

Ethical Dimensions in Sciencewise

A review of public perceptions of ethical issues
from the Sciencewise dialogues

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Summary

Sciencewise-ERC has held thirteen public dialogues on science and technology since 2005. This review is for the Science and Trust Expert Group of the Department of Business, Innovation and Skills (BIS). It provides a quick examination of the public perception of ethical and trust issues emerging from these dialogues.

Broadly, people were likely to be positive about developments in science and technology that promised gains in choice, quality of life, health, longevity, convenience, time-saving and reduced environmental impact. However, potential impacts on freedom, privacy, social equity, vulnerable groups such as the mentally ill or very young, or on 'natural and human values' were regarded with varying degrees of suspicion or hostility.

Common themes

Three common lessons about the public participants' attitudes to the science and its governance can be identified. First, public attitudes are formed not only in relation to particular technologies and the potential benefits and risks of the technologies, but in relation to the policies and values that shape the **social distribution of impacts**. The calls for science to serve a 'social good' suggest that public participants see the government as playing an important part in shaping the social purposes of science and technology and ensuring that the benefits are equitable.

Second, public attitudes to risk, uncertainty, and regulation tend to be concerned with perceived constraints in the capacity and co-ordinating ability of government to manage complex and unforeseen risks. In particular there were **low levels of trust and confidence** in the resilience of government leadership to stand firm against perceived vested interest in industry, and concern among public participants about the role of private ownership in research, development and delivery.

Third, there is consistent demand for more **open discussion and public involvement** in policymaking relating to science and technology. Discussions about science and technology can benefit from public input in a number of different ways. The challenge for government is to trust the public's ability to understand and contribute meaningfully to such policy discussions, find ways to incorporate members of the public directly in them and open up decision making processes to wider public scrutiny.

Differences across topics

Differences of ethical opinion tended to be most pronounced *within* dialogues, rather than between. Participants wrestled with different perspectives, balancing unknown outcomes between different winners and losers, and stepping into a range of philosophical and values based positions. Often it was about looking at rights and the most common dichotomy was between libertarian / individualistic and communitarian / collective values systems: between upholding free choice, consumer rights and personal well-being, and the protection of wider societal outcomes and social goods. Mirroring this were desires for 'modernising' IT and labour saving technology,

competing against concerns to preserve ‘traditional’ values and qualities in the way we work, provide social care or manage the land.

Different science topics did tend to create their own areas of debate. **Medical research** was always highly valued, but it raised issues about what illnesses (and age groups) were most deserving, how the safety of a donor should be protected, and the moral rights of embryos and human genes. **IT science** tended to raise issues around consent and privacy, and the misuse and governance of data. **Food and environmental science** stirred debates on the containment of risks, and impacts on wider social and natural systems.

For downstream technology products the public were keen to be empowered through information, particularly **labelling on risks**, so they could make choices for themselves, rather than have their behaviour regulated. They were also keen on the provision of restitutions and guarantees.

The public were concerned about **risk** in science. They were most supportive of research that had the potential to offer clear benefits (e.g. clear medical / clinical benefits), and wanted to see more invested in understanding side-effects of potential applications. They understood that risk and uncertainty were sometimes unavoidable in emerging technologies, but encouraged all players to be much more open about the uncertainties and unknowns they face (e.g. through transparency ratings). They wanted government and businesses to take responsibility for unintended consequences, and explain how they would deal with worst case scenarios. There were calls for more research and tighter regulation until more is known about the long-term side effects of some science on humans and the environment.

The public most often asked for stronger, more enforced **regulation**, but in certain cases also feared over-regulation. The public wanted to know who was responsible for policing and oversight, they wanted to be assured that different parts of government were co-ordinating (and governance maps were raised as one route to support this) and wanted public policy to be coherent in managing the costs and benefits of possible research products. Most of all the public wanted a government that was resilient to commercial lobbies and vested interests.

Across all dialogues the public called for more **public engagement and oversight**, to shore up trust in government processes, as well as to inform a longer term vision of science and society strategy. However, this was not just about holding events, but about engendering a long term cultural change that would increase transparency and openness in science and government, across all processes and decisions.

1. Introduction

1.1. *The Sciencewise dialogue projects*

Since 2005 Sciencewise-ERC has engaged over 2,000 members of the public in over thirteen dialogue processes (Table 1). Each project has explored people's attitudes to evolving science and technology and highlighted their ethical concerns and perspectives². This short review explores the main ethical opinions emerging from these projects³.

Table 1: Sciencewise dialogue projects to December 2009

Code	Title	Area of dialogue
RB	Risky Business	Attitudes to climate change and technology with young people
TG	Trustguide	Perceptions of risk, security and trust on the internet
ND	Nanodialogues	4 dialogues to assess attitudes to environmental applications of nanotechnology (e.g. land remediation)
NEG	Nanodialogue Engagement Group	Review of over 10 nanotech engagement projects, including environmental and medical applications
DM	Democs	Card games in schools on vaccinations, animal experimentation and climate change
SCWL	Community Exchange	Community discussion of science issues with their MP
DF	Drug Futures	Future of brain science, including treatments and policies for addiction, dementia and cognitive enhancement
SH	Science Horizons	Eight science themes: advanced materials and robotics, body and mind sciences, energy, information handling & knowledge management, nanotechnologies, network interactions, security, sensors & tracking
HY	Hybrid and Chimera	Regulation and legislation of hybrid cells in medical research and treatment
ST	Stem Cell	Regulation and legislation of stem cells in medical research and treatment
DNA	Forensic use of DNA	Use of forensic DNA in judicial process and creation of a DNA database
IB	Industrial biotechnology	Use of GM and other biotech in industrial, environmental and agricultural processes, including for energy and food
BES	Big Energy Shift	Community explorations of level carbon and energy savings technologies

1.2. *An ethical framework*

In broad terms, ethical science can be defined as science that is fair, legal and transparent. The Universal Ethical Code for Scientists, launched by the UK government's Chief Scientific Advisor in 2007, identifies seven broad principles based on rigour, respect and responsibility (Box 1).

² Ongoing dialogues in 2010 include Synthetics Biology, Food, Geoengineering, Low Carbon Communities and Animals with Human Materials. They are engaging several thousand further people.

³ This 6 day desk review project was commissioned in December 2009 by the Public Trust group of the Science and Society unit of BIS, to help feed into the Science and Society Strategy of the UK

Box 1: The Universal Ethical Code for Scientists

Rigour, honesty and integrity:

- 1) Act with skill and care in all scientific work. Maintain up to date skills and assist their development in others.
- 2) Take steps to prevent corrupt practices and professional misconduct. Declare conflicts of interest.
- 3) Be alert to the ways in which research derives from and affects the work of other people, and respect the rights and reputations of others.

Respect for life, the law and the public good.

- 4) Ensure that your work is lawful and justified.
- 5) Minimise and justify any adverse effect your work may have on people, animals and the natural environment.

Responsible communication: listening and informing.

- 6) Seek to discuss the issues that science raises for society. Listen to the aspirations and concerns of others.
- 7) Do not knowingly mislead, or allow others to be misled, about scientific matters. Present and review scientific evidence, theory or interpretation honestly and accurately.

Source: www.dius.gov.uk/science/science_and_society/public_engagement/ethical_code

This overview is based loosely on this ethical framework. It explores public perception on maximising and distributing the social benefits of science, minimising adverse impacts, and managing rights and risks. It examines levels of trust in corporates and government, public perception of trust, and how trust can be improved through management of risks and public transparency across all areas of science policy development.

1.2.1. Positive attitudes to science and technology

Across all projects the public remain upbeat and excited about the potential for science and technology for improvements in the quality of life and health, whether it be hybrid or stem cell research to create new cures (HY, ST), technology to tackle climate change (RB, IB, BES) or nanotechnologies to clean dirty water (ND, NEG). The twin themes of personal quality of life and wider social benefits are seen as key drivers for scientific advancement (SH).

“People’s attitudes to nanotechnologies are not significantly different from their attitudes to any new technology—and they are generally positive. Many people want Britain to be a world leader in nanotechnology.” (ND)

“Once the initial barriers of lack of knowledge were overcome,...the overall feeling amongst the group was one of excitement about the possibilities for the future that IB could offer and how the many different applications might allow for a fundamental re-organisation of the way industry operates.” (IB)

All technology sectors were broadly supported but medicine trumped environment which trumped information technology. Medical technologies were always given high importance (e.g. IB, SH), despite ethical challenges (e.g. HY, ST).

“A survey done at a Citizen Science @ Bristol event placed similar emphasis on health and environmental benefits. Of 98 respondents, 43% prioritised funding for biomedical nanotechnology research ‘to help cure disease’, alongside 21% in favour of environmental nanotechnologies and 13% who prioritised computer technologies” (ND)

“Medicine was an area where science was felt to bring more benefits than drawbacks... Unlike other applications which came under intense scrutiny and question, participants could only see the positives of IB in medicine. Participants could identify with the benefits that medical applications of IB could bring, for example in producing insulin for diabetics.” (IB)

Environmental and energy technologies were also perceived to be important (despite some concerns over the motive of industry), particularly of they could promise clean water, new fuels or a transition to a lower impact way of life (IB, BES, ND, NEG).

Growing awareness about climate change moulded attitudes to science.

“Public perceptions of IB are informed by ... concerns about the economic climate, concern about climate change, levels of understanding (and misinformation) about science and technology; and levels of trust in Government and in industry.” (IB)

The recent economic recession also seemed to have sparked increased concern for the ‘national interest’, with a hope that Britain could lead the world in new technology, job creation, growth and development (e.g. IB).

“Whilst the UK’s research standing was perceived to be good relative to Europe and on a par with the US, there was a sense that the UK was now starting to get left behind.” (ST)

“While suspicious of ‘Government’, people are supportive of ‘the national interest’. People are particularly protective of the UK’s position in relation to global economies and interests; keen that we get our ‘fair share’ by gaining economically from developing industrial biotechnology... There is a great deal of enthusiasm for the idea of Britain as leaders in new science and technology fields which appeals to people’s sense of national pride. Related to this is an interest in what IB developments in the UK might mean for regional labour markets and ‘British’ jobs.” (IB)

1.2.2. Balancing social costs and benefits

Underlying all dialogues was a desire to maximise social benefits from publically funded science, while minimising social costs. This was seen as the moral duty of publically funded science. Science should be ‘socially grounded’ in real benefit (e.g. NEG).

“Particular emphasis has been placed on nanotechnologies’ ability to serve a social purpose. A recommendation by NanoJury UK illustrates this point: ‘If

public money is to be spent, then it should go on those technologies that contribute towards the solving of longer-term issues, such as health and environmental problems. This should be combined with the use of incentives and strings-attached for the private sector” (ND – Nanojuries)

“For nanotechnologies to be acceptable to the public, government needs to ensure that: Any possible risks are offset by real benefits (health and environmental) to the consumer, not just the manufacturer, and Nanotechnologies do not exploit people who are less affluent (here or abroad).” (ND)

The public saw the ‘science good’ as a mix of outcomes, from those that largely benefitting the individual to those with broader advantages for the community as a whole. Sometimes those benefits might be connected (e.g. early diagnosis kits could save time both for individuals and take some of the load from GP services.)

Most of the science topics considered had potential costs and risks too. The analysis of these costs – in particular who or what would bear the costs - formed a core part of the ethical discussions.

In broad terms, where the social benefit was high the public was prepared to accept higher trade-offs. As an example: one of the most contested ethical debates was the use of stem cells for research. Potentially very significant medical breakthroughs for serious incurable diseases needed to be balanced by the rights of the embryo, and safeguards for the mother. The core of the ethical debate focused on defining ‘serious’ disease, and therefore establishing when benefits might outweigh costs. While it was agreed that stem cells should only be used to treat disease without other cures, there were strong debates about whether diabetes, cosmetic surgery or diseases only affecting older people should also be included (See Box 2).

Box 2: When do the benefits justify the costs – example from Stem Cell research

For public participants within the Stem Cell dialogue, the most significant driver was the potential of stem cells to treat serious diseases, particularly life threatening, debilitating and degenerative conditions for which current treatments were of limited therapeutic use. The necessity to use stem cell treatments only for serious diseases was stressed. This was not only due to the ethics of using embryos, and hence the means justifying the ends; but also due to patient safety and the uncertainties around stem cell science at this early stage.

However, what constitutes a serious disease was contested. Whilst at one end of this continuum diseases such as cancer, Alzheimer’s and Parkinson’s, together with serious injury, were viewed as worthy areas for research; at the other end, cosmetic applications such as face creams were not. However, there were many applications such as the growth of new teeth or treatments for acne or baldness that were more contested – though generally considered not to be serious enough to merit use of embryonic stem cell lines. This was further complicated when considering the needs of different patient groups – for instance whether treatments should be targeted towards the diseases of ageing versus treatments for conditions that affect younger people. Support was shaped by motives for research - for instance there was resistance to the use of stem cells for the purposes of human enhancement. It was also shaped by the wider implications of technical innovations, such as the potential for human reproductive cloning.

Source: Stem Cell dialogue

1.2.3. Not science for science sake

Ultimately, while the public are pro-science and development, they are also cautious about using science for science's sake, especially when an existing technology might suffice. Science should be proportionate to need, and to potential impact. As the costs, risks or unknowns rise, there is always the question of whether the application is really needed, and whether the research will yield results unobtainable from other means.

“People need to know what it's for rather than research for research's sake, there has to be an end in sight.” (HY)

“If there was another way of doing it (e.g. a skin cell) I would much prefer this route. However I still feel that we should try it both ways.” (HY)

“Participants were extremely positive about IB in pharmaceuticals... It would seem that in this area, where there is seen to be no alternative (unlike, for example, bioplastics, where the alternative is perceived to be a change in our way of life), possible drawbacks and implications are given far less weight.” (IB)

2. Social distribution of science impacts

Developing a route map to balance the social costs and risks with the social benefits, was the goal in many of the dialogues. Often this involved balancing rewards for some people with costs to others, thus much of the debate focused on the social distribution of costs and benefits, to specific social groups or value bases, and the prevention of externalities and injustices.

2.1. ***Ethical governance of science and innovation should protect these groups...***

Social groups most discussed included vulnerable groups, particularly the poor or ill, ethnic minorities, the poor or those in developing countries, and those who cannot speak for or defend themselves.

2.1.1. **Poorer countries and ethnic minorities**

The public expressed concern that any potential risks associated with nanotechnologies would disproportionately affect poor and marginalised people, in the UK and abroad (ND – Small Talk). They felt the only benefit would be to the manufacturing industries and professionals, not the poor or unemployed.

“The Small Talk project report calls for government to ensure that any possible risks are offset by real benefits (e.g. health or environmental) to the consumer, not just by increasing profits for industry. It also asks that

government take measures to ensure that the development of nanotechnologies in the UK does not involve the exploitation of less-affluent people here or internationally.” (ND)

There were also concerns that biofuels and bioplastics would remove land and food for populations in the third world (IB).

The public was also concerned about the bias of money spent on western medical research, rather than diseases in developing countries. If diseases prevalent in the middle class western world, such as heart disease, degenerative diseases and cancers, are likely to gain the most medical investment, what impact would this have on managing of malaria or AIDS (ST)? The accessibility of stem cell research and treatments to non-white ethnicities, in the UK and abroad, was also seen as important.

Concern for ethnic minorities was also central in debates about winners and losers in the use of forensic DNA. A number of the panellists felt that the disproportionate number of black and Asian men on the National DNA database had a criminalising effect on ethnic minorities, and was caused by the police propensity to target and arrest individuals from particular communities. Making the database universal was seen as one solution of the problem (Box 3).

Box 3: DNA Database could contribute to discrimination of ethnic minorities

Some participants in forensic DNA debate suggested that the existence of the National DNA Database was actually contributing to discrimination by recording and thus criminalising large numbers of people. It was thought that an individual's presence on the database would be interpreted as indicating a propensity towards criminal activity, whether they had been found guilty of a crime or not. These concerns were compounded by a lack of trust of formal institutions, particularly the government and the police.

Statistics relating to BME communities and the database, the historical actions of the government and the police, the extension of their authority and doubts about their legitimacy arising from events such as the Iraq War and the murder of Stephen Lawrence gave rise to suspicion that information relating to DNA may be misused by those in authority.

Source: Forensic DNA dialogue

2.1.2. Terminally and mentally ill

The public also identified the mentally ill as a vulnerable group, this time in response to drug treatments. Participants felt that drugs were often prescribed too easily and for too long. Many also saw the use of drugs as a means of controlling people whose behaviour society did not understand, found difficult to deal with or could not afford to manage with real social care. This was a particular issue when informed consent was difficult to obtain or the patient had limited ability to understand the potential risks. Some questioned whether drugs are used simply because they are the cheapest option, rather than the most effective. The public wanted to see a better understanding of the physical and social causes of mental illness, alongside drug research.

Those with severe degenerative diseases were also seen as a vulnerable group. They were more likely to consent to experiments with novel and potentially dangerous therapies (e.g. stem cell treatments that could cause teratomas and cancers as side effects). However most felt that patients should be able to trial experimental treatments, particularly where the existing treatment was not effective, providing there was informed consent and the risks had been fully explained. Individual rights and autonomy were seen to be two of the key principles underpinning such treatments and research.

“Despite many of the ethical issues associated with ES cells, the morality of not treating patients with serious diseases when there were tools available to gain understanding and potential therapies generally outweighed these concerns.” (ST)

2.1.3. Young people

Protection of young people was always uppermost in the public’s mind. For instance young people’s use of drugs was viewed differently from adult drug use, regardless of the type of drug under discussion. A strong priority was placed on the need to protect the developing brain and to prevent behaviour that might lead to addiction or mental health problems later in life (DF).

Young people were also a concern in the Forensic DNA dialogue. Many felt forcible DNA collection from young people might be deemed abuse. The debate focused on issues of consent, parental control and appropriate levels of force in relation to age. Some of the public felt that the collection of DNA from everyone at birth would decriminalise the entire database, and avoid forced DNA sampling. However others felt that collection at birth would be a fundamental breach of human rights, as babies would be unable to give their consent and there would be issues of implied criminal intent. Similarly, most participants were against the idea that, in the future, it might be acceptable to vaccinate babies against addiction (DF). However, the possibility of vaccines being used by adults was received more positively.

2.1.4. The unborn child

The public’s concern for the very young extended to the rights of the unborn child, particularly the embryo (of less than 14 days), and this was explored in the stem cell and hybrid embryo dialogues.

A small but significant proportion of the public viewed the embryo as having an absolute moral status. They believe that human life begins at the point of conception and embryos, no matter how young, should not be used for research and treatment.

The majority of participants, however, took a more ‘relative’ or ‘situational’ ethical perspective (i.e. shaped by the external context, rather than an immutable set of values). They did not believe five day embryos -which are no bigger than a grain of sand- are fully human, and believed that the potential of embryonic stem cells to cure

many deliberating and devastating diseases outweighed ethical concerns about using them. The range of perspectives is described in Box 4 below.

Box 4: Stem Cells – Ethical perspective on different sources of cells

There were broadly three groups of attitudes to stem cells:

Confident supporters - who emphasise the enormous benefits that the research promises, supporting the use of stem cells for basic as well as for therapeutic research, and rejecting various ethical objections to the use of embryos.

Selective acceptors - who reject the use of embryos under certain but not all circumstances, and endorse the use of adult stem cell research and the collection and storage of umbilical stem cells.

Pro life critics – who hold the view that life should never be created to grow spare parts for another person and indeed that embryos, however they are sourced, should not be used for research purposes at any stage in their development.

These views were dependent of the source of stem cell considered:

Adult stem cells were one of the least controversial sources, particularly due to the view that individuals either involved in the donation or clinical use of AS cells have given their consent. The principal concerns around adult cells were clinical, concerning their limited plasticity, and difficulties in growing cells in vitro. These clinical issues however had ethical dimensions: plasticity concerns were seen to limit the clinical reach of AS cells – a significant concern given that the principle of universal access strongly endorsed by all groups.

Cord blood use was generally viewed favourably by public respondents and highlighted in particular by those opposed to embryo research. There were, however, ethical concerns in this area. The first related to the collection of cord blood at birth and the need to ensure the mother and baby were not put at risk. The second related to the tension around public and private banking of blood, and the potential for people to be exploited by the commercialisation of this area. The third, and related concern, was that the storage and handling of cord blood was clinically safe, particularly in the private sector, and that this area had due oversight from regulators. Private storage was supported despite concerns that a two tier health service would develop if such treatments became available.

Foetal stem cells were the most controversial of the tissue-specific stem cell sources. For certain participants and stakeholders this was due to the view that any use of aborted fetuses was morally wrong. However, the bigger concern for the majority of respondents related to the issue of consent, and the potential exploitation of women. There were concerns that women should be able to specify the broad uses to which foetal material was put - including for stem cell research. This issue, which was also raised in relation to the use of embryos, is likely to complicate the consent process, conflicts with the current Polkinghorne guidelines and may forge significant issues for the governance of the science in the future.

Source: Stem Cell dialogue

Most of the public were generally supportive of research using spare embryos donated from patients undergoing fertility treatment and, to a slightly lesser extent, research using human embryos created from donated gametes.

For embryo sources the public are more comfortable using embryos (or indeed umbilical cords) that already exist and which will be destroyed if not used, rather than harvesting embryos specifically for research purposes.

“I think its better to donate them than just leave them, put them in the freezer, and argue over it when you get divorced.” Swansea man, participant in the deliberative work (HY)

“Why would you object to donating your embryos if it goes to a good cause? Abortion goes to nothing.” Glasgow man, participant in the deliberative work (HY)

Overall the moral status of the embryo was only one factor among many with concerns for the donor women’s welfare being as, if not more, important for many participants. In particular there were direct conflicts between the right of the woman to know how her foetal stem cells would be used, and the existing Polkinghorne guidance that there should be no such knowledge, to ensure a foetus is never ‘grown to order’.

2.2. Ethical governance of science and innovation should protect these values and rights

The ethical debate on reducing social harm and risk also extends to more intangible values, including rights and freedoms, and perspectives on what is deemed ‘natural’ or ‘human’.

2.2.1. Nature and what’s ‘natural’

There is a wide-spread sense that life is special among the public, at least to some degree, as discussed above with regard to stem cell research. However those who object to human-animal embryo research (hybrid and chimera) do so because of a sense that the *human* is special. Although the mixing of human and animal material is not new, for many people it was the first time they have been aware of the intention and some viewed this idea with disgust. Associations were drawn with incidents such as the Northwick Park drug trials, Frankenstein and the deep unease of a ‘chimera’ being created by hubristic scientists. There were also concerns re cost-effectiveness, cross mutation of animal disease and results not being applicable to humans.

“It seems unsafe to carry out procedures that are unnatural in the sense of being impossible by natural processes. It seems risky to do something that nature prevents.” (HY)

A contrasting view saw the use of animal eggs as an alternative to human eggs a necessary option in research, rather than a preferable one. Some respondents emphasised the very short supply of human eggs and risks for women involved in harvesting them.

“Given the difficulty and potential risks to women who donate eggs this would be a safer and potentially richer source of eggs.” (HY)

“There is still a great deal that could be learnt using animal studies.” (HY)

The debate between the use of hybrid versus the use of natural embryos, as possible alternatives, set two highly emotive ethical values against each other – the rights of the embryo and safety of women, versus ‘unnatural’ experimentation

2.2.2. Social interaction and the 'human touch'

In robotics discussion (SH) people valued the personal touch and human dimension in services, but were hostile to technologies - often time-saving ones - that would enable more simulation of 'humanness', and perhaps the substitution of human care. Human distinctiveness was perceived to be dependent on personal face-to-face interaction, and the discussions pointed to deep ambivalence about virtual worlds and mediated experiences.

The public is also cautious about the erosion of traditional and 'natural' qualities in everyday life and is concerned about 'dehumanising' work, home and social life. It is unclear whether this is about the change *per se*, or the motivations of powerful forces 'foisting' change upon them. These concerns range from the perceived domination of young people's lives by computer technologies (SH) and the potential of tele-working to separate workers from community (SH), to the potential of pharmaceuticals to replace social care in mental health care (DF) or of cognitive enhancers to devalue personal satisfaction by 'unnaturally' modifying the healthy brain and engendering a more competitive and unequal society.

"There was considerable ambivalence about many of the technologies in question. Broadly, technologies are supported that seem to promise more health, independence (e.g. for the elderly), convenience and quality of life. There is corresponding suspicion of technologies perceived to bring risks to safety, scope for loss of privacy and autonomy, social divisiveness (e.g. because of costs) and lack of genuine human interaction (e.g. use of robots for domestic care)." (SH)

While the public was keen to see productivity and freedom gains from tele-working, they also wondered if the loss of social interaction in home and work life might lead to less satisfying lives (SH), and whether robotics in the home might one day dehumanise social care (SH).

In drug futures (DF) the public were interested in anti-dementia drugs but questioned whether existing approaches using complimentary social care were not more effective, and more humane, despite being more expensive. Moreover, there was a concern that investment may 'medicalise' societal issues such as ageing to the neglect of care and support (ST).

"Despite the widely recognised value of medicines, there was a feeling that people often choose the 'quick fix' of pharmacological medication, in preference to seeking out longer-lasting solutions to their problems. More specifically, a great majority of participants felt that medication is used too early and too quickly in treating mental health problems. Many felt that an increasing number and range of 'mental states' are being seen as 'problems' and being treated with a greater number of drugs." (DF)

The development of cognition enhancing drugs to delay or halt dementia was supported by participants but there was caution about their use in healthy people. The public felt such drugs could exacerbate what was as an already over-competitive

culture, with the potential for people to feel forced to use cognition enhancers to compete for jobs or qualifications (see Box 4).

Box 4: Ethical concerns with new drugs in brain science

Cognitive enhancers: Drug enhancement was seen to be 'unnatural' and less desirable as a stimulant to brain power than 'natural enhancement' (e.g. diet, exercises). People also expressed fears about the adverse effects of such drugs, equality of access to them, undue pressure to use them, and their possible effect in devaluing unaided achievement.

Human enhancement challenges traditional ideas about medicine, i.e. that the role of medicine is to overcome some sort of impediment to normal physical or mental functioning, and thereby restore an individual to 'normal' health. An intervention that may enhance an individual beyond normal health therefore cannot always be easily accommodated within existing ethical perceptions. This stems from a sense that enhancement is a misuse or corruption of medical techniques, despite physical enhancement, through cosmetic surgery and other means, gaining increasing acceptance (DF)

Source: Drug Futures dialogue

The modernist's excitement for the future was mixed in equal measure across all projects with a conservative's appreciation of what already works, mixed with a sentiment for the 'simple life' in which natural, trusted, old fashioned community values prevailed.

"Participants' first and preferred response to the challenges we face was to re-evaluate modern life, before embarking on anything new. For example, refining existing processes to make them more efficient. However, there was also some resistance to new ways of doing things, seen to often present new issues, illustrating a contradiction in public reaction to new developments."
(IB)

The public were fearful of losing the 'human touch'. While technical advances might be impressive, the public sometimes asked whether the problems they sought to solve were about social relations and values, than technical solutions.

2.2.3. Freedom of choice

The implications of freedom of choice – for individuals, their families and wider society – also generated intense discussion. 'Communitarian' desires for traditional societal values were sometime challenged by 'libertarian' desires for individual choice, rights and freedoms. This was particularly played out in discussion of drug policy. Participants debated the potential consequences of widening or narrowing the choice of drugs that individuals can legally consume, of changing the way drugs are distributed.

Although many people expressed strong concern about the inappropriate use of psychoactive substances, there was strong support among participants for an individual's right to make their own decisions about whether or not to use recreational drugs, medicines for mental health or cognition enhancers. Interventions that might reduce individual choice were generally rejected (see Box 5).

Box 5: Drugs - When do we not have the right to chose?

There was support for the individual right - subject to age, and supported by education - to make one's own choices, irrespective of the type of drug use in question (DF). However for as many participants, freedom to choose which **'recreational' drugs** they use was offset by a high level of awareness of the harms associated with illicit and licit drugs. Support for medical innovation and freedom of choice was often coupled with concerns that science might 'go too far', or that drugs and medicines might increasingly be used as a quick fix for wider social problems.

Of the on-line participants around half said there should be no limits on recreational drugs if use has no impact on anyone else. However, since this was seen as unlikely, participants felt that limits need to be imposed to **minimise harm**. Some participants considered harms to include only the immediate risks to the user and others, such as accidents or injury resulting from intoxication, but more participants included the wider harms to the user's family, drug-related crime, violence and social problems resulting from family disruption and the economic cost of treating drug users.

Similarly, the right of healthy people to chose to use **cognitive enhancers** was also questioned. Though they might aid performance in certain jobs, for example through decreasing impulsive behaviour, and increasing focus and problem-solving skills, there was a feeling that these benefits were outweighed by concerns over **coercive use** by employers (particularly pressure on soldiers to use in the battlefield – and a competitive pressure that meant 'normal' performance was no longer enough).

Source: Drug Futures dialogue

Discussion of drug policy raised discussion about a range of possible policy options, summarised as moralist prohibition, pragmatic harm reduction and liberal permissive (see Box 6).

Box 6: Three ethical approaches to regulating personal choice in drug policy

It is possible to distinguish three general approaches in thinking about the ethical principles underlying the regulation of drugs. First, an attempt to eliminate drug use is most likely to be based on the moralistic prohibition idea that drug use is bad in itself and so should be prohibited in all circumstances. Second, a pragmatic harm reduction strategy takes as its foundation the idea that a chief responsibility of governments is to protect the life and health of its citizens, and therefore its drug regulation should be adjusted to minimise harm. Third, a liberal permissive approach would be to put the autonomy of individuals ahead of their health and wellbeing, and to allow drug use unless it can be shown to harm third parties. The UK Drug Strategy is one of harm reduction and to implement the harm reduction strategy it is necessary to come to a firm view of first, the regulatory strategies available, together with their costs and benefits, and second, the harms different drugs can cause.

Source: Drug Futures dialogue

In all freedom of choice debates, the provision of information was seen as key in personal choice. For instance, providing there was informed consent and the potential risks had been fully explained, there was public support in trialling experimental therapies with patients. In stem cell research the public believed the views of patients should be paramount when making decisions around the development of stem cell therapies. Equally, public participants supported the right of the individual to choose whether they donated their cord blood to the NHS, chose to store it privately or requested incineration.

However, sometimes the public felt choice could also be distraction. This was particularly true for climate change policy. In relation to low carbon living and alternative energy the public sometimes reported overload and confusion and a desire for less or no choices at all, or for the choices to be the responsibility of government (SH, BES).

2.2.4. Privacy and anonymity

The public spoke up for rights to privacy and anonymity almost as much as they spoke up for the right to choose.

“There is the potential for nanotechnologies to enable greater forms of government and business control over everyday life...” (ND)

Rights to personal intellectual property were debated in depth regarding the use of genetic data, and predictive gene therapy.

“The ethical side of gene therapy was a real issue ... When we actually talked about the ethical and moral issues with gene therapy there was actually real disagreement over it. It was very interesting, in fact the whole day was interesting” (DNA)

With DNA fingerprinting some panellists felt that collection of DNA at birth would be a fundamental breach of human rights as babies would be unable to give their consent (as discussed above). Concerns also related to how information might be used in the future, especially given the huge range of personal medical information that DNA provides and debate about who exactly owns personal genetic material, once extracted.

For predictive gene therapy, most participants felt that for a test to have any value it would have to be considered in the context of the support available and the clinical use of the test results. Overall, participants felt that there would be more value in understanding drug use within a social context than could be gained by focusing on genetic factors (Box 7).

Box 7: Attitudes to gene & DNA therapy and DNA fingerprinting

For instance advances in genetic understanding and **DNA technology** can be expected to define groups of young people who show a specific risk to harmful drug addiction or use. Assuming that the accuracy of a test was high and that the genetic change identified was strongly predictive, participants could see both benefits and disadvantages. For instance, on the **upside** tests could provide parents with an opportunity to intervene in a more direct manner and to inform them about environmental and social factors that might lead to the expression of the genetic predisposition. Also, the development of genetic tests and increased understanding of genetic factors linked to addiction could lead to new treatments. Tests could contribute to a greater social acceptance of - and more sympathetic attitudes towards - people with addiction problems. However, on the **downside**, tests could generate concerns around the disclosure of information and the discrimination of those with a ‘positive’ result. Tests could lead to anxiety about how friends and family would respond to news of a ‘positive’ test.

The concept of a universal **DNA fingerprint database** offered many benefits, including the protection of the innocent, much quicker solving of crimes and removal of the current emphasis on ethnic minorities. However panellists discussed at length the balance that ought to be struck

between concerns regarding civil liberties and the potential and actual benefits to society. During the course of panel dialogue, two broadly competing perspectives emerged. On the one hand some of the panel felt that, while the forensic use of DNA and the database may be beneficial tools for the achievement of the above aims, those wielding the tools could not or should not be trusted to utilise them effectively.

Some also thought it would be a fundamental breach of human rights as babies would be unable to give their consent. Many of the panel's debates reflected concerns about the extent to which parameters established now could be **misused in the future**, the potential for genetic modification in the future and the potential abuse of stored information. The identification of a 'violent' or similar gene and the use of this sort of information to 'predict' whether someone would be a criminal or predisposed to criminal activity was a concern. This gave rise to further debate around the ownership of genetic material and the degree to which that ownership was revoked as a result of criminal activity or even where DNA had been discarded – for example, on a cigarette butt. Once again competing perspectives arose, with some panellists feeling that ownership of one's genetic material was retained irrespective of where the DNA was, while others felt that once it had left the body it was no longer owned by the individual.

Source: Forensic DNA dialogue

There was also considerable anxiety and mistrust about genetic fingerprinting technologies (DNA), gene therapies (DF) and cybersecurity (TG). Specifically there were concerns about the security, privacy and integrity of databases holding personal information and calls for safeguards against abuse of technologies by authorities or criminals (SH).

3. Trust, risk and regulation in science

Ultimately it is government that will need to manage the social distribution of costs and benefits from science, through its policy and regulation. Unfortunately the dialogues revealed low public confidence in government to be an effective and trustworthy regulator. There was a constant fear that profit motives and vested interests in industry would compromise public safety, firm governance and social good.

“Many of the dialogues revealed a striking trust deficit. Great value was placed in perceived (or not) independence of organisations, and the default attitude to Government and business tended to be one of suspicion or outright mistrust.” (SH)

There was evidence of considerable concern among public participants about the government's and industry's ability to manage complex and unforeseen risks and calls for more research and tighter regulation until more is known about the long-term side effects of some science on humans and the environment.

3.1. Public trust in science

This lack of trust was moderated by perceptions of key players in the science world. Some people expressed feeling a lack of control over the direction in which science itself is heading. Their default assumptions tended to be that developments are 'done

to the public' and that citizens are largely passive – sometimes hopeless - in the face of change.

“Many discussions focused on participants’ concerns about potential risks associated with nanotechnologies. In particular, participants expressed concern that they did not feel informed of what goes on in nanotechnology research and development, and that there is no way for them to have an input.” (ND)

3.1.1. Trust in scientists

There was mixed perception of scientists themselves. Some expressed great trust in the work undertaken by scientists and medics, but many of the participants felt quite far removed from medical research and considered there to be a lack of communication about scientific and medical advancements.

“It seems to be secretive. I don’t think that we the general public feel as though we are in touch with it, or we’re being informed.” (participant – HY)

Some participants were concerned that there are a small number of scientists who are irresponsible in their pursuit of knowledge, regardless of the controls in place. These fears were piqued by the research into animal human hybrids, where fears of Frankenstein science were most acute.

“This surely follows on from Nazi experiments during World War II.” (HY)

“For instance we have allowed abortion - now murders of children are almost daily events. ... If this research on human-animal embryos is permitted, what is to say that in a few years laws will be passed to legalise bestiality.” (HY)

In other cases the concern was less about the malevolence of scientists, and more about the weaknesses of human nature. For instance the creation of a human-animal embryo was thought to be the beginning of ‘the slippery slope’ (HY, ST).

“It is human nature; you always want to push the boundaries to see what is going to happen if you just go a little bit further.” (Participant HY)

“I’m sure they’ve done it already.” (re mixing human and animal materials - participant – HY)

“How do you control illegal research by people that are not applying for licenses?”

3.1.2. Trust in industry

The concern that technology is being developed by industry in order to make profits, rather than in response to societal needs was a common theme. The main driver for

distrust in industry was the ‘profit motive’ and the belief corporates will put life, health and environment at risk in order to achieve financial returns, especially if risks were likely to manifest well into the future.

“The involvement of the private sector raised new questions about both the means and ends of research. Participants expressed concern about the social purposes to which stem cell technologies were directed, particularly if governed by private rather than public interests. The values of openness, transparency and disclosure must not be lost in commercialisation.” (ST)

“...the drive to make a profit was seen to be irreconcilable with an environmental agenda.” (IB)

In the industrial biotechnology dialogue the public welcomed the environmental potential of industrial biology, but there were hard questions about its real environmental credentials and claims of opportunistic corporates keen to make money using an ‘environmental’ sell.

Concerns about the private sector extended beyond the UK, with foreign industry and regulation often perceived with more suspicion than our own.

“A large proportion of the public think that regulations will not be able to prevent the widespread use and application of stem cell research. Pressures from abroad are cited as a concern here” (ST)

3.1.3. Trust in government

The public’s fundamental distrust and anxiety over the motives of corporates is magnified by a perceived inability of government to regulate them. Trust in ‘authority’, in the abstract, tended to be low, sometimes surprisingly so.

Some distrust stemmed from suspicion of mal-intent.

“There is pervasive anxiety about potential abuse of technologies. It is also widely assumed that policymakers in government and big business are not candid with citizens. For example, a common reaction to low-carbon technology stories was to suppose that carbon quotas would amount to a new ‘stealth tax’ and/or a means of surveillance of citizens’ consumption.” (IB)

“Concerns related to the role, remit and agenda of national government and the general public’s level of trust in the government to store DNA information safely and use it only for the purpose for which it was obtained.” (DNA)

Other distrust stemmed from doubt that government has the ‘resources to monitor industry’, the co-ordination required to keep up with developments (NEG) or the ability to effectively roll out enforcement on the streets (e.g. police in DNA finger printing).

“There was a recognition that the police as well as the general public needed better educating so that tools such as the DNA database, provided in order for the police to be able to carry out their roles effectively, were not perceived by the public as being a further means of discrimination.” (DNA)

In the nanodialogues participants were concerned at the lack of a co-ordinated picture of the research taking place, the government departments responsible or the safety testing that had taken place. The lack of clarity over whom makes decisions about the development of nanotechnologies, and on what basis these are made, surprised and worried participants, as did the lack of a register of which organisations were involved in nanotech.

“There was also a general concern that Government does not have enough resources to be able to properly monitor developments in IB. Some participants’ signalled the need for further central Government co-ordination over the control of IB regulation” (IB)

“I don’t trust the Government to put enough money in to regulate it to our satisfaction” (participant - IB)

Thus, the initial public perception of government is of a regulatory structure that is weak and unreliable, vulnerable to private interests, and vulnerable to dangerous products slipping through the net.

3.2. Approaches to building public trust

The dialogues revealed a variety of opportunities to build public trust in science and technology, and improve ethical practise in the governance of both upstream science and downstream technologies. In general people see the danger residing in poor regulation rather than specific hazards associated with the science.

“What would reduce your concerns about science? Greater and clearer accountability and regulation (‘checks and controls being evolved alongside new technology, and finding out what people think of it and how they will be affected’); more control for individuals over access to information; more public debate about, and evaluation of, science and technology developments.” (SH)

3.2.1. Provide information about technologies

For downstream technologies, where products and technologies are already in the market place (GM, nanoproducts, internet security), the public believe government and business have an ethical duty to do more to provide clear product information - about content, impacts and possible side effects. This would serve to increase consumer confidence and allow citizens to make more informed choices.

“All manufactured nanoparticles should be labelled in plain English, classified, and tested for safety as if they were a new substance” (ND)

“Government should continue work to identify the potential risks of nanotechnologies and nanomaterials, and create new regulation and laws for labelling on the basis of that research.” (NEG)

The public also wanted to see the provision of balanced, trusted information on recreational drugs.

“Most of the participants felt that scare tactics, moralising or ‘just say no’ approaches to drugs education were ineffective, primarily because they were often at odds with young people’s own experiences. Many participants saw a good drugs education programme as one that provides balanced and honest information about the benefits, as well as the harms, associated with drugs.” (DF)

This is particularly important where traditional regulation may be impossible, such as the internet. Here the public called for citizen empowerment – including education about internet security and risks – rather than tighter controls (TG).

“Education and assurance underpin confident use and informed decision making in ICT ... it is evident that current education measures are failing both the teenaged and adult populations” (TG)

This mirrored calls for increased awareness and education about rights in relation to DNA finger printing.

“A more informed public would allow a much more transparent and accountable system, and would also enable policy-makers and stakeholders to provide informed guidance on what the public actually want...Recommendations made around public and police education were designed to improve trust, increase transparency and accountability, improve public awareness and, in the long term, develop a more effective system of crime detection and prevention.” (DNA)

3.2.2. Provide rights, restitutions and guarantees

Once technologies are in the market place, the public not only wanted clear information, they also wanted to know what the rights, restitutions and guarantees were available should things go wrong. This was mainly discussed regarding internet commerce, which is vulnerable to financial fraud and for data protection, where privacy could be breached (TG).

Consumers were more likely to place their trust in something that provides safeguards (responsibility, restitution and guarantees were high on the agenda), rather than something that claims nothing can go wrong in the first place.

“Today’s user is an informed, cynical individual; they cannot be bought with empty gestures. They need to be provided with the facilities to make their own judgements, and learn from their own mistakes.” (TG)

“People are willing to take risks online as long as they are informed and it is clear how any undesired consequences will be addressed...Hand in hand with restitution go guarantees. It is at best inefficient and at worst dishonest to try to convince users that technology is entirely secure and trustworthy... a far more effective means of lowering barriers to use is the provision of guarantees.” (TG)

“the ability to access and manage data that is held about us would be welcomed because it improves transparency and therefore increases confidence. In practice this means providing users with the means to view, rectify and even remove information that is held about them, and this should be supplied in conjunction with providing stronger guarantees about how personal data will be used, stored and accessed. (TG)

3.2.3. Better understand risks

With both upstream and downstream science the public called for scientists to work with the utmost care and professionalism, invest in the highest quality safety procedures and reduce side effects wherever possible.

“Risk involved in treatments – particularly due to the potential for tumours to arise from undifferentiated cells in therapies and for tissue rejection - was a concern across all groups.” (ST)

“Stem cell banks were generally supported, providing that effective governance and quality control procedures were in place to avoid the exploitation of donors and to prevent the spread of diseases.” (ST)

The public felt that increasing ethical and safety standards would help give companies a competitive advantage in the long run.

They were particularly concerned if little was known about the potential negative impact of a new technology. Many wanted to see greater research into side effects.

“Companies who use nanotechnology in the environment should be obliged to do long-term research, in real-life situations. They should constantly monitor for unpredictable effects and be flexible in the face of changing circumstances. New types of testing and modelling should be used to increase our understanding of the effects of nanoparticles.” (ND)

“There was also concern that insufficient measures have been taken by authorities to address the new and often unknown properties of nanomaterials” (ND)

There were calls for more use of the ‘precautionary principle’ (i.e. science technologies should be treated as dangerous until proved safe). In nanotechnology this would mean all new particles were treated as hazardous unless proved otherwise.

“The public called for a more precautionary approach to the introduction of novel nanotechnologies - including a specific call for manufactured nanomaterials to be treated as hazardous and their release into the environment to be avoided until more is known about their impact. The report also called for an interdisciplinary research centre to conduct and monitor research on the possible adverse effects of nanotechnologies.” (ND)

Public anxiety heightened further if there was potential for side-effects to manifest in an uncontained environment, e.g. outside the confines of the laboratory, hospital, factory or other controlled environment. This included fears of GM feedstock cross-contamination, modified bacteria infecting humans, nanoparticles leaking into water courses. Some of these fears were fuelled the sense of ‘unleashing’ unnatural or ‘mutating’ organisms into the ecosystem.

“The main concern running through deliberations on the different aspects and applications of IB was the use of GM in any application. For some, the issue was one of principle; is GM right? But for others of greater concern was how GM crops and GMOs can be contained and, if it was not, what the implications are for people, the environment and ecosystems.”

Where GM / IB products were proposed to be used in situ, or as part of an industrial process rather than end product, there was less concern.

“The research and development of medical advancements through IB was understood to take place in a more controlled environment. Participants did not deem there to be as many variables, such as weather, crops, animals involved in the medical process as in others. “I’m okay when it’s in a controlled environment, in a lab, but not when it’s outdoors” (IB)

The concern over containment of side effects, and control of risks, also extended to leakages of personal data from ‘virtual’ environments such as the internet or databases (e.g. the DNA database).

“Attendees reported that as more data is gathered and stored electronically, particularly in centrally controlled databases, they feel more vulnerable. Much of this vulnerability is focused on a lack of control over who is collecting their data, who might have access to it, how their data may be used now or in the future and the potential for function creep.” (TG)

3.2.4. Disclose uncertainties, rate transparency

Where risk could not be fully predicted, or completely controlled, then the public wanted to know. The public were particularly keen that risk and uncertainties were disclosed, even if they could not be reduced, and systems were in place to distribute

fairly any potential costs from unintended consequences. They sensed a pervasive culture in institutions that meant risks and unknowns could not be discussed in public.

“The side effects of drug treatments for mental disorder were often seen to be as debilitating as the disorder itself... Many expressed the view that greater acknowledgement of the severity of adverse effects by consultant psychiatrists would be welcomed.” (DF)

“Concerns around the future use of genetic information were exacerbated by ... the use of techniques such as low copy number (LCN). Some panellists felt that the use of evidence based on LCN techniques in court compromised the judicial process, particularly since there was limited public understanding of ‘photocopying’ processes and the implications of such techniques on the integrity of samples and thus the profiles they generated.” (DNA)

More generally the public felt that private interests inhibit open and honest discussion about uncertainties. There should be full disclosure of uncertainty, and mechanism in place to ensure accountability for this, including the possibility of trust and disclosure ratings for companies.

“If regulation involves management of uncertainty (because of gaps in knowledge about safety or any other issue), then government should explain this issue clearly because the public is likely to expect that regulation is based on firm evidence and is a guarantee of safety.” (NEG)

“The.. government should be open about uncertainties in science governance, both in terms of unforeseen risks of particular technologies and of the mechanisms available for dealing with those risks and uncertainties.” (ND)

“Open discussion around uncertainties in the science was fundamental for trust in their development long term. There were concerns that private investment may limit the potential for this.” (ST)

Related to this there was discussion about how to change the attitude to uncertainty. Some felt that scientists were naturally ‘closed’ and did not like to discuss uncertainty, while others felt private sector interests stopped open discussion.

“It was highlighted by social scientists that the culture of science often made it difficult for individual researchers to voice concerns over uncertainties and risks, making open discussions difficult.” (ST)

“A key implication therefore becomes how we talk about how we talk about uncertainties. This is not an academic point: it is precisely the manipulation of uncertainty surrounding stem cells which is where the debate takes place. The most notable instance of this was the propensity to over-claim benefits and under-claim risks in relation to private firms collecting and storing cord blood.” (ST)

3.2.5. Clarify governance structures and processes

Across all projects there is a call for the public to ‘know how science policy decisions are being made’, and to be more transparent about the mechanisms of regulation and oversight. The public want to know how these are coordinated and who is ultimately accountable. This will ultimately help build public confidence.

This was particularly true for nanotechnologies whose multidisciplinary nature may result in applications slipping through the net of existing regulations, with no agency ultimately responsible for setting and maintaining safety standards.

“An issue identified by public participants has been the lack of coordination and overview of the UK nanotechnology field - whether in terms of the research that is taking place, the government departments that are responsible, or the testing that has been done on the safety of new nanotechnologies. The lack of clarity about who makes decisions about the development of nanotechnologies, and on what basis these are made, has surprised and worried public participants.” (NEG)

“A register of all organisations involved in nanotechnology is needed.” (ND)

A key proposal to support this process, proposed by NEG, are technology governance maps, specific documentation that outlines how responsibilities for the regulation and funding of new and emerging science and technology are distributed across the public sector (Box 8).

Box 8: Increasing transparency in regulation – lessons from the nanodialogues

The challenge for government and the science community now is to continue to make the governance of new science and technology more transparent, in order to foster the development of a more mature and open relationship between science and society. NEG proposes three steps towards this goal.

- 1) The first is to produce specific documentation that outlines how responsibilities for the regulation and funding of new and emerging science and technology are distributed across the public sector. Such ‘**technology-governance maps**’ should present, in a clear and accessible way, the key players, regulators, funding structures, and policy timetables for a particular area of science and technology.
- 2) The second is to publicise information about where **public money** is spent on new and emerging technologies.
- 3) The third is for government to be **open about uncertainties** in science governance, both in terms of unforeseen risks of particular technologies and of the mechanisms available for dealing with those risks and uncertainties.

Source: NEG dialogue

Decision-makers also need to be more open about the constraints facing science governance. As highlighted in the NEG dialogues, if the public continues to raise concerns that seem unrealistic or beyond the remit of decision-making institutions, then government needs to make clear why it is unable to address those concerns. An important function of public engagement in science and technology should be to raise awareness of how science decision-making works, and to clarify what levers of change do and do not exist.

3.2.6. Regulate to appropriate levels

With respect to levels of regulation, there were mixed views. In some cases the public felt regulation was working well.

“In the course of the consultation there was a great deal of support for the current regulatory structure, with emphasis placed on the need to regulate such research tightly and with high levels of scrutiny.” (HY)

In others there were concerns about haphazard and illogical regulatory policy, with calls for regulation that is consistent and proportional.

“There was a widely held view that current drug classification is 'confused, inconsistent and arbitrary' and needs rethinking.” (DF)

In other projects there was a call for more leadership in legislation to stimulate collective citizen and industry action.

“Eventually the Government has got to say – We think this is the best way forward. We as individuals can't make that decision, as we don't know what it is. They have to do more, like the smoking ban. People won't like it, but they'll get used to it.” (BES)

While under regulation was initially a major concern with industrial biotech (with participants seeking reassurance on almost every aspect) participants later become concerned about over-regulation. There was a concern that regulation might impede progress, particularly within the UK, and mean that industrial biotech would develop only in countries which permitted it. The comparison between different regulatory approaches in the US and EU prompted many respondents to express concern that Britain might fall behind.

“We need strong regulation, I support it but not to the extent that industries are hampered” (participant - IB)

“Regulation of IB is a careful balancing act. Whilst the primary concern was to know that the public are protected, participants were perturbed by evidence of over-regulation.” (IB)

Similarly in stem cell research there was a tension highlighted between the permissive European legislative framework and the tight regulation in the UK acting as ‘brake on innovation’ (see Box 9).

Box 9: Pros and cons of regulation in stem cell research

The UK was viewed as relatively sophisticated in stem cell regulation compared to most European countries. The consultative approach to embryonic stem cell regulations in the UK, both with Parliamentarians and public engagement was supported and built trust in governance, (though there were notable exceptions to this view from Church and pro life groups). Some thought the permissive legislative framework and the tight regulation in the UK acted as ‘brake on innovation’. However, the

regulatory framework also provided the UK with a competitive advantage in this area, in terms of the development of stem cell lines with high safety and ethical standards. Also, strong regulation was needed to build public confidence in the absence of clear tangible benefits from the work. Despite this, there were still concerns around transparency and whether scientists were conducting research out of the public gaze.

In some cases, when the public have examined specific regulations comparatively and in greater detail (e.g. UK stem cell regulations, which are strict compared to the EU) there is a perception the UK's regulation is perhaps overly sophisticated, and that 'red tape' stacks up against scientists, or is inconsistently applied across the field. As before, this reflects tensions between a desire to protect the vulnerable and unheard, while also wanting the UK science sector to thrive and lead internationally.

Source: Stem Cell dialogue

3.3. Transparency, oversight and public involvement

In almost every dialogue the public wanted decision-making processes in science and technology to be socially grounded: to serve a social purpose, to incorporate ethical and social considerations into the setting of funding priorities and to be transparent and trustworthy. Public involvement was seen as key to this.

“Science should be responsive to public concerns. People have an ethical right to be involved in decision making, due to the fact that they have donated the material for research.” (ST)

“There have been repeated calls for more open decision-making on nanotechnologies, including more opportunities for members of the public to influence the development of nanotechnology policy and research.” (NG)

“The need to protect and exploit intellectual property rights needs to be balanced with the need to disclose information in the public interest. Research councils and universities should account for these factors when commercialising research” (ST)

Lay person scrutiny becomes even more critical when public money is involved.

“If public money is being spent, then members of the public and invited representatives of a wide range of organisations (including different social groups and faiths) should form a committee that decides at what stage(s) of research public juries should be set up. This committee needs to be open to groups in society, other than just experts. If private money is being spent, public juries should have a role at the outset of the research to look at the ethical and possible social and environmental impacts of potential end products.” (ND Nanojuries)

3.3.1. Multilateral decision making

The public see decision-making in science as a complex process that requires a wide range of inputs. The majority believe that decisions should not be made any one party

but that it should be a ‘three-way dialogue between the government, the public, and scientists’ (NEG) – see Box 10.

“The monitoring and regulation of nanotechnology needs to be done by a broad group of people, including Defra, the Environment Agency, environmental NGOs and lay people” (NEG)

“The public should be involved at all levels of the research process. Engagement, however, should be different at different levels of the research process.” (ND4)

Box 10: Should the public be able to vote on science funding allocations?

In a survey done at a Citizen Science event, 13% of respondents agreed with the suggestion that the public should be able to vote on funding allocation for nanotechnologies; 13% believed that nanoscientists are better equipped to do this task; 16% said that it is the government’s job; and 52% agreed with the statement that ‘it should be a three-way dialogue between the government, the public, and scientists’

Source: Nanodialogues

The public are also keen that as many voices as possible—including scientists, members of the public, NGOs, and industry—be heard at the different stages of decision-making.

“We recommend the formation of a new group that contains specialists and lay people to oversee research, monitoring, regulation, and communication of issues about nanotechnology. This group would feed into all relevant government departments and agencies. It should have the power to recommend new areas of research.” (ND)

“...a more accountable and transparent infrastructure would enable the public to monitor what was happening on a regular basis.. this monitoring capability... would aid the legitimacy of the database as well as ensuring that the parameters of its usage responded to the ethical, moral, social and legal concerns of the public, rather than to scientific developments and institutional requirements.” (DNA)

The Sciencewise dialogues have shown the public fully able to participate in complex scientific and technical topics.

“The public are capable of appreciating the value of research, of having complex discussions around scientific uncertainties, and helping to consider social consequences.” (ST)

Yet both government (and business to a lesser extent) were seen as the agencies with most responsibility for taking action to avoid harmful outcomes, given the difficulties for the public in understanding all the issues or making much difference through personal action.

“I know there are experts out there who are concerned about nanotechnologies as well, and if our group adds to that sense of caution then

that's a good thing. But for us to want to take the decision ourselves would be a step too far." (NEG)

3.3.2. Public and scientific appetite for involvement

In the vast majority of dialogue projects the public universally appreciate the experience of being involved in dialogue with decision makers and scientists. 80% came away from the stem cell dialogue feeling dialogue is 'very important'. 70% said they had learnt something and it had changed their views. These evaluation figures are typical of many of the projects.

"There was great appreciation from participants in the deliberative work and the public meeting for being consulted and a strong desire from people to continue to learn about issues such as this." (HY)

"The Deliberative Panel process was very well received by the participants: people liked the engagement they had with issues and the expert speakers. There was a widespread view that the deliberative process ought to be used more and that this would be healthy for public life and policy. However, people need reassurance that their views really will be taken seriously and will inform policy discussions." (SH)

There were also widespread benefits for scientists. The active involvement of scientists in public dialogue activities can create space for scientists to reflect on the wider social implications of their work, thus helping to 'put science into context'. There is also evidence that such activities can contribute to generating greater support and enthusiasm in science communities for public dialogue and communication (Box 11).

Box 10: What are the benefit of public dialogue to society

The review of 7 dialogue projects for NEG concluded that not only does dialogue inform policy and research, 1) it creates 'reflective science' a space for scientists to reflect on wider social implications of their work, putting 'science into context' and shaping ethical awareness of their science. 2) carefully facilitated dialogue can create mutual understanding overcome negative preconceptions and cultural barriers between public, scientists and policy makers. 3) Citizen too become more aware, able to provide critical input, become more active in society and potentially able to provide critical oversight suggested (e.g. DNA).

Source: Nanodialogue Engagement Group

3.3.3. Creating a culture of engagement

Despite the success of many of the dialogue events, commentators in the Stem Cell dialogue warned that public engagement should not be seen as a set of one-off discussions. Instead dialogue needs to permeate research culture, rather than being done by special people in special places. Whilst formal exercises undoubtedly have a

role to play, running another big event is perhaps not the most crucial issue. Rather it is imbuing professional culture and practice with the spirit of open discussion and public engagement. This in turn implies creating wider cultural shifts in how institutions relate to the public, and to public scrutiny.

“The final conclusion relates to wider relationship between science and the public. It refers to the soft infrastructure of governance noted earlier - the social relations, informal networks and professional cultures which also act to shape and control the field.” (ST)

The possible role of key institutional leaders, such as research councils, is described in the Box 12 below.

Box 12: Role of Research Councils and funders in creating cultural change

The role of research councils is shifting as the role of research shifts, from a focus on grant administration to taking a much more active role in the shaping of technologies in society. There have been major strides in this area recently – not least in the form of science in society programmes with the research councils and a general trend towards greater lay involvement in policy making. Whilst many of the issues that have been raised through the dialogue fall outside the core scope of research councils, there is an opportunity to work with institutions in the public and private sectors to help ensure messages are taken forward. Moreover, there is also the opportunity to build on foundations and work with individual scientists - through programmes, training and support – to help create an institutional culture of research that places public value at the heart of research decision making.

Source: Stem Cell dialogue

4. Conclusions

Broadly, across the Sciencewise dialogues reviewed, people were likely to be positive about developments in science and technology that seemed to promise gains in choice, quality of life, longevity, convenience, time-saving and environmental impact. However, potential impacts on social equity, freedom, privacy and human autonomy and skills were regarded with considerable suspicion or hostility (SH).

In all the dialogues the public tackled complex trade-offs against competing ethical and social values. Most common were when libertarian values (or personal freedom based values, civil liberties) were set squarely against communitarian values (or social good based values, wider societal rights). Box 13 on stem cell research below provides an example.

Box 13: Ethical frames for decision making in stem cell research

At the heart of all of the ethical dilemmas around stem cells was how to make choices in society. There was a tension between an **individualistic / libertarian** view, which highlighted an individual’s right to make choices around stem cell uses, with patient autonomy fundamental. The counter view was **collective / communitarian** and concerned the need to balance individual rights and interests with that of the community as a whole.

Overall, the libertarian view was more dominant in the workshops – evidenced by the favouring of people’s rights to store their cord blood, or take a risky treatment or donate human eggs for research – despite the wider societal consequences of this. A more communitarian view was evident on a number of concerns around cosmetic treatments. However, in many instances where a more

restrictive view on the governance of stem cells was argued – the payment of donors or patients in clinical trials for instance - at heart the main concern was the impact of payment on individual autonomy to make free choices, rather than the impact on society more broadly. As noted, what really constitutes a free choice given uncertainties, social pressures and the hype around the science, is complex.

This tension is of importance to the governance of stem cell science. There needs to be consideration as to when individual choices should shape science and technology, and when societal concerns, even when not held by the majority, should have more sway. One of the concerns around the debate - as expressed by church groups and pro life groups, and acknowledged by certain government stakeholders - was the need to ensure ethics continued to be taken into account in shaping this field in future.

Source: Stem Cell dialogue

Another common trade-off was between the desire for labour and time saving devices, and concerns that traditional ‘natural’ values may be lost: people valued convenience and time-saving highly, but were anxious about concomitant loss of skills, independence and human interaction. People also wanted personal safety, health and security, but disliked the degree to which enhancements might only be available at the cost of significant provision of personal information.

Despite differences between the Sciencewise dialogues, three common lessons about the public participants’ attitudes to the science and its governance can be identified. First, public attitudes are formed not only in relation to particular technologies, but also to the policies and values that shape their use. Public participants were not only concerned with the potential benefits and risks of technologies, but also with who the benefits and risks are most likely to affect and therefore a desire for equity. Second, public attitudes to risk, uncertainty, and regulation tend to be concerned with the ability of regulation and regulatory authorities to manage complex risks. Furthermore, there was evidence of considerable concern among public participants about the government’s and industry’s ability to manage complex and unforeseen risks, alongside calls for more research and regulation until more is known about the long-term implications. Third, there is consistent demand for more open discussion and public involvement in policymaking relating to science and technology (NEG).

“The politics of science are subtle. There are questions about the science we need and the science we want; questions about uncertainty, evidence and burdens of proof; questions about ownership, access and control. We need to learn how to open up and debate these questions in public.” Jack Stilgoe, Demos (Nanodialogues)

What is the scope of government influence in all this? The calls for science to serve a ‘social good’ suggest that public participants see the government as playing an important part in shaping the social purposes of science and technology. Although government and other public bodies have a powerful role in steering and regulating scientific research and development, technological trajectories emerge from a complex combination of forces that include private investment, market forces, public interest, and individual enthusiasm, not to mention chance. Although government alone cannot be held responsible for them, it can play a more or less dominant part in seeking to influence them.

The public want the government to take a strong ethical lead to ensure that science and technology develop in a socially responsible way, with commercial interests marshalled for good. They also want government to build capacity in how it does this, and be transparent about its processes. Suggestions from dialogues include protecting values and rights through laws, guarantees and restitutions, publishing technology governance maps, rating companies for openness on risks and uncertainties, or ensuring more joined up regulation across departments. Ultimately it will also require the involvement of the public in oversight and scrutiny, as well as co-design of public science policy.

The fact that many of these dialogues focus on broad aspirations and concerns for the future of science in society also suggests that the public participants, like the proponents of upstream engagement who initiated these activities, see a role for the public at the strategic level of science policy. Upstream discussions about science and technology can benefit from public input in a number of different ways. The challenge for government is to trust the public's ability to understand and contribute meaningfully to such policy discussions, and to find ways to incorporate members of the public directly in them.

References

Final Reports and documentation of all the projects referred to above are available from <http://www.sciencewise-erc.org.uk/cms/projects/>