

What *is* public engagement with human genetics and what is it *for*?

Differentiating between policy practice and 'social movement'

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Abstract

Focusing on qualitative research in the UK between 2003-2007 amongst a variety of different publics engaging with human genetic technologies, this paper addresses the issue of what 'public engagement' *is* and what it *is for*. Providing typologies, examples and accompanying rationales of engagement, the paper differentiates between definitions of public engagement as a type of *policy practice*, and public engagement as '*social movement*', where publics frame issues on their own terms, generally outside the policy sphere. Thus as well as being a policy tool, public engagement can also be understood in terms of network relationships between individuals and groups, occurring in many different circumstances and taking many forms. Public engagement as social movement is shown to be extremely 'hybrid', consisting of multiple publics who interact over complex issues in complex ways; ethnography as a methodology enables a nuanced understanding of these narratives. The paper also argues that public engagement defined as social movement is an end in itself. These are citizens engaging in deliberative democracy, complementing public engagement as part of a governance framework, and contributing to citizenship stakes through the forms their participation takes and the issues they raise.

Introduction

'Public engagement with science' is a key discourse, and a key strategy, in academia, science/industry and especially policy (Leshner 2003, Wynne 2006, Rowe et al 2005, Bucchi 2004). But what *is* public engagement and

what is it *for*? The concept is used in different ways and means different things to different people. Informed by theories of deliberative democracy (Habermas 1987, Dryzek 2000, Fischer 2000) and by social movement theory (Diani 1992, Melucci 1996), this paper shows that a distinction can be made between public engagement as *policy practice* –governance-, and public engagement as '*social movement*', whereby publics frame issues on their own terms, generally outside the policy sphere. Public engagement can thus also be understood in terms of network relationships between individuals and groups, as well as being a specific policy tool.

The paper argues that public engagement defined as social movement is an end in itself. These are citizens engaging in deliberative democracy, complementing public engagement as part of a governance framework and contributing to citizenship stakes in terms of their participation and the issues they raise. Such engagement performs important functions, such as civil society capacity building, and creating social change. Thus, identifying and analysing public engagement outside the public sphere is sociologically important in terms of identifying forms of civil society engagement and their significance (such as increasing levels of consumer interaction with available bio products); in identifying key frames which are 'framed out' of the policy process; and in identifying publics' concern about the limitations of the mechanisms of governance. Findings from studying 'social movement' forms of public engagement clearly have the potential to inform policy and political directions and debates more generally about science and society. Ethnography as a methodology, and particularly participant observation (PO) is thus argued to be an important form of 'upstream public engagement' (Wilsden and Willis 2004), able to identify emergent, plural, often ambivalent public responses to complex issues.

Embedded within the question of what public engagement *is*, and *is for*, is the issue of who 'the public' are. Academics have differentiated between 'the general (lay) public' and specific publics as 'expert', engaged stakeholders (Fischer 2000, Wynne 1996, 2006, Collins and Evans 2002,

Evans and Plows 2007) and/or 'interest groups' (Tait 2001). Qualitative research conducted during 2003-2007 which forms the evidence base for this paper¹ traced the social dynamics of multiple 'publics' as they engaged with human genetics, identifying core areas of public interest and concern. This research identified that there are multiple publics, multiple issues at stake, and many 'entry points' into complex debates on human genetics, and many ways of 'framing' them.² Importantly, not just 'interest groups' but many different sorts of publics are predisposed to engage with human genetics if catalysed by variables such as being personally motivated by specific issue triggers and also by how these issues emerge and are framed as public debates, or emerge as points of consumption. For example, a 'member of the public' asked to donate DNA to the Wellcome Trust biobank, could then become an engaged, expert, stakeholder. Someone buying a genetic test kit online can also be described as an engaging member of the public. 'Human genetics' is a fast-moving field. The term covers a complex set of networked connections between 'wet bench' science, technologies as research tools, and (potential, actual) applications such as genetic tests and drugs, which all represent and catalyse a melange of discourses, ideas, meanings, values, 'lifeworlds' (Habermas 1987). Thus, the social field is complex and 'messy' (Law 2006). Whilst there are plenty of 'usual suspects'- very vocal voices (such as those of 'expert scientists', or pro-lifers) and some quite predictably polarised debates and discourses, there is also a great deal of ambivalence and complexity, in that people often move 'beyond for and against' in the ways in which they engage with, and frame, issues.

The paper firstly discusses, and provides some examples, of public engagement as policy practice, arguing that this performs a specific function which has important benefits but also significant limitations, not just in terms of what the process can deliver in terms of policy outcomes, but in terms of how publics and their potential input are defined (as stakeholders, or not) and 'framed' (Plows 2007). This has implications for

¹ <http://www.lancs.ac.uk/fss/cesagen/politics/index.htm>

² See Evans et al (2006), Evans and Plows (2007), Welsh et al (2007), Plows and Boddington (2006) and Plows (2010 forthcoming) for more project findings and analysis

citizenship stakes in relation to the impact of public engagement; what is debated, at what point in the process, by whom, and with what outcomes. This is particularly important given that definitions of public (citizen)'s duties and responsibilities, as well as rights, are at stake; for example, it has been suggested that we have a 'duty' to participate in biomedical research (Harris 2005). Thus while some commentators are optimistic about 'bio citizenship' (Rose and Novas 2004), such discussions often assume that participation in and access to deliberative democracy is a level playing field; this is, to say the least, highly questionable (Plows and Boddington 2006).

As a counter to being 'framed' by policy makers and others, some publics are deliberately choosing to mobilise outside the policy arena. This type of public engagement as 'social movement' is often representative of a reflexive critique of power relations and agenda setting, in specific contexts, such as the environmental and health risks of nanotechnology, or concerns about prenatal genetic screening policy. The paper shows how such publics are 'challenging codes' (Melucci 1996) and why they do so, and why it is important to identify and study them. Informed by previous research by the research team (Chesters and Welsh 2006, Plows 2003, 2004, Doherty et al 2003, 2007), the project identified emergent social networks, groups and individuals who were becoming engaged in the debate but whose existing frames and forms of engagement were in some cases less well represented in consultation processes and in other policy/public settings than some more visible others. It is predominantly these groups, networks and individuals who are the focus of this paper. Examples of protest activity and other public engagement outside the official policy process are given in the last half of the paper identifying 'prime movers' (McAdam 1996) and 'early risers' (Tarrow 1998) who are setting the stakes of the debate in their own terms, for example through protests, publications and workshops. Such events are a window shedding light on the more latent and hidden nature of informal networks of activist and campaign groups, and show how activists develop capacity.

Section One: Public Engagement as Policy Practice: Overview

Dryzek (2000) discusses public engagement as policy practice in terms of 'strong' deliberative democracy. Such public engagement is part of the 'democratic governance' of technologies, aims to enrol identified 'stakeholders' in set processes, and is a specific practice, with specific aims and agendas. For example:

Consultation is ... a form of engagement that is appropriate when the policy process is already underway and there is an intention to make changes or deliver specific outcomes. It therefore does not invite an open debate on very broad areas of public policy, nor does it empower those who participate with the final decision...

Cabinet Office (2007: 7)

Examples of UK policy focused public engagement traced during the 'Emerging Politics' project include consultations on human egg sourcing for stem cell research³; the Human Fertilisation and Embryology Authority (HFEA) launched a consultation in 2006 called *Donating eggs for research: safeguarding donors*⁴. Another issue which was the subject of public consultation was the technique prenatal genetic testing. The Human Genetics Commission (HGC) launched a consultation in 2004 entitled *Choosing the future: genetics and reproductive decision making*⁵. Other, more complex, forms of public engagement as policy practice have seen the development of 'hybrid governance' whereby publics and 'expert stakeholders' have been enrolled onto forums, panels and committees and made (arguably) a direct contribution to policy at different levels. This has included, for example, academic involvement designing and running

³ This issue has been seen to be relevant to the human genetics debates because eggs would be specifically used for stem cell research, flagged (by the HFEA and other stakeholders such as patient groups and scientific research institutes) as potentially providing cures for diseases with a strong genetic component such as Huntingtons disease and Alzheimers.

⁴ http://www.hfea.gov.uk/cps/rde/xbcr/hfea/donating_eggs_for_research_safeguarding_donors_consultation_FINAL.pdf

⁵ <http://www.hgc.gov.uk/UploadDocs/DocPub/Document/ChooseFuturefull.pdf>

stakeholder forums such as citizens juries on issues such as nanotechnology (Rogers-Hayden & Pidgeon 2006, Singh 2008); stakeholders such as patient groups running public events which feed back to policy; stakeholder membership on advisory groups which inform the regulatory process such as the HGC.

Importantly, academic and stakeholder calls for better public engagement post the 'deficit model' of public understanding of science (Wynne 1996) and drawing on concepts of patient 'embodied expertise' (Kerr et al. 1998a, b) have led to more participatory models of public engagement being developed to encourage the involvement of 'expert publics' and 'engaged publics' in the regulatory process (Singh 2008, Rogers-Hayden and Pidgeon 2006, Evans and Plows 2007). Bucchi (2004) has identified, and recommended the development of, 'cross talk' between 'publics' and scientists, in order to facilitate knowledge transfer. A related development has been a discourse on 'upstream' public engagement (Willis and Wilsden 2004, Wynne 2006, Ferretti and Pavone 2009) which explicitly seeks to enrol stakeholders early on in the regulatory process. It is certainly the case that many 'stakeholders' and 'members of the public' are engaging with public engagement processes of the types listed above, and it is also clear that many of these processes are more inclusive, and aim for 'best practice'. However for some, even 'upstream' public engagement of this type is way downstream:

'Demos has ... produced a report, See Through Science, that calls on industry, government and scientists to involve concerned groups in shaping research into problematic subjects such as nanotech at a much earlier stage than commercialisation. The problem with this argument is that for a development to be seen as 'concerning' ... usually happens well after industry and government have set their targets ...'

Corporate Watch (2005)

This above quotation from the UK NGO Corporate Watch⁶ explains why many engaged publics, despite policy moves towards participatory 'best practice' raise a number of concerns, firstly about the 'end of pipe' nature of public engagement as policy practice, in that it occurs once a specific trajectory of technological development is well in process. There are thus a linked set of concerns over power relations and agenda setting; who and what is really 'upstream'? Further, who identifies the stakes of public engagement? A consistent finding from the 'Emerging Politics' project was the identification of public concerns about how issues are 'framed' in public/policy debates (eg, 'for or against') and who was framing them. Many participants in such processes felt frustrated by the terms of the debate. Further, those (policymakers and others) who identify the stakes also by default identify the stakeholders. Which publics get identified as stakeholders in key debates and brought to the policy table, why, and with what outcomes? These questions are essential for assessing the health of deliberative democracy.

The HFEA (2006) public consultation *Donating eggs for research: safeguarding donors* is discussed to illustrate some of these points. This consultation related to policy shifts in 2006/7 (predating the HFEA 2008 Act) on the acquisition of human eggs specifically for stem cell (cloning) research. The consultation remit initially asks the question; should eggs be donated specifically for stem cell research? However the document in fact assumes this is a given, framing the issue in terms of 'risk management': '*safeguarding donors*'. 'Framing' concerns were also raised by UK feminists relating firstly to the way 'informed consent' for the procedure was defined in the consultation document (Plows 2008). Significant questions were raised about the conditions under which informed consent was likely to be sought, for example. Further, there was also concern about the transaction of human eggs framed in the document in terms of egg 'sharing' and also 'donation'. Dickenson (2007), and Sexton (2005) are amongst feminist 'prime movers' defining the transaction as 'trade'. The limitations with the terms of the debate and

⁶ <http://www.corporatewatch.org.uk/>

how it was set, the conditions under which the issue emerged into the policy arena in the first place, and the way the debate was subsequently conducted through the consultation process, were thus a point of contention for some UK and international feminists in 2006 and 2007.

Section Two: Public Engagement As 'Social Movement'

The rest of this paper focuses on specific examples of public engagement as 'social movement', defined here as grassroots, self initiated forms of mobilisation including protest activity. Public engagement of this sort can be understood as a series of networked relationships between different sorts of publics, occurring in many different circumstances and taking many forms. In discussing examples, this section seeks to explain what public engagement of this type is *for*, showing that publics who engage outside of the policy process doing so for a number of reasons including 'tilting the frame' (Steinberg 1998), seeking to re-frame the debates *on their own terms*, not those set by powerful elites. It is important to identify and study these forms of public engagement in their own right. They are significant social spaces, and provide data not only about the process of mobilisation itself, but also about stakes and stakeholders who generally tend not to figure on policy lists of 'usual suspects'. Such activity has 'intrinsic value' as part of social life which has meaning for the participants and helps them develop capacity such as developing knowledge stakes and network contacts. Other rationales given for action by participants show that such engagement is aimed at influencing public debates, policy directions and the decisions other powerful actors such as 'big pharma'. Further, studying the nature of such engagement contributes to an understanding of how people are negotiating highly complex and ambivalent terrains. For analysts and policy makers wishing to understand what issues are at stake for 'the public', studying such activity thus provides an opportunity to broaden the stakes of the debate and incorporate the views of other stakeholders into the decision making process.

In the 'Emerging Politics' project, as part of a broader methodological approach, in order to understand more fully what sorts of public views and voices might be engaging with human genetics, participant observation (PO) was undertaken amongst a case study of actors who generally had an environmental and social justice perspective on human genetic technologies, and also Disability Rights informed perspectives. A 'social and environmental perspective' on human genetics is defined here as a critique of 'geneticised' accounts of health and identity and concerns about the policy implications of this (Plows 2010 forthcoming). The following quotes taken from interviews give a flavour of this perspective:

there's such a fixation these days on genomics and the gene has all the answers. Whereas the glaringly obvious health issues, like ... malnutrition ... in mums and kids ... are blatantly ignored.

'Alice' , bio infomatician

... my life in the last two years has been a hundred percent better because I've been in housing which meets my needs ... they're spending huge wads of money on [genetics], when they could be fixing the day to day problems of people that have all sorts of conditions by spending that money elsewhere.

'Sally', Disability Rights campaigner

Participant Observation (PO) was conducted at the events organised or attended by these sorts of publics, in the process identifying who is catalysing and participating this mobilisation, what the targets of the engagement are and the rationales for action. Interviews with these and other key individuals were also conducted. Groups and networks were also identified through their online presence. The project identified a number of typologies of public engagement and reasons why different public groups carried these out. Importantly, these repertoires of action were (are) not restricted to groups who mobilise in opposition to different human genetics applications (the focus of this paper) but also, groups

who mobilise to support them, such as patient groups, parents of sick children, and so on (Plows 2010 forthcoming).

It is important to re-emphasise that for many of these groups, networks and individuals, the governance of human genetics and 'techno-science' generally (such as agenda setting; how the issue is 'framed' by the policy process) catalyses or informs mobilisation as well as the trigger of the issue itself. These are frames which move the debate well beyond risk identification in specific contexts. The following quotes (taken from interviews unless otherwise indicated) discuss campaigner's concerns about the 'framing' of debates:

... the debate is framed as a simple binary opposition ... it's painful to try and explain the nuances...

'Simon', genetics watchdog campaigner

... the [stem cell] debate has been framed in a certain way, you're either for or against ... so other issues, other considerations ... cannot be expressed

'Lucy', sustainable development campaigner

... How do we avoid being cast as opponents of medical research and individual liberties? ... How much do we focus on the technologies themselves, and how much on the social justice and global equity values that motivate our concerns?

Text from Berlin civil society genetics event report 2003

The final quotation also emphasises how people struggle to 'frame' issues in their own terms when the stakes are complex.

The research identified that many people explicitly critiqued the governance of science and technology. 'Lucy', for example, asked the question:

... Is regulation therefore just a fig leaf on the free market model, whereby markets dictate techno-scientific moves and governance struggles to keep up?

'Lucy'

Activists in France who in 2004 occupied a site earmarked for a major nanotechnology research site, claim they did so as a means of 'direct democracy', signalling impatience and/ or lack of trust in the governance process:

... potential consequences and benefits drawn by research can't be nor debated nor controlled by the populations ... Shutting this site ... is attempting to stop a project that we refuse It seems to us essential to interrupt «development »'s headlong rush ...

Text taken from press release circulated online: *Activists in Grenoble France occupy construction site for Minatec Nanotech centre 2004-12-13*

Such 'direct democracy' is contributing to the debates on its own terms and is arguably an important form of citizenship necessary to redress power imbalances within existing governance frameworks. 'Mike' argues that

... what we need to get to is ... the politics of new technologies ... a real live politics of how new technologies impact on society, how society has some control over that

'Mike', technology watchdog campaigner.

These are extremely important contributions to citizenship and science debates and address the 'bigger picture' underlying different scientific 'controversies'.

We now turn to an overview of typologies of public engagement as 'social movement'. These include (but are not restricted to) workshops, awareness raising and networking, and protest events; and four case

study examples are discussed in more detail below. Importantly, many of these publics as individuals or as campaign groups also do contribute to the policy process through consultation processes, for example, and are thus engaged in many hybrid forms of engagement. Other groups, networks and individuals deliberately stay outside the policy process and only participate through forms of engagement they generate themselves. Firstly, the project identified and participated in a number of workshops organised by public groups and networks for their own benefit. These can be seen as 'convergence spaces' (Routledge 2003) which both reflect the current state of network capacity and catalyse further mobilisation. These events tend to be consciously aimed at capacity building within existing networks and groups; they are put on by the organisations and networks, as an internal resource. Some of these events are thus only advertised 'internally' and knowing about them can often mean that one has to have pre existing knowledge of the particular social network, making these events difficult (and in some cases, impossible) to access by 'outsiders' and thus challenging sites to study. Again the benefits of ethnography-participant observation (PO)- are clear as a means of understanding this type of public engagement. An example is a workshop on enhancement held in Oxford in 2006 which was attended by a number of 'prime movers' in the UK social and environmental justice movement. This event was 'invite only' and was thus restricted to people within pre-existing networks within a strong network where friendship, trust and a shared background of action and campaigning, were key to their presence at the event.

Another important form of public engagement as social movement is awareness-raising and networking. This covers a wide range of different types of information creation and dissemination including e- networks, blogs and websites, publications, public events, and specific campaigns. This cluster of activities tends to represent the more public facing aspect of network, campaign group and NGO activity, for example the publications produced by the UK NGO Genewatch, the international NGO ETC Group or (to give an example from a different set of civil society networks) the "pro genetic" organisation Genetic Interest Group. The production of these resources from networking to publications is aimed at

raising awareness amongst the 'general public', increasing membership (whether formal or informal) of specific campaign groups and networks, and also aims to put agendas and issues into the public sphere for further debate and/or to affect the political direction of events. Such activity is often catalysed by specific policy developments, such as the HFEA's decision to allow the use of 'donated' eggs for stem cell research, or developments in the private sphere, such as the increase in commercially available genetic tests, which has catalysed a number of reports by the watchdog Genewatch. Engagement of this type can be short term (linked to a timeline around a specific campaign over a policy decision), long term or often a mix of both.

Protest events are another important form of public engagement as social movement. Protest activity often performs a symbolic function ("challenging codes") and not always (or just) a disruptive one. Looking at the form, target and rationales for protest events and the makeup of participants can inform an understanding of what issues are at stake. Often, these protests are as much about the way the issue is being governed as much as the implications of the issue itself. UK protest events about 'human genetics' were not often identified during the 'Emerging Politics' project. It is possible that relatively few protest events occurred because the stakes are still 'emergent' and highly complex, and thus it is hard for affected or interested publics to know how and why to 'draw lines' and focus on targets even where there is an identified grievance. Also, as the quotation drawn from the Berlin civil society event points out, to voice opposition places one at risk as being seen as 'anti technology'. The fact that issues are emergent and highly complex may also explain why several protest events were unusually 'hybrid' in terms of the people who made up the protest.

Four specific examples of types of public engagement as social movement are now discussed. The first example is a protest organised by "People Against Eugenics" (PAE) in October 2004. This was a small demonstration organised and attended by genetics watchdog, social justice and disability rights campaigners; and significantly, also attended on the day by some

'pro life' campaigners. The demonstration was catalysed by a conference, held at the Royal Society, entitled "*Ethics, Science and Moral Philosophy of Assisted Human Reproduction*", which had invited several speakers known to take controversial positions on issues such as the use of genetic reproductive technologies for screening out disabilities, and the use of germline cloning for 'human enhancement'. The Disability Rights (DR) campaigners were particularly concerned that the conference had no one from a DR perspective speaking. Demonstrators handed out leaflets to participants from outside the premises in a low key, good natured event. An important finding was the presence of 'pro life' activists at this demonstration. They had been invited by some of the Disability Rights activists with whom they had had previous contact. Very significantly, these pro life activists were seemingly happy to hand out a leaflet, written by the PAE protest organisers, which clearly stated that those present were supportive of reproductive rights to choose- ie were *not* anti- abortion. The presence of the pro life activists caused some consternation amongst the event main organisers, and there were several interesting conversations between pro life activists and other campaigners about why being concerned about prenatal testing was more than simply an issue of 'embryo rights'. Campaigns over complex issues which enrol issues important to a number of different 'lifeworld' perspectives, appear to have a tendency to attract very 'strange bedfellows'⁷ (Evans et al 2006).

The second example is a Down's Syndrome protest that took place in 2003. The following account is taken from the press release of the protest which was catalysed by the then impending uptake of Pre implantation Genetic Diagnosis (PGD) as an 'opt out' prenatal genetic screening programme in the UK and highlights (as the PAE action above also showed) that the exclusion of certain perspectives from 'official' and elite debates is itself a trigger for direct action. It also, like the PAE protest, shows how people use protest as a means of re-framing debates they feel have already been set, or from which they are excluded, or both.

⁷ See also pro life activists who set up the 'Hands Off Our Ovaries!' campaign group together with some feminists about the use of women's eggs for research (Plows 2008)

On May 19th [2003], a group of people with Down's Syndrome and their supporters disrupted the International Down's Syndrome Screening Conference at Regents College in London ... t[elling] the doctors that [they] oppose[d] Down's Syndrome screening and that people with Down's Syndrome are people not medical problems The protesters ... had written to the conference organisers in advance and asked to speak, but were refused It is unacceptable that doctors discuss better ways of preventing people with Down's Syndrome being born, whilst excluding their voices from the debate. This runs directly counter to one of the main demands of disabled people: 'Nothing about us without us'... This should be the start of a national debate on prenatal screening.

[from circulated press release 2003]

Such action sends a strong signal about inclusion and involvement of stakeholders and it was clearly a very important early warning about how to conduct debates and policy in sensitive and highly complex arenas. Significantly, it is important to note that the stakes raised by the participants and organisers in the above text have nothing at all to do with the status of the embryo: they are about identity, value, and citizenship.

The third example is another protest over the use of unregulated nanoparticles. On December 9th 2004, THRONG (The Heavenly Righteous Opposed to Nanotech Greed) disrupted the '*Nanotechnology- delivering business advantage*' conference in Buckinghamshire, UK presenting a 'can of worms' award to one of the conference participants, Harry Swan, formerly of Monsanto. The symbolic and 'playful' nature of much UK direct action (Wall 1999, Szerszynski 2002) is evident; the THRONG activists dressed as angels to disrupt the conference, stating:

“where these nano fools rush in we angels fear to tread”⁸

The identification of specific corporations' operations as a clear target for criticism and action, and the use of such action as a means of framing broader concerns about risk and uncertainty, echoes previous campaigns against GM crops which were focused on the operations of specific companies such as Bayer and Monsanto, with clear critical reference to globalization processes. Such actions are likely to seed further mobilizations within the UK. As the social movement literature would predict (Diani 1992, Doherty et al 2003), activists with pre existing social bonds developed through previous cycles of contention, and new actors brought into these networks, are developing strategies to oppose the development and commercialisation of nanotechnology and Converging Technologies. Whilst the NGOs tend to have a more formal and 'static' identity, the more radical networks tend to develop multiple, micro identities and campaign 'brand names'. These reflect the more informal, often 'biodegradable' processes of social network interaction (Diani 1995) which spawn specific direct action events.

The final example is a capacity building event; the genetics and science workshops held during the European Social Forum (ESF) in London in 2004. The ESF is an annual, very well attended event consisting of European grassroots networks, groups, NGOs and far-left political parties, and is an important event in the constantly co-constructed process of global civil society networks which have been termed the "anti" [alter] globalisation movement. Whilst high visibility 'summit hopping' by 'the movement of movements' to protest at meetings of the G8, the World Trade Organisation and the G20 (and latterly, Copenhagen) is part of a now long established repertoire of action (Seattle 1999 was a decade ago), events like the ESF show the more latent work of movement capacity building. The ESF is a 'convergence space' (Routledge 2003, Welsh et al 2007) which aims to develop network capacity and catalyse further action. The list below gives the titles and the organisers of the workshops provided at the ESF on the topic of human genetics, bioscience

⁸ From THRONG press release- quote by THRONG 'angel' Sarah Phimms.
<http://www.angelsagainstnanotech.blogspot.com/>

more generally, and science and society. It shows what human genetics developments/applications were catalysing mobilisation at the time, how these were framed, and which groups and networks were 'prime movers' and 'early risers'. These are very much emergent frames and show the process of meaning construction in action. PO provided clear evidence that networks and groups are taking the opportunity to build capacity through information sharing and discussion.

Human genetics/omics workshops

1) *Developments in Human Genetics*

Organisation: GeneWatch UK, Human Genetics Alert, Institut Mensch Ethik und Wissenschaft, Gen Ethisches Network

2) *Bar coding people - Individualised health care or money making scam?*

Organisation: GeneWatch UK

3) *Human cloning and genetic engineering: what's at stake?*

Organisation: Human Genetics Alert

4) *Prenatal screening: eugenics or women's rights?*

Organisation: Human Genetics Alert

Related workshops-

Resisting corporate monopolies and new enclosures

Organisation: ETC group (Action Group on Erosion, technology and Concentration), Green Party of Europe, Protimos

This above was one of several workshops specifically on nanotechnology and Converging Technologies.

Science and society workshops:

1) *What Research Policies Are Appropriate in Another Europe?*

2) *'Science and Citizenship'*.

3) *A European Science Social Forum (ESSF)*

These last three workshops, by far the most 'official' with academic and relatively 'big name' speakers and international NGO presence, had a definite policy orientation. They were the most strategic in terms of wanting to enter into the policy arena and re-frame the stakes of policy debates. Soon afterwards at a 'Science in Society'⁹ high profile public participation event in Brussels, some of the same 'prime movers' 'launched' the ESSF, presenting a discussion document on Framework 7 (FP7), the European funding scheme, criticising how budgets were allocated and identifying a number of concerns with the emphasis on funding science and technology projects.

Conclusion

Based on case study work amongst UK publics engaging with 'human genetics', this paper has tackled the issue of what 'public engagement' *is* and what it is *for*, differentiating between public engagement as policy practice and public engagement as social movement. Firstly, it has provided examples of public engagement as policy practice. Moves towards 'best practice', such as 'upstream' public engagement and more participatory form of deliberation which draw on concepts of public expertise, are the result of public and academic input into policy processes and reflect developments in deliberative democracy with regard to citizen involvement with scientific development. However, participants in these policy focussed 'deliberative democracy' processes are entering a terrain which is not neutral; the technologies have already emerged along specific trajectories, or are projected to given the political and economic investment in them. Thus public engagement as policy practice is still inevitably subject to major power imbalances and hence the extent to which publics can influence emergent technological trajectories through such engagement processes is questionable (Rowe et al 2005, Plows and Boddington 2006). Further, many publics feel that the debates about these technologies have been framed in terms which are too narrow, or

⁹ http://ec.europa.eu/research/conferences/2005/forum2005/index_en.htm

which are not conducive to discussing issues they feel to be at stake. Indeed, it is clear that policy led public engagement can in fact 'frame out' important perspectives, perhaps especially in complex and ambivalent terrain.

Identifying, and studying, public engagement defined as 'social movement' is part of a solution to a problem: that participation in and access to deliberative democracy is not a level playing field. Public engagement as policy practice can be complemented and informed by other forms of data collection and sociological research. We have seen that as a counter to being 'framed' by policy makers and others, some publics are deliberately choosing to mobilise outside the policy arena. This type of public engagement as 'social movement' is often representative of a reflexive critique of power relations and agenda setting, and constitutes an important contribution to citizenship stakes simply by making this point about access to and impact on decision-making, and secondly by bringing other perspectives and knowledge bases to the table. The case study groups and networks in this paper are reflexively 'tilting the frame' to re-frame the debates on 'human genetics' – which often tend to be debates about health and identity, to include issues of social and environmental justice (Plows 2010 forthcoming).

Public engagement defined as social movement is clearly an end in itself for those who are catalysing and participating in these forms of action, and it is clear from the examples given in this paper that building capacity within their own networks, contributing to public awareness, and using direct action as a means of directly influencing (and indeed embarrassing) those with power, are important goals for many campaigners who are engaging outside of the policy process. Clearly, many also hope that this type of action will also affect policy outcomes, for example by influencing public opinion which in turn impacts upon policy. Understanding social life more generally as a type of public engagement can inform policy agendas and identify emergent public trends which are important sociologically in their own right. Narratives of network relationships between complex, hybrid publics engaging with complex, hybrid types of 'techno science' are

key to an understanding of public engagement as 'social movement'. Another important example of emerging social trends identified through ethnographic research are 'bio consumers' buying 'bio products' such as genetic test kits, or attending stem cell clinics for anti aging treatments. These 'bio consumers' are an important social phenomenon which needs critical sociological attention, for example in terms of what is driving this market trend and the implications for these bioconsumers, not least in terms of how they blur lines between patient and consumer identities.

This paper has argued that ethnography is therefore a useful method which enables 'upstream public engagement' in 'messy' (Law 2006) social fields, identifying issue frames and 'prime movers' as they emerge and engage. This can help to answer important 'baseline' questions: what are the emergent issues for 'the public'? Which publics are mobilising and why? What are the key stakes which they raise? This is not a definitive methodology – the project represents a small soil sample of a complex terrain- but such techniques can be used to collate data which together with other qualitative and quantitative approaches, can inform a more nuanced and sensitive debate on the issues and values at stake.

References

- Chesters, G. & Welsh, I. (2006) *Complexity and Social Movements: Protest at the Edge of Chaos* London: Routledge
- Corporate Watch (2005) 'Nanotechnology: What it is and how corporations are using it' *Corporate Technologies 1*
- Diani, M. (1992) 'Analysing Social Movement Networks', in Diani, M. and Eyerman, R. eds *Studying Collective Action* London: Sage
- Dickenson (2007)'Property in the Body: Feminist Perspectives' *Cambridge Law and Ethics Series 3*
- Doherty, B. et al (2003) 'The Preferred Way of Doing Things: The British Direct Action Movement' *Parliamentary Affairs* 56: 669-86
- (2007) 'Environmental Direct Action in Manchester, Oxford and North Wales: A Protest Event Analysis' *Environmental Politics* vol 16, 5 805-25

- Dryzek, J.S. (2000) *Deliberative Democracy & Beyond: Liberals, Critics, Contestations* Oxford: Oxford University Press
- Evans, R. et al (2006) 'Towards an Anatomy of Public Engagement with Medical Genetics: Strange Bedfellows and Usual Suspects' in Atkinson, P. et al (eds) *New Genetics, New Identities* London: Routledge
- Evans, R. & Plows, A. (2007) 'Listening Without Prejudice? Re-Discovering the Value of the Disinterested Citizen' *Social Studies of Science* Vol. 37, 6 827-53
- Ferretti, Maria Paola; Pavone, Vincenzo (2009) 'What do civil society organisations expect from participation in science? Lessons from Germany and Spain on the issue of GMOs' *Science and Public Policy*, Volume 36, Number 4, May 2009 , pp. 287-299(13)
- Fischer, F. (2000) *Citizens, Experts, and the Environment: The Politics of Local Knowledge* Durham: Duke University Press
- Habermas, J. (1987) *The theory of communicative action* Boston: Beacon Press
- Harris, J. (2005) 'Scientific Research is a Moral Duty' *Journal of Medical Ethics* 2005; 31: 242-48
- HFEA (2006) *Donating eggs for research: safeguarding donors*
- HGC (2004) '*Choosing the Future: genetics and reproductive decision-making*'
- Irwin, A. & Michael, M. (2003) *Science, Theory and Public Knowledge* Maidenhead: Open University Press
- Law, J. (2006) *After Method: Mess in Social Science Research* London: Routledge
- Leshner, Alan I (2003) Editorial: Public Engagement with Science, *Science* 14 February 2003: Vol. 299. no. 5609, p. 977
- McAdam, D. (1986) 'Recruitment to high-risk activism: the case of Freedom Summer' *American Journal of Sociology* 92, 64-90.
- Melucci, A. (1996) *Challenging Codes: Collective Action in the Information Age* Cambridge: Cambridge University Press
- Plows, A. (2003) '*Praxis and practice: the "what, how and why" of the UK environmental direct action (EDA) movement in the 1990s*' PhD Bangor: University of Wales

----(2004) 'Activist Networks in the UK: Mapping the Build-Up to the Anti-Globalization Movement' in Carter, J. and Morland, D. eds *Anti-Capitalist Britain* Gloucester: New Clarion Press

---- (2007) 'You've Been Framed! Why Publics Mistrust the Policy Process' *Genomics Network newsletter* 6, 22-23

-- (2008) 'Egg Donation in the UK: Tracing Emergent Networks of Feminist Engagement in Relation to HFEA Policy Shifts in 2006' in Molfino, F. & Zucco, F. eds *Women in Biotechnology: Creating Interfaces* New York: Springer

----(2010 forthcoming) *Debating Human Genetics: Contemporary Issues In Public Policy And Ethics* London: Routledge

Rogers-Hayden, T & Pidgeon, N (2006) Reflecting upon the UK's Citizens' Jury on Nanotechnologies: NanoJury UK 3 *Nanotech. L. & Bus.* 167 (2006) Routledge, P (2003) 'Convergence space: process geographies of grassroots globalization networks' *Transactions of the Institute of British Geographers* 28(3) 333-49.

Rowe, Gene et al (2005) Difficulties in evaluating public engagement initiatives: reflections on an evaluation of the UK GM Nation? Public debate about transgenic crops *Public Understanding of Science*, Vol. 14, No. 4, 331-352 (2005)

Sexton, S (2005) 'Transforming 'Waste' into 'Resource': From Women's Eggs to Economics for Women' presented at Reprokult workshop 'Commodification and Commercialisation of Women's Bodies' at Femme Globale Conference 10 Sep 2005

Singh, Jasber (2008) The UK Nanojury as 'upstream' public engagement, *Participatory Learning and Action*, Volume 58, Number 1, June 2008, pp. 27-32(6)

Steinberg, M. (1998) 'Tilting the frame: Considerations on collective action framing from a discursive turn' *Theory and Society* 27, 6: 845-872.

Szszszynski, B. (2005) 'Beating the Unbound: Political Theatre in the Laboratory without Walls' in Giannachi, G. and Stewart, N. *Performing Nature: Explorations in Ecology and the Arts* Frankfurt: Peter Lang

- Tait, J. (2001) 'More Faust than Frankenstein: the European debate about the precautionary principle and risk regulation for genetically modified crops' *Journal of Risk Research* 4:2,175-89
- Tarrow, S. (1998) *Power in Movement: Social Movements, Collective Action, and Politics* Cambridge: Cambridge University Press
- (Wall 1999
- Welsh, I. Evans, R & Plows, A (2007) 'Human rights and genomics: science, genomics and social movements at the 2004 London Social Forum' *New Genetics and Society* 26/2
- Wilsdon, J. and Willis, R. (2004) *See-through science; why public engagement needs to move 'upstream'* London: Demos
- Wynne, B. (1996) 'May the Sheep Safely Graze? A Reflexive View of the Expert-Lay Knowledge Divide' in Lash, S. Szerszynski, B. & Wynne, B. (Eds) (1996) *Risk, Environment & Modernity: Towards a New Ecology* London: Sage
- (2006) 'Public Engagement as a Means of Restoring Public Trust in Science - Hitting the Notes, but Missing the Music?' *Community Genetics* 2006/9 211-20