

BOX: continued

This more sophisticated understanding of the context in which these decisions are made is also informing the debate about whether doctors should be permitted to override those decisions. “The fact that these family decisions are more complicated than had been recognised has already led people to step back from calls for legislation,” says Clarke.

Consultations between patients and clinicians become more problematic when the relationship between genetics and the disease in question is less clear-cut than it is for monogenic disorders. Most diseases are the result of a complex interplay between many genes and environmental factors. Lifetime risk of developing coronary heart disease, for example, or type 2 diabetes cannot be diagnosed with any accuracy through simple genetic testing, and yet, they too run in families.

Health policy in the UK and US is increasingly encouraging clinicians to incorporate patients’ family history data of both diabetes and heart disease into primary care assessments that are intended to identify those at high risk and to motivate lifestyle changes to improve people’s health. In the case of heart disease, clinicians combine a patient’s family history, age, blood pressure, cholesterol levels and lifestyle factors such as smoking, to calculate the probability that they will develop the disease within the next ten years.

The trouble is, according to Egenis’s Paula Saukko, that, in line with policy recommendations from the National Institute for Clinical Excellence (NICE), the clinicians treat family history as the baseline genetic component of the disease, which can only be mitigated by lifestyle change. This is not only scientifically simplistic, but it is also a source of confusion and concern for patients.

After all, family history is about more than genes - families also share habits, lifestyles, socio-economic class and geographical location, all of which can also have an impact on disease risk. Confusion arises when, for example, patients are told that their family history puts them at high risk even though they are aware that their own lives bear little resemblance to those of their grandparents who died of heart attacks after years of heavy smoking, poor diet or unhealthy working conditions. In this respect, patients’ understandings of family history are richer and often more sophisticated than the advice being given to them by medical experts.

Saukko’s work also casts doubt on the effectiveness of the lifestyle advice being offered on the basis of the tests. While giving up smoking does reduce heart disease risk dramatically, other behavioural changes have more marginal benefits. People who start jogging or change their diet in response to the medical advice can end up being very disappointed when they return for a follow-up months later to find their risk has not come down, especially if they’re another year older, which itself pushes the risk up. Such simplistic public health messages can generate false expectations among patients and leave them feeling betrayed by the advice they receive.

“Family history could actually be quite a useful concept if it was used as a basis for wider discussions about biological, behavioural *and* social influences on disease risk,” says Saukko. “But with its narrow emphasis on the biology, it’s an impoverished public health policy.”

The **ESRC Genomics Network (EGN)** is dedicated to examining the social and economic consequences surrounding the development and use of the science and technologies of genomics.

The EGN includes 3 ESRC funded Genomics Centres - **Cesagen**, **Egenis** and **Innogen** – and the **Genomics Policy and Research Forum**. These investments range across 5 universities, and involve over a hundred researchers, from professors to PhD students, as well as administrative and support staff and a rotating cast of visiting research fellows. The Network is one of the largest social science investments in the ESRC’s current portfolio, and is growing into the largest concentration of social scientific research on genomics in the world.

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The Making of Public Policy

The celebrated television comedy series *Yes Minister* was a sustained and insightful analysis of the politics of policy making. Policies may be expedient rather than wise. Research may be used to support a favoured policy rather than to arrive at an independent assessment of how good a policy is. Policies may be subverted as they are put into practice, or even before.

Twenty-first century ‘Yes Ministers’ may find their lives even more complex. Genomics and the contemporary life sciences raise new challenges for policy makers. For one thing the science is complex and rapidly changing. On top of this, genomic investigations may tell us about not just the individuals who consent to participate in research studies but about their relatives and even about succeeding generations - people who simply cannot give (or withhold) their consent. Hospitals, museums and laboratories already hold large amounts of material that is rich in genomic information, even though no one realised how much information could be held in old anthropological and medical samples.

Government mandarins have also had to deal with the rise of another phenomenon: the increasing role of public consultations about policies and technological options. Public preferences now feed into policy choices.

Social scientists have long been interested in the relationship between research and the formation of public policy: how does research actually feed into policy-making and what are the best ways for policy actors and researchers to relate to each other? ESRC Genomics Network (EGN) researchers realise that these familiar questions are raised anew now that many different forms of expertise are needed to contribute to policy advising. EGN research has focused both on case studies and on issues of principle.

Engaging conversation

Hands up all those in favour of public engagement... In 2007, few would deny the importance of involving the public in policy debates about science and technology. Over the past two decades, prompted in part by a perceived distrust in science, and by a series of high-profile public-relations disasters – eg. nuclear waste, GM, BSE - scientists and their political masters have been seeking ways to connect with a public that they increasingly feel they need to have on their side.

Initial efforts were clumsy, based on the assumption that discomfort with new technologies was the result of ignorance, and that all the public needed to see the light was a better grip of the underlying science. Now, however, the emphasis is on conversation rather than conversion. Policymakers and scientific institutions talk of “upstream engagement”, and how direct dialogue with the public should be a “normal and integral part” of the science policy process and the activities of scientists. Public attitude surveys, focus groups and citizens’ juries are all tools of the science-policy trade, and public engagement has been written into the job descriptions of scientists funded by the UK’s research councils.

Social scientists also have been influential in the transformation. They have contributed to a growing appreciation that science is a part of society rather than apart from it; that non-scientists possess a range of expertises that can inform the scientific process; and that when it comes to deciding how society should incorporate scientific developments, scientists are just regular citizens like the rest of us. But the work of social scientists doesn’t stop just because everybody agrees that public engagement is a Good Thing.

In practice, engagement is always going to involve compromises: if it’s too exhaustive, decisions won’t get made; too shallow, and it becomes a token gesture. Should every voice be at the table? Or are some voices more important than others? Which voices are being heard? And are they actually being listened to?”

Who is this public that everybody is busy engaging with? By definition, it is those who take part in public engagement exercises. But according to work at Cesagen, there is a diverse ecosystem of different publics out there who, while engaged with issues to do with new biotechnologies, remain disengaged from the policy process.

Alex Plows and her colleagues have been collecting and analysing conversations taking place below the policy radar: conversations on internet discussion-boards and weblogs, at protest meetings and other self-organising civil society gatherings such as the European Social Forum.

"It's like taking soil samples from a very muddy field," says Plows. "The more stones you turn over, the more wriggling life you find." It's an ecosystem that includes "Cyber-Goths" talking online about transhumanism, feminist academics discussing egg donation, people with Down's Syndrome concerned about natal screening, and grassroots social-justice activists who object to commercial interests in science. "There are multiple issues being raised, in multiple conversations, with multiple strands of cross-over and overlap, by multiple publics who are normally portrayed simply as either pro or anti," says Plows.

This complexity does not suit policymakers, who need to assess public opinion quickly and efficiently so that the policy process can move forward, she says. Indeed, last year, the Human Fertilisation and Embryology Authority (HFEA) licensed a clinic to offer discounted IVF treatment to patients willing to provide eggs for research, even before it had completed its public consultation exercise around that very topic.

Plows' interviews with members of these emerging political networks suggest that they are deterred from engaging with the policy process by its simplistic binary view of public opinion, which provides little room for nuanced opinions. When public debates set out to establish whether the public are for or against a technology, people who are critically supportive of science find it hard to raise their concerns without being assigned the "anti" label, for example.

If people are to be able to truly engage with issues, public engagement needs to be seen as an end in itself rather than a means to an end, says Plows. Framing public debate in general terms such as 'What is health?' or 'How can we be healthy?' would provide us all with the opportunity to have a genuinely enlightening conversation.

At Innogen, researchers are exploring the possibilities for public engagement in stem cell research, a rapidly developing field that, on the one hand, might yield important treatments for a range of degenerative diseases, but on the other, is generating public unease about the source of the materials under study and the techniques that it employs.

The 'Talking Stem Cells' project aims to identify social, cultural and ethical issues that emerge as the science unfolds. But it is also an experiment in how best to conduct public engagement in order to shape the trajectory of the science in ways that make it more socially acceptable or ethically robust.

The researchers start by assembling a range of focus groups representing the diverse spectrum of publics with an interest in the science, including patient groups, stem cell scientists, clinicians, and past and prospective IVF patients. Having identified the key issues raised by each group, they then mix the participants to explore them in more depth, before taking the debates to wider public and policy arenas. "Good engagement can bring differing sides together and allow them to investigate rather than categorise each other," says Sarah Cunningham-Burley.

"We have found no great resistance to stem cell research, or to science in general," she says. Neither is there a clear dividing line between the opinions of scientists and non-scientists. The commercialisation of research, for example, is a source of concern for participants across the spectrum, as is the discourse of "hope and hype" that surrounds stem cell research. Scientists, it emerged, recognise that therapies are likely to take much longer to develop than they promise, while patient groups express cynicism towards the status quo, but are also aware of the pressures that scientists are under to promote their research. The researchers may now seek to involve the media in a future dialogic event, with a view to challenging the ways in which science is promoted and reported, by bringing journalists, scientists and publics together.

Effective public consultation is essential to the success of scientific initiatives that rely on public cooperation. The Scottish The Scottish Family Health Study (SFHS) - part of a collaborative project between universities and the NHS called Generation Scotland - aims to investigate how genetic, environmental and lifestyle factors influence common diseases. To do this, it needs to recruit 50,000 volunteers from families willing to provide DNA and tissue samples and to allow scientists access to their medical records over ensuing decades.

EGN social scientists have been involved in the project from its inception, engaging with potential volunteers to identify concerns over issues of confidentiality, consent, ownership and access, which may act as barriers to participation, and exploring solutions to the problems raised. One such barrier concerned the fact that pharmaceutical companies would have access to SFHS data, which is crucial if the project is to lead to the development of therapeutic products. Many interviewees were uncomfortable with the idea of private companies profiting from others' altruism, but said they were prepared to tolerate the situation if a proportion of company profits were to be donated to good causes such as the NHS, for example."If you are going

to give people a voice, you have to listen, and be prepared to make changes on the basis of what they tell you," says Innogen's Gill Haddow. SFHS is now considering ways to implement such a benefit sharing scheme into its management.

As public engagement becomes routine, however, so too does the temptation for interested parties to influence policy outcomes strategically. Pressure groups can gain purchase in public debates by overplaying the environmental or health risks of scientific developments. And at the same time, scientists are becoming increasingly skilled at mobilising public opinion in support of their own positive visions of emerging technologies. Stem cell research centres are being re-branded as centres for regenerative medicine, for example, even though most of the research they do.

The result is what Innogen's Robin Williams calls "compressed foresight", whereby policy decisions can be caught between utopian and dystopian visions of the future. Depending on which vision grabs the imagination of policymakers and the

public, a new technology can get picked up on the grounds of utopian promises; others are rejected in the basis of dystopian ones. Environmental groups are already mobilising about the dangers of synthetic biology – as new a technology as there can be, given that synthetic organisms don't and might never, exist – while proponents are selling it as a source of green energy. And yet, says Williams, "those promises are uninformative as to a technology's ultimate consequences." Gene therapy hasn't lived up to the high expectations that were held for it. On the other hand, when lasers were first developed in the 1970s, nobody was predicting the multitude of uses - in CD-players, supermarket checkouts and surgical instruments - they are put to in 2007. Back then, the applications were expected to be scary, military ones. But those were the days before public engagement in science had been invented.

Social scientists cannot predict the future robustly either, of course. "If we could, we would be running multi-million-pound corporations," says Williams. "But we are at least able to alert people to problematic expectations."

BOX: Family Matters

Since the 1990s, sections of the medical profession have been talking tough regarding a problem that can lead to people with life-threatening conditions being denied access to crucial medical attention. The worry is that some people who test positive for genetic predispositions to disease endanger relatives by failing to tell them that they too might be affected, and professional medical bodies such as the Royal College of Physicians and the Nuffield Council have called for legislation that would allow doctors to depart from the normal duty of confidentiality if necessary and contact other family members directly.

It is certainly the case that in some situations, the consequences of withholding genetic information from relatives can be disastrous. Some cancers of the colon and thyroid are the almost inevitable consequence of underlying genetics. Without intervention, people who carry a single copy of a mutated APC gene, for example, are destined to develop polyposis coli, a lethal bowel cancer of middle age that is usually untreatable by the time it presents. Surveillance or preventative surgery can reduce the risk to carriers, but that is only possible when people *know* they are carriers.

Cesagen's Angus Clarke, who is also a professor of medical genetics at Cardiff University, is concerned that a "legislative sledgehammer" to crack this particular nut would be counter-productive. Like many other clinicians and genetic counsellors, he considers that the situation is best improved by engaging and working *with* families to encourage them to pass on information appropriately. And that requires knowledge about *why* patients sometimes don't pass it on.

Interviews with patients conducted by Clarke's Cesagen colleagues have revealed that their decisions about whether and when to inform relatives of test results are the product of subtle and often complex family situations and dynamics, and that there may even be positive reasons for their choosing not to disclose information. Sometimes, they might withhold information, or delay providing it, out of consideration for a relative who they think, for whatever reason, won't be able to take the bad news. In other situations, they might know that a particular relative is likely to react badly in other ways, and blame the messenger. On rare occasions, patients are even party to confidential family information that they are unwilling to disclose to clinicians – that someone is not the biological father of their child, for example. "Clearly, what goes on in families makes it more complicated than that people simply can't be bothered to pass on information," says Clarke.

Through an awareness of that complexity and the difficult issues they might be dealing with in consultations with patients, clinicians and counsellors can be better placed to offer more sensitive, appropriate advice, rather than just passing off a reluctance to disclose as ignorance or wrong-headedness, he says. [continued over](#)