and Society (iCS)*. Attended by 90 delegates from 25 countries, the intellectual focus of the conference was a critical appraisal of the potential benefits and challenges of social media technologies for democratic governance.

Papers covered such areas as e-campaigning, cyber-activism, surveillance, citizen journalism, digital citizens and e-democracy. Keynote speakers included highly acclaimed



Some of the Regenerative Medicine delegates gathered together

### Networking Democracy? New Media Innovations in Participatory Politics, Babeş-Bolyai University. 25-27 June 2010

An international three day symposium entitled *Networking Democracy: new media innovations in participatory politics* was jointly organised by SATSU associate director Brian D. Loader, research post graduate Dan Mercea, SATSU administrator Sarah Shrive-Morrison and Romanian colleagues

scholars in the field: Lance Bennett (University of Washington, USA), Donnatella della Porta (European University Institute, Italy), Brian D. Loader (University of York, UK), Bruce Bimber (University of California at Santa Barbara, USA), Bill Dutton (Oxford Internet Institute, UK) and Rodica Mocan (University Babeş-Bolyai, Romania). A selection of the papers will be published in a forthcoming special issue of *Information, Communication and Society (iCS)*.

## Publications

Throughout 2009/10, SATSU colleagues have worked hard to disseminate their research findings in publications and conference papers

- Allen-Robertson, J. & Beer, D. (2010) 'Mobile Ideas: Tracking a Concept Through Time and Space', *Mobilities*, 5 (4), Forthcoming.
- Bahadur, G. & Morrison, M.. (2010) 'Patenting Human Pluripotent Cells: Balancing Commercial, Academic and Ethical Interests', *Human Reproduction* 25 (1): 14-21.
- Beer, D. (2009) 'Can you dig it? Some Reflections on the Sociological Problems Associated with Being Uncool', *Sociology* 43 (6): 1151-1162.
- Beer, D. (2009) 'Power through the algorithm? Participatory Web cultures and the Technological Unconscious', *New Media & Society* 11 (6): 985-1002.
- Beer, D. & Burrows, R. (2010) 'Consumption, Prosumption and Participatory Web Cultures: An Introduction', *Special Issue of Journal of Consumer Culture* 10 (1): 1-10.
- Beer, D. & Burrows, R. (2010) 'The Sociological Imagination as Popular Culture', in, Burnett, J., Jeffers, S. & Thomas, G. (eds.) *New Social Connections: Sociology's Subjects and Objects*. Basingstoke: Palgrave Macmillan. pp. 233-252.
- Brown, N. (2009) 'Beasting the Embryo: The Metrics of Humanness in the Trans-species Embryo Debate', *Biosocieties*, 4 (2), 147-163.
- Hardey, M. & Loader, B.D. (2009) 'The Informatization of Welfare: Older People and the Role of Digital Services', *British Journal of Social Work*, 39 (4): 657-669.
- Kerr, A., Woods, B, Nettleton, S. & Burrows, R. (2009) 'Testing for Food Intolerance: New Markets in the Age of Biocapital' *BioSocieties: An Interdisciplinary Journal for Social Studies of Life Sciences*, 4 (1): 3-24.
- Loader, B.D. Hardey, M. & Keeble, L. (eds.) (2008) *Digital Welfare for the Third Age : Health and Social Care Informatics for Older People*. London: Routledge.
- Lupiáñez-Villanueva, F., Hardey, M., Torrent, J. & Ficapal, P. (2010) The integration of Information and Communication Technology into medical practice, *International Journal of Medical Informatics*, 79 (7): 478-491.
- Nettleton, S., Woods, B., Burrows, R. & Kerr, A. (2009) 'Food Allergy and Intolerance: Towards a Sociological Agenda' *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 13 (6): 647-664.
- Nettleton, S., Woods, B., Burrows, R. & Kerr, A. (2010) 'Experiencing Food Allergy and Food Intolerance: An Analysis of Lay Accounts', *Sociology*, 44 (2): 289-305.
- Reed, D. J. (2009) 'The Performativity of a Volunteer Based Telecare Service', In B. Loader (ed.), *Digital Welfare for the Third Age: Health and Social Care Informatics for Older People*, London: Routledge, pp.112-132.
- Reed, D. J. (2009) *Observing and Quoting Newsgroup Messages: Method and Phenomenon in the Hermeneutic Spiral*. LAP Lambert Academic Publishing.
- Reed, D. J. & Monk, A. (2011) 'Inclusive Design: Beyond Capabilities Towards Context of Use', *Universal Access in the Information Society (UAIS) Special Issue on Innovations in User Sensitive Design, Research and Development*, 10 (3), 1-22.
- Reed, D.J & Webster A. (2009) 'Architectures of Motility: ICT Systems, Transport and Planning For Complex Urban Spaces', in C. N Silva (ed.) *Handbook of Research on E-Planning: ICTs for Urban Development and Monitoring*, Hershey: IGI Global, pp. 365-387.
- Uprichard, E., Burrows, R. & Parker, S. (2009) 'Geodemographic Code and the Production of Space', *Environment and Planning A*, 41 (12): 2823 - 2835.
- Webster, A. (2009) 'Information and Communication Technologies and Healthcare: User-centred Devices and Patient Work', in B. Loader, M. Hardey and L. Keeble (eds.) *Digital Welfare for the Third Age: Health and Social Care Informatics for Older People*, London: Routledge, pp 63-76.
- Webster, A. (2009) 'Innovative Genetic Technologies, Governance and Social Accountability', in P. Atkinson, P.E. Glasner and M.M. Lock (eds.) *Handbook of Genetics and Society: Mapping the New Genomic Era*, London: Routledge, pp 486-502.
- Webster, A. (2009) 'Expressing the Gene: The Discursive and Institutional Regulation of Genetics', in P. Atkinson, P.E. Glasner and M.M. Lock (eds.) *Handbook of Genetics and Society: Mapping the New Genomic Era*, London: Routledge, pp. 263-267.
- Webster, A., Brown, N., Douglas, C., Lewis, G., Kaye, J., Tutton, R. & Williams, N., (2008) *Public Attitudes to Third Party Access and Benefit Sharing: Their Application to UK Biobank (Final Report)*. <http://www.egcukbiobank.org.uk/assets/wtx052208.pdf>
- Webster, A. Douglas, C. & Lewis, G. (2009) 'Making Sense of Medicines: 'Lay Pharmacology' and Narratives of Safety and Efficacy', *Science as Culture*, 18 (2): 233-248.

## Publications

Webster, A. Douglas, C. & Sato, H. (2010) 'Emergence of Asbestos-related Health Issues and the Development of Regulatory Policy in the UK', in H. Sato (ed.) *Management of Health Risks from Environment and Food*, London: Springer, pp. 63-100.

Webster, A. Douglas, C. & Sato, H. (2010) 'BSE in the United Kingdom' in H. Sato (ed.) *Management of Health Risks from Environment and Food*, London: Springer, pp 221-267.

Wideroff, L., Phillips, K.A., Randhawa, G., Ambs, A., Armstrong, K., Bennett, C.L., Brown, M.L., Donaldson, M.S., Follen, M., Goldie, S.J., Hiatt, R.A., Khoury, M.J., Lewis, G., McLeod, H.L., Piper, M., Powell, I., Schrag, D., Schulman, K.A. & Scott, J. (2009) 'A Health Services Research Agenda for Cellular, Molecular and Genomic Technologies in Cancer Care' *Public Health Genomics*, 12 (4): 233-244.

A special issue of the *Journal of Consumer Culture* was edited by SATSU members David Beer and Roger Burrows in 2010. This issue attempts to place some general developments in web cultures within the broader context of contemporary consumer culture and to contribute toward wider debates about the increasing participation and activity of the consumer within acts of consumption. This might be thought of as the ongoing problematization of the distinction between the producer and the consumer. This issue is dedicated to the understanding of consumption in the context of the new participatory web cultures that have risen to prominence over the last few years and which have now become established parts of mainstream culture. It has become clear in recent years that the developments in what is sometimes termed 'Web 2.0', defined by user-generated content and spoken of in terms of a rhetoric of user participation and collaboration, have had significant implications for consumption itself and for the study of consumer cultures. This special issue is dedicated to exploring these issues.

## Conference Papers

Beynon-Jones, S. (2010) 'Time, Timing and Narrative at the Interface Between Science, Policy and Citizenship - A Xenotransplantation Case Study', *EASST*, Trento, Italy. 2-4 September 2010.

Fearon, K. & Reed, D. (2009) 'Second Life for Teaching and Learning', *Poster Presentation: Learning and Teaching Conference*, University of York, 10 June.

Machin, L. (2009) 'Cord Blood Banking: Initial Observations', *Innovative Health Technologies: Health Systems in Transition Workshop*, Internet Interdisciplinary Workshop, University of Catalonia Spain. 26-27 November 2009.

Morrison, M. (2009) 'Measuring Innovation: A Brief Introduction to the REMEDiE Project', *Innovative Health Technologies: Health Systems in Transition Workshop*, University of Internet Interdisciplinary Institute, University of Catalonia, Spain. 26-27 November 2009.

Morrison, M. (2010) 'European RM Firms and their Strategic Approaches', *Regenerative Medicine in the 21st Century*, University of Wisconsin Madison, USA. 9-10 June 2010.

Morrison, M. & Cornips, L. (2010) 'Visions of Health and Wealth: The Role of Expectations in Commercial Regenerative Medicine', *EASST*, Trento, Italy. 2-4 September 2010.

Nettleton, S. & Uprichard, E. (2010) 'A Slice of Life: a Glimpse into Menus and Memories of Mass-observers in 1945 and 1982', *2nd BSA Food Study Group Conference*, The British Library Conference Centre, London, UK. 5-6 July.

Reed, D. J. (2009) 'Notes Towards an Inclusive Digital Economy', *INCLUDE 2009. Inclusive design into innovation: Transforming Practice in Design, Research and Business*. Royal College of Art, London, UK 5-8 April.

Reed, D.J. (2009) 'Designing for Non-users', *Client-Centred Technology for Healthy Ageing, One Day Workshop*, York, UK. 20 April.

Reed, D. J. (2009) 'An Exploratory Literature Review in Support of an Inclusive Digital Economy', *Prepared for Inclusive Digital Economy Network*, May 2009.

Reed, D. J. (2009) 'The Performativity of Data', *Workshop: Innovative Health Technologies: Health Systems in Transition*, Internet Interdisciplinary Institute (IN3), Barcelona, Spain. 26-27 November.

Reed, D. J. & Light, A. (2010) 'Contested Vulnerabilities in the Performativity of Age and Technology', *EASST*, Trento, Italy. 2-4 September.

Reed, D. J. & Olivier, P. (2010) 'Ubicomp and the Technologist as Worldmaker', *XVII ISA World Congress of Sociology*, Gothenburg, Sweden. 11-17 July.

Uprichard, E. (2009) 'Classifying (Splintered) Classifications', *Value and Measure*, Goldsmiths, University of London, UK. 18 Sept.

Uprichard, E. & Nettleton, S. (2010) 'Meta-methodological Issues Involved in Researching the Changing Social World: Food, Time and Temporality in York', *Session 18: Research a Changing World, ISA World Congress of Sociology*, Gothenburg, Sweden. 11-17 July.

Uprichard, E. & Nettleton, S. (2010) 'Foodles of Change', *British Sociological Association*, Glasgow Caledonian, UK. 7-9 April.

# Brown Bag Seminar Series

## Autumn Term

The SATSU Brown Bag lectures are comprised of invited speakers from the University of York and other institutions. While the audience benefits from cutting edge research and writings, relevant to the study of science and technology, the title of the series indicates the relaxed nature of each event. Speakers are therefore welcomed by engagement, discussion and debate and perhaps the intermittent munching of a sandwich. This past year we have again welcomed a wide range of speakers into the unit. In

the autumn term of 2009 this included Dirk Stermerding and Ellen van Oost, visiting scholars from the University of Twente. Dirk talked about the social construction of genomics as a new regime of innovation, while Ellen spoke to the emerging development and social roles for robots with a focus on the ethical implication of robots as companions. Mike Hardey from Hull York Medical School challenged the audience to think about medical practice in different ways by invoking the notion of

'medicine 2.0' to categories instance of online, interactive information sources and their impact upon patient expectation.

Neil Pollock from the University of Edinburgh, talked about the role of 'promissory organisations and agents' who simultaneously influence the nature and acceptance of future technologies. We also heard from our own Michael Morrison who spoke about the medicalisation of growth and the social construction of growth hormones.

## Spring Term

In the Spring term Roger Burrows, our head of department, gave a talk about the 'descriptive turn' in sociology and exciting work involving new forms of data visualisation. Andrew Webster, the Director of SATSU, spoke about the issue

of 'impact scores' in the social sciences and beyond, specifically in relation to the new REF scheme. After this, Catherine Montgomery gave a talk about the 'co-production' of gender and technology in HIV prevention. Andrew Balmer, from

Nottingham University gave a talk about fMRI imaging in relation to deception detection. Finally Siân Beyon-Jones, from SATSU finished up the term with a talk on the social construction of abortion.

## Summer Term

The summer term Brown Bag seminar series enjoyed a delightful mix of home, national, and international speakers, presenting on a wide range of interests relating to SATSU's core research themes.

Professor David Hesmondhalgh, from Leeds University, started off the term's series, with an interesting presentation debating the place of Creative Labour in contemporary society.

Visiting student Lucas Cornips then presented on the work he had been doing with Michael Morrison for the REMEDIÉ project.

Another SATSU guest, Vincenzo Pavone,

was next to present his work on PGD in Spain. Vincenzo discussed how the diffusion of PGD in Spain is associated with the interaction between the growing momentum of embryonic stem cell research, and an expansion of IVF business along the Mediterranean coast. Doctoral student Paul Ellwood, from the University of Leeds, followed with a presentation on external expectations and demands for nanotechnology laboratories.

Liz Sourbert from the University of York's Centre for Women's Studies (CWS) presented findings from her thesis about property rights and reproductive body parts.

Another University of York doctoral student, Zeyi He, gave the next talk on her thesis, which examines data production and Wikipedia. Ilke Turkmendag, from Policy, Ethics and Life Sciences Research Centre (PEALS) in Newcastle was the penultimate presenter and discussed the provision and acquirement of human reproductive tissues for stem cell science. German doctoral student Sandra Appleby-Arnold finished the term's series with a presentation on the differences in cord blood banking between the UK and Germany.



## REMEDiE: Regenerative Medicine in Europe

Professor Andrew Webster  
Dr Nik Brown  
Dr Graham Lewis  
Dr Michael Morrison

Regenerative Medicine in Europe (REMEDiE) is a collaborative, interdisciplinary project bringing together the social sciences and humanities, funded by the European Commission's Seventh Framework Programme, and involving researchers from the Universities of York, Hannover, Vienna, the Basque Country, Kings College London, and the Central European University in Hungary. Regenerative medicine is an umbrella term that describes the application of novel biomaterials including (stem) cells, genes and biodegradable scaffolds to augment the human body's innate capacity for self-repair and regeneration. The aim of REMEDiE is to explore and interpret the socio-economic, political and bioethical implications for Europe of global developments in this dynamic and expanding field of biotechnology and biomedicine.

SATSU's involvement with REMEDiE entails project commitments to map and analyse the commercial development of regenerative medicine by European firms (Dr Michael Morrison with Dr Beth Kewell of the York Management School), mapping global developments in regenerative medicine to produce a database of companies, clinical trials and patent activity (Dr Graham Lewis), and overall co-ordination of the project (Professor Andrew Webster). The University of York also hosts the project website at <http://www.york.ac.uk/satsu/remedie/>. The REMEDiE team have met four times to co-ordinate, plan and integrate research input from the different partners, the second and fourth of these meetings incorporating



REMEDiE project partners at King's Manor, University of York.

significant project participation in important conferences. In May 2009 the second day of the *Beyond Pattison: Challenges to Stem Cell Translation and Policy* conference, held at the Wellcome Trust in London, served as an inaugural presentation of the goals and research aims of the six REMEDiE partners as well as articulating the project's overall vision. (US) provided a major international platform for disseminating mid-term findings of the project and highlighting key issues emerging from the research thus far.

Most recently, the *Regenerative Medicine in the 21<sup>st</sup> Century: Managing Uncertainty at the Global Level* conference, held 9-10th June 2010 in Madison, Wisconsin provided a major international platform for disseminating mid-term findings of the project and highlighting key issues emerging from the research thus far.

The REMEDiE partners are now working towards the completion of the project, the outcomes of which will be presented at the final project meeting and conference in 2011. The project has also produced a number of important outputs to date, the

SATSU component of which includes a commentary on the effects of the economic downturn on the biotechnology industry for the *Biotechnology Journal* by Andrew Webster and Beth Kewell, a discussion of stem cell patenting in *Human Reproduction*, on which Michael Morrison was a co-author, and submission of written evidence to the UK House of Commons Bioengineering Inquiry 2010.

Further dissemination and publication activities are planned including a presentation on the rhetorics of promise and risk in regenerative medicine at the forthcoming European Association for the Study of Science and Technology (EASST) annual meeting in September 2010.

Website: <http://www.york.ac.uk/satsu/remedie>

## The Political and Moral Economy of Umbilical Cord Blood Banking

Dr Nik Brown  
Dr Laura Machin  
Dr Danae McLeod

In 2009 SATSU began work on its £264,000 ESRC research grant exploring the political and moral economy of umbilical cord blood banking. The aim of the project is to explore the changing patterns in organisation, donation and deposition of blood stem cells. In particular, to explore new forms of consumption parental responsibility and the changing balances between public and commercial bioscience that are emerging as a result of cord blood banking. The research is organised around three interrelated work packages: the banking sector itself; policy making and governance; and finally, the views and perspectives of donors, depositors and parents.

Nik Brown, who is the PI on the project, developed the proposal based on his previous work examining the history of haematopoietic stem cells. He was joined on the project by Professor Andrew Webster (co-applicant) and two research fellows; Dr Laura Machin and Dr Danae McLeod.

Over the course of the last year, the team have been conducting interviews with senior members of the private and public cord blood banking sectors, regulators and policy makers, and after receiving ethics approval, with midwives, obstetricians, neonatologists, and senior members of the Royal Colleges.

Focus groups with pregnant women and their partners as well as members of wider society have been conducted, and documentary data

has been collected, with Danae focusing particularly upon analysing internet chat room discussions, culminating in a paper being drafted on the knowledge economy and cord blood banking for the journal *Sociological Research Online*.

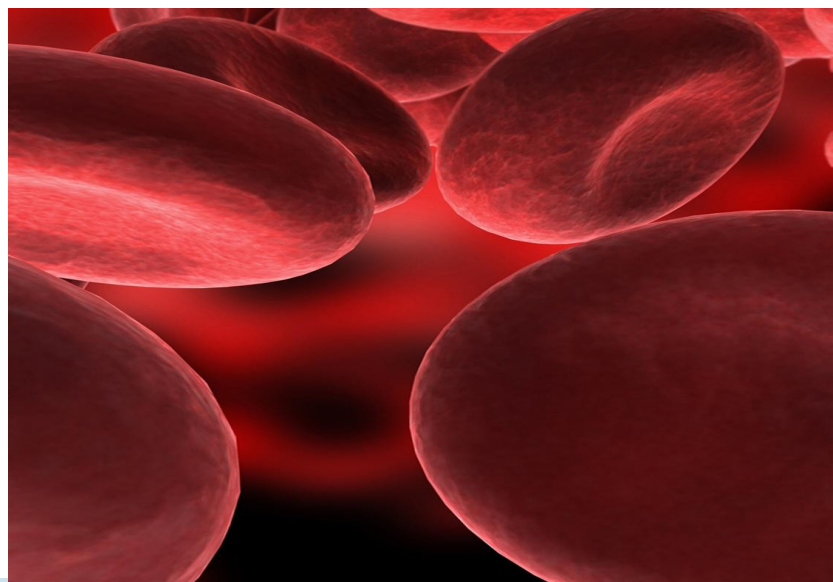
During the project, donors and depositors have been interviewed. They were mainly recruited through parent and baby groups and as a result of this contact, the team have been requested to write articles for the July edition of the National Childbirth Trust magazine.

Laura has attended the Anthony Nolan Trust/ British Society for Bone Marrow Transplantation (BSBMT) two-day conference on cord blood transplants in London on behalf of the project. Nik has presented to the haematology department at St. James Teaching Hospital in Leeds on the global trade of cord blood. This presentation was based upon a paper recently submitted to the journal *Social Science and Medicine*. The team have also a feature article in the journal of the BSBMT (Summer 2010).

The project has been timely given the surge of interest in the UK over cord blood banking, as illustrated by the government allocating £10 million to increase the amount of cord blood collected for the public bank and the current drive to develop a national strategy for the next 10 years. An All Party Parliamentary Group has been established around cord blood and Laura has had the opportunity to represent and raise awareness of the project at these meetings.

Both Nik and Laura will be presenting two papers at the British Sociological Association Medical Sociology Conference at Durham later in 2010. Nik's paper develops an anthropology of 'waste' and 'surplus' in the context of the cord blood economy. Laura will be presenting on the relationship between cord blood collection and reproductive rights. Both papers, together with a number of others, are in preparation for publication.

Website: <http://www.york.ac.uk/satsu/stem-cell-banking>



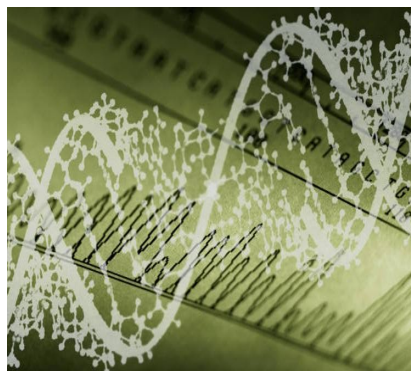
## Impact of Citizen Participation on Decision Making in a Knowledge Intensive Policy Field: Xenotransplantation (CIT-PART)

Dr Nik Brown  
Dr Sian Beynon-Jones

The CIT-PART project aims to compare the history of xenotransplantation policy-making across multiple countries and, in particular, seeks to explore the opportunities which existed for citizen participation in the policy process. It is funded by the European Commission's Seventh Framework Programme. Within SATSU, Nik Brown and Siân Beynon-Jones are leading a case study of the UK's xenotransplantation policy process. Their CIT-PART project partners are working on country case studies which include Austria, Canada, Denmark, Italy, Latvia, the Netherlands and Sweden.

Fieldwork for the UK case study (consisting of interviews with relevant policy makers and scientists as well

as an analysis of policy literature) is largely complete, and preliminary findings were presented at the 3<sup>rd</sup> project workshop in Riga (14<sup>th</sup>-16<sup>th</sup> June 2010). The UK team were also recently invited to represent the CITPART project at a workshop in Cambridge (1<sup>st</sup> June 2010) which brought together scientists, social scientists and regulators to discuss the history of xenotransplantation in the UK.



The wider CIT-PART project is reaching the end of its first reporting period and, in its next phase, will focus on the finalisation of the individual country cases and the co-ordination and integration of this data. This process will be facilitated by the production of a series of comparative papers for a proposed special issue of *Science and Public Policy*. The UK team will contribute a paper to this special issue, and will present this in draft form at *The European Association for the Study of Science and Technology 2010* in Trento. In addition to this paper, they are also preparing a separate article for *Health, Risk and Society*, which addresses the history of the UK's xenotransplantation policy process.

Website: <http://www.york.ac.uk/satsu/research/biosciences>

## Older People: Public Services and Information Technologies

Michael Hardey  
Brian Loader

Following completion of a three year project funded by the Department of Health Brian Loader, Michael Hardey and Leigh Keeble edited the book *Third Age Welfare: Health And Social Care Informatics For Older People* Routledge (2009).

The research project examined the use of information technology by both professionals involved in the care of older people and the role played by older people. Broadly, it was found that older people were only passive participants in, for

example, the assessment of their needs that involved the use of information technology. With the increasing emphasis on the delivery of public services partly through resources such as the internet the research team has gone on to highlight the opportunities and limitation of this trend.

In particular, the potential a new category of 'system outcastes' who may be victims of data errors or through data processing found not to be entitled to citizenship rights was highlighted in a paper in the *British Journal of Social Work*; Hardey, M. & Loader, B.D. (2009) 'The

Informatisation of Welfare: Older People and the Role of Digital Services', *British Journal of Social Work* 39(4):657-669.

Website: <http://www.hyms.ac.uk/research/sociology-social-policy>



Front cover of Loader, Hardey and Keeble (2008)

## E-health

Michael Hardey

An ongoing collaboration with the Open University of Catalonia (see Flupianez Lupiáñez-Villanueva, page 4) is examining the nature of e-health in Europe.

Using data from an extensive survey of health professionals in Catalonia a number of papers have been written. One focuses on how doctors are using information technologies and our statistical analysis resulted in the model of a 'integrated doctor'. For these doctors information technology is has become an essential tool and aid to their clinical practice. They may also engage in email interaction with patients.

We hope to undertake a further survey so that we can map how the number and role of integrated doctors has change over three years.

Related research into the way Web 2.0 resources and user generated information is changing e-health has resulted in the publication of research about patient reviews of doctors;

Hardey, M. (2010) 'Consuming Professions: User-review Websites and Health Services', *Journal of Consumer Culture*, 10 (1): 129-149.

This work seeks to understand the tensions between professionals and their clients in a time when health is increasingly seen as a matter of choice and individual responsibility. Under such conditions is the choice of doctor the same as, for example choosing a holiday and looking at customers experiences of a particular hotel?

Website: <http://www.hyms.ac.uk/research/sociology-social-policy>



## Health Bodies and Obesity

Michael Hardey

Obesity appears as 'the' public health issue and ongoing work with the University of Limerick is seeking a critical engagement with current health policies.

The research is also understanding what it is like to been categorised as obese and relate such experiences to theoretical work on masculinities.

Some findings are reported in; Monaghan, L.F. & Hardey, M. (2009) 'Bodily Sensibility: Vocabularies of the Discredited Male Body', *Critical Public Health*, 19, (3 & 4): 341 – 362.

This work continues with a study of heterosexual men's relationships and their beliefs about their bodies and health.

Website: <http://www.hyms.ac.uk/research/sociology-social-policy>



Courtesy of Michael Hardey

## Food Matters: A Sociological Case Study of Food and Eating Across the Life Course in York 1945-2010

Dr Emma Uprichard  
Dr Sarah Nettleton  
Sarah Shrive-Morrison

The project is currently half way through, with a year and half to go. So far, much of that time has been spent on collecting the documentary sources from the Mass Observation Archive. This has included two key sources in particular: the 1945 Food Directive which includes daily menus of individuals of various ages at that time; and the 1982 Winter Directive which includes over 300 letters responding to various food related questions, such as;

- what foods you choose not to eat; why?

- are there moral, health, political, religious and personal for not eating certain foods?
- what foods have been introduced to diets over the lifetime?
- memories of food, including food 'loves' and food 'hates'?

The project is about to move into its second phase of the project which will involve conducting intergenerational focus groups with local York residents aged from 7 years to over 76, and one to one interviews with key informants working in key food related outlets in York.

Website: <http://www.york.ac.uk/res/foodmatters>



Local Yorkshire produce. Image taken from Food Matters website

## Doctoral Projects in SATSU

**James Allen-Robertson**

James' PhD looks at the history of the digital distribution of media and examines various impacts that it has had on the creative industries, law and politics. The work charts the underground history of digital distribution and its roots in piracy networks, utilising a form of documentary analysis developed for the research that utilises a wide variety of traditional and unconventional sources. The second part of the research focuses on how digital distribution is bringing about a re-imagining of cultural production, driven by uncertainties over ownership, licensing and access, resulting in politicised conflicts over what our new forms of cultural production should look like.

**Bao Chang-Huang**

Peter's thesis examines the socio-technical systems in Taiwan's education regimes to examine the risk governance problems within hierarchical organisations. The thesis focuses on three issues; the relationship between risk in people's daily lives and the trend of risk by analysing historical records; secondly, the attitude of managers, who are the key persons facing and managing the risks and whose attitude may be influenced by the organisational culture; and finally, the opinions of risk managers who deal with risks in different positions as members of hierarchical organisations.

**Abbi Hobbs**

See page 16

**Kimberly Jamie**

Kim's PhD is funded by the ESRC and Pharmacy Practice Research Trust (PPRT) and focuses on pharmacogenetic technology (PGx) and its relationship with, and potential impacts upon, the pharmacy profession in England at a time when this profession is experiencing major practice changes. Kim is using semi-structured interviews with pharmacists and PGx stakeholders to understand how recent developments in PGx will affect the occupational status of the pharmacist; whether the changing role of pharmacists is likely to affect the uptake of PGx technology and, within this, what the specific implications of PGx for pharmacists working in hospital-based settings, in specialist pharmacy services and those in community practice will be.

Website: <http://www.york.ac.uk/satsu/people/>

# Research Biographies

## Research Fellow: Dr. Siân Beynon-Jones

Siân joined SATSU in November 2009 and is a Research Fellow on the European Commission Framework Programme-7 supported project *Impact of Citizen Participation on Decision Making in a Knowledge Intensive Policy Field (CIT-PART)*.

For her undergraduate degree she studied Molecular Genetics at the University of Dundee (1999-2003). During the course of this degree she became interested in the social implications of the new life sciences, in particular, the developments which were taking place in the Human Genome Project, and the increasing uses which were being made of genetic testing within clinical contexts.

In order to pursue these interests, she undertook a taught MSc in Science and Technology Studies at the University of Edinburgh (2004-2005), which provided her with the training necessary to transfer from the natural to the social sciences. Following this degree she was awarded a 1+3 (MSc by Research +PhD) ESRC studentship at the Institute for the Study of Science, Technology and Innovation at the University of Edinburgh (2005-2009).

Her doctoral research explored how Scottish health professionals define what is to count as expert (i.e. authoritative) knowledge in their work as abortion providers. This work revealed how health professionals' knowledge claims about abortion are interwoven with particular framings of femininity, socio-economic class, age and ethnicity, and also highlighted the ways in which these framings resonate with the discourses on abortion which dominate contemporary UK law and public debate on the subject.



Siân's research interests include feminist theory, the construction of expert knowledges concerning reproductive and other biotechnologies, and the demarcation of human/non-human boundaries within these contexts. Many of these interests are central to the current project in which she is involved, which addresses the history of the policy process surrounding xenotransplantation in the UK. As a technology, xenotransplantation generates questions concerning the basis of 'human' identity, as well as the uses which human beings can legitimately make of those who they define as 'non-human'.

Crucially, in the UK these questions have been articulated within a

science policy culture where only certain persons have been authorised to speak as 'experts,' making it vital to explore the ways in which this category (and thus, the possibilities of participation in policy-making) becomes constructed.

Website: [http://www.york.ac.uk/depts/soci/about/s\\_beyn.htm](http://www.york.ac.uk/depts/soci/about/s_beyn.htm)

# Research Biographies

## Research Fellow: Dr. Michael Morrison

Michael joined SATSU at the University of York as a research fellow in 2009. He is currently working on the European Commission Framework Programme-7 supported Regenerative Medicine in Europe (REMEDIÉ) project, where he is responsible for the co-ordination of work package 1, investigating and mapping the commercial development of regenerative medicine in Europe.

Michael has a background in the biosciences, holding a BSc (Hons) in Biology from the University of St. Andrews (2000) and has previously worked for an Oxfordshire-based biotechnology firm. This has allowed him to bring an understanding of scientific and technical concepts to his current work. In 2001-2 Michael studied for a Masters by Research and Thesis with the interdisciplinary *Institute for Genetics and Society* (IGBiS— now incorporated into the Department of Sociology) at the University of Nottingham. The taught components of this programme involved learning about the STS approach to the study of science and technology, as well as training in social research skills and theory. Remaining at Nottingham, he spent a year collaborating with Professor Paul Martin on a report evaluating the potential of genomic medicine for the Royal Pharmaceutical Society of Great Britain, before undertaking an ESRC-supported PhD (2008), also at IGBiS.

Michael's doctoral thesis combined historical documentary analysis with contemporary interview data to produce a socio-technical account of the development of human Growth Hormone (hGH) as a biopharmaceutical drug. Using a case-study framework, the thesis traced the development of the drug for contrasting applications, primarily



the treatment of childhood short stature and its off-label use as an anti-ageing agent, and drawing on a US-UK comparison to highlight the role of academic-industrial networks and tacit social values about the meanings of short stature and old age in shaping the medical use of the hormone and the framing of particular applications as legitimate or otherwise. Many of Michael's core research interests are reflected in this work; the development, social shaping and commercialisation of novel biotechnologies (growth hormone is produced by recombinantly engineered cell cultures), and the way in which these disruptive technologies affect (and are affected by) existing socio-cultural relationships and values.

Michael's current work on the REMEDIÉ project develops some of these themes in the context of regenerative medicine (cell therapy, stem cells and gene therapy) focusing in particular on key strategic issues for European firms wishing to develop regenerative therapies using these novel biomaterials. Such issues include the choice of cell sources (stem cells vs somatic cells), selection of therapeutic targets, and whether to develop autologous or allogenic tissue products. Michael also has research interests in the history of medicine and medical technology, and (sociology of) bioethics, especially with regards to the concept of human enhancement technologies.

Website: [http://www.york.ac.uk/depts/soci/about/s\\_morr.htm](http://www.york.ac.uk/depts/soci/about/s_morr.htm)

# Research Biographies

## Doctoral Student: Abbi Hobbs

Abbi Hobbs graduated from University College London in 2004, with a BSc (First) in History and Philosophy of Science. After a year working in York she took a Masters (Distinction) in Research Methods: Genetics, Biorisks and Society under a 1+3 studentship from the ESRC. She transferred her award to the University of York in 2006 to undertake her PhD under the guidance of Dr Nik Brown.

Her thesis, 'Reconstructing Drug Addiction: A Sociological Examination of the Development of Vaccines for Drug Addiction' is looking at the development of active immunotherapies or 'vaccines' for drug addiction, a new technology that is being developed by a number of biotechnology firms. It examines the way in which these vaccines are being shaped by new scientific knowledge, changing ideas about the nature of addiction, established policies and practices for drug treatment, and the potential social and ethical concerns raised by their use. In particular, it focuses on the changing scientific and moral discourses surrounding addiction and the rights and responsibilities of parents and children with respect to vaccination. She is currently writing up and hoping to submit in Autumn 2010.

Abbi took 3 months out of her PhD between January to March 2009 to take up a three-month ESRC fellowship at the UK Parliamentary Office of Science and Technology, POST, which is the UK Parliament's in-house source of independent and accessible analysis of public policy issues related to science and technology.

Her research was on the topic of 'futures' work, following on from a recommendation in a 2007 House of



Commons Public Administration Select Committee report, which suggested that the UK Parliament strengthen its capacity to think ahead and engage with outside experts and the wider public. The work resulted in a POSTnote (no.322) on the key characteristics of futures work and its current use by governments and parliaments. It covers futures work at national and local levels, and the extent to which it needs to consider social and other trends alongside developments in science and technology. It was published in May 2009 and can be downloaded for free at: [www.parliament.uk/parliamentary\\_offices/post/policy.cfm](http://www.parliament.uk/parliamentary_offices/post/policy.cfm)

Whilst writing up her thesis, Abbi has also been working since February

2010 on a European social science research project on Biobanks, led by Professor Herbert Gottweis from the Life-Science-Governance Research Platform at the University of Vienna, Austria. The project is a multi-site comparative study about the perception of biobanks in different publics in Germany, Austria, France, the Netherlands, Finland, Greece and the UK. The project is funded by the Austrian Genome Project (GEN-AU), an Austrian government program set up by the Ministry for Science and Research in September 2001.

Website: <http://www.york.ac.uk/depts/soci/research/reshobbs.htm>

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