

**ESRC Genomics Network Genomics and Identity Politics  
Workshop Series 2008-2009**

**Constructing/Contesting Mobilizations:  
Biopolitics, Activism and Identity**

27 June 2008, Institute for Advanced Studies, Lancaster University

**Workshop Report**

## Background to the Workshop

This was the second workshop to be held as part of an initiative by Cesagen, Egenis, Innogen and the Genomics Forum for Policy and Research to jointly investigate dimensions of the use of genomics and genetic knowledge in the contemporary politics of identity. The collaboration takes the form of five workshops held across the network, each of which concentrates on an aspect of the overarching theme that draws upon the particular expertise and interests of each centre. The first workshop, held at Egenis at Exeter University focused on debates about categorization and definition of ethnicity in governmental practices of census-taking and immigration, the second workshop – as reported here – discussed forms of health activism, the third workshop in the series will examine the forensic use of DNA and the expansion of genetic databases for law enforcement, the fourth workshop will consider concepts of family and parent-child relationships within legal, political, clinical and scientific domains. The final workshop, scheduled for May 2009, will be synoptic, bringing together the issues addressed and explored over the previous year. Go to [www.genomicsnetwork.ac.uk](http://www.genomicsnetwork.ac.uk) to find out more about the series and future events.

The workshop reported here was held at Cesagen, Lancaster University, on 27 June 2008 and involved twenty-three participants from the Genomics Network and other leading academic centres in the UK and Canada, France, Ireland, and the United States.

The workshop aimed to examine three interrelated questions: How should we conceptualise forms of patient and public activism associated with health, medicine and science? Do these forms of activism entail the substantiation of new collective forms of identity? What challenges do these pose for thinking about politics and identity more broadly? Accounts of contemporary biopolitics describe a significant historical shift away from the state as the guarantor of health to the emergence of multiple actors mobilising around health, medicine and the promises of science. How we understand these actors as constituting particular forms of collective social action is highly contested. One perspective has tended to highlight questions about how actors mobilise, create and draw on resources, establish organisational structures, and seek to influence the political and scientific agenda. Another perspective is more concerned with the way these actors represent new forms of sociality and are creating new forms of collective identity.

The event was organized by Richard Tutton, Flo Ticehurst and Alex Plows, all at Cesagen. Thanks are due to Kate Wright and Keith Calvert at Cesagen Lancaster who provided vital administrative support, and to Rachel Dechenne who prepared a transcript of the workshop on which much of this report is based.

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## Workshop Programme

### Session I: Conceptualising and Constructing Health Activism

Steven Epstein (UC San Diego) // The Politics of Multiple Hybridity: Understanding the Organization of Health Activism

Steve's paper engaged with the definitional and conceptual issues that social scientists face when speaking about the apparent growth in health activism. Drawing on his recently published *Inclusion: The Politics of Difference in Medical Research* (2007), Steve argued that this activism might increasingly be taking hybrid form. By way of background, he noted how Science and Technology Studies (STS) scholarship has paid greater attention to health activism which reflects in part a growing concern with biomedicine as well as an interest in how advocacy groups provide ways of understanding concepts such as identity, solidarity and personhood. At the same time, STS scholars face a series of definitional problems when it comes to describing precisely the kinds of groups and collectivities in which they are interested. One interesting feature is that many of these groups actually operate across different boundaries, blurring divisions between the state and social movements, experts and lay people, the market and civil society. Discussing his recent research, Steve argues that the groups which promoted a set of policies to make biomedical research more inclusive of women, racial/ethnic minorities and the elderly were in fact hybrid, involving those on the 'inside' and 'outside', from members of Congress to key figures in scientific institutions. He concludes that this hybridity was actually key to the success of the movement as a whole. One of the conclusions he draws from his research is that social scientists might benefit from shifting their focus from the individual group to the 'field' of activism in which it operates and how it shapes what other groups do.

Vololona Rabearisoa (Ecole des Mines) // Patient Organizations, Scientific Activism and Politics of Causes: Between Singularization and Generalization

Volo began by reflecting on the different approaches to the study of patient organizations. The first has emphasized how these organizations demonstrate the ability of lay people to participate in often technical arenas and so attests to the emergence of 'scientific citizenship'. The second has looked at how these organizations are new forms of social movements at the heart of which is scientific knowledge – this may involve struggles for recognition from scientific authorities or, through the use of concepts such as biosociality, a discussion of how this knowledge is involved in the construction of new forms of collective identity. Volo's paper focused on the idea of 'cause', as a concept that cut across the two approaches – which can be simultaneously understood both politically and scientifically. Her presentation drew on her current research in France looking at a collaboration that has been underway since 1998 between paediatricians, geneticists, child psychiatrists and parent organizations to review the diagnoses of children as 'autistic'. The enormous uncertainties surrounding the diagnosis and treatment of the young people she describes leads to this collaboration. Volo argues that the high level of uncertainty about these young people and their condition means that disciplinary boundaries between clinicians and scientists can be set aside and interdisciplinary discussion can take place. Even more impressively, she suggests that there is more focus on the day-to-day living issues with greater importance given to anecdotal and familial histories of suffering and difficulty.

Celia Roberts (Lancaster U) responded to these two papers before the workshop divided into the first 'breakout' session.

## Session 2: Biosocialities and Biopolitics of Health Advocacy

Sharon Batt (Dalhousie U) // Constructing and Contesting Visions of Citizenship

Sharon's paper presented findings from ongoing research conducted in Canada on breast cancer activism, and, in particular, the role played by pharmaceutical companies in supporting advocacy groups. The paper was framed by a theoretical engagement with the concept of biosociality and how it has been interpreted and elaborated by a number of authors, particularly Nikolas Rose. Sharon's research has questioned whether accounts of 'biosocial communities' described what she had experienced as the 'hurly-burly and heartbreak of patient group activism'. Sharon argued that patient and health advocacy groups are highly political structures and are sites of ongoing contestation and resistance. Looking at the example of the Canadian 'National Breast Cancer Group', she suggests that pharmaceutical funding can shape the internal agendas and affect public policies of groups in ways that might be profound and yet, to outsiders (including the membership), invisible or opaque. Therefore, a theory of activism must recognize power imbalances; pharma "partnerships" are an example of where the parties involved have a dramatic inherent power imbalance. Through such partnerships, pharma companies impose regimes of corporate surveillance in which they gather knowledge about the group's dynamics, its weaknesses and internal faultlines that the company can later exploit to its advantage. In conclusion, Sharon argued that biosociality accounts have been overly superficial in their understanding of the politics of activism. For some groups, the reductionist and corporatist values inherent in the marketing of biotechnology are the very targets of the group's activities. Patients' groups may function as sites of knowledge about biotechnology, but they can also be sites in which knowledge is distorted or masked, for example by the exploitation of hope. Moreover, identities independent of the health/ disease axis may be more central to a group's advocacy than the biological (e.g., environmental, social justice, emotional, political).

Sahra Gibbon (UCL) // Being 'Vociferous Fundraisers': Charity and the Civics of Breast Cancer Activism in the UK

Framed in terms of the 'biosocialities of breast cancer genetics', Sahra's presentation drew on the research she has done in the UK on the interface between a burgeoning growth in breast cancer activism and the application of the knowledge and technologies associated with the discovery of the two BRCA genes in the mid and late 1990s. At the same time as helping to enable an emerging field of genomic medicine and science, these meeting points are in fact diversely configured with uneven consequences across a lay/practitioner divide and beyond a clinical interface. Given the way these developments must be also be linked to a long standing culture of gendered health activism and a range of institutional cultures, it is also a situation which is not easily rendered only in terms of novelty or simply as mobilization 'from the ground up'. In this paper, Sahra focused on one particular set of institutional parameters that has been central to the emergence of BRCA genetics and continue to inform the dynamics between publics and science in the UK; that is the civics and citizenship of a dominant charity infused culture of breast cancer activism. Drawing on research work undertaken with a breast cancer research charity, she examined what different narratives of involvement and identification reveal about the character of breast cancer 'activism', the dynamics between science and publics, as well as the meaning and instrumental use of 'expert knowledge' and 'advocacy'. Her conclusion was that we need to think through the influence of powerful institutional domains, such as cancer charities, and their close relationship with the state and publics in the UK, and the consequences this has for theorizing the relationship between biopolitics, activism and identity in the context of breast cancer.

Orla O'Donovan (University College Cork) responded to these two papers before the workshop divided into the second of the 'breakout' sessions.

*Note on format:* Each session also involved a breakout period during which workshop participants moved into three groups to address in depth the issues raised by the speakers and discussants and brought their own experience and other ideas to the table for discussion by the group. The final session of the workshop was a plenary session and I summarize below some of the major themes and concerns that were discussed during that session.

## **Notes from the Plenary Session**

The final session of the workshop was a plenary discussion that reviewed some of the earlier debates that we had in the smaller, breakout groups and identified some new issues.

### ***Consequences and outcome of health activism.***

One of the issues discussed in this session addressed how the evaluation of health outcomes could become a tool or a kind of policy instrument for talking about the 'effectiveness' or impact of forms of health activism. For instance, we might ask whether state-led initiatives to encourage greater patient involvement, resulting in greater representation and better ways of involving people in decision making, have led to improvements in health? One could ask how much extra health is achieved as a result of this new policy?

There was a question, however, of how one judges success. Do we, as analysts, sometimes make the assumption that we know from the outset the range of criteria from which we are to judge success? In fact, activist groups might accomplish various different kinds of outcomes but not necessarily those that can be measured in formal ways by governmental agencies. The consequences of some forms of activism can be more diffuse, such as transformations in cultural meanings or opening up new arenas of debate. From the point of view of the social scientist, it is therefore important to register this side of things to avoid seeing a movement as a failure because, for example, it has been co-opted by the pharmaceutical industry or has not brought about a tangible outcome.

### ***Health Social Movements and 'Public(s)'***

There was reflection on the position and meaning of the 'public' in the discussion about social movements in health and the formation of activist groups. It was noted that there is currently a significant programme in 'public engagement' especially in the arena of health and medicine. This has become a vital aspect of health policy politics. There is a politics associated with the 'sectional politics' of health activism, but there is also a larger movement in which social scientists are also in some sense implicated, to become involved in public engagement.

The example of the UK National Institute for Clinical Excellence (NICE) was used to describe how this institution has divided the 'interested' publics from the 'disinterested' publics, which reflects a broader understanding that public engagement should serve to bring into being a public that has no interests in the matter at hand. The 'ordinary' citizen, therefore, is enrolled into bodies such as the NICE Citizens Council to balance out the interestedness of the stakeholders.

It was also argued that it is more useful to study particular social movements rather than seeking to identify a public because these provide a more specific, locatable object of study. The 'public' is not something that we should aim to study except in the sense of how the public is rendered as a certain political object through the technologies of public engagement such as citizens' juries, opinion polls,

market research, and the like.

It was further observed that in the UK context public consultation and public engagements have effectively become mandatory. It has been argued that the rise of public engagement in science is partly a result of a crisis of legitimacy. However, the situation could be more complicated than that. Many institutions today, such as the Wellcome Trust, are employing classic market research tools which were historically used to measure political legitimacy. How should we understand this development in relation to health activism? Are some of these things merely legitimization? In response, it was noted that we could characterize the current period in terms of the reported proliferation of 'bottom-up' groups alongside the institutionalization of public engagement by various agencies associated with the state, which might be thought of as 'top-down'. It was asked how, analytically, one could put these apparently parallel developments together?

But it was also said that one needed to be cautious when using the 'top-down and bottom-up' model since what appear to be a bottom-up phenomenon, an organization of the 'grassroots' and therefore with some kind of authenticity, might be what O'Donovan has discussed as examples of 'astroturf' organizations, created and fostered by powerful interests aligned with the state.<sup>1</sup>

### **Relationships between 'the Academy' and Activism:**

The relationship between academics and the academy and activists and activism also surfaced as major strand of the discussion, and addressed various dimensions of this relationship.

How do health activists view social science? Is social science of use to them? Would activists wish to engage in dialogue with social scientists? Although there has been discussion of how health groups and other activist groups take up scientific knowledge, there has been less attention paid to where they have taken up knowledge from the social sciences and the humanities and use it for their purposes. It was pointed out, however, that the recent work of Katrina Karkazis on Intersex activism in the United States provides one such example of this happening.<sup>2</sup>

In many academic areas, there is not the expectation that non-academics should be involved but in this area there is a pressure to include representatives of health activist groups, although none were present on the occasion of the workshop (invitations had been extended but not taken up). In response, it was said that it was valuable and legitimate for academics to have their own space for discussion. It was further noted how this comment itself illustrated the power of the claim-making of such groups that, as academics, we are not under the same pressure to involve activists as industry or government. The claims made by those groups are quite powerful to resist; they cannot be denied a seat at the table and perhaps this is reflected in current policies. At the same time, it was observed that good research practice involves some kind of moral or social obligation to involve, communicate and discuss one's findings at different stages with those whom we have dealt as 'objects' of study.

It was then pointed out that the roles and identities of academic and activist are not necessarily so clear-cut. Numerous academics (some of them were at the workshop) have a history of activism, although this can be something that is marginalized in the academy. It was said that inhabiting the dual positions

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<sup>1</sup> Orla O'Donovan (2007) 'Corporate colonization of health activism? Irish health advocacy organizations' modes of engagement with pharmaceutical corporations', *International Journal of Health Services*, 4, 37, 711-733

<sup>2</sup> Katrina Karkazis (forthcoming) *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (Duke University Press)

of academic and activist could be uncomfortable. In some countries, however, this might be more acceptable than in others. In the UK, for example, it was observed that this would be quite difficult to do because it undermines one's legitimacy in both worlds. On the other hand, at Lancaster University as at other academic institutions, academics have been committed to social change of one form or another such as in relation to environmental issues. It is important, too, not to see activism as the exclusive means of doing politics; teaching in women studies for example can be seen as engaging in very political work, but not taking the form of activism. It was further observed that the label of activist was itself problematic and perhaps reflected changes in political discourse, by which the more general term 'activist' had come to replace more ideologically-laden identities associated with the left and feminism.

### ***Biosociality and Health Activism***

A major theme addressed in two of the talks in the second session concerned the analytical value of 'biosociality', which was then reflected in the plenary discussion. It was recognized that since it was originally advanced by Paul Rabinow in 1992, it has been taken up by a number of authors, notably Nikolas Rose and Carlos Novas. There has been recent criticism of this concept which has focused on its empirical grounding, whether it provides an accurate description of contemporary activities, whether it is a generalized phenomenon or more limited to particular times and places. Discussion centred initially on the question of whether biosociality describes a historically-specific phenomenon? Is this a new phenomenon, or a fashionable way to account for something that has a much longer development? For instance, it was argued that there is a long history of illness-based social movement of one sort or the other but often with a very different kind of political configurations from those of the present day. What is of interest today is whether there has been a shift in power relations, whether the roles of different kind of actors, people with diseases, of researchers, of medics and careers, and so on, have shifted.

How we define and understand 'biosociality' was seen to be contestable. It was argued that there is a risk that this concept makes it sound simpler than it is, i.e. that people are organizing around biology. But in what sense is it biology? Is not biology already, in an important way, social? It was also asked to what extent is biosociality attributed to the impact of new genomic knowledge, and that this might be limited to a few, specific cases. Moreover, it was argued that as opposed to thinking about biology – in terms of the production of scientific knowledge – it would be better to think in terms of the body, of the somatic as Rose and Novas do when they talk about 'somatic individuality'. In response to this comment, it was suggested the work of feminists on the corporeal was very relevant to this discussion about biosociality. Feminism has been successful in identifying that there are corporeal dimensions, but that these are not synonymous with biology in the sense of the 'scientification' of that word. These debates about biosociality were also recognized as being part of a broader argument that there is a process of 'biologization', whereby we are increasingly seeing our identity in bodily terms.

By way of conclusion, it was suggested that the concept of biosociality was relevant in terms of enabling us to conceptually make sense of what is going on. Although it has been an influential way of thinking about current subjectivities, new conceptual tools were also needed.

### ***Health Activist Groups as Co-producers?***

The session closed with some discussion about the nature of labour and production in contemporary economy and society. In other arenas, such as computer programming, corporations are enrolling their consumers or users as producers. Web 2.0 domains such as Facebook or Second Life can also be viewed as productive zones. Perhaps this could also be extended to health activism whereby such groups become involved in both the consumption and production of biomedical knowledge? Pharmaceutical industry support for the creation or sustaining of patient groups could be interpreted in terms of the concept of "worlding" developed by the geographer Nigel Thrift when he talks about how

a cultural world is generated around a product.<sup>3</sup>

It was noted that patients are required to do more and more work in the production of their own illness; they are asked to be involved in satisfaction surveys, focus groups, or hospital management. It was asked in what ways we might see being ill as sometimes being constitutive of a form of labour, as has been argued in relation to clinical trials for instance.

The workshop was told that the NHS in the UK has been involved in setting-up a web-based forum to give feedback into the health service based on patients' experiences as a means of bringing about service change and service improvement. It constitutes, too, a new form of production of knowledge about the experience of using services that is now being valued by the state. In response, it was said that these forms of patient involvement were actually highly individualized.

The workshop closed with thanks from the chair to the speakers, discussants and participants for their contributions to the day.

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<sup>3</sup> Thrift, Nigel (2006) "Re-inventing invention: new tendencies in capitalist commodification" *Economy and Society*, Volume 35 Number 2 May 2006: 279 -306

## Biographies

### Speakers

**Sharon Batt** has had a career as a writer and community activist and is currently completing an interdisciplinary PhD at Dalhousie University in Halifax, Nova Scotia. Her doctoral research is a case study of pharmaceutical funding of breast cancer groups in Canada from 1991 to 2007. Following a cancer diagnosis in 1988, she wrote *Patient No More: the Politics of Breast Cancer* (1994; Gynergy Books), which won the 1995 Laura Jamieson Award for best feminist book published in Canada.

**Steven Epstein** is Professor of Sociology at University of California at San Diego and Director of the Science Studies Program. His areas of academic interest include the sociology of biomedicine, health and illness; sociology of science and scientific knowledge; gender, sexuality and race. In 1996, Steve published the influential *Impure Science: AIDS, Activism and the Politics of Knowledge* (California UP) and, in 2007, *Inclusion: The Politics of Difference in Medical Research* (Chicago UP).

**Sahra Gibbon** is a Post-Doctoral Research Fellow in the Department of Anthropology at University College London. She has studied the social and cultural dimensions of developments in breast cancer genetics, which was published in 2006 as *Breast Cancer Genes and the Gendering of Knowledge* (London, Basingstoke; Palgrave Macmillan). She is continuing her research in the area, exploring the changing and dynamic relationship between 'publics' and 'scientists' in an era of genomics in the comparative cultural context of the UK and Cuba.

**Vololona Rabeharisoa** is a Maître Assistant in Sociology at the Centre Sociologie de l'Innovation at the Ecoles des Mines, Paris. She is interested in the role of scientific and technological research in society, especially in the consequences of the growing involvement of potential beneficiaries of research in the scientific debates and activities concerning them. In collaboration with Michel Callon, Vololona has studied the history of the mobilization of biological and clinical research by the French Muscular Dystrophy Association (AFM), focusing on the emergence of new forms of sociality around human genetics.

### Discussants

**Orla O'Donovan** is a Lecturer in the Department of Applied Social Studies at University College Cork. Her research and teaching interests include the politics of health and medicine, patients' organisations and social movements for health, the cultural and economic power of the globalised pharmaceutical industry, post-development school ideas about science and technology, feminism and strategies of resistance. Her recent research has included a Royal Irish Academy-funded study of Irish health advocacy organisations and their modes of interaction with the pharmaceutical industry.

**Celia Roberts** is a Lecturer in the Department of Sociology at Lancaster University. She is interested in questions of responsibility and risk in contemporary biomedicine, and in how patients come to make decisions about engaging with new medical technologies. Her book, *Messengers of Sex: hormones, biomedicine and feminism* (Cambridge University Press, 2007) explores the role of hormones in producing sexually differentiated bodies. She is also the co-author (with Sarah Franklin) of a book on genetics and reproduction, entitled *Born and Made: An ethnography of preimplantation genetic diagnosis* (Princeton University Press, 2006).

## Organizers

**Alex Plows** is a Cesagen Research Associate based at Cardiff University. Her long-standing research interests are in mapping radical activist discourses and mobilisations in the UK over genomic/ biotech issues from the mid 1990s onwards. She was employed on a Welsh Assembly/ ERDF funded research project evaluating sustainable development before joining Cesagen during phase one.

**Flo Ticehurst** is the Communications Officer for Cesagen and based at Cardiff University. She is responsible for internal and external communications for Cesagen. Flo also works part-time as Genetics and Society Research Officer for the Wales Gene Park. In this role she supports the network of researchers at Cardiff University involved in research focusing on ethical, legal and social aspects of genetics and works with Wales Gene Park colleagues to develop and deliver education and public engagement projects.

**Richard Tutton** is a Senior Lecturer at Cesagen Lancaster. Richard works at the intersections of the social studies of science and medical sociology, and has interests in the social and ethical issues of banking human tissue for genomics and biomedical research and the implications of contemporary life sciences for identity and citizenship. He has published work in these areas in sociological and science studies journals and co-edited a book, *Genetic Databases: the Socio-Ethical issues in the Collection and Use of DNA* (Routledge, 2004).

## Participants

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The logo for CESAGEN is displayed within a dark olive green rectangular box. The text "cesagen" is written in a white, lowercase, sans-serif font, with the "c" and "e" being slightly larger than the other letters.