



the gen

SOCIAL SCIENCE

International rescue:

Can social science help save the world?

Living with the genome – ten years on

Social science matters

Do pills mean progress?

The economic and social lives of data intensive sciences



16

International rescue



20

Living with the genome – ten years on



26

Do pills mean progress?

Welcome

to our September 2010 issue of *the gen*. This autumn, our feature articles highlight what EGN social science researchers can offer both the UK (p10) and international policy making processes (p16). We also wish the human genome a happy 10th birthday (p20), offer ways to navigate the data deluge that accompanies today's research practices (p28), argue the case for social science funding (p15) and investigate whether pills mean progress (p26).

As always, we'd like you to tell us what you think. Please send letters, comments or suggestions to info@genomicsnetwork.ac.uk or write to **Genomics Network Newsletter, ESRC Genomics Policy and Research Forum, University of Edinburgh, St John's Land, Holyrood Road, Edinburgh, EH8 8AQ**

FEATURES

10

Policy engagement in the EGN

As the EGN gets ready to host events at the UK's political party conferences for the first time this autumn, we look at how our research has already fed into life-science-related policy decisions.

15

Social science matters

In an open letter to David Willets MP, Egenis' Director urges the Science Minister not to make social science one of the government's spending cuts casualties.

16

International rescue

Researchers across the Network consider how social science can help international development policy avoid past mistakes.

20

Living with the genome – ten years on

Dr Steve Sturdy and Ken MacLeod from the Genomics Forum discuss what the human genome's 10th birthday means for them.

26

Do pills mean progress?

Innogen's Dr Rebecca Hanlin investigates the relationship between researching vaccines and medicines and supporting health care systems in developing countries.

28

The economic and social lives of data-intensive sciences

Cesagen details its attempts to curate and analyse the data deluge that accompanies modern day research into the contemporary life sciences.

REGULARS

3 RESEARCH NEWS

5 WEB BYTES

6 CENTRE NEWS

14 DIRECTOR'S COMMENTS

22 NETWORK EVENTS

24 NETWORK PEOPLE

31 MY WORKING LIFE

Funding success for Innogen

Innogen and other partners received a £444,000 award under the Technology Strategy Board Regenerative Medicine Programme: Value Systems and Business Models. The project, “A Therapy Realization Pathway Tool (TRPT) applied to three representative regenerative medicine therapeutic products (REALISE)” will be led by the Scottish Stem Cell Network (SSCN) on behalf of a consortium which involves Roslin Cells Ltd, KLCE Consulting Ltd, the ESRC Innogen Centre and other University of Edinburgh academics.

The REALISE project will develop a software based tool for researchers and companies. The tool will allow people to better understand and plan the optimal route for the commercialisation of new regenerative medicine therapies. In the first instance, the tool will be used to develop commercialisation plans for three new therapies currently in development with Roslin Cells. In addition it will form the basis of a generic tool with wider applications in the pharmaceutical, medical device and diagnostic sectors.

Professor Joyce Tait, Dr James Mittra, Dr Michele Mastroeni and Heather Lowrie from Innogen will be working on this project which will be completed by November 2011.

Children with autistic traits remain undiagnosed

Ginny Russell, a PhD student at Egenis, has published a paper in the *Journal of Child Psychology and Psychiatry*. The study, conducted with colleagues from the University of Bristol and Peninsula Medical School, found that many children who have autistic traits are never diagnosed clinically and receive no support, therefore, from educational or health services.

Ginny’s study found that a large number of undiagnosed children displayed autistic traits at levels comparable to the traits displayed by children who held a clinical diagnosis. However, the undiagnosed children were not deemed eligible for extra support at school or by specialized health services.

“Diagnosis currently holds the key to unlocking intervention from school systems and health programmes,” says Ginny. She points out that the study also shows that there is a gender bias in diagnosing children with autistic spectrum disorders – boys are more likely to receive a diagnosis than girls, even when the girls display equally severe symptoms.

Full article at:
<http://www3.interscience.wiley.com/journal/123327359/>

Report on ‘Democs’ returns interesting results

In 2007, the Genomics Forum received a small grant from the Scottish Government to undertake public engagement activities relating to synthetic biology, an emerging scientific discipline that is receiving considerable media and policy attention. We used this grant to develop a version of Democs, a public dialogue tool. Results from the project now suggest that synthetic biology is a relatively difficult subject for the average citizen to engage with. The Democs game has served to open up questions that people had not previously thought about, rather than helping to crystallise their thoughts about already known issues. It would be premature to draw strong conclusions at this point about overall support for, or concerns about, synthetic biology amongst UK or Scottish citizens. People are not familiar enough with the issues, and will need more time to digest and reflect.

As with nanotechnology, the case of synthetic biology may indicate the limitations of upstream engagement, at least in the short term. From this sample of people, there did not emerge a serious fundamental objection to the very idea of synthetic biology. There was strong overall support in the voting for most possible applications, particularly from participants working in the sciences (as might be expected). But there was also a sense of caution from many people about the import of making significant modifications of this sort.

For a copy of the report and further information contact:
Christine.Knight@ed.ac.uk

New publication from the EGN’s Genetics & Society book series

A new book *Debating human genetics: Contemporary issues in public policy and ethics* was published by Routledge in July. The author is former Cesagen researcher Dr Alexandra Plows, who worked on Cesagen’s Phase 1 flagship project “The emerging politics of human genetic technologies”. The book is based on ethnographic research conducted during this project, and focuses primarily on the UK publics who are debating and engaging with human genetics, and related bio- and techno-science.

By grounding the concepts and issues of human genetics in the real life narratives and actions of patient groups, genetic watchdogs, scientists, policy makers, and many other public groups, the book exemplifies how human genetics is a site where public knowledge and value claims converge and collide, and identifies the emergence of ‘hybrid publics’ who are engaging with this hybrid science.

Sustainable bioenergy funding and workshop on human enhancement

Dr Theo Papaioannou (Innogen) and Open University colleague Dr Les Levidow will receive £182,973.92 from the ESRC to investigate knowledge production processes for sustainable bio-energy. The main research question is: how do discourses, practices and interests of techno-scientific knowledge figure in selecting national research priorities for sustainable bio-energy from a wider range of options?

Possible explanations lie in different actors' models of valuable knowledge, competitiveness, and environmental sustainability.

Theo also organised a half day international workshop on 'Human Enhancement and Distributive Justice: What are the Implications for Policy and Practice?', held at the Open University on 23 June 2010. The workshop recognised that new life sciences innovation offers not only the prospect of applications with profound impact on social and economic life but also the possibility of changing basic parameters of human nature with significant impact on distributive justice. Speakers included academics from Italy, Ireland and the UK.

Police investigations

'The use of forensic DNA technologies in police practice' is a new project headed by Dr Christine Hauskeller and Dr Dana Wilson-Kovacs at Egenis. This area of research has developed from earlier work on genomics and identity politics, in particular the engagements with the National Policing Improvement Agency following the workstream event 'Genetic suspects: Emerging forensic uses of genomic technologies'. The study will explore the modelling of faster DNA testing kits in a current joint effort by law enforcement agencies and the industry supplying forensic technology to improve police work. Its findings are intended to enhance debate about the use of DNA technologies, and to inform evidence-based policies on the use of science and technology in police practice. Dr Wilson-Kovacs will participate in workshops and carry out interviews with members of the police force and forensic services.

Centre for Nanotechnology in Society (CNS) collaboration

Dr Emma Frow (Genomics Forum) and Dr Jane Calvert (Innogen) have been awarded an ESRC-SSRC Collaborative Visiting Scholars grant to work with the Centre for Nanotechnology in Society (CNS) at Arizona State University. Emma and Jane will each spend 3 weeks at CNS in October/November 2010, to do some comparative work on the roles of social scientists in nanotechnology and synthetic biology. The ESRC Genomics Network will host a return visit from CNS scholars during 2011.

Doing research, creating impact

- How do research projects imagine and then enact their impacts?
- How does context affect what projects promise and what they do?
- Why does doing what projects say they will not guarantee expected outcomes?

In collaboration with the Finnish Environment Institute and North Karelia University of Applied Sciences, Cesagen researcher Dr Ruth McNally has been experimenting with a novel method for providing answers to some of these pressing questions. Their experiment was the first ever to use PROTEE, a tool developed in an EU project that Dr McNally worked on previously, to learn about the challenges of trying to achieve scientific impact with excellence. The project they studied involved a field trial with genetically modified trees.

To find out more, contact R.McNally@lancs.ac.uk or see: Helena Valve, Ruth McNally and Ari Pappinen (2010) 'Doing research, creating impact: Using 'PROTEE' to learn from a genetically modified tree field trial' *Science and Public Policy*, 37(5), June, pages 369–379.



£17.99

NATURE AFTER THE GENOME

EDITED BY DR SARAH PARRY (INNOGEN) AND PROFESSOR JOHN DUPRE (EGENIS)

This new book features a series of case studies that explore the relationship between developments in genomic technologies and our knowledge and understanding of nature. The book draws on the research findings from the ESRC Genomics Network. Jane Calvert (Innogen), Barry Barnes (Egenis) and Claire Waterton (Cesagen) have contributed chapters.

Published by Wiley-Blackwell, ISBN 978-1-4443-3396-1



Are there 'genes for' traits?

BioNews, a website which aims to provide balanced and timely news and comment on genetics, embryo/stem cell research and related areas, invited Egenis director Professor John Dupré to write about media coverage reporting 'genes for' various traits. His comment argued that "the term 'gene for trait X' is diverse in meaning and potentially highly misleading". He concluded, "The uses that appear most often in the media have no causal implications of the kind typically assumed by the casual reader. A great deal of confusion could be avoided if the expression were avoided altogether."

http://www.bionews.org.uk/page_54781.asp

Genotype

The Forum has launched a new blog, 'Genotype' providing comment and discussion on topical life science issues. Visit <http://esrcgenomicsforum.blogspot.com/> to find out more.

Writers wanted

Innogen are on the lookout for guest contributors to write short posts on Biodigital Futures for the Innogen Blog over the autumn. Contact Clare de Mowbray at c.demowbray@ed.ac.uk to find out more!

Innogen Insider: <http://innogencentre.blogspot.com/>

sciSCREEN blog

Cardiff sciSCREEN has recently launched a blog: <http://cardiffsciscreen.blogspot.com>

Cardiff sciSCREEN, a collaboration between Cardiff University's MRC Centre for Neuropsychiatric Genetics & Genomics, Cesagen and Chapter Arts Centre, uses cinema to promote the engagement of society in the complex field of biomedical science and genetics.

EGN conference 2010 now online

A dedicated website for 2010's annual EGN conference is now live. Visit <http://www.genomicsnetwork.ac.uk/forum/conference2010> for the latest programme news, further information on the conference's key themes, plenary sessions and workshops, as well important details about the event's registration process.

EGN on TV

YouTube has arrived at the ESRC Genomics Network! Get the lowdown on our latest research and activities, find out how you can collaborate with EGN researchers and learn more about key issues in the contemporary life sciences.

<http://www.youtube.com/genomicsnetwork>

Delivering Global Promise Through the Life Sciences Conference 2010

Monday 6 & Tuesday 7 December 2010
OECD Conference Centre, 2, rue André Pascal, Paris

For further information visit www.genomicsnetwork.ac.uk
or email forum@genomicsnetwork.ac.uk



in partnership with



What should happen to your brain after you die?

Gengage (The Scottish Healthcare Genetics Public Engagement Network), managed by the Genomics Forum, has published the results of a public deliberative event on brain banking. 'What should happen to your brain after you die?' was run as part of the Edinburgh International Science Festival and featured expert speakers including Professor James Ironside, (Professor of Clinical Neuropathology, University of Edinburgh, and Director of the MRC UK Brain Banks Network) Professor Richard Reynolds (Professor of Cellular Neuroscience, Imperial College, London, and Scientific Director of the UK Multiple Sclerosis Tissue Bank) and Ms Tracey Millar (Research Nurse Co-ordinator, MRC Sudden Death Brain and Tissue Bank).

More than 50 participants gathered at the Royal College of Surgeons in Edinburgh for three hours of lively debate and facilitated round table discussions which addressed issues around brain banking and brain donation for research.

The event was chaired by Kenneth Boyd (Professor of Medical Ethics, The University of Edinburgh). Full details and speakers' presentations are available on <http://tinyurl.com/35gugkq>.



Innogen involvement in OECD workshop on environmental biotechnology



Professor Joyce Tait CBE,
Scientific Advisor at the ESRC Innogen Centre

Professor Joyce Tait CBE, Scientific Advisor at the ESRC Innogen Centre, has been invited to participate as the Rapporteur in an OECD workshop on "The Future of Environmental Biotechnology: Science, Technology, Policy and Society". This two-day workshop will be hosted by University of Bologna (Italy) and held on 16-17 September 2010 in conjunction with the 14th International Biotechnology Symposium and Exhibition in Rimini.

The workshop is designed to address a number of key issues related to biotechnology innovations impacting the environment. The results of the workshop discussions, together with a number of case studies and the country policy reviews distributed beforehand, will be used to develop the first version of an OECD Policy Report on critical issues in environmental biotechnology. The workshop will also help define the way forward for improving delivery of innovation-led green growth through uses of biotechnology in the environment.

Swiss symposium

A symposium proposed by Egenis researchers has been accepted by the prestigious Brocher Foundation in Geneva.

'New developments in non-invasive prenatal genetic testing: Ethical, legal and social implications', organised by Dr Susan Kelly and Dr Hannah Farrimond, will take place with 30 invited participants at the Foundation in November next year. The Brocher Foundation is a non-profit making institution which supports multidisciplinary study of the ethical, social and legal issues of medical research and new medical technologies.

The symposium will bring together experts from around the world who are engaging with the development of non-invasive prenatal genetic diagnosis (NIPD) to consider how it will, or should, shape future prenatal health policy and regulation. It will explore, for example, whether NIPD technologies raise new questions about the moral and public health justifications for routine antenatal screening and testing.

It is hoped the event will also lead to the creation of an international 'network of expertise' about the ethical, legal and social implications of NIPD, which could be called upon to advise governments and other regulators as they develop policies on the clinical implementation of NIPD.

Is medical ethics really in the best interest of the patient?

The Centre for Research Ethics and Bioethics, Uppsala University and Cesagen organised 'Is medical ethics really in the best interest of the patient?', a conference held in Uppsala, Sweden in June.

In his keynote lecture, Professor Tom Beauchamp (Georgetown University) presented his critique of the traditional distinction between research and practice, illustrating this with case studies to show that how research is regulated can cause problems when what is actually going on looks more like clinical practice.

Professor Donald Chalmers (University of Tasmania) addressed the question of whether Research Ethics Committees (RECs) are properly equipped to work in the best interests of participants in an increasingly globalised research environment. In the same session, Dr Simon Whitney (Baylor College of Medicine) presented a provocative account of his view that regulation slows research and therefore costs lives. As respondent, former Cesagen member Professor Søren Holm (Manchester University) steered a course between these two perspectives, asserting that "ethical review is both an important ethical safeguard and overburdensome and unnecessarily bureaucratic". These three keynotes sparked an animated and diverse discussion between panel members and from the floor.

News Bites

→ Colour Coded

Egenis's Staffan Müller-Wille guested on Radio 4 in June as an interviewee on *Colour Coded*. The two-part programme explored why we tend to define people by their skin colour. Staffan talked to the programme's presenter, Trevor Phillips, chair of the Equality and Human Rights Commission, about Linnaeus and the categorisation of race.

→ Edinburgh Book Festival success

For the fifth year running, the ESRC Genomics Forum sponsored a series of events at the Edinburgh International Book Festival. Discussions ranged from what it means to have virtual friends in your life, and how environmental influences affect intelligence to contemplations on the future of human beings. As usual, there were lively discussions between audiences and our stellar cast of speakers which included renowned author Iain M Banks, TV's Jason Bradbury, one of the world's most influential Twitterati, Kevin Warwick, Cybernetics Professor and the world's first cyborg and David Shenk, journalist and best-selling author.

→ Genomics poetry competition

Further to the success of the Forum's 2009 Genomics Short Story Competition, Pippa Goldschmidt, Forum Writer in Residence, launched a poetry competition this summer asking writers to write a poem of not more than 50 lines on the theme of 'improving the human'. Winning entries are expected to be announced in November 2010 and published online and in a special printed collection. Judges for the competition include Gwyneth Lewis, Wales' first national poet, Peggy Hughes, from the Scottish Poetry Library (SPL), and Professor Steve Yearley. The competition is being run in association with the SPL.

Investigating online psychiatric genetic tests

A new study will examine the impacts of direct to consumer (DTC) access to genetic tests for serious psychiatric disorders. The project, funded by the ESRC and the NWO, is a collaboration between Egenis and the Virtual Knowledge Studio at the University of Maastricht.

The research will examine how products, genetic science, consumers and health information are represented on online sites and will also examine claims and promises being made in the controversial area of psychiatric genetics. The study will also examine perspectives on psychiatric genetics and DTC genetic testing by user groups (persons living with a psychiatric diagnosis, family members and carers, as well as health care professionals).



Egenis senior research fellow Dr Susan Kelly said: “The internet provides consumers with direct access to genetic tests and personal genetic information, potentially unmediated by healthcare professionals. These developments raise questions about patient empowerment, regulation, and the ability of consumers to make health care and lifestyle decisions on their own, or in improved partnership with healthcare providers.”

Prestigious academic prize for Associate Director of Cesagen

Professor Brian Wynne, Associate Director of Cesagen, Lancaster University, has been awarded the prestigious J D Bernal Prize for his distinguished contribution to the social studies of science.

The Bernal Prize is the highest honour given by the Society for Social Studies of Science (4S), and is awarded annually. Previous recipients have included Donna Haraway, Joseph Needham, Sheila Jasanoff and Thomas Kuhn.

On learning that he would be receiving the award, Professor Wynne said: “It is humbling to realise the stellar company in which this award places me. The insights which the field nurtured by 4S has struggled to develop and communicate over the last forty years are central to a much larger work which needs to be done. This is to imbue the new global relations between East and West, North and South, global and local, and the anxious instrumental frenzy of innovation which this fuels, with a genuinely cosmopolitan, adventurous, grounded humility in the knowledge which we claim gives us license. The only proper response to this award is now to begin to try to earn it.”

Judged by genetics?

The Forum, with the British Council, hosted a lively discussion exploring the controversial issue of using DNA testing to determine the nationality of asylum seekers as part of the Scottish Parliament’s 2010 Festival of Politics.

An expert panel including representatives from the Scottish Human Rights Commission, Scottish Refugee Council, and Strathclyde University debated the pros and cons of using genetic testing to verify an asylum seeker’s country of origin, as well as broader questions about science taking precedence over personal experience or history.

Dr Steve Sturdy, Deputy Director of the ESRC Genomics Forum, commented, “Before implementing DNA testing for asylum seekers it is vital that we take stock of just what tests can and cannot tell us, and how such information might relate to the circumstances under which asylum seekers come to this country. The Genomics Forum was delighted sponsor this event, which provided a valuable opportunity to debate what may literally be questions of life and death.”

See <http://tinyurl.com/347gvfm> for further information on the EGN’s research into some of the issues surrounding ‘identity’ politics. www.festivalofpolitics.org.uk/index.htm



Applying research tools and techniques to other areas

Innogen's interdisciplinary approach to genomics research has led to new research tools and techniques, high profile academic papers and unique insights. Recently, a number of colleagues have been awarded funding to apply these research methods to other areas:

Sustainable Practices (ESRC/Defra/Scottish government)

A new three-year project on Sustainability asks 'How Might Social Science Influence Public and Policy Debates About Sustainable Consumption And Behaviours?' Dr Sarah Parry is the Principal Investigator for the Engagement, Interaction and Influence work-package. Sarah will build on previous research on public engagement into this new empirical area to establish new ways of thinking about behaviour in political, policy and public debate.

Interdisciplinary research: Natural Environment Research Council (NERC)

Innogen's expertise in research at the interface between the social and natural sciences led to funding from NERC to conduct an interdisciplinary learning review of the QUEST programme.

Clean Technology (British Academy)

Dr Stuart Parris will apply research methods from his PhD work on biotech companies to a new project analysing the clean technology sector.

News Bites

→ **Research careers advice**

Professor Robin Williams, Innogen Co-Director, was invited to run a session on Research Careers at the Tomorrow's Giants Conference in London on 1 July, co-hosted by The Royal Society and *Nature*. The conference brought together scientists and policymakers to gather scientists' vision of the next 50 years.

→ **Presentation to Chemical Heritage Foundation**

In May, Cesagen researcher Dr Richard Tutton was invited to speak at 'Personalizing Medicine Here and Now: Empirical Studies of Post-Genomic Medicine' at the Chemical Heritage Foundation, Philadelphia. He presented a paper entitled 'Democratizing Genomics? Expectations and Constructions of Personal Genomics Futures'.

→ **Genetics in the dock at Hay**

Egenis Director Professor John Dupré joined Lord Robert Winston at 'HowTheLightGetsIn', the world's only philosophy and music festival, at Hay-on-Wye, to discuss whether or to what extent our genes define who we are. Professor Dupré was a discussant in the session 'Genetics in the Dock', together with Lord Winston, Lewis Wolpert and Mary Midgley.

→ **EASST: 'From biodigital lives to bioIT worlds', 2 – 4 September 2010, Trento, Italy**

Cesagen members Professor Larry Busch, Dr Adrian Mackenzie, Dr Ruth McNally, Dr Richard Tutton and Dr Kate O'Riordan are convening a conference track on a data-related theme at the European Association for Science and Technology Studies Conference. Papers will focus on the mingling of IT and biological sciences in many settings. It comprises papers ranging across personalized genomics, proteomics, synthetic biology, standards, and population studies.

Policy engagement with the ESRC Genomics Network

The ESRC Genomics Network has a strong track record of engagement with the policy and regulatory process in the UK, Europe and internationally.

Cesagen

Based at Lancaster University and Cardiff University, Cesagen is a multidisciplinary centre investigating the economic, ethical and social factors that shape knowledge in genomics and other life sciences.

One policy arena where Cesagen research is making a significant international contribution is the United Nations Convention on Biological Diversity that is expected to adopt a new protocol on access to genetic resources and benefit-sharing at the 10th Conference of the Parties in Nagoya, Japan, in 2010.

Dr Paul Oldham, a social anthropologist, has participated in these debates since 2001. In 2009, Dr Oldham made two contributions to debates on the protocol: a discussion paper, focusing on the possible role of “commons” or “open source” licensing models under the protocol, and 20 pages of legal text proposals for possible insertion into the negotiating text for the new protocol.

These text proposals were reviewed by the 113 Parties at the 8th meeting of the Working Group on Access to Genetic Resources and Benefit-Sharing. In the first reading proposals were placed on screen with a requirement that one or more Parties sponsor them. The Africa Group of countries sponsored the Cesagen proposals through two subsequent readings, and they were then incorporated into a negotiating text known as “the Montreal Annex”.

Negotiations on access and benefit-sharing for the world’s genetic resources are heavily contested. This has led to a focus on the minimum that can be agreed by governments. The time for commons approaches

www.genomicsnetwork.ac.uk/cesagen/research

has not yet come. A streamlined Co-Chairs text now serves as the draft protocol and governments are concentrating on difficult issues such as agreement on check points for compliance with rules on benefit-sharing and access to pathogens.

In debates during July 2010 Dr Oldham worked with public researchers to promote recognition of non-commercial research within the protocol. Dr Oldham also presented a joint study with United Nations University on ‘disclosure of origin in patent applications’ and global statistical indicators for patent activity for biodiversity. This collaboration is now being extended to debates at the World Intellectual Property Organisation and World Trade Organisation.

This is an unusual case of policy engagement combining independent research inputs with direct participation in drafting and negotiating an international protocol. It reveals the need for a long term approach to impacts on policy, an ability to work across multiple disciplines, and the patience to identify independent research contributions to inform what are often very challenging debates that may affect all our futures.

For more detailed information about this work please visit: <http://tiny.cc/ja4ng>

Through www.genomicsnetwork.ac.uk you can access our policy briefings, research reports and responses to public consultations.

Many of our events are open to representatives from the public and third sectors. We invite you to join us at one of our multidisciplinary workshops, which focus on a wide range of topics relating to science, technology and innovation. You may also be interested in our 2010/11 workstream on Health Technologies and Health Systems.

If you have an enquiry about the Genomics Network's research as it relates to policy, please contact in the first instance:

- **Christine Knight**, Policy Officer, Genomics Forum
Tel: 0131 651 4743
- **Flo Ticehurst**, Communications Officer, Cesagen
Tel: 029 2087 0024
- **Claire Packman**, Communications Officer, Egenis
Tel: 01392 269 126
- **Jennifer Foley**, Communications and Policy Officer, Innogen, Tel: 0131 650 2842

Egenis

Based at the University of Exeter, Egenis is a centre of expertise in questions concerning the development and societal impact of the life sciences. The success of Egenis is closely linked to its interdisciplinarity, joining social science, humanities and biological expertise.

Egenis's ongoing and new projects examine and elaborate on emerging uses of genomics in society and in science. These include investigations into stability and change in biology, medicine, and social and political institutions such as the systems of patenting and the law, surveillance, and the formation of personal and social identity.

Centre staff engage with policymakers, user groups and other stakeholders, including clinicians, by involving them in their research and discussing findings with them. We are creating a global network of scientists, social scientists and lawyers working on the regulation of data-sharing and data-driven research. We are working closely with the National Police Improvement Agency on our 'Forensic DNA' project, and with other police bodies including local forces. The project 'User perspectives on direct-to-consumer psychiatric genetic tests', involves close liaison with health care practitioners and mental health user groups. Researchers on the 'Non-invasive prenatal genetic diagnosis' project are working with third-sector organisations such as the charity Antenatal Results and Choices, and with the Fetal Anomaly Screening programme. Discussions include an extension of the screening programme in the NHS and the introduction of further prenatal tests, and the regulation of testing outside the clinical setting, for example fetal sex-selection tests available over the internet.

www.genomicsnetwork.ac.uk/egenis/research

The Egenis response to the Human Genetics Commission (HGC) consultation on a framework of principles for direct to consumer genetic testing included a proposal for improving regulation, including ISO standards for such tests. John Dupré and Staffan Müller-Wille both gave presentations at the HGC seminar 'Understanding Genetic Discrimination'.

The Genomics and Identity Politics project has led to an expert workshop being organised with the HGC on 'The use of molecular technologies to assess the country of origin of immigrants'. The important policy implications raised in the dialogue with the HGC led them to identify a need for a such a workshop to facilitate the 'joining-up' of those institutions that use these technologies and those that develop policies and regulations regarding their use, including the Home Office. The project raises awareness of the methodological problems involved in trying to relate social categories such as ethnicity to genetic and other molecular data derived from human tissue.

The project 'Stem Cells in Context', led to an invited contribution to an expert report to the Austrian Government and a special expert hearing of the German Central Ethics Commission on Stem Cell Research. Lead investigator Christine Hauskeller met with the HGC, and the team submitted evidence to the House of Lords Science and Technology Committee. They have given more than 20 presentations to scientists and at workshops and conferences, including participating in the BBSRC/MRC Stem Cell Dialogue event.

Egenis staff have provided written input to a range of other reports and consultations, including to the Nuffield Council on Bioethics, the Department of Health and the Human Genetics Commission.

Innogen

www.genomicsnetwork.ac.uk/innogen/research

Based at the University of Edinburgh and the Open University, Innogen studies innovation in genomics and the new life sciences; how these new technologies are governed and regulated; and the impact of life science innovation in developed and developing countries.

Innogen has developed an extremely influential programme of research on the 'Appropriate Governance of the Life Sciences'. This programme encompasses strategic innovation issues in the life sciences; how innovations are governed and regulated; and the resulting innovation trajectories that determine which products are developed and which companies take the lead in developing them.

Some of our insights in this area were summarised in a report to the OECD on 'Health Biotechnology to 2030' as part of the wider OECD programme on 'Biotechnology Futures: Designing a Policy Agenda'. The importance of the role of regulatory systems in the innovation process is a fundamental part of our research findings, and a major feature of this report.

Andrew Jack of the Financial Times approached Innogen Professors Joyce Tait CBE and Joanna Chataway (now also part-time Director of Innovation Policy at RAND Europe) to lead a session on regulation at the Financial Times Global Pharmaceutical and Biotechnology Conference in November 2009. The session, entitled 'Smart regulation: the key to radical transformation', asked how a more strategic, integrated approach to regulatory reform could deliver radical transformation in the innovative capacity of the pharma and biotech sector. The session was chaired by the Executive Director of the European Medicines Agency (EMA), and senior management figures from the US Food and Drug Administration, Pfizer Ltd and PATH India

joined Professor Tait on the panel. The presentations were well received and we continue our highly influential work in this area, with a series of high-profile policy workshops under development.

The Scottish Government has shown strong interest in our work, specifically on the life science industry in Scotland. Dr Alessandro Rosiello's research was cited in the new Innovation Framework for Scotland published in 2009.

Innogen has also made key policy contributions to synthetic biology, an emerging field in the life sciences. Professor Tait is a member of the Scientific and Technical Council of the International Risk Governance Council (IRGC), based in Geneva. Professor Tait and Innogen PhD candidate Heather Lowrie produced a highly praised Concept Note for the IRGC and other policymakers on the Risk Governance of Synthetic Biology.

Dr Jane Calvert is also heavily involved in social science research on synthetic biology. Dr Calvert was appointed to the Royal Academy of Engineering Working Group on synthetic biology, which published the report 'Synthetic Biology: Applications and implications' in May 2009. Dr Calvert also sits on the Nuffield Council of Bioethics Working Party on Emerging Biotechnologies and the BBSRC/EPSC Synthetic Biology Dialogue Oversight Group.

Other Innogen colleagues are involved in a number of Committees and Working Groups including the UK Department for International Development (DFID) Research Into Use Programme, Human Genetics Commission, UK Biobank Ethics and Governance Council, Nuffield Council Working Party on New Approaches to Biofuels, and Food Standards Agency GM Dialogue Steering Group.

Genomics Forum

Based at the University of Edinburgh, the Forum pioneers new ways to promote and communicate social research on contemporary life science and ensures that research from the Genomics Network informs policy, scientific practice and public debate.

As the ESRC Genomics Network's (EGN) dedicated knowledge exchange unit, part of the Genomics Forum's role is to ensure that EGN research connects with public policy debates, bringing outstanding social science into decision making in the UK, Europe and internationally. In part, the Forum achieves this by supporting the network's own policy engagement initiatives, and ensuring that network researchers are fully informed of opportunities to engage with the policy process. The Forum also runs its own programmes to bring social scientists and policymakers together, including events, publications, exchange and collaboration schemes.

The Forum's Bright Ideas Programme is our flagship residency or fellowship scheme open to government and third-sector professionals working in life science and biotechnology policy. The programme allows individuals to spend up to two months in residence at the Forum, with time and space to undertake a programme of work tailored to their own interests. Outputs can include research articles or reports, shorter briefings, workshops or public events, or any other activity that offers benefit to the Forum and the partner organisation. The scheme is highly flexible and financial assistance is available for travel, accommodation and subsistence.

The Forum also runs regular multidisciplinary workshops involving policy makers and regulations on a wide range of issues relating to science, technology and innovation; recent topics have included development policy, epigenetics, and forensic uses of genomic technologies.

www.genomicsnetwork.ac.uk/forum

Events may be produced in collaboration with public or third sector organisations, and we engage in larger-scale partnerships for conferences and major events. The Genomics Network's 4th Annual Conference is organised by the Genomics Forum in collaboration with the OECD Global Forum on Biotechnology, taking place in Paris in December 2010.

Part of the Genomics Forum's goal is to promote longer-term engagement and dialogue between social scientists and policymakers via ongoing workstreams. For instance, a workstream on plant genomics began in 2006, comprising a series of interdisciplinary workshops and expert meetings coordinated by a steering group of senior plant scientists, policy advisors, and social scientists. Together, the group worked towards the integration of research findings across the natural and social sciences, and the development of an agenda for future research tying in with wide-ranging topical policy discussions (including climate change, food security, energy security, land use, and biodiversity conservation). The workstream has impacted the agenda of the Joint Nature Conservation Committee and OECD Working Party on Biotechnology.

The Forum's policy-relevant publications include briefings, research reports and consultation responses, all of which may be accessed via our website. Recent briefing titles include 'Engaging the Public with Genomics Through Literary Networks and Fan Communities' (May 2010) and 'New Research on the Human Fertilisation and Embryology Act 2008' (October 2009).

The Forum prides itself on its innovative, creative and flexible approach to engagement between social science and policy. Please don't hesitate to contact our Policy Officer, Christine Knight, to explore possibilities for new initiatives. ■



Director's Comments



Devising a new species of social research?

There are two enormous benefits to working at the Genomics Forum aside from its location on Edinburgh's Royal Mile. There is the fact of being at the hub of the unprecedented investment in innovative social science on today's life sciences represented by the ESRC Genomics Network. This year, widely recognised as the tenth anniversary of the first publication of the human genome, there seems no more exciting intellectual topic in the human sciences.

And there is also the chance in the Forum to develop a new kind of social research entity: a centre that is concerned with taking social research to the heart of public and policy debates about genomic medicine, about the environmental implications of genomic interventions and about the way we human beings understand ourselves and each other. Though the idea of a Forum was invented by the ESRC and its advisers, there existed no blueprint – it was literally unprecedented. And so the Forum's team, with our Advisory Board and the support of the rest of the Network, has been working out in concrete detail what this Forum should look like.

The Forum in phase II

Now in the first year of its Phase II, the Forum has grown into its newly devised shape. Our view is that the Forum is a novel form of organisation that explores innovative avenues to promote social research on the contemporary life sciences, reaching beyond the academic social science constituency to engage a diverse range of audiences. These include audiences in the natural sciences and medical research, but the aim is also to connect social science findings to policy and practice in the non-academic world and to communicate with and engage members of the public. Our programme of activities is designed to generate stimulating, provocative dialogue with all of these audience types.

The Forum continues to pioneer new forms of outreach. This year, with the rest of the EGN, the Forum is, for the very first time, offering sessions on the social and policy aspects of genomics at the UK-wide political party conferences. And, right at the end of 2010, we are leading the ESRC Genomics Network Conference which is being held at the OECD Conference Centre in Paris, in partnership with the OECD's Global Forum on Biotechnology. This event is the first time the OECD has taken a systematic look at what the social sciences (beyond economics) can bring to their policy-making and intelligence around this topic. The aim will be to consider how knowledge in the life sciences is governed, shared, regulated and managed, and to explore new linkages between the life sciences and information and communication technologies. The event will also underline how the latest social science research into genomics science can help inform key global economic and policy decisions.

In today's age of austerity, there is increased pressure on academic researchers to show how their work has influence and relevance. Set up to focus on impact, the Forum feels that it is swimming with the current. We sense we have a great opportunity to demonstrate the tangible contribution of the social sciences and to argue not just for the relevance of the EGN but for the social sciences more broadly. Perhaps as never before, the social and life sciences are entangled and intertwined, with future applications and developments in plant science or personalised medicine for example, posing direct ethical challenges or raising new questions for regulation and legal control. We view it both as our responsibility, and as an exciting opportunity, to make a leading contribution to national and international discussions about the future applications of life-sciences technologies.

Social Science Matters

An open letter to the new coalition government

David Willetts MP

Minister of State (Universities and Science)
House of Commons
London SW1A 0AA

Dear Mr Willetts,

The coalition government has pledged to educate its members on scientific issues, and you are already making good that promise, holding briefing meetings for MPs. Clearly, this government takes science seriously. I would like to urge the government to take social science equally seriously.

What is social science for? One vital function, and one fundamental to the role of the ESRC Genomics Network, is the in-depth examination of the wider social context of new technologies and practices based on emerging science. This is an essential precondition of their sensitive and sensible introduction, with the implications having been fully considered and with coherent regulation ready in place.

Medicine and food production, two areas central to the work of the EGN, provide many illustrations of the dangers of rushing to implement new technology without proper deliberation about risk and impact. It is social science which can provide evidence about such risks and likely impacts, and facilitate the introduction of appropriate legislation. The Human Fertilisation and Embryology Act, despite being admirable in many respects, also illustrates the dangers of leaving the legislation around such ethically and politically difficult issues to be bolted on later, with the practices being legislated already in existence.

Among EGN partners Egenis researchers, for example, are working to identify attitudes to prenatal genetic testing, before cheaper and more informative tests become part of routine prenatal healthcare. New genetic technologies are being developed which will have profound effects on clinical practice and on patients. Social science can offer vital insights into the effective translation of these new technologies into the clinic, ensuring that new practices do not become routine without adequate consideration of the insights and perspectives of parents, clinicians and regulators.

This is just one area. Elsewhere in the Network, an Innogen project is carrying out research into international product development partnership and the distribution of medicines in developing countries. Cesagen researchers are exploring the personal genomics market, a market which is currently largely unregulated. This is a development that has caused considerable concern, but there is little consensus on how potentially harmful the consequences might be or what legislative response would most effectively mitigate them. Evidence-based insight into these questions to aid regulation and best practice, the province of social science, is essential.

In times of austerity and stringent cuts it is easy to assume that science is a necessity but social science is a luxury we cannot afford. That is not the case.

Yours sincerely,



John Dupré
Director, Egenis

SOCIAL SCIENCE

International Rescue: Can social science help save the world?

A recent workshop held at the Genomics Forum considered what international development policy could learn from history. And, as it turns out, it's quite a lot.

Take, for example, the much maligned 'Green Revolution', which grew from American R&D initiatives in the fifties that aimed to alleviate rural poverty and promote rural development in Asia. Since that time, critics have (amongst many things) accused many of the designers of that first wave of programmes of being arrogant. Often technology transfer projects that sent over fertilisers, pesticides, or high yielding crops came unstuck because they failed to incorporate local farming knowledge or appreciate the problems faced by small farmers.

From a historical viewpoint, however, none of this should have been a surprise. Lessons learnt by development practitioners over the previous fifty years in Central Europe, Japan or even some British, French and Dutch colonies were that when Western methods failed, success could be had by using indigenous farming practices as a starting point. It has sometimes been difficult to translate these local insights into broader initiatives, however.

Fast forward another half century. While international development thinking has moved on, the attraction of technocratic solutions to complex problems is still apparent. Some interest groups still regard biotechnology as a panacea, set to ultimately eradicate hunger, disease and poverty. Mixed impacts means that initial optimism has been tempered somewhat, but new technologies, such as biofuels, may provide new opportunities for biotechnology to play a developmental role. Only if we acknowledge local knowledge and complex contexts, however.

One size doesn't fit all...

Whether biotechnology projects can improve food security and livelihoods in developing countries is the focus of much ESRC Genomics Network research. In some cases, such as research by Egenis Co-Director Professor Steve Hughes and his collaborators from Ghana and the Netherlands, this work goes further than just being sensitive to local needs.

“The older models of international development are dependent on a one way flow of supposed beneficial technology that you package up, and sometimes re-jig a bit for different scales of use, but basically it is a non-negotiable, one size fits all,” says Hughes.

“The work we have done has started at the other end and said: here's farmer practice. If you want to understand what benefits the technology that we know about could bring to that scenario, you've got to actually take notice of the nature of what farmers already do.”

The team Hughes is part of is looking at ways of helping farmers in West Africa, who have essentially been breeding new crop varieties for millennia, by applying plant genomic technologies to their informal seed exchange systems.

In these extensive systems, seeds change hands at market or via other, more informal routes, and can end up grown on farms considerable distances from where they were originally bred; however, with West Africa being one of the world's most linguistically diverse regions, differences in seed variety names don't always reflect meaningful genetic differences. As such, one particular name might refer to several different seed varieties, or vice versa.

“The sorts of genetic fingerprinting we can offer are ways in which you can tag what's being exchanged, so farmers aren't swapping the same seed varieties backwards and forwards but with different names attached,” says Hughes.

Outside attempts to get widespread adoption of a few 'superior' seed types just don't work with these informal networks, he adds. In fact, in trying to understand them, the researchers have even likened the seed systems to the collaborative, editorial-free nature of open source projects like Wikipedia.

“The way in which we have started to think about what role genomics could play was to think about the system as a learning machine, with feedback learning instead of instructional learning.”

Feedback learning in this case refers to a state where there is no prior determination of what is right or wrong, explains Hughes. What is best, as regards local adaptation and food security, is essentially whatever works for any particular farmer.

“The older models of international development are dependent on a one way flow of supposed beneficial technology that you package up ”

But what about in practice? Hughes acknowledges there are a number of hurdles to be overcome for this science-backed 'farmer first' approach to work, not least of which is a shift in both policy and funding. “When you meet scientists working in international development it's not too difficult to persuade them of this idea. Whether the funders are listening or not is another matter. It's really a matter of putting in small amounts of money in specific places to people who can do things on the ground, and not rolling in a big aid programme.”

Professor James Smith, Director of Developing Country Research at Innogen, argues that re-orienting research is difficult because of the realities of the systems that generate it:

“The donors may be keen to affect change, but the scientists and institutions they work in can be resistant. Its not simple to reorganise research, you can't simply suggest to scientists they ought to be doing something else. Their work is mediated by their own aspirations and professional norms and values and it is obviously challenging to be asked to negotiate these things, particularly when one is already working in a challenging environment.”

“One can look at the 70-year history of failure in developing a vaccine for trypanosomiasis in Africa. So much expense, effort and ambition was invested in the project that it took a very long time for someone to finally say enough; donors, development practitioners and scientists were all complicit in this to varying degrees and perhaps the immediacy of trying to save lives and livelihoods sometimes make it difficult to keep perspective. We are only human.”

Process not outcomes...

There does at least seem to be an increasing awareness amongst the public health policy community that science isn't the be all and end all.

Back in the seventies, the focus was on health system strengthening, whereas recently, most policies in this area have been concerned with the medical research side – developing a vaccine against AIDS, eradicating malaria, combating trypanosomiasis, leishmaniasis, Chagas disease – and no doubt science can go a long way towards reducing the disease burden of Africa and other developing regions.

However, improving public health in these countries is a hugely complex process and it is equally essential to address market failures of products, in addition to constructing policies that improve the supply of appropriate new health technologies. Innogen's research into health innovation has uniquely centred on Public-Private Partnerships (PPPs), organisations established to fund scientific research and fill these gaps in the innovation cycle. PPPs are seen as a way of bringing private sector efficiency together with existing public sector infrastructure.

“What's interesting about bringing in a social science perspective is that we are looking at the process of innovation and the network and linkages between different organisations, and trying to think about the most effective way of ensuring success,” says Dr Rebecca Hanlin. “Often people are less interested in the process than the outcome.”

“In several places we've worked and with several people we've interviewed you commonly come across the attitude that it doesn't matter who we partner with, as long as we get the product out at the end.”

“We've found it does matter who you partner with and it matters how it works, because if it doesn't work correctly, you lose time, money and the support of other members of the partnership.”

As well as providing a greater understanding of the innovation cycle, the research has also led to what Hanlin calls “an openness towards critical thinking” amongst members of the partnerships regarding the way that they operate. For example, the work has led to a seven year relationship working with the International AIDS Vaccine Initiative (IAVI); a relationship that Hanlin says has evolved.

“Initially the research was us, as outsiders, studying the IAVI and the process that they have undertaken. But increasingly we are being much more involved in IAVI thinking. I wouldn't say we have a partnership, we are still seen in an independent light, but increasingly they are asking for our thoughts and feedback from the research so they can incorporate those into their own work.”

Safeguarding our natural resources

Much of modern biotechnology is founded on knowledge gained from studying and adapting the wealth of biological material. Ironically perhaps, seventy per cent of the world's biodiversity resides within just 12 of the planet's poorest nations, which makes safeguarding these fragile ecosystems and the myriad services they provide us a developing world issue as much as a developed world one.



In 2007, a consortium of scientists from 25 countries started to create what was termed a “telephone directory of all species” by producing a unique DNA barcode for each one.

The Barcoding Life Initiative (BOLI) aims to catalogue half a million species by the end of its first phase in 2015. BOLI essentially promotes itself, not only as a tool in the conservation of endangered species, but as a way of reconnecting a “bio-illiterate” public with nature. Many have commented on the validity of this idea, and writing in the journal *Public Understanding of Science*, Cesagen researchers Dr Rebecca Ellis, Dr Claire Waterton and Professor Brian Wynne have questioned whether there is such a thing as a “universal general public” waiting for the relevant digital tools and technology (essentially, the promised handheld barcoder) with which to identify nature in a “globally standardized fashion”.

The authors suggest this idea has developed in isolation from “the rich and manifold ways in which diverse human cultures and societies are (already) found to be entwined and interdependent with various, equally diverse natures.” They go on to say that in order to support its democratic and information-based ideals, BOLI needs to “nourish an active crafting of varying, diverse publics”.

This, they argue, has “implications for its techno-scientific development”. In other words, Professor Wynne states, if BOLI is to ever truly be successful in its goal of helping to conserve biodiversity it “needs a greater understanding of first, how DNA-barcodes represent ‘global biodiversity’, and what is excluded in such extremely reductionist and heroically

ambitious forms of representation? And second, who in future might use such a DNA-barcoder, as well as how and why they would, and what else this mass collective use, as a scientific imaginary, might entail?”

The key to success?

If social science can bring so much to improve the lot of scientific projects in developing nations, then where was it when the original architects of the Green Revolution were spreading new agricultural technologies across the world?

Dr Steve Sturdy, Deputy Director of the Genomics Forum explains: “In a sense the interesting thing about the lessons of history and its successes and failures is that before the sixties, there wasn’t any social science involved. It wasn’t social scientists who were advising on this. Where it was successful, it was much more to do with the political settings, places like East Germany or Japan and it was the scientists themselves who were sensitive to the political system.

“So it was more the ideological perspective that scientists brought to their work than any explicitly social scientific insight. If there was a social perspective it was implicit in the political perspective that people came from.”

We can’t expect today’s green revolutionaries to be ardent communists, with a background in collective farming. But unlike their predecessors they do have the benefit of being able to look to social science for greater insights into the challenges their technology is attempting to address.

And perhaps then, history might stop repeating. ■



Counterpoint

Shaun Ruysenaar, South African Food Security Expert, PISCES (DFID) www.piscs.or.ke

The importance of history is history?

In South Africa, there appears to be much support for the use of GM food technology on the basis of yield improvements in test studies (normally funded by GM multinationals) despite the international and local research community acknowledging that these technologies are unlikely to work in the “African” context. The reality is that we work in systems in which the politics of technology seems much more powerful than days gone by and though the motives of powerful corporates and struggling governance are now fairly well understood, this does not automatically allow social scientists to change it for the better...

A different, but equally important caution acknowledges that while social science can and should enable technological innovation to the benefit of the developing world, there is a danger that when it comes to adopting biotechnologies, a social scientist can do as much damage by allowing or blocking “progress” as the scientists can do by not acknowledging the social and political contexts or environmental consequences.

To my mind, if social science is to make a difference, its focus should not only be an outward appreciation of the social complexity in which technology fails, but an inward reflexivity of why such lessons should be important. Proclaiming social science’s value to development comes with the recognition that it should not repeat the same historical mistakes our counterpart technocrats have for the past century.



Living with the genome – ten years on

Dr Steve Sturdy and Ken MacLeod from the Genomics Forum share their thoughts on some medical and cultural changes effected by the sequencing of the human genome ten years ago.

Dr Steve Sturdy, Deputy Director, Genomics Forum

The announcement, in June 2000, of the first draft sequence of the human genome was widely hailed as heralding an era of dramatic transformations not just in health and medicine, but in the way we experience and understand our very selves: life with the genome, we were told, would be very different from what had gone before. Ten years on, has this expectation been borne out? Has the human genome become part of our everyday experience? And if so, in what ways?

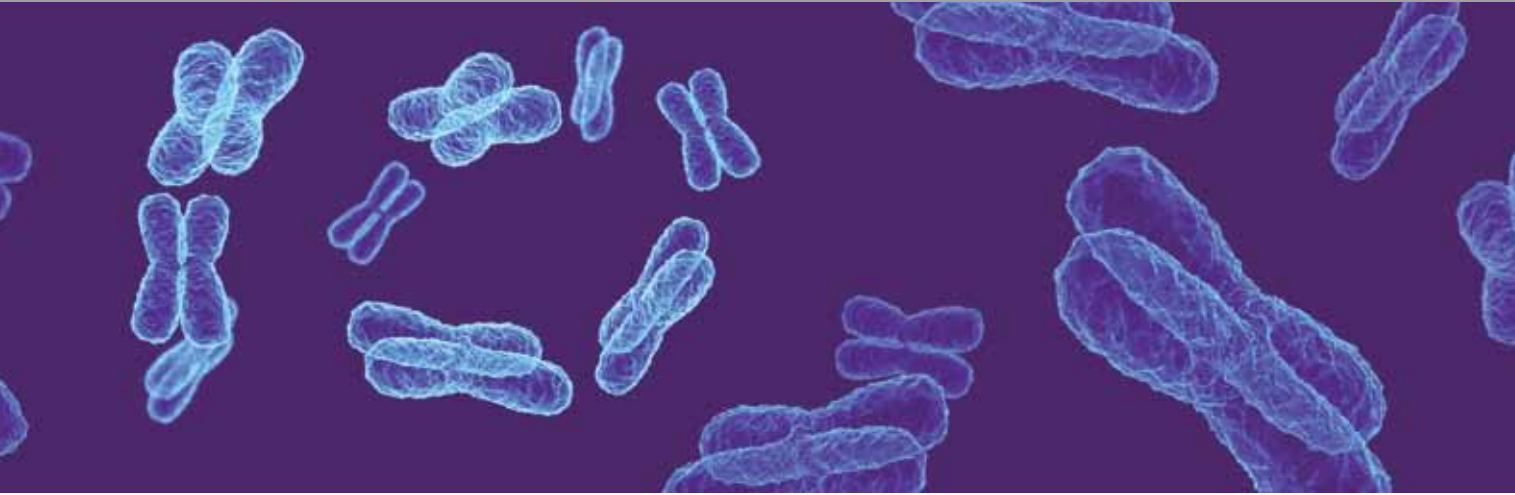
An obvious place to start is with medicine. It was widely expected that the sequencing of the human genome would lead to radical innovations in the prevention, diagnosis and treatment of illness. In particular, hopes were pinned on the advent of a new era of “personalised medicine”, in which medical interventions would be tailored to the specificities of individual genomic constitutions. Certainly, the last ten years have seen a proliferation of new tests to identify inherited predispositions and to diagnose particular genetic variants of disease. And in some instances, at least, such tests have indeed led to refinements in treatment – for example by predicting how an individual will respond to the anticoagulant warfarin. But at the same time, genomic tests have also introduced a range of new uncertainties into the delivery of healthcare.

Genetic testing – do we need to know?

Questions arise, for instance, where a genetic test reveals an inherited condition or predisposition which may be shared by biological relatives. In such cases, those tested may face difficult choices, not just about their own therapeutic or preventive options, but also about whether to inform their relatives or even whether to have children. For the growing numbers of people who undergo such tests, health is becoming a family matter to a greater extent than ever before. Moreover, the situation is further complicated by the fact that

many genetic tests offer, not the kind of unequivocal yes/no answer that we tend to associate with more conventional forms of diagnostic testing, but only probabilistic information about the risk of developing a particular condition or the likelihood of responding to a particular treatment. Under such conditions of uncertainty, doctors are understandably reluctant to make hard-and-fast recommendations about treatment or reproductive choices, and responsibility for medical decision-making increasingly falls on patients and their families. If life with the genome has opened up new opportunities for preventing and treating illness, it has also multiplied the kinds of dilemmas with which the sick and the potentially sick are confronted.

At least within the realm of organised healthcare, individuals are often supported in addressing those dilemmas through the provision of expert genetic counsellors, who can provide information on the nature of the risks faced by patients and their families, and who are experienced in understanding the human as well as the technical aspects of the choices that individuals must make. But many others find out about their own genomes in a setting where expert advice and understanding may be difficult to come by, namely in the sphere of commercial direct-to-consumer (DTC) genomic testing. Unlike medical tests, which usually test for one or at most a handful of disease genes, DTC companies such as 23andMe offer entire suites of tests covering not just disease risks but also inherited non-medical traits such as eye colour and ancestry. In providing so much information in a single package, DTC tests reflect the sheer richness of our genomic inheritance in a way that medical tests do not – and as such, it might be argued that they provide a more realistic experience of what the human genome is all about. Seen in this light, public recourse to DTC testing – chiefly undertaken, it seems, for recreational rather than serious medical purposes – is to be welcomed as a valid form of popular engagement with the human genome and with the science through which it is being realised.



The future looks bright...

In the absence of expert interpretation and explanation, however, there is a danger that DTC tests may also tend to over-simplify popular understanding of genomic information; and the richness of individual biography may be reduced to simplistic ideas about biological determinism. In the event, I suspect we can be reasonably sanguine. For many of us, the risk of popular over-simplification may be mitigated by the more considered ways we experience our genomes in the context of organised healthcare. In future, it is likely that we will encounter the human genome in an even wider range of settings and circumstances than we do at present. That is surely no bad thing. Given the sheer diversity of the ways in which our genomes influence our lives, it is only fitting that something of that diversity should be reflected in the way we come to live with the genome.

Ken MacLeod,

Writer in Residence, Genomics Forum

The big surprise – as unexpected as the craters on Mars, when the first probes sent back photos in the 1960s – was how few genes there are in the human genome: 25,000, give or take, over nine-tenths of which are shared with chimps and a good proportion with the sea-slug and the banana. There just aren't enough genes to account for every variation in human bodies, let alone brains and behaviour – and just as well, because genetic determinism is something we can do without.

Thinking about the cultural consequences of the Human Genome Project's success, I've come to the provisional and paradoxical conclusion that it has undermined genetic determinism and demystified the gene. This is paradoxical because at one level a frivolous genetic determinism has entered the language. Companies claim to have innovation 'in their DNA'. I've seen a women's magazine article that said in passing that gay men have 'the shopping gene'. Evolutionary

psychology has become pop psychology: women's supposed greater colour discrimination has been attributed to their Stone Age female ancestors' supposed specialization in fruit-gathering. Of course, if for some reason subtle colour discrimination was seen as a male attribute, it could be attributed to Stone Age hunters' need to spot animals hiding in the bushes.

A cultural shift?

The use of genetic metaphor to indicate innate and unchangeable characteristics may be largely a matter of availability. In the 1990s, such characteristics were said to be 'hard-wired', a metaphor drawn from computer science. Computers were the big new thing of the 1990s, just as genomics were the big new thing of the 2000s. But as computers and the Internet became part of everyday life they ceased to be mysterious, and computer metaphors dropped out of everyday speech. A similar shift, I think, is going on with the gene.

Because the more the genome is experienced as something that can be broken down into components, and these components shifted about, re-inserted, changed, bought and sold, digitised and reconstituted off the shelf, the less the gene can be seen as a mysterious controller.

The biological components of ethnicity and nationality are similarly sliced and diced. Comparative gene frequencies as indicators of ancestry are much less fraught than notions of 'blood' and 'race' and much more precise. They strongly suggest that cultural change has been far more significant in recent human history than genetic change. Three-quarters of the UK population may be descended from people who arrived when the ice left, but their language and culture have changed again and again, and are changing still.

I think part of that change, over the next decade of the human genome, will be the fading of the notion that if some characteristic is genetic, it can't be changed. It'll be interesting to see what, if anything, will take the gene's place as metaphor. ■

September

Conference session: 2 September 2010
From biodigital lives to bioIT worlds at EASST (The European Association for the Study of Science and Technology)
Venue: University of Trento, Italy
Organised by: Cesagen
Contact: Dr Ruth McNally
r.mcnally@lancaster.ac.uk | 01524 510842

ESRC Genomics Network: 13 September 2010
The politics of plants
Fringe Event at the Green Party Conference
Venue: Birmingham Conservatoire, Birmingham City University
Time: 12.00pm
Contact: Dr Christine Knight
christine.knight@ed.ac.uk | 0131 651 4743

Cesagen workshop: 17 September 2010
Microbiology, genomics, and beyond: Regulating dual use technologies into the 21st century
Speakers: Graham Pearson, chief executive Chemical and Biological Defence Establishment MOD Porton Down 1991-95, assistant chief scientific advisor (non-proliferation) MOD; Michael Imperiale, Department of Microbiology and Immunology, University of Michigan Medical School; Darryl Galloway, Former Director, Joint Science & Technology Office, US Defense Threat Reduction Agency
Venue: The Wellcome Trust, London
Time: All day
Organised by: Cesagen
Contact: Professor Adam Hedgecoe
hedgecoeam@cardiff.ac.uk | 029 2087 0024

ESRC Genomics Network: 21 September 2010
Pills or progress: improving healthcare in Africa
Fringe Event at the Liberal Democrats Conference
Venue: Hall 13, Arena and Convention Centre, Liverpool
Time: 6.15pm – 7.30pm
Contact: Dr Christine Knight
christine.knight@ed.ac.uk | 0131 651 4743

Seminar: 27 September 2010
Food security
Speaker: Professor Michael Winter, Director of the Centre for Rural Policy Research, University of Exeter
Venue: ESRC Innogen Centre, University of Edinburgh, Old Surgeons' Hall Seminar Room, High School Yards, Edinburgh
Time: 3.30pm – 5.00pm
Contact: angela.mcewan@ed.ac.uk

ESRC Genomics Network: 28 September 2010
A secure society? Technological solutions to social challenges?
Fringe Event at the Labour Party Conference
Venue: Manchester Central Convention Complex
Time: 7.00pm – 8.00pm
Contact: Dr Christine Knight
christine.knight@ed.ac.uk | 0131 651 4743

October

Seminar: 4 October 2010
Speaker: Professor Marc Bedau (Reed College, Portland, Oregon)
Venue: Byrne House, University of Exeter
Time: 3.00pm – 4.30pm
Organised by: Egenis

ESRC Genomics Network: 5 October 2010
Why science needs social science: the case of genetics
Fringe Event at the Conservative Party Conference
Venue: Scherzo room, Hyatt Regency Hotel
Time: 5.45pm – 7.00pm
Contact: Dr Christine Knight
christine.knight@ed.ac.uk | 0131 651 4743

Policy event: 6 October 2010
Synthetic biology – the next industrial revolution
Speakers: Prof Joyce Tait, Dr Jane Calvert, Dr Peter Robbins, Dr Emma Frow
Venue: The Scottish Parliament

Seminar: 11 October 2010
Speaker: Dr Helen Middleton-Price, Director of NOWGEN
Venue: Byrne House, University of Exeter
Time: 3.00pm – 4.30pm
Organised by: Egenis

Cesagen public lecture: 14 October 2010
Sustainable diets: too complex, too nanny state – or inevitable?
Speaker: Tim Lang, Professor of Food Policy, City University, London
Venue: The Banqueting Suite, Lancaster Town Hall, Lancaster
Time: Doors open 6.30pm, followed by a reception with locally sourced produce
Contact: Keith Calvert
K.Calvert2@lancs.ac.uk | 01524 510842

November

Cesagen Cardiff open day: 4 November 2010

Venue: Committee Rooms 1 & 2, School of Social Sciences, Cardiff University. This event will highlight Cesagen's research based at Cardiff University

Time: 11.00am – 3.00pm, to include lunch

Contact: Flo Ticehurst | ticehurstf@cf.ac.uk | 029 2087 0024

Workshop: 11 November 2010

Genomic subpopulations and health systems responses EGN workstream workshop

Speakers: Professor Andrew Hattersley, Professor Neil Avent, Dr Antonia Cronin, Dr Maggie Shepherd and Dr Daniela Bezemer

Venue: Byrne House, University of Exeter

Time: 9.30am – 5.30pm

Organised by: Egenis

Contact: l.c.dobb@exeter.ac.uk

Seminar: 15 November 2010

Speaker: Professor Giovanni Boniolo (Campus IFOM-IEO, Italy)

Venue: Byrne House, University of Exeter

Time: 3.00pm – 4.30pm

Organised by: Egenis

Seminar: 22 November 2010

Genetic technologies and the reconstitution of knowledge-practices in UK livestock breeding

Speaker: Dr Carol Morris (University of Nottingham)

Venue: Byrne House, University of Exeter

Time: 3.00pm – 4.30pm

Organised by: Egenis

Seminar: 29 November 2010

Speaker: Professor Jon Frampton (University of Birmingham)

Venue: Byrne House, University of Exeter

Time: 3.00pm – 4.30pm

Organised by: Egenis

Cesagen public event: 29 November 2010

Voyages of discovery and biodiversity

Speaker: Sarah Darwin

Venue: Cardiff

Contact: Flo Ticehurst
ticehurstf@cf.ac.uk | 029 2087 0024

Further details to be confirmed

December

Cesagen cross-site seminar: 4 December 2010

Biocomplexity in host-parasite systems

Speaker: Professor Jonathan M Wastling, Head of the Department of Comparative Molecular Medicine, School of Veterinary Science, University of Liverpool

Venue: Lancaster University, broadcast via video link to Cardiff University

Time: 2.00pm

Contact: Dr Oscar Forero
o.forero@lancaster.ac.uk | 01524 510837

Conference: 6 – 7 December 2010

Delivering global promise through the life sciences: Annual EGN conference

In partnership with the OECD

Venue: OECD Conference Centre, Paris

Organised by: Genomics Forum

Contact: Toni Freitas | toni.freitas@ed.ac.uk | 0131 651 4736

Seminar: 13 December 2010

Speaker: Dr Mathias Grote (University of Exeter/Max-Planck Institute)

Venue: Byrne House, University of Exeter

Organised by: Egenis

Time: 3.00pm – 4.30pm

January

Cesagen cross-site seminar: 14 January 2011

Genomics and race discourse in Latin America

Speaker: Peter Wade, Professor of Social Anthropology, Manchester University

Venue: Lancaster University, broadcast via video link to Cardiff University

Time: 2.00pm

Contact: Dr Oscar Forero
o.forero@lancaster.ac.uk | 01524 510837

March

Cesagen public lecture: 31 March 2011

Speaker: Professor Allen Roses (Duke University)

Venue: Cardiff, TBC

Contact: Professor Adam Hedgecoe
hedgecoeam@cardiff.ac.uk | 029 2087 0024

Further details to be confirmed



Peer review panel at stem cells conference

Egenis Deputy Director **Dr Christine Hauskeller** organised a panel discussion as well as being a workshop speaker at this year's UK National Stem Cells Network (UKNSCN) international conference in Nottingham in July.

Dr Hauskeller spoke in the workshop session 'Beyond the lab: Social science analysis of innovation in regenerative medicine', and organised the panel discussion 'Practices of peer reviewing and their influence on research', joined by Prof Peter Andrews (Sheffield), Dr Bernd Pulverer (EMBO) and Dr Kirsten Patrick (BMJ).

The UKNSCN is the body tasked with improving the coordination of stem cell research.



New reader at Cardiff School of Social Sciences

Congratulations to **Dr Win Tadd** who joined Cesagen as Operations Manager in July last year. She has recently been promoted to Reader at Cardiff School of Social Sciences. She has also been awarded funding of £0.25million with co-applicant Sinead O'Mahony of Cardiff University's Medical School, for a project focusing on 'Organisational culture in the NHS: A feasibility study to measure the impact on older people'.

Her current research projects are both funded as part of the Comic Relief and the Department of Health (DoH) PANICOA (Prevention of Abuse and Neglect in the Institutional Care of Older Adults) programme. The first is 'Dignity in practice: An exploration of the care of older adults in acute NHS trusts' (£450,000) and the second is 'Promoting Excellence in All Care Homes' (PEACH) (£480,000).



Promotion for Innogen Co-Director

Innogen Co-Director **Professor James Smith** has been promoted to a personal chair in African and Development Studies at the University of Edinburgh. He will continue with his work in Innogen but will also become the first director of the University of Edinburgh's Global Development Academy, which will launch in Autumn 2010. His latest book, *Biofuels and the Globalization of Risk* (Zed), will also be launched in the autumn. The book draws on Innogen-supported research and research undertaken under the auspices of the UK Department for International Development-funded bioenergy and development research consortium.



Exploring data-intensive science

Dr Sabina Leonelli (Egenis) has successfully concluded her British Academy-sponsored pilot project on data-driven research in the biological and biomedical sciences. She organised an international workshop on the topic, gathering prominent sociologists, historians and philosophers of biology from Europe, the USA, Mexico and Australia. Proceedings were opened by a public debate: 'Data-driven science: why and how?' between Professor Tony Hey of Microsoft and Professor Doug Kell of the BBSRC.

The workshop, whose proceedings will be published as a special issue of *Studies in the History and Philosophy of the Biological and Biomedical Sciences*, focused on the conditions under which data disseminated online can be used to inform future discoveries. Dr Leonelli will now head a major project on this issue involving collaborative research with social and natural scientists both in Europe and the USA.



Leverhulme Trust Early Career Fellowship award

Daniele Fanelli was awarded a Leverhulme Trust Early Career fellowship, for three years, to conduct the project "Bias, Misconduct and the Hierarchy of the Sciences". This project will review and unify theories and models predicting how scientific objectivity and integrity might be influenced by methodological and socio-economic factors, and will test these predictions using newly-developed quantitative tools. Results will help settle a long-standing controversy on the existence of a Hierarchy of the Sciences, and will contribute to international efforts to foster research integrity.



Award for Heather Lowrie

Innogen PhD student **Heather Lowrie** was awarded the Joyce Tait Prize in Science, Technology and Innovation Studies at the University of Edinburgh for her Masters dissertation on the insurability of emerging risks.

This links to Innogen's work on the risk governance of synthetic biology for the International Risk Governance Council. Heather will commence a three-month ESRC Placement in September 2010 with a reinsurance broker and a speciality property and casualty insurer and reinsurer based in the City of London.

During her placement Heather will focus on decision-making in the underwriting process, including classes of business such as general liability, energy liability and pharmaceutical product liability. This will include observing face-to-face transactions between underwriters and brokers at the Lloyd's insurance market.



Wellcome Trust bioethics fellowship

Congratulations to Cesagen's **Dr Alex Hillman**, who has been awarded a Wellcome Trust Bioethics Fellowship. Her study will evaluate how developments in scientific, biotechnological and clinical understandings of dementia impact upon ethical practice in memory clinics. Through ethnographic research and a critical engagement with debates over the meaning of autonomy – and by extension the meaning of respect for autonomy – the study will explore the applicability of utilising this established ethical principle within practices of disclosure in memory clinics.

Standing between new knowledge and technologies, clinical practice and patients' own understanding and experience of dementia, memory clinics offer a unique setting in which to evaluate – and perhaps reconfigure – the principle of respect for autonomy and its role in shaping how clinical information about memory problems are shared.

Alex is a qualitative medical sociologist with a particular interest in the care and treatment of older adults in clinical settings. Her previous work has focussed on the relations between older people's needs and experiences of clinical care and the organisational cultures of acute medicine.

Staff moves

Forum

The Forum is delighted to welcome **Toni Freitas** (toni.freitas@ed.ac.uk) as our new Events Manager and **Alison Caldecott** (alison.caldecott@ed.ac.uk) who will be covering Press and Communications duties during Emma Capewell's maternity leave.

Egenis

Egenis has welcomed a new centre secretary, **Laura Dobb**. Laura, who is originally from Vancouver, Canada, has previously worked for UC Berkeley and Simon Fraser University.

We also said hello to PhD student **David Wyatt**. David's study 'How DNA matters: An ethnographic investigation of police practices', will support Egenis's 'Use of forensics' project – see p4.

Research Fellow **Sabina Leonelli** is currently on maternity leave, but no baby news at time of writing.

Congratulations to **Alex Powell**, who has successfully completed his PhD.

Innogen

Dr Michele Mastroeni joined Innogen earlier this year to work with Dr Alessandro Rosiello on our EU FP7 project on Targeted Innovation and has settled in well to the team.

Deborah Spencer was awarded the ESRC CASE studentship on 'The Role of Brokerage Organisations in Knowledge Exchange Processes: The Case of Genesis Faraday Partnership' (supervisors C Lyall, A Bruce, D Telford, S Nutley) and will join Innogen in autumn 2010.

Congratulations to **Dr Gill Haddow** who gave birth to a beautiful baby girl in June. Gill will be on maternity leave until 2011.

Dr Lois Muraguri left Innogen, Open University to take up the role of Assistant Director, Policy and External Affairs at Galvmed, a registered charity and not-for-profit global alliance of public, private and government partners based in Edinburgh.

Lara Crossland has left the post of Communications & Networking Officer at Innogen to take up a full time position with Research Councils UK – Beacons for Public Engagement Initiative. We warmly welcome **Jennifer Foley** who will be taking over this role in September.



Do pills mean progress?

Diseases like malaria, AIDS and TB kill millions of people around the world, with children in developing countries particularly at risk. Research into vaccines and medicines is vital, but so is supporting health care systems. Life-saving drugs, which often require refrigeration, need to be transported across continents to reach remote and rural areas. Qualified staff need to store medicines, diagnose diseases and administer treatment, and the medicines need to be affordable to some of the poorest people in the world. Pills are certainly important, but we can't lose sight of the bigger picture.

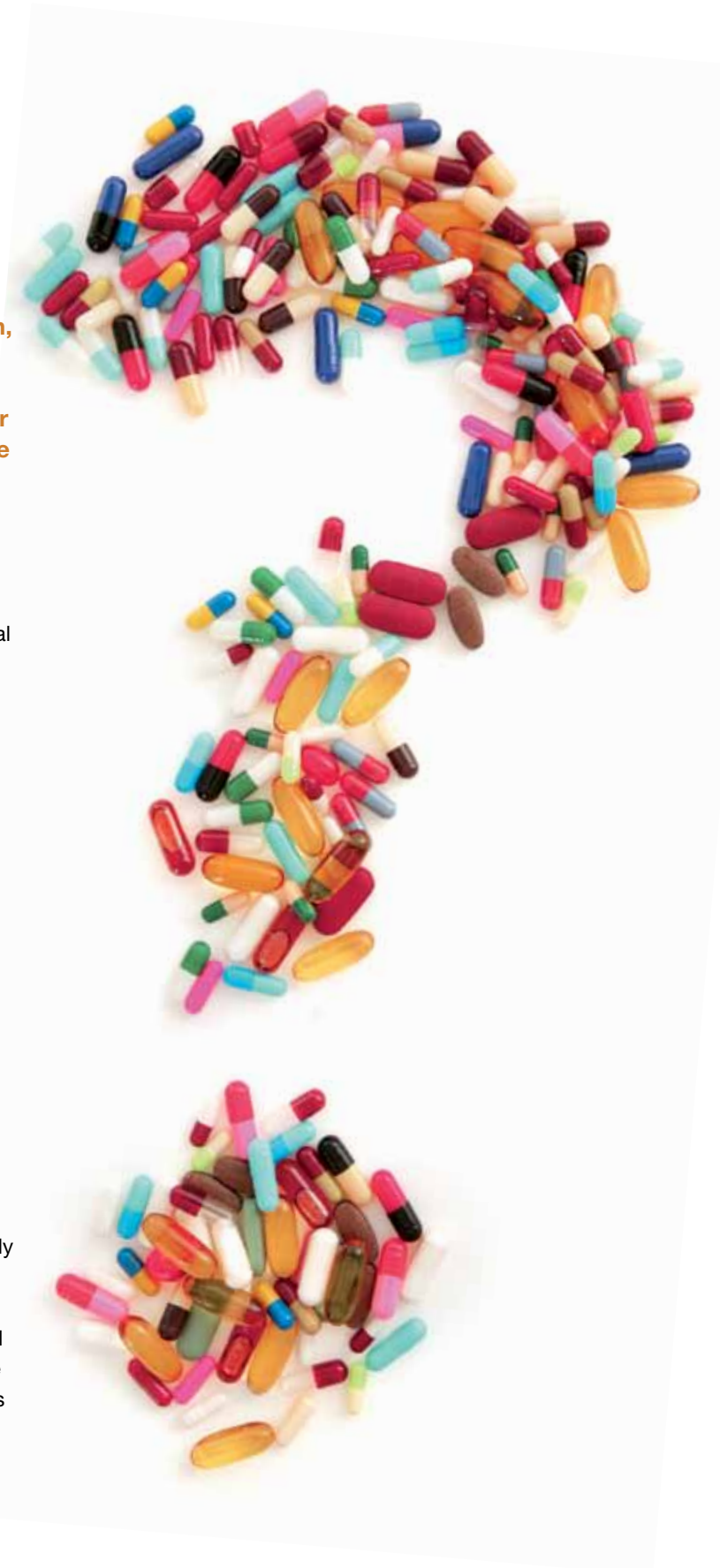
At Innogen, we have extensively researched international Product Development Partnerships including the International AIDS Vaccine Initiative and the Malaria Vaccine Initiative. These partnerships brought together researchers from the public and private sector in developed and developing countries to develop life saving medical products. They have made good scientific progress, but their social contribution has been just as important. Training staff, building networks, creating infrastructure and so on has proved to be incredibly valuable to the health care systems in developing countries.

Functioning health care systems not only help to deliver current treatments effectively but also support the development of new medicines.

Big pharma & developing countries

The big pharmaceutical companies have become increasingly aware of the need to refocus their markets; towards the markets of 'the poor' in Africa and Asia. Earlier this year the Access to Medicines Index ranked European pharmaceutical companies, and UK based GSK in particular, as having done the most in terms of research, patents, pricing and donations to improve access of medicines to the poorest in the world.

However, Innogen's research has highlighted a variety of issues that need to be considered.





Big pharma or local industry?

The first issue is the relative merits of big pharma over local industry. Innogen researchers, through reviewing the components of a health innovation system relevant for African countries for the New Partnership for Africa's Development (NEPAD), found that in some cases, building local industrial capacity was as useful as simply accepting donations or purchasing medicines from established often Northern based pharmaceutical companies. However, increasingly it isn't the pharmaceutical companies based in the US or UK that are important for Africa but those in India and China. Innogen researchers continue to investigate this issue through a case study of the Zimbabwean pharmaceutical industry and a project with colleagues in the Open University on 'Southern sources of innovation'.

Distributing medicine

Second, whichever mechanism is used to supply medicines to a main central medical stores department or equivalent, there is still the issue of how they are then distributed to those that need them most. Innogen researchers have reviewed the role of different actors in delivering medicines, especially the role of not-for-profit and non-governmental organisations.

Cost

The affordability of drugs is linked to how much end consumers have to pay for drugs due to their country's system of healthcare. Many African countries are dominated by an out-of-pocket payment system for drug supply; in some African countries up to 90% of household expenditure on healthcare is spent on drugs. Innogen has an ongoing research project that is concerned with reviewing what is needed to ensure equitable supply of pharmaceutical products, including essential medicines to Africa. At the same time however, the cost of drugs is in part determined by the regulatory environment that is promoted.

Innogen researchers have reviewed the extent of the strengthening of patent laws as a result of the Trade Related Intellectual Property Rights (TRIPS) agreement. This presents a significant institutional change for developing country industry. In particular, Innogen researchers have analysed Indian pharmaceutical firms' strategic response to the strengthening of patent law. The research shows that Indian pharmaceutical firms responded to anticipated regulatory change with the potential to disrupt their current systems by making small incremental changes to current processes in addition to new, radical changes. The question we have to ask now is, can African based pharmaceutical companies do the same?

Ensuring long term progress

Many of these issues relate to a wider set of systemic factors determined by the country, regional and international policy environment. It is also important to understand attitudes, and associated policies, towards the importance of health and innovation systems and their inter-linkages.

“Ensuring medicines get to those who need them most is a complex policy challenge as well as a scientific one”

The research Innogen has conducted has outlined the importance of capacity building and capability strengthening. This includes both political empowerment and the strengthening of local governance structures to ensure a coordinated approach to policy and practice by African governments and donors. Policymakers need to recognise how scientific and technological innovation fits with agendas from other policy arenas such as health, education, the economy and see beyond the provision of a pill as being the 'technofix' to tackle disease effectively. Ensuring medicines get to those who need them most is a complex policy challenge as well as a scientific one. ■





Cesagen spotlights the economic and social lives of data-intensive sciences

From virus to organism, from bench to bedside, from patents to protests, genomic sciences are data-intensive endeavours. Their constant negotiation with ever-greater volumes and varieties of data exemplifies much wider problems faced by scientists, clinicians, policy-makers and consumers as they seek meaningful information amongst multiple and voluminous digital sources. The ongoing digitisation of records, images and administrative data, the collection of data from sensors, transactions and many web, internet or mobile communications have been described as a ‘data deluge.’

Cesagen’s research both analyses shifts towards data-intensive societies and also seeks ways to critically channel the digital data deluge into social and economic studies of the contemporary life sciences. It includes studies of specific data-intensive sites, attempts to re-purpose data analysis techniques, and experiments in collaborative data analysis across a number of settings, and building capacity for open source social science analytics using tools such as the “Research Desktop”.



The Research Desktop allows researchers to search multiple sources, aggregate, visualize and export results. Image: Paul Oldham

Sociomics core facility

Dr Paul Oldham, Dr Stephen Hall, Dr Oscar Forero, Dr Ruth McNally, Dr Adrian Mackenzie

Sociomics is a hybrid word expressing the entanglements between the post-genomic biosciences and the social sciences and humanities that study them, and convergences in the challenges they each face and the solutions they adopt to manage and exploit the opportunities of data-intensive research.

Cesagen’s Sociomics Core Facility (SCF) combines IT expertise with social science and humanities research questions, and ways of making critical interventions with policy-makers and indigenous peoples in Latin America.

SCF tools and resources: These include the EPO World Patent Statistical Database (PATSTAT), Vantage Point Analytics and Text Mining Software, Catalogue of Life, OUP Wordsmith corpus linguistics software, hand-held GPS devices, IssueCrawler, R, and Wiki analysis.

SCF Research Desktop: Developed by Paul Oldham and Stephen Hall, the Research Desktop provides a search query interface for various databases including Pubmed, PatentLens, Google Scholar, YouTube, and Wikipedia.

See <http://sociomics.lancs.ac.uk/desktop2>



Biodiversity, intellectual property and access and benefit-sharing

Dr Paul Oldham, Dr Stephen Hall

This research project is developing ways of curating, combining, analysing and visualising big databases. Its goal is to democratise access to information that is economically, socially and politically important for indigenous peoples, civil society and policy-makers in developing countries.

The project is developing methods to locate biodiversity in patent databases and indicators to monitor patent trends. This involves capturing and curating 60m records from the World Patent Statistical database. These analyses have been used as evidence on the implications of patenting for developing countries at the UN Convention on Biological Diversity (see page 10).

Protecting human rights with GIS and associated technologies

Dr Oscar Forero

An important concern amongst diverse stakeholders working in the fields of natural resources management and sustainable development is the potential negative effects that the technologies and methodological practices of digital geography are having in the implementation and development of the rights of peasant, indigenous and tribal peoples worldwide.

Case studies from Northwest Amazonia and the Andes illustrate the type of challenges stakeholders face when techno-scientific and traditional knowledge of natural resources are combined in digital forms. In these cases the concept of 'geopiracy' is neither appropriate nor helpful for solving conflicts arising from the digital merger. Instead, there is a need to develop protocols, codes of conduct and a best practice guide. See Forero, O. 'Digital technology uses for sustainable management of natural resources in multicultural contexts'. *Development in Practice* (in press).

Genomics and data-centric discourse

Dr Adrian Mackenzie

Genomics could be seen as an attempt to render biology in digital data. This attempt shifts ways of knowing toward the discovery of patterns and associations. For instance, in association studies (e.g. GWAS) and in metagenomics. This project focuses on how data is done in genomics by studying a richly varied and dynamic intermediary object, the open source statistical programming language and visualization environment R. It is one place where the multiple making sense of biological data occurs. R is heavily used across biological settings, especially in the analysis of high-throughput data from microarrays and sequencing.

R can also be used to map and analyse how people actually encounter different kinds of data. Just as biologists and bioinformaticians write R scripts to access file, database, and instrument data, social scientists can use R to 'read' the tens of thousands of pages, narratives, images, numbers and documents associated with the nascent science of synthetic biology. These include text mining several thousand patents, scientific papers, media coverage, policy documents, and 'scraping' the many DIY biology, open source biology and 'openwetware' websites, particularly the website of the student synthetic biology competition – the international Genetically Engineered Machine (iGEM) competition.



Visualisation of a proteomics actor-network on the Web, created using IssueCrawler software.

The social lives of post-genomic data

Dr Ruth McNally

This project develops methods to follow the production, distribution, exchange and use of data in proteomics and genomics at three research sites.

1 Data machines

Data production and output from the ‘inscription devices’, the high-throughput instruments.

2 Data factories

Data flows through a second generation genome sequencing centre in a global market for data production and services.

3 The Web

Data on-line. The post-genomic sciences are e-sciences. Using Web metrics to locate and monitor them in action.

See: McNally, R. (2005) ‘Sociomics! Using the IssueCrawler to map, monitor and engage with the global proteomics research network.’ *Proteomics*, Pages: 3010-3016. Also, McNally, R. (2010) ‘Will the real public please stand up! Proteomics perspectives on “issue-network theory”.’ Cesagen Working Paper.

Testing times: markets, expectations and controversy in personal genomics

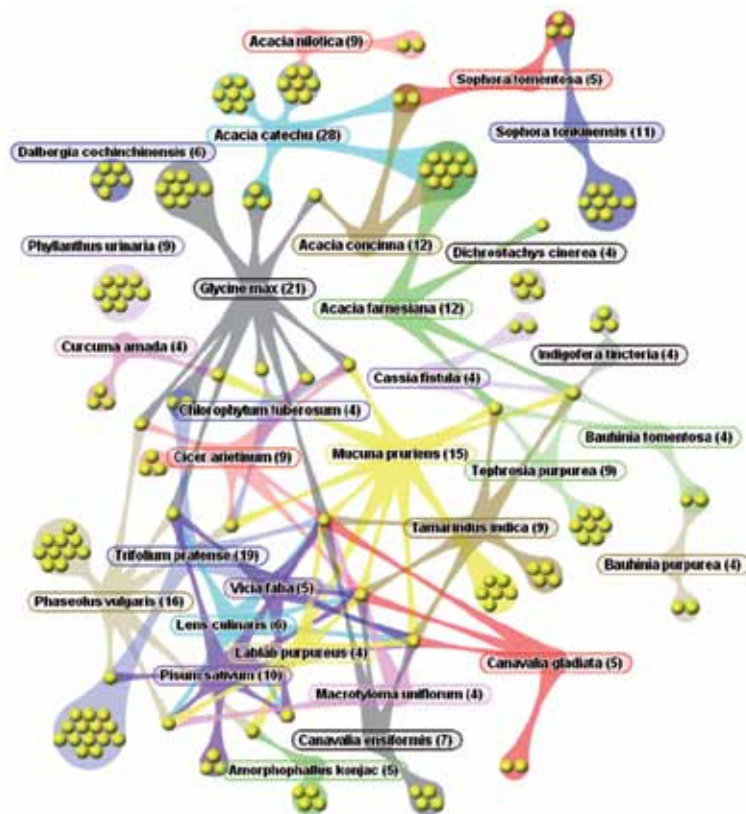
Dr Richard Tutton, Professor Adam Hedgecoe, Dr Paul Martin

This project is a collaboration between Richard Tutton and Adam Hedgecoe (Cesagen Lancaster and Cardiff respectively) and Paul Martin (Nottingham University). It explores the development of the personal genomics industry, in particularly the activities of the companies 23andme and Navigenics. One focus is the way in which complex, ambiguous genomic information is presented to the users of such services, and the kinds of socio-technical expectations associated with such data.

Technolife

Dr Kristrun Gunnarsdottir, Dr Adrian Mackenzie, Dr Paul McCarthy, Professor Brian Wynne

EU FP VII ‘Transdisciplinary approaches to lifeworld imaginaries and ethics for emerging technologies including GIS, border security technologies, and embodied ICTs’ is a 3 year project (2009-2012) with partners in Bergen, Copenhagen, Versailles, Barcelona and Tartu. This project pilots new methods for investigating the structuring of technoscientific imaginaries. It couples film and facilitated online forum discussions with structured discourse analysis to explore the formation of contemporary sensibilities in specific technological zones such as Geographic Information Systems, biometrics and ICT-related body enhancement. TechnoLife aims to show how the dynamics of technoscientific imaginaries play a part in the development of relevant and timely policy initiatives. Cesagen has participated heavily in the design of the TechnoLife online system.



An Aduna Cluster Map of plant species from South East Asia in the claims of patent documents (yellow). Image: Paul Oldham.



My Working Life

How did you end up working at the Genomics Forum?

Prior to coming to the Forum, I was a researcher and research manager at the AHRC/SCRIPT Centre in the University of Edinburgh's Law School. While at the SCRIPT Centre I was involved in collaborative projects with colleagues from the ESRC Innogen Centre and attended a number of workshops and seminars at the Forum. When my contract at the SCRIPT Centre was coming to an end, the position of Gengage Network Officer was (fortuitously) advertised. I was delighted to get the job and have thoroughly enjoyed working with everyone at the Forum and on the Gengage sub-groups over the past several months.

Have you always been interested in genomics?

When I was 10, I decided I would be either a doctor or a lawyer. I became a lawyer, but have had an enduring interest in medicine and medical ethics. My interest in genomics arose out of my PhD thesis, which examines the issue of how to include people 'well' in the governance of biobanks. As my thesis focuses specifically on the interrelationship between benefit-sharing and public engagement, the position with Gengage has provided a unique opportunity for me to explore public engagement from a different perspective and to reflect critically on my own work.

What are you currently working on?

We are currently developing the Gengage programme for the next year. On the back of this year's successful events, we are considering a series of deliberative public engagement events around brain donation and brain banking, as well as workshops to tie in with the new SQA Higher and Advanced Higher biology curriculum. We are also enhancing the website and adding a section for links and resources related to healthcare genetics.

What have been your highlights of the last 12 months?

The highlights this year have been the Brain Bank event Gengage organised as part of the Edinburgh International Science Festival, and the Second Annual Gengage Conference, which focused on teaching genetics in schools. These events were very well received and the feedback strongly supported future events of this kind.

Who is your current work of interest to?

The work of Gengage is of interest to a wide variety of stakeholders, including healthcare professionals, patient groups, science communicators, public engagement practitioners, scientists, social scientists and other academics, policy makers, teachers and the wider public. Gengage aims to bring stakeholders together to share information and good practice, promote research, provide training and capacity building and facilitate discussion around the social and ethical issues raised by healthcare and medical genetics in Scotland.

What is the most satisfying part of your job?

For me the most satisfying part of the job is when we receive positive feedback from participants at our events. One teacher who brought upper year students to the Gengage annual conference in June said her students were 'inspired'. Knowing that you have contributed in some way to a young person's interest in genetics is very rewarding.

What is most frustrating?

Funding. Gengage has been generously supported by the Scottish Government Health Department since 2008. However, funding is only available until July 2011. Considering the important work Gengage does around healthcare genetics in Scotland, we are looking for additional funding to extend the project beyond July 2011. In the current economic climate, this could prove to be quite challenging.

What do you feel have been your key achievements?

Hiring an excellent assistant – James Kelly – who is something of an IT wizard and who has been an invaluable addition to our Gengage team.

Where would you like to be in 10 years' time?

I intend to stay in academia and to pursue teaching and research interests around biomedicine and genomics. As I will rapidly be approaching retirement in 10 years, I would also like to be making plans that involve a beach and cocktails with little umbrellas! ■

Further information about Gengage, The Scottish Healthcare Genetics Public Engagement Network, may be found at:

<http://www.gengage.org.uk/>

Gengage is managed by the ESRC Genomics Forum

cesagen

ESRC Centre for Economic and Social Aspects of Genomics

Cesagen at Lancaster University

Tel: +44 (0)1524 510842

Cesagen at Cardiff University

Tel: +44 (0)29 2087 0024

Email: cesagen@genomicsnetwork.ac.uk
www.genomicsnetwork.ac.uk/cesagen

egenis

ESRC Centre for Genomics in Society

Egenis at University of Exeter

Tel: +44 (0)1392 269 140

Fax: +44 (0)1392 264 676

Email: egenis@genomicsnetwork.ac.uk

www.genomicsnetwork.ac.uk/egenis

genomics forum

ESRC Genomics Forum at the University of Edinburgh

Tel: +44 (0)131 651 4747

Fax: +44 (0)131 651 4748

Email: forum@genomicsnetwork.ac.uk

www.genomicsnetwork.ac.uk/forum

innogen

ESRC Centre for Social and Economic Research on Innovation in Genomics

Innogen at the University of Edinburgh

Tel: +44 (0)131 650 9113

Fax: +44 (0)131 651 4278

Innogen at the Open University

Tel: +44 (0)1908 654 782

Fax: +44 (0)1908 654 825

Email: innogen@genomicsnetwork.ac.uk

www.genomicsnetwork.ac.uk/innogen

Published by: ESRC Genomics Network, Managing Editor: Emma-Elizabeth Capewell, Editors: Lara Crossland, Claire Packman, Flo Ticehurst

Graphic Design: Heehaw Digital

The ESRC Genomics Network (EGN) is Cesegen, Egenis and Innogen, examining numerous aspects of the social and economic significance of genomics, and the ESRC Genomics Policy and Research Forum, tasked with connecting this research with national policy.

The ESRC Genomics Network Newsletter is FREE and published twice a year.

To subscribe please contact: info@genomicsnetwork.ac.uk

Image credits: ©iStockphoto.com/DNY59 (p6), ©iStockphoto.com/CostinT and ©iStockphoto.com/spxChrome (p8), ©iStockphoto.com/iSci (p9), ©iStockphoto.com/lisegagne (p14), ©iStockphoto.com/hidsey (p26), ©iStockphoto.com/unalozmen (p27), ©iStockphoto.com/TimAbramowitz (p28).

Disclaimer:

The views and opinions expressed in this publication are those of the contributors and authors of the articles, and are not necessarily the views and opinions of the ESRC or the ESRC Genomics Network. Whilst every effort has been made to ensure the accuracy of the information provided, neither EGN nor its employees or agents can be held responsible for any inaccuracies or omissions in this publication whether caused by negligence or otherwise.

Copyright © ESRC Genomics Network

The University of Edinburgh is a charitable body, registered in Scotland, with regulation number SC005336.