

Science and gender, ethnicity, and the lifecycle

ESRC Science in Society Programme

malefemaleblackwhitechildrenadults









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Preface

The science-society relationship is recognised as no longer being one in which the needs of the public are dictated by those in authority. But what is it to become? How can those in government, science and the private sector facilitate the science-society relationship more effectively? How can the public in all its diversity become more engaged in the production of science and its role in society? 3

The goal of the ESRC's Science in Society Programme is to explore and help develop the rapidly changing relations between science (including engineering and technology) and the wider society. These brochures are intended not only to bring together the findings of research projects in the Programme, but also to draw on wider insights into the relationship of science and society.

To that end, although these brochures provide an overview of academic research, they hope to prompt questions that go beyond the academic to the role of science and technology in daily life and experience, in all its diversity. 'The science-society relationship is no better illustrated than in the area of our own personal lives'



Foreword

The pervasive nature of the science-society relationship is no better illustrated than in the area of our own personal lives. How and why science affects us all individually, and the effects of our personal experiences in shaping our perceptions of science and technology, are all part of the story that this section of the Science in Society Programme has to tell.

One of the Programme's intentions is to recognise the highly diverse nature of science and the different types of expertise that exist within communities. Several of the research projects in this brochure comment on how personal identity influences the use and acceptance of scientific and technological advances. They consider, for example, how women in developing countries react to health professionals in western medical centres and ask whether these centres can respond to their needs without first changing their approach to accommodate a different perspective on personal identity and self-knowledge. This personal response to science exists in our own lives too, as many of us will confirm that it is usually the youngest members of the family who can work the video recorder or DVD player with ease, whereas the older members look blankly at the flashing display and don't know what to do. There are many people who can't work a mobile phone or don't use e-mail, not because they are actually incapable of doing so, but because they do not see how these technologies fit into their existing picture of themselves as a person. To improve how we use technology, or make our use more efficient or less resource-dependent, we need to examine how our identity affects our relationship with science, and then reconsider our approach to it.

These are the kinds of questions that are asked by the researchers whose work is discussed in these pages. I hope that you will find them thought-provoking and that they will demonstrate the richness and diversity of the social science research that has been commissioned through the ESRC's Science in Society Programme.

Steve Rayner Science in Society Programme Director



Executive Summary

How do aspects of social identity, like gender, ethnicity and stage in life, influence the way people see the world – and what does it mean for their relations with science and technology? Does science and technology comprise objective facts or is its creation and reception shaped by cultural values and assumptions?

Science and technology shape not only our present environment, but also our future. Recently, there have been concerns that the public is experiencing 'a crisis of trust' with regard to science and technology. Some have argued that this is because of negative and sensational media coverage, but others have pointed out that policymakers and scientists often find it difficult to communicate scientific research and its implications. Research suggests that this is because experts lack a nuanced understanding of the enormous diversity of 'the public', and the factors helping to shape the attitudes of its members.

We live in a diverse society: apart from gender difference and multiple age groups, society comprises people of many different ethnicities and religions, people with different interests and beliefs. All of these aspects are part of people's identities, helping to shape how they see the world, their values, their behaviour, and their interaction with science and technology. But, as this document shows, the relationship between science and identity is seldom a straightforward, linear connection. Social identity is a complex and, necessarily, fluid phenomenon. It is shaped by events and experiences; it helps us all to play the many different roles of our daily lives.

Five projects under the theme Science, Gender Ethnicity and the Life Cycle, explore the role of identity in the perception and composition of scientific knowledge. They aim to deepen understanding of the engagement between the public (in all its variety) and experts in scientific and technological knowledge. They do this, at the simplest level, by showing how aspects of identity - including age, gender, ethnicity and cultural values – may shape the production, communication and reception of science and technology. The projects explore:

- How social identities influence people's experiences and perceptions of, and responses to, interventions of science and technology in daily life.
- How aspects of individual and collective identity are, in turn, shaped by people's experiences of scientific and technological discourses
- How the production of scientific knowledge and its communication are shaped by the assumptions of scientists and policymakers.

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"The relationship between science and identity is seldom a straightforward, linear connection"

Each project has focused on a particular community, and explored how it faces a specific scientific or technological development:

- Gender Theories and Risk Perception: A Secondary Analysis investigated how gender influences perceptions of risk. It re-examined the survey results of previous research in this area, and asked how cultural assumptions can influence how scientists interpret the results of their own research.
- Public Perception of Gamete Donation in British South Asian Communities, looked at public understandings of gamete donation amongst British South Asian communities and why South Asian women and men may or may not consider donating or receiving eggs and sperm.
 These extend far beyond simple questions abo the specific risks that new scientific discoveries technologies present. People's responses to scie are often a mixture of concerns about a much wider range of questions. These include question relating to personal matters. For example, will t
- Boundary Work, Normal Ageing and Brain Pathology explored how the effects of ageing are described and understood by different communities, both experts and nonexperts.
- Asbestos Diseases: Scientific Definitions and Gendered Identities examined the experience of asbestos-disease among two groups of workers, one in the Northern Cape, South Africa, the other in Dagenham, in London (UK), including the role played by the medical and legal professions, examining how this experience impacts on their identity and gendered relations.
- Childhood Vaccination: Science and Public Engagement in International Perspective used ethnographic and survey methods to explore the perspectives and decision-making processes of parents, regarding the vaccination of their

children and their participation in medical research. This project was conducted in Brighton, UK, and The Gambia.

Together, these projects provide unequivocal evidence of the role played by identity in society's interaction with science and technology, and vice versa. Different identities bring with them particular values and beliefs, which will influence people's engagements with scientific knowledge in a complex variety of ways.

These extend far beyond simple questions about the specific risks that new scientific discoveries or technologies present. People's responses to science wider range of questions. These include questions relating to personal matters. For example, will this disrupt my vision of the world and my role in it? Will it change my understanding of who I am and how I should behave? Will it challenge how my family live or put members of my family in danger? But they also include guestions about impacts on society. For instance, will a new technology create new divisions in society or reinforce existing ones? Is it possible to fix this social problem with technology? And, inevitably, questions about accountability, authority and responsibility. For example, who will watch over the governance of this new technology and make sure that the costs and the benefits are fairly distributed? Who will be in control of this technology? Who will do well from its use and who will have to pay?

Not taking account of the role of identity in the science-society relationship may have far-reaching consequences at local, national, and global levels. If particular social groups perceive certain technologies as in any way unwelcome or irrelevant, this may prevent them from participating in related programmes. Such disaffection in the face of government programmes may generate widespread public anxiety and distrust; non-participation may pose threats, for example, to public health.

Perceptions of science and technology not only affect how members of different communities participate in the reception of science and technology, but also its development. This may discourage some from pursuing science and technology education or training; it may influence whether and how they have access to technical decision-making and/or the design of programmes and public policy.

Most research on science in society has concentrated on the attitudes of the public. However, it is also essential to understand the ways in which different cultural assumptions can influence the production and dissemination of science and technology. Several of the projects show how scientists and policymakers tend to assume that members of the public will receive scientific information in particular ways; expecting that people will respond either pretty much the same way as they do, or by conforming to certain stereotypes.

In conclusion, the projects under this theme, Science, Gender, Ethnicity and the Life Cycle, emphasise the following:

The importance of identity: every kind of public engagement with new technology, from debate, to regulation, to specific programmes and policies must take the question of identities and their impacts into account.

- Multiple publics: as we come to understand the importance of increasing engagement with the public, we must also understand that this must be rooted in an understanding of the diversity and fluidity of that public. This not only means that there are many different social groups, but also that individuals may move between different social groups.
- Risk and relationships: people rarely use technical data to decide that science and technology is risky, instead their attitudes are shaped by a far wider range of concerns, based on experiences, relationships and beliefs about who they can trust and who is to blame when things go wrong. It is crucial to understand how different identities, the values and beliefs they encompass and the relationships they structure, influence people's concerns about science and technology.
- Shaping the expert: identity does not only influence the views and values of publics, but also that of the scientists and policymakers who are designing programmes, and conducting or interpreting research, and those who disseminate public information about science and technology. Scientists and policymakers need to be careful of their own assumptions: How will members of the public receive and respond to scientific information? What shapes their attitudes to and conclusions about science and technology?

The projects reveal how science in society is shaped by the relationship between culture and the production and communication of scientific knowledge.

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Introduction

Science and its discoveries are a profound part of our lives. From the production of the food that we eat, to the medicines we take when we are ill, from the technology of our transport, to the circuits inside our mobile phones, it is hard to think of any part of our existence that is not shaped by scientific knowledge and its application in many different forms.

Science and technology shape not only our present environment, but also our future. As we learn more about the world around us, we are able to monitor, learn and potentially respond to local, national and global challenges of many different kinds. We might assume that these advancements would make us feel more secure. Nevertheless, developments in science and technology still provoke anxiety across the wider public. Recently, commentators have argued that this is increasing, and they highlight two particular reasons for this trend:

- The erosion of deference and the 'risk society': Reflecting events within the academic realm, many have observed how, outside the universities, people's belief in science has been shaken. Some see this as one of the side-effects of the historical trends of the last 60 years, which have brought us into a period characterised by the breakdown of previous norms and traditions, the erosion of trust in institutions, and the rise of uncertainty, a greater sense of insecurity and awareness of risks (Giddens 1990, Beck 1992, Smart 1993).
- The appreciation of uncertain cause and effect: Others have argued that this greater sense of insecurity has arisen because of changes in scientific practice itself. Increasingly, scientists are beginning to acknowledge that for many phenomena, a single explanation is not enough. For example, the language of biomedicine is now concerned with 'risk factors', 'triggers' and 'genetic predispositions' rather than simple statements of cause and effect. Such explanations may seem frustratingly vague and imprecise to patients (Cohn 2000).

In 2000, the House of Lords Science and Technology Committee put forward the idea that public anxiety about science and technology had reached a 'crisis of trust', which was dominating public reactions in certain areas of UK science policy-making (House of Lords 2000). However, as Dame Onora O'Neill observed in the 2002 Reith Lectures, it may not be so simple: "The supposed 'crisis of trust' may be more a matter of what we tell inquisitive pollsters than of any active refusal of trust, let alone of conclusive evidence of reduced trustworthiness. The supposed 'crisis of trust' is, I think, first and foremost a culture of suspicion."

"It is hard to think of any part of our existence that is not shaped

Her argument was that this culture of suspicion is stirred up by the media, whose reports often focus on more shocking and controversial stories, or draw particular attention to the possible dangers of new technologies for the sake of a good story. Sometimes these dramatic reports do manage to capture real public feeling, but often they seem to be doing little more than trying to create a sensation. "There is plenty of more or less accurate reporting, but this is very small comfort if readers can't tell which are the reliable bits. What we need is reporting that we can assess and check: what we get often can't be assessed or checked by non-experts. If the media mislead, or if readers cannot assess their reporting, the wells of public discourse and public life are poisoned. The new information technologies may be antiauthoritarian, but curiously they are often used in ways that are also anti-democratic. They undermine our capacities to judge others' claims and to place our trust."

But even if we accept that inadequate media coverage can whip up negative public reactions to advances in science and technology – what information can we turn to that might provide an alternative, trustworthy and more balanced view? For a long time, public bodies have been poorly equipped to communicate more helpful accounts of scientific research and its implications. Underlying this is the lack of a nuanced understanding of the factors helping to shape public attitudes, and the enormous diversity of that group described in the media and policy documents as 'the public'. This term, although convenient, can lead to all kinds of deceptive thinking. It suggests that there is one group of people out there, who all share the same kinds of ideas and attitudes as each other. On the contrary, the obvious truth is that 'the public' is really 'the publics', made up of lots of different groups of people. We live in a diverse society: apart from gender difference and multiple age groups, society comprises people of many different ethnicities and religions, people with different interests and beliefs. All of these aspects are part of people's identities, helping to shape how they see the world, their values, their behaviour – and their interaction with science and technology.

As an example, consider the delivery of public health. What happens when the recipient of public health services is from a different culture from those who design or deliver them, and has a very different way of seeing the world? For example, one project in this theme, Public Perception of Gamete Donation in British South Asian Communities explores how Muslim men and women in British South Asian communities regard the new reproductive technologies now available. Do they consider current services for egg and sperm donation acceptable within the framework of their cultural and religious values? What would be the personal and social implications for those participating in donation at this time, or for the new relationships that donation might create? The project Asbestos Diseases: Scientific Definitions and Gendered Identities provides another example, demonstrating the differences between a particular community's understanding of the asbestos-related disease Pleural Plagues, and the conflicting definitions established by the medical and legal professions.

Another assumption often made about people's concerns about new technologies, is that they are worrying primarily about scientific questions, in particular the specific risks that new scientific discoveries or technologies present.

In fact, people's responses to science are often a mixture of concerns about a much wider range of questions. As the project Gender Theories and Risk Perception: A Secondary Analysis sets out, when people consider the risk factors of a new technology such as mobile phones or genetically modified foods they do consider their own and others' vulnerability, but they also consider wider guestions, for example about responsibility and accountability: who will be in control of a particular technology? Who will do well from its use and who will have to pay? Will a new technology create new divisions in society or reinforce existing ones? Who will watch over the governance of a new technology and make sure that the costs and the benefits are fairly distributed? The project Childhood Vaccination: Science and Public Engagement in International Perspective describes how this kind of range of concerns can be seen in the perspectives and decision-making processes of two groups of parents (one in Britain and one in the Gambia), regarding the vaccination of their children and their participation in medical research.

The influence of identity on our interactions with science and technology shapes not only the perceptions of the public, and the way its different members receive information, but also the approaches of those who research scientific knowledge and develop new technologies, and those who disseminate public information about science and technology. The project *Boundary Work*, *Normal Ageing and Brain Pathology* explores this idea, analysing how different communities, including scientific communities, think about the meanings and effects of ageing, and how the different ideas developed across these communities influence each other. As we try to gain a better understanding of what influences people's assumptions about and responses to science and technology – we must bear in mind that the people in question are inside the laboratory, as well as outside it.

This brochure explores some of the common assumptions that shape our thinking with regard to the issues discussed under the theme, *Science, Gender Ethnicity and the Life Cycle*, and presents some of the cross-cutting themes that emerge. All the research brought together here examines how particular social groups (selected for their particular stage of life or their social identities) engage with specific programmes or presentations of aspects of science and technology and vice versa.

We end with some of the implications that these projects have raised about the relationship between science and aspects of identity, such as gender, ethnicity and the lifecycle. Rather than offering a definitive conclusion, this final section is intended to prompt further thinking and raise questions about the communication and implementation of science in society.



Challenging Common Assumptions

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The Science in Society projects under the theme, *Science, Gender Ethnicity and the Life Cycle*, explore identity, the composition of scientific knowledge, and how these two interact:

First, the nature of identity: How do aspects of social identity, like gender, ethnicity and stage in life, influence people's engagement with the world? What does this mean for our understanding of the nature of society and the use of terms like 'the public'?

Second, the composition of scientific knowledge: Does science and technology consist of simple, objective facts? How is scientific knowledge shaped by context and the cultural values and assumptions of those who produce it?

Finally, if we acknowledge that the particular identity of a social group will shape how it receives and engages with scientific knowledge, and the nature of scientific knowledge is also shaped by the cultural identities of those that produce it, what might this tell us about the role played by science and technology in society?



Identity: Who do you Think I am?

The self constructs the world from experience so that... two people look at the same object and see different things, participate in the 'same' event and experience it quite differently. (Cohen 1994: 190).

'Thirty two years old', 'female', 'Ukrainian', 'a physicist', 'lesbian', 'concerned about the environment': each phrase or word is a simple description of a person. But what can these, or similar, simple descriptions of a person tell us? What do we mean when we use them to refer to other people, or to ourselves? What do people assume when they use them, or hear them, about us?

The answers to these questions are surprisingly complicated. For example, when we use them to refer to other people, we often mean them to convey much more than just how those people appear. We are also often saying something about how we expect those people to behave, what we expect them to believe, how we think they see, and interact with, the world. In short, we are trying to convey something about that person's identity.

Of course, from the point of view of the person or group being described, can such brief descriptions ever really be enough? Usually, when faced with such a stilted account of ourselves, even if the categories used to describe us are correct, we still feel that they offer inadequate accounts of who we think we are. We may be afraid that others will assign certain characteristics or behaviours to us, just because we belong to a particular social group, when we think of ourselves, our identity, as something much richer and more complex.

As this suggests, the concept of identity is far from simple. It comprises both social and personal aspects. 'Social identity' describes the way in which an individual identifies with a particular social group. Most of us have very many different social identities - that is, we manage to identify with a variety of social groups, each of which has different characteristics. As a very simple example, just think how differently we behave in various situations, for example when we are at work or with our family or in the company of different friends. Consider how different political or religious beliefs influence behaviour and create different views of the world. A different sense of belonging, or not, to a particular group, with specific characteristics, can create a different sense of self in different situations. Most of us hold many different social identities simultaneously, expressing the many different ways in which we engage with the world.

'For most of us, most of the time, our identity develops implicitly''

And this brings us to 'personal identity'. The fact that each of us may have many different social identities is not to say that we are made up of lots of different personalities, or can be reduced to a series of separate roles that we play. These social identities are all aspects of a single person, who, in all these different settings, despite even radical changes in his or her life, retains a "subjective sense of continuous existence and a coherent memory" (Erikson 1968). This subjective sense of self is our personal identity.

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The concept of identity is complex and multidimensional, comprising many aspects, for example subjective and objective, private and social. Different circumstances bring particular aspects of our identity to the forefront, so that one aspect will play a larger role in directing our behaviour in one situation, and another may dominate in other circumstances (Mach 1993).

In this light, the nature of identity appears not just as many-layered, but also as fluid and adaptable, responsive to other people, situations and events. Just as, consciously or unconsciously, our identity shapes how we engage, directly or indirectly, with the world and with each other, in turn our engagement with the world and with each other shapes our identity. When changes happen to us, disrupting the flow of our lives, we usually adapt how we see ourselves in response, maintaining a sense of continuity by reconstructing how we think of ourselves, how we behave. We may add new aspects to our identity or change existing aspects: the creation of identity, is the creation of the self -a flexible, ongoing process (Cohen 1994).

For most of us, most of the time, our identity develops implicitly. Often people do not think consciously about the nature of their identity until they are in some kind of crisis that prompts them to examine who they are and what they want. Perhaps an aspect of who a person is becomes a reason for their being in some way marginalised or excluded from the rest of society or from a significant social group that used to include them. Sometimes a crisis will put different aspects of a person's identity at odds, highlighting how they hold beliefs that are in fact incompatible, making conflicting demands on their behaviour and attitudes.

The projects within this theme of the Science in Society Programme explore how different aspects of identity play a role in the engagement of particular social groups with science and technology. The first two projects, *Gender Theories and Risk Perception: A Secondary Analysis* and *Public Perception of Gamete Donation in British South Asian Communities* both described in more detail later, show how the particular identities of certain social groups may influence how they perceive the risks of specific technologies.

Project: Gender Theories and Risk Perception: A Secondary Analysis

Professor Nick Pidgeon and his research team examined how gender influences perceptions of risk.

The project started from the fact that many existing surveys of public risk perception have established that identity plays a key role in how people think about the risks presented by science and technology. It is clear that people rarely judge environmental and technological hazards as risky strictly in terms of how probable it is that an adverse event will occur in the future. In fact, people are much more likely to decide that something is potentially dangerous on the basis of everyday beliefs about the world, its people and groups. Such judgements will be based on shared experiences, social relations and world-views, and beliefs about who to trust (eg Poortinga and Pidgeon, 2003, 2005) and who is to blame when things do go wrong - all factors that are informed by people's identity.

There is now a long history of quantitative research into public risk perceptions, stretching back to the mid-1970s when the first survey work on attitudes towards nuclear energy was conducted. While many of the traditional demographic identity categories (for example, age, socio-economic status) tend not to be related to people's concerns about risk, one robust statistical effect does stand out in many such quantitative surveys: that is, that women do show slightly higher concerns than men about a range of environmental and technological hazards. However, such studies have failed to offer adequate explanations for why this effect might be occurring. On the surface, these findings might appear to support a commonly held stereotype that women are just more

anxious, more prone to worrying about risk than men. In fact, many would say that this evidence is just what we should expect, since it conforms to a widely held belief that women tend to worry more about these kinds of threats. However, this project set out to examine the meaning of gender identity, and its relationship to risk concerns, at a far deeper level.

The project uses insights from contemporary gender and risk theory, coupled with a secondary qualitative analysis of group discussions where men and women talk about a range of risk issues (including nuclear power, GM agriculture, climate change, mobile telephones and genetic testing). It poses the fundamental question, why might some women and men respondents show different levels of concern about environmental and technological hazards?

In methodological terms the project is innovative in seeking to combine insights from both quantitative and qualitative research methods. While broad surveys of perceptions are useful for identifying general trends, detailed qualitative analysis, of the kind conducted here, is needed to uncover the ways in which people account for and understand risk, and the identities (man, woman, scientist, worker, protestor) they invoke when talking about it.

The initial results of this project challenge the stereotype that women just worry more than men. From the data analysis so far, it is clear that both men and women draw, in a highly nuanced way, upon a range of complex discourses when trying to explain to others their feelings and concerns about risk. These include themes of anxiety, care for self and others, threat and personal vulnerability or invulnerability, as we might expect, but they also include wider concerns such as the hope and desire for technological fixes or the acceptance of more pragmatic approaches and solutions; accountability for risk in local, national or global terms; trust in, and responsibility for, risk management.

The themes of vulnerability and responsibility are both congruent with other recent research from the US that suggests that it isn't the case that women tend to be more concerned about environmental and technological hazards. On the contrary, a number of the quantitative statistical results might possibly be explained in terms of a particular sub-group (typically comprising men), who may feel they are particularly invulnerable to the hazards of the world. Such individuals, compared to all others, evince particularly low levels of concern about scientific and technological risks (Satterfield et al. 2004). This then raises the much broader guestion of whether there are particular identities (not just gender identities) that people might adopt, or are compelled to take on in certain circumstances, which lead to particular feelings of subjective vulnerability or invulnerability to hazards.

As we go to press, this project is not yet complete, and it must be stressed that these are only preliminary findings. However, even these are instructive, not only intimating the crucial role that identity may play in influencing our beliefs about science, technology and the environment, but also, by leading us to question a popular gender prejudice in this domain.

Gender Theories and Risk Perception: A Secondary Analysis

Professor Nick Pidgeon and Dr Karen Henwood of Cardiff University, and Professor Alan Irwin of Liverpool University

Why do men and women respondents, in quantitative surveys of public risk perception, show different levels of concern about environmental and technological hazards?

This project aims to:

- draw on the theoretical resources available within gender theory to develop a theoretical platform to account for these findings
- illustrate the complex relationship between gender and perceptions of technological and environmental risk – and through this the ways in which identity (not just limited by gender) has the potential to shape experiences of science and technology.

http://www.sci-soc.net/SciSoc/Projects /Identity/Gender+theories+and+risk+ perception.htm

Project: Public Perception of Gamete Donation in British South Asian Communities

Following on from earlier work on the social meanings of childlessness (Culley et al. 2006), this project focuses on members of British South Asian (Indian, Pakistani and Bangladeshi) communities. It aims to examine the public understandings of gamete donation amongst British South Asian communities and to explore issues regarding the willingness of South Asian women and men to consider donating or receiving eggs and sperm.

Within the UK, since 1991, 25,000 children have been born by treatments using donated gametes or embryos. Gamete donation, as a technique used in new reproductive technologies, has been described as one of the most contentious elements of assisted conception (Blyth and Landau 2004), because it transgresses the established boundaries of biological and genetic procreation between two individuals. This project addresses how this specific aspect of the new reproductive technologies (NRTs) is understood within British South Asian communities.

This investigation covers new ground. Although social science has acknowledged the need to identify public engagement with science and technology at local levels (Irwin and Wynne 1996, Sturgis and Allum 2004), there has been little, if any research that has addressed the public understanding of NRTs. More recently, new genetic science has tended to ignore the potential impact of ethnic identity and cultural/religious contexts on these processes. This has led to the privileging of dominant ethnicities, despite the potentially significant consequences of genetic technologies for women and men from racialised groups. The methodology included 14 focus group discussions with a total of 100 participants; ten groups with women and four with men, together with interviews with other key players, including infertility practitioners, counsellors, support group workers, community development workers and faith representatives. An event was held to generate dialogue between the stakeholder groups, which was attended by 65 delegates.

The research has produced a wealth of data, and analysis has generated findings relevant to a range of debates concerning new reproductive technologies, including: understandings of family, kinship and procreation, health and social policy, research ethics, and science-society relations. These are being written up in full as outputs targeted to a range of audiences, but the key conclusions include the following:

There is a low public profile within British South Asian communities of the processes involved in third-party assisted conception. Although many were aware that gamete donation was possible, few reported having been made aware of a shortage of eggs or sperm and no respondents had seen any publicity relating to the need for more donors. Most felt that South Asian couples might use this technique as a treatment of last resort, but there would be great disapproval within the community. Alternatives to using donated gametes as a response to infertility were commonly discussed, for example polygyny and, especially, informal adoption within families.

"Participants expressed many concerns about the social and personal implications of the new relationships that gamete donation might create"

- For Muslim participants, the significance of understandings of Islam for the framing of acceptability or appropriateness of views and behaviour in relation to NRTs was very evident. Donating and receiving gametes is generally considered religiously unacceptable in Islam (especially among Sunni Muslims), although there was some uncertainty expressed by participants around this issue.
- There were marked differences in the perception of egg and sperm donation. Donated sperm in particular was constructed as a 'risk object' (Hilgartner 1992), that is, it was viewed as a potential social and cultural threat. The process of egg donation was seen as more benign. Both women and men regarded gestation and birth as generating an important 'biological' link between birth mother and child, in the absence of genetic parenthood. Using donated sperm, however, was regarded as highly problematic since it did not allow the male to play his culturally important role in procreation and family continuity, and was seen as likely to lead to conflict and rejection.
- The donation of gametes was also perceived as a highly gendered activity. Women were perceived as having an increased corporeal and emotional connection with the 'egg' that made the act of altruistic donation difficult to contemplate. However, while the male was seen as having less 'attachment' to his sperm, both women and men saw gametes as potential children. Given the cultural and in

some cases religious, value of children and family in South Asian communities, this is likely to be a further disincentive to engaging in donation.

South Asian women and men framed their discussions of gamete donation in terms of an explicit unease and uncertainty. Their narratives suggest that this process is perceived as inherently risky and these risks can be categorised into bodily risks, emotional risks and relational risks. Bodily risks were generally less dominant than emotional and relational risks. Participants expressed many concerns about the social and personal implications of the new relationships that gamete donation might create, and discussed ways of negotiating these risks and uncertainties. Being a donor or potential recipient of donated gametes was felt to be potentially highly damaging to personal, social and community relations, and therefore participants were certain that those who underwent these processes would not disclose the information within their community.

The analysis highlights possible cultural specificities in ideas of procreation and kinship. Kinship considerations and consequences of gamete donation were widely discussed. When participants described what they thought and how they felt, they framed it in the context of a concept of family that goes beyond the nuclear form. Participants also constructed specific views of 'substance' and relatedness in their accounts of what is passed on in ('natural' acts of) procreation, and what is 'matched' when

donated gametes are used. Their narratives were often ambiguous and contradictory, sometimes, for example, privileging genetics as the basis of identity and at other times demonstrating a sense of relatedness that was more performative and dynamic. The findings also illustrate the different ways in which people distinguish between what is given and what is made – what might be called biological, what might be called social.

Both this project and the previous project on gender and risk explore how aspects of social identity may shape perceptions of science and technology. They show how existing cultural understandings and perceptions of science/ technology among specific groups play a crucial role in the ways they understand and negotiate the possible risks of scientific innovation.

But they also lead to another observation – about the cultural assumptions of those responsible for the creation and communication of science and technology. In both projects, we see scientists and policymakers tending to assume that members of the public will receive and respond to scientific information in particular ways, either (as in Lorraine Culley's project) pretty much the same way as they do, or (as Nick Pidgeon's project suggests) by conforming to certain stereotypes. This leads us to raise questions about the relationship between culture and the production and communication of scientific knowledge.

Project

Public Perception of Gamete Donation in British South Asian Communities

Dr Lorraine Culley, De Montfort University, Leicester

How are new reproductive technologies and gamete donation understood among British South Asian communities and how does this impact the willingness or otherwise of individuals from minority ethnic communities to engage with this process?

This project aims to:

- enhance knowledge of the impact of diverse ethnicities on understandings of gamete donation
- increase awareness of the reasons for the shortage of gamete donors from minority ethnic communities.

http://www.sci-soc.net/SciSoc/Projects /Identity/Public+perceptions+of+gamete+ donation.htm



Science and Technology: Truth or Fiction?

Western science is itself an ethnoscience marked by specific conventions, boundary techniques and values (Franklin 1995).

The traditional view of science is that it comprises objective – and unquestionable – universal knowledge. It is a public realm of cumulative fact, independent of context, researched following a rational method and reported with impersonal and unbiased detachment. Some still hold this view, but in general, its strength and prevalence is fading. In the academic world it has been challenged by the work of historians of science, such as Popper, Lakatos, Kuhn and Merton, and, more recently, research in the field of science studies (Warner 1995).

Of course, the idea that science should be subjected to any kind of critical social scientific inquiry arguments continues to be vigorously contested (Gross and Leavitt 1994). But in response commentators have observed that this defence itself occurs precisely because science is a source of profound cultural values: "Science is defended so vehemently because it is cultural, not because it is extracultural" (Franklin 1995). The citadel of 'true science' has been stormed from a number of different directions. These include:

- Geographic and historical cross-cultural comparisons, exploring the global, national, regional and local aspects of scientific practice, and how it has developed over time (Warner 1995, Franklin 1995, Harding 1994, Jasanoff et al. 1995).
- Ethnographies of the laboratory anthropological studies of the cultures that develop among communities of scientists working within laboratories. These have suggested that social and moral values shape the approach of scientific communities, influencing how they construct their investigations and express their conclusions and therefore constructing what emerges as 'scientific fact'. For example, particular methods of documenting or communicating information can reinforce or undermine its significance as 'scientific fact'. It might be because particular communities privilege certain kinds of reasoning as acceptable, while devaluing other kinds (Latour and Woolgar 1986); or there may be tacit knowledge that exists in certain scientific communities (Mackenzie and Spinardi 1995).

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"Scientific knowledge cannot be divorced from the culture that produces it"

Feminist cultural analyses have drawn attention to the ways in which cultural and moral assumptions influence approaches to biomedicine, especially new reproductive technologies (Martin 1987, 1991, Strathern 1992). Recent research has also focused on the relationship between gender and the scientific industry, and on gender and technology (Ackers 2004, Greenfield 2002). In this light, we have to consider not just behaviour within the laboratory, but also how cultural values influence the formation of the laboratory itself. For example, work is being done on the ways in which cultural assumptions about the roles of marital partners influence the gender balance within science careers. It shows how in relationships in which both partners have scientific careers, the progression of the male partner usually takes predominance. This is reinforced as the "greater security and remuneration attached to the more advanced career (together with concerns about potential interruptions to women's careers for child rearing) often tilts the balance in favour of stabilising male positions." (Ackers 2004: 198)

Just like any other human activity, the practice of science is susceptible to our hidden assumptions, for example cultural values. As we have seen with the two previous projects, aspects of identity are likely to influence how people interact with science and technology; and scientists are just as prone as non-scientists to interpret what they see and hear in the light of their own views about the world, their values, beliefs and aspirations.

Scientific knowledge cannot be divorced from the culture that produces it. As these projects have shown, both experts and non-experts within and outside the laboratory, play a role in communicating, organising and deploying scientific knowledge, and in shaping policy. However, our culture is infinitely more complex than just these two groups: as the next project reveals, as well as experts and non-experts, there are other groups with other interests who also play their part in shaping the role of science in society.

Project: Boundary Work, Normal Ageing and Brain Pathology

In the third project under this theme, Professor John Bond and his team at Newcastle University explored how the effects of ageing are described and understood by different communities, both experts and non-experts. It explored how these different understandings influence each other, and how, as they interact, they change over time:

The central finding from this study is the continuing uncertainty involved in clinical, scientific and public understandings of dementia, associated conditions and diagnoses.

Scientific uncertainties are highlighted by competing and contrasting biological theories that are used to explain the causes and development of dementia. Clinical uncertainties are reflected in the protocols used to diagnose and treat dementia in different clinical settings within different health care systems by different clinical specialities. Meanwhile, public uncertainties remain about the relationship between dementia and normal cognitive ageing.

These different understandings are dynamic and interactive. As scientific knowledge changes or different biological understandings are accepted within the scientific community, so these understandings are translated into clinical practice and responded to by the wider public. Equally public understandings of dementia and cognitive impairment influence the way that science is conceived and clinical practice undertaken. The study found that this was particularly evident in the case of what is now called Mild Cognitive Impairment (MCI).

MCI raises different questions for different groups. For biomedical scientists, MCI is a puzzle requiring further research. For clinicians, it represents a way to work with patients presenting with early memory complaints. For patient advocacy groups, it is a way to communicate the message that dementia is a progressive disease that starts earlier than clinical diagnoses.

Commercial interests influence the generation of biomedical knowledge, clinical practice and patient behaviour.

The project showed how the official labelling by the regulatory agencies of MCI as a condition that preceded dementia was pivotal in opening a potential new market for pharmaceutical agents. A number of the experts interviewed in the study expressed concern about the role of pharmaceutical and biotechnology companies in sponsoring research and the influence this had on the fixing of MCI as a treatable condition. Internet marketing, direct advertisements to the public and increasing fears and concerns about memory impairment represent a considerable potential for anti-dementia drugs. For some respondents MCI highlighted a negative trend towards a consumer-driven healthcare market, which would undermine the so-called 'collectivist' European social model that pooled health risks and responded equitably to healthcare needs within the context of scarce resources.

The use of the diagnoses of MCI in clinical practice changes throughout the course of the study.

For some clinicians MCI is a useful formal diagnosis facilitating discussion with patients. The ability to give a diagnosis is felt to respond to the patient's need for a label, and it can help patients plan for the future. In some healthcare contexts the provision of a formal diagnosis is essential for patient reimbursement of health care costs. For other clinicians. MCI is not used as a formal diagnosis and adds nothing to the clinical understanding of mild cognitive impairments and dementia. The study found that different uses of MCI reflect the organisation of healthcare systems, for example between the consumer and market-oriented system found in the US, and the more collectivist systems in western Europe and Canada. The use of MCI in clinical practice was also found to reflect the evidence-based culture in some countries. For example, in the UK the use of guidelines and protocols throughout the healthcare system is coupled with clinicians expecting a higher level of scientific validation before changing their clinical practice than do colleagues in the US.

es of MCI in clinical ghout the course of lay knowledge and understandings of cognitive impairment and dementia.

> The caregivers of people with dementia and their international advocacy organisations are also important players in this process. The study highlights the tension between the demand from younger generations for the development of therapies that prevent the diseases associated with cognitive impairment and the needs of people who already have dementia and those close to developing it. It also found a different approach to risk with advocacy organisations arguing for greater risk-taking than traditional regulatory authorities in the uptake of new therapies for cognitive impairment and dementia.

Project

Boundary Work, Normal Ageing and Brain Pathology

Professor John Bond, Newcastle University

How are the meanings and effects of ageing (a normal biological process) constructed differently by specific communities of practice and their publics? How do they work to define, organise and enact at the boundaries between normal and abnormal cognitive ageing?

This project aimed to:

- explore both expert and lay public constructs and discourses about normal/abnormal ageing and the boundary between them, through analysis of scientific debate and dispute and culturally embedded knowledge
- understand how these discourses interact and influence each other in daily life.
- http://www.sci-soc.net/SciSoc/Projects /Identity/Boundary+work+normal+ ageing+and+brain+pathology.htm

This study revealed how biomedical, social and commercial developments are, separately and together, transforming understandings of the boundary between 'normal' and 'abnormal' cognitive ageing, both for clinicians and wider society. It demonstrated this through a particularly innovative approach to the results, in which it attempted to involve different users of the research in the interpretation of the study findings, through workshops with older people, advocates of older people, informal carers, clinicians, dementia researchers and social scientists. Participants concluded that MCI was of limited utility for clinicians and older people and that there was an important role for existing carers in formulating research and policy on early diagnosis and prevention of cognitive impairment. Participants highlighted the dangers of propagating ageist attitudes through awareness campaigns about the risks associated with dementia and memory loss.

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Cross-Cutting Themes: Exploring Perceptions and Engagement

Whatever position we choose to take on the 'truth-value' of science, it cannot be denied that the production and communication of scientific knowledge both inside and outside the laboratory is shaped by the interaction of different social groups.

Aspects of identity have multi-layered implications for this process, shaping:

- Overt responses to particular interventions by science and technology in daily life: For example, do people perceive science and technology as a challenge to the ways they want to live their lives or as a facilitator? Will they engage in particular science and technology programmes, ignore them or protest against them?
- Implicit responses to interventions by science and technology: Do they disrupt people's visions of the world, or of their role in it? Do they change people's understanding of who they are and how they should behave? Are people more confident about a future in which science and technology can always find an answer to any problem, or do they fear the insidious spread of technology?

Identification of, and attitudes to, authority: When people are establishing the credibility of expertise and authority, do they gravitate to local/culturally embedded knowledge or novel scientific knowledge?

This section presents two projects that explore some of these questions. The last two projects under this theme have each conducted research in two different locations, so that, in each case, the findings could be compared and contrasted. The first, Asbestos Diseases: Scientific Definitions and Gendered Identities examines the experience of asbestos disease among two groups of workers, one in the Northern Cape, South Africa, the other in Dagenham, in London. The project also highlights the role played by the medical and legal professions and the effect and impact of experience of these professions on the subjects' identity and gendered relations. The second, Childhood Vaccination: Science and Public Engagement in International Perspective led

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by Professor James Fairhead, University of Sussex and Professor Melissa Leach, Institute of Development Studies at the University of Sussex, used ethnographic and survey methods to explore the perspectives and decision-making processes of parents, regarding the vaccination of their children and their participation in medical research. This project was conducted in Brighton, UK, and the Gambia.

Each project explored the complex nature of identity of a particular social group, and how that identity shaped that group's understanding of, and interaction with, particular kinds of scientific knowledge, how scientific knowledge may be shaped and constructed by different disciplines – for example, medicine or the law – for different purposes, and how those different understandings of, and ways of talking about, science and technology may interact and influence each other. Working with communities of workers in South Africa and London, Dr Linda Waldman is examining how differently scientists and bureaucrats, and communities frame the risk and harm of asbestos disease. Her project explores how the experience of asbestos disease affects personal bodily experiences, understandings of identity and social relations. The description below explores in more detail the results of her work amongst asbestosworkers in Dagenham, London.

According to medical science, asbestos-related diseases fall into four main categories: mesothelioma, lung cancer, asbestosis (or pleural thickening) and pleural plaques. Most funding and medical research focuses on mesothelioma, which is widely recognised as the more serious and debilitating disease. As one South African doctor succinctly summarised: "[life expectancy is] nought to two years with zero recovery, regardless of treatment". Pleural plaques, on the other hand, are largely described as 'benign' (Mossman and Gee, 1989), or as one UK lawyer suggested "You'll die with it, not of it". In January 2006, the House of Lords declared that pleural plagues were 'inert' and ruled that UK sufferers could no longer claim compensation or sue if diagnosed with pleural plaques.

These assessments of asbestos-related diseases are made by scientists and, as illustrated by the House of Lords' ruling, they influence the legal categorisation of harm. The dangers of unwarranted compensation and increased stress were listed amongst the primary reasons for this ruling: "There is a danger that those ... who make a business out of litigation, will encourage workers who have been exposed to asbestos to have a CT scan in order to see whether they have pleural plaques for the sole purpose of bringing claims for compensation. Such a practice will tend to create stress and anxiety where none exists" (Grieves v. FT Everard & Sons ; 2006: 17). Asbestos diseases, alongside other toxic threats, are, however, widely recognised for their insidious and fearsome nature (Douglas and Wildavsky, 1982; Bourke, 2005). The idea that litigation for pleural plaques is unnecessary or increases stress is thus completely absurd from the perspective of those people who experience the diseases.

In 1998, 12 men, members of Britain's General Union (GMB) branch in Dagenham, were diagnosed with pleural plaques. These thermal insulation engineers or 'laggers' have worked with asbestos virtually all their adult lives and have intimate experience with asbestos-related diseases. Their earning capacity and their identity as men is intricately related to their experiences as laggers in Dagenham.

Dagenham is part of the London Borough of Barking and Dagenham located on the river Thames. In its heyday Barking and Dagenham was highly cosmopolitan, attracting a range of industries that all relied heavily on asbestos. Nowadays, the borough has the lowest average income in London with most people earning in the region of £13,000 a year, accompanied by low levels of education. It is the back end of London, or "the whipping boy of the A13" as one pleural plaques sufferer described it. In addition to these structural conditions, "[t]here are high levels of long-term illness and men have the third lowest life expectancy in London" (Barking and Dagenham Council, 2002: 4).

The laggers, who meet fortnightly at the Dagenham Working Men's Club to discuss their exposure to asbestos and their colleagues' compensation claims, have lived in the area all their lives. Their intimate knowledge of asbestos disease has been acquired since their families first moved to Barking and Dagenham to take advantage of the new industrial opportunities. These families formed the industrial labour force of Barking and Dagenham. They were also widely exposed to asbestos. Consequently, they have watched many family members die of asbestos-related diseases: "We all have brothers, we come from a trade, we are all family. I lost my brother, an uncle who died at 42 and was a lagger like myself. My father died of lung disease. I also had a cousin diagnosed". Their experience watching family members suffer and dealing with doctors and lawyers, has led to deep suspicion of the medical and legal establishment. Their view resonates with those recorded by Burnham (1982) and Brown (1979) on how modern scientific medicine might support capitalist interests and undermine people's health in US contexts, or, to put it another way, as Jasanoff has argued, "Politics is never far from view when one is observing science in action around topics of immediate social concern" (1996:410).

"Life expectancy is nought to two years with zero recovery, regardless of treatment"

Precisely because these laggers have been exposed to asbestos and precisely because they know the associated dangers and suffering, laggers avoid medical examinations. Doctors are believed to conceal men's positive diagnoses in order to protect companies; to downgrade men's conditions to pleural plaques rather than admitting the full extent of their disease; and to substitute older, healthy x-rays for recent, infected x-rays in order to avoid litigation and compensation. Even more significantly, laggers do not accept the medical categorisation of asbestos-related diseases described above. The medical and legal terms 'benign' and 'inert' are a mockery of their experience of pleural plagues: they "diagnose us in the beginning with pleural plaques, but it becomes asbestosis or mesothelioma either in the hospital or in the following weeks".

These men identify as workers, husbands and fathers; they are fundamentally concerned with their ability to bring in money and to support their families. As Gilmore suggests, the ability to have children, to protect one's dependants and to provide for one's family are universal criteria of manhood (1990). In meeting these elements of masculinity, the laggers have become caught up in the housing boom and in the materialistic consumption of the 21st century. Despite the fact that housing prices in Barking and Dagenham are the lowest in London, many of these men battle to meet their mortgage and other daily expenditures. In addition, the contractual nature of their business means that they do not benefit from the usual social

protection mechanisms. They have no sick benefits, no injury compensation, no means of surviving if they are not earning.

These structural conditions, coupled with their intimacy with other asbestos sufferers, lead to significant opposition to the legal and medical models of pleural plagues. As indicated above, they do not see pleural plaques as inert and benign; rather all asbestos diseases are progressive. pleural plaques are an indication of the men's extensive exposure to asbestos. They point to the presence of other, worse diseases, as evidenced by the fact that some of the 12 men diagnosed in 1998 have died. The presence of pleural plaques also connotes a significant crisis in the men's ability to maintain their lifestyle and identity (cf Moore, 1988; Hearn and Morgan, 1990). Furthermore, pleural plaques affects their fitness, breathing and general ability to work, making it hard for the laggers to keep up the certain speed of hard physical labour they need to ensure stable income levels. Finally, the chairman of the GMB explains that "The mental stress caused by pleural plaques is very severe. Eighty per cent of the men diagnosed with pleural plaques die of asbestosis. ... It's about the mental stress – they think they are on the way to mesothelioma''. Mesothelioma, as a form of cancer, is highly stigmatised. Not only is cancer frequently a metaphor for bad, unwanted experiences, it has been seen as 'naturally loathsome', an 'invisible contaminant' that invades the body (Bourke, 2005; Erikson, 1990).

As the disease signals their inability to work as laggers, their failure as providers to wives and families and their imminent demise, they withdraw from the GMB, losing friends and separating themselves from their support structures. The men's ability to create and sustain their masculine identity is significantly undermined. Despite the widespread tendency to see identities as multiple, hybrid, fluid and fractured (Connell, 1987; Moore, 1993), these men's identity appears solidly grounded in their experiences as Dagenham laggers and as family providers. The experience of asbestos disease fractures their identities and defines their crisis. The stress and the emotions associated with diagnosis "lead to the negotiation of the boundaries between self and other" (Bourke, 2005: 354).

Ultimately, there is no one left for them to turn to and no sources of authority that they trust (Furedi, 1997). The legal establishment, medical science, trade unions and the government are all viewed as being on the side of business and industry. The legal decision, based on 'scientific evidence' that pleural plaques are benign and that sufferers cannot sue for compensation removes the final opportunity laggers have to claim some money, while still alive, in order to provide for their families and fulfil their role as men. The failure to litigate while still relatively healthy and to be able to invest compensation in ways that would allow them to feel confident that their families are provided for, increases, rather than reduces, their stress as they struggle to maintain their identity and role as men, laggers and providers.

Not being able to sue for pleural plaques means waiting for the disease to progress to asbestosis or mesothelioma. Once this happens, and because of the delayed diagnosis (Higgs, 2006), a lagger's life expectancy is so limited and his quality of life so contracted, that suing for compensation requires too much energy. By this stage, the brutal reality is that the sick men face imminent death.

Despite the confidence with which the Law Lords accept the medical categorisation of asbestos disease and harm, science cannot determine what exposure leads to pleural plaques or to other, more severe diseases: "Medical science cannot prove whose asbestos is more likely than not to have produced the cell mutation which caused the disease" (Barker v. Corus (UK) plc (formerly Saint Gobain Pipelines plc), 2006: 5).

Because of this, the House of Lords ruled recently that responsibility for mesothelioma could be apportioned, despite previous understandings of the disease as indivisible. The Law Lords have "reversed years of precedents by issuing a pro-defendants verdict which could, if the ruling stands ... deprive thousands of UK asbestos victims of billions of pounds of compensation in the coming decades" (Kazan-Allen, IBAS, 03.05.2006). This legal decision means that the laggers have no further options for resolving tensions in their identities. Widescale public mobilisation has resulted in new legislation, passed in June 2006, reversing this ruling. While this benefits those laggers who are diagnosed with mesothelioma, their battle to change the legal and scientific understandings of pleural plaques continues.

This project comprises a close examination of a community under stress, revealing a detailed account of the complex nature of identity among a particular group of male workers. It demonstrates how scientific knowledge may be differently constructed within different communities and what can happen when, within a society, those constructions clash. In this case, the tragic results of that conflict, that is the inability of the laggers to claim compensation and be able to fulfil their role as providers for their families, challenges their own sense of identity. It shows how aspects of identity may not only shape, but also be shaped by, interactions with different kinds of scientific knowledge. This is also a theme of the next project.

Asbestos Diseases: Scientific Definitions and Gendered Identities

Project

Dr Linda Waldman, Institute of Development Studies, University of Sussex

How does people's experience with asbestos-related diseases, and with the resultant medical and legal discourses that surround these diseases, impact on their identity and gendered relations?

This project aims to:

- work from personal narratives (in two local sites, one in South Africa and one in London) to understand different cultural responses to scientific discourses
- address the extent to which communities shape their identity in relation to their gendered experiences of science and law
- understand the intersection between science and identity in daily life.

http://www.sci-soc.net/SciSoc/Projects /Identity/Asbestos+Diseases.htm

Project: Childhood Vaccination: Science and Public Engagement in International Perspective

This project considers the range of influences shaping different perceptions of scientific knowledge. These include those at the personal level, such as individual and family health histories; the local level, such as a community's understanding of the nature of disease and immunity; the national level, such as information in the media; and the global level, such as attitudes towards international institutions. But the project also considers how identity is shaped by scientific knowledge, especially in situations of challenge or conflict. This includes both the identity (and associated behaviours and beliefs) that people take on for themselves in particular circumstances, and the assumptions made by one group of people about the behaviour and beliefs of another group.

Childhood vaccination is a good example of a rapidly advancing, universally relevant scientific field where there is rapid change – at times, crisis – of public engagement with science, and at the same time a requirement for public confidence. This study set out to explore science-society relations in European and African settings, asking how and why parents make decisions about their children's vaccination. It focused on the inter-section of routine vaccination with the MMR controversy in the UK and Medical Research Council orchestrated vaccine research in The Gambia.

The project looked at how local understandings of, and knowledge about, disease and immunity, along with broader experiences of the state and of science shape people's perceptions of the risks of vaccination – and how differently they think about the trade-offs between social and individual benefits and risks. In addition, it explored how vaccine scientists and public health professionals conceive of public perspectives around vaccination, and how staff in the frontline of medical delivery mediate professional and public views.

In the UK, policy discussions and professional views of parents' engagement with MMR have been dominated by consideration of the scientific and media information that have shaped their choices. This has led health policy to focus on information and education campaigns. The project questioned this reasoning, showing how wider personal and social issues shape parents' choices about vaccination.

Mothers' narratives show, how their practices around MMR are shaped by their personal and family health histories, their readings of a child's particular health vulnerabilities, questions of personal confidence, particular engagements with health services, and friendships and conversations with others. Although many see vaccination as a personal decision which must respond to the particularities of a child's immune system, 'MMR talk' among parents, which affirms such conceptualisations, has become a social phenomenon in itself.

A postal survey of Brighton mothers confirmed that socio-economic class and information sources are less important in shaping compliance with the MMR regime than existing

"This interacts, at a personal level, with intense parental observation and evaluation of each child's particular health history"

ideas about immune system susceptibility and family health history, early thinking about MMR and attitudes to other types of injections given during early childhood, and the use of homeopathy. When deciding about MMR, only 12 per cent considered possible benefits for other children. Overall, the study suggests the importance of emergent public discourses about individual responsibility and personalised immunity in the UK for shaping parental response to the MMR controversy.

In the Gambia, the study also revealed contrasts between the perspectives of health institutions and of parents. Regarding routine vaccination, health professionals see acceptance as evidence that parents favour modern healthcare. In contrast, the study found that parents view immunisation as one of many practices for promoting infant strength and health, and see the value of vaccines as improving general health, more than preventing specific diseases. While infant clinics are attractive social occasions for some women, encouraging attendance, others feel excluded or worried by them due to their own social circumstances, their child's health and the judgement of others about these.

Whereas health professionals see those parents who do not vaccinate their children as neglectful, either through ignorance or in prioritising travel or trade, the study found that mis-timings usually arise through events that could affect anyone. These difficulties include family misfortune or practical difficulties in getting to the clinic, which can be compounded by clinic logistics or conflicts with clinic staff. The project's survey of 1,600 mothers found that the numbers who did not vaccinate their children is higher in urban than rural areas, and is associated with poverty-related factors, linked to forms of exclusion at the clinic. A mother's education makes no difference to this aspect in rural areas, undermining the assumption that high vaccination uptake reflects modernising knowledge and scientific rationality.

Similar contrasts emerge for research participation. The study found that parents treat medical studies as part of normal health practices rather than as a separate scientific entity. Whereas medical researchers place heavy emphasis on formal bioethical procedures and informed consent for participation in a trial, and see public engagement as a matter of trust in modern science, a project survey found that only six per cent of participants in a major pneumococcal vaccine trial could say accurately what it was about. Rather, the consent process is often overtaken by gender and power relations, while many parents reflect on trial participation through broader cultural perceptions, for example, regarding the significance of blood. In The Gambia, the researchers observe that core cultural ideas about strength and wellbeing stress the significance of blood and other bodily fluids. They found that the vaccine programme is seen by numerous participants in the MRC programme as, on the one hand, an opportunity to gain access to therapies that will strengthen and enhance their blood, but, on the other, a risk, since it allows their blood to be stolen

(without being paid for, unlike the system in Gambian hospitals), creating a sense of suspicion and injustice.

The Gambian study shows that the categories used by health professionals to describe vaccination 'compliers' and 'defaulters', and trial 'acceptors' and 'refusers' obscure the range of experiences, concerns and dilemmas faced by parents as they seek to raise their infants and keep them healthy. Debates around informed consent need to move beyond just the moment of decision and consider the wider social context, including emergent public discourses about the significance of blood in evaluating both health and wider socio-economic relations.

In both British and West African settings, parents think about and discuss vaccination issues as part of wider conversations about child wellbeing. This interacts, at a personal level, with intense parental observation and evaluation of each child's particular health history, strength and vulnerability, and at a social level, with debates and controversies about vaccine science. These, in turn, are playing into particular cultural attitudes about health and social relations in each location – what the researchers called "an age of personalised immunity" among the UK parents; and what they termed "an economy of blood" in The Gambian group.

As this demonstrates, public engagement with (globalised) vaccine technologies is strongly influenced by many different factors, rather than being simply a matter of, say, people's trust/distrust of state, scientific, corporate and global institutions. Aspects of identity influence people's responses to science and technology and, in turn, are shaped by them. The dynamics between the different social groups in this project provide examples of how and why people can make assumptions about the identities of other social groups, thinking they understand the reason for their behaviour (describing them as, for example, 'vaccine defaulters', or even as 'blood stealers') and then reacting to what they think is happening. Through collaboration and user interaction, the research findings from this project are being used to support reflection on new modes of public involvement with science and technology programmes.

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Childhood Vaccination: Science and Public Engagement in International Perspective

Project

Professor James Fairhead, University of Sussex and Professor Melissa Leach, Institute of Development Studies, University of Sussex

This project investigated aspects of the science-society relationship in the context of childhood vaccination, focusing on the case of measles, mumps and rubella (MMR) in Brighton, UK, and on the intersection of routine vaccination with Medical Research Council (MRC)-orchestrated vaccine research in The Gambia.

It explored:

- how different parents' concerns are shaped by conceptual frameworks and knowledges around disease and immunity, and broader experiences of the state and of science and how different people consider trade-offs between social and individual benefits and risks
- how vaccine scientists and public health professionals conceive of public perspectives around vaccination, and how 'frontline' staff mediate professional and public views?

http://www.sci-soc.net/SciSoc/Projects /Globalization/Childhood+vaccination.htm

and public health of public accination, and how e professional and

on communities with asbestos-related diseases reveal the range of understandings among different social groups around science and technology, technologies and disease, and technological risk, demonstrating how local knowledge and experience may exert an authority equivalent to, or greater than, that of scientific knowledge. The projects' demonstration of how aspects of identity shape interactions with science and technology, and vice versa - among both experts and nonexperts - provides critical insights into the problematic interface between policy development and practical implementation that exists in current approaches to the governance of science.

Both this project and Linda Waldman's project

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Conclusion: Enhancing Understanding and Inclusion

Society needs to do a better job of asking what kind of tomorrow we create with the possibilities that science offers. Such decisions are governed by values, beliefs, feelings; science has no special voice in such democratic debates about values. But science does serve a crucial function in painting the landscape of facts and uncertainties against which such societal debates take place. (Lord Robert May, President of the Royal Society, Anniversary Address, 2001).

The projects under the theme, *Science and Gender, Ethnicity and the Life Cycle*, all aim to improve understanding of the engagement between lay-public and experts or government around scientific and technological knowledge.

They do this, at the simplest level, by showing how social identities play a key role within both the expert and non-expert scientific communities in shaping conceptual frameworks and knowledge around new technologies, exploring:

- how social identities influence people's experiences and perceptions of, and responses to, interventions of science and technology in daily life
- how aspects of individual and collective identity are, in turn, shaped by people's experiences of scientific and technological discourses
- how the production of scientific knowledge and its communication are shaped by the assumptions of scientists and policymakers.

"Society needs to do a better job of asking what kind of tomorrow we create with the possibilities that science offers"

However, the impact and relevance of these projects comes from the depth and detail they bring to their investigations. Each project has sought to develop a richer understanding of the role played by aspects of identity in the production, communication and reception of science and technology within a particular community. Focusing on very specific situations, these projects have examined the crucial elements that create and shape such identities and how they interact with other social forces, such as commercial interests. They have shown that social identity is both complex and fluid, changing in reaction to myriad events and influences at local to global levels.

As we might expect, and as the projects reveal, the ways in which identities shape interactions with scientific knowledge is hugely varied. Different identities bring with them particular values and beliefs, and the projects examine in depth what roles these play. All of these projects have considered how identities influence perceptions of the risks of particular science and technologies. For example, Lorraine Culley's work examines in-depth the influence of culture on the participation of British South Asians in reproductive technologies; James Fairhead and Melissa Leach expose the variety of different understandings of vaccination among various social groups. Other observations are also made, for example, Nick Pidgeon's work on risk and gender and John Bond's project on conceptions of ageing reveal how different cultural assumptions can influence scientists' understanding of the results of their own research, while Linda Waldman's work shows how particular experiences of science and technology, specifically the diagnosis of asbestos-related diseases, may be a factor in disrupting identities.

As these projects suggest, there may be farreaching consequences for society – local, national, global – of not taking account of the role of identity in the science-society relationship, and the many questions it raises. For example, as a number of the projects show, if particular social groups perceive certain technologies as carrying risk, this may prevent them from participating in related programmes. In Linda Waldman's project on asbestos-disease sufferers in Dagenham, the seemingly unbridgeable gap in perceptions of risk between those of the community and those promulgated by the legal and medical profession is having tragic implications for individuals, their families and communities. A similar problem is revealed at a national and international level by James Fairhead's and Melissa Leach's cross-cultural investigation of attitudes to vaccination. This shows how, although vaccination may be considered by policymakers as a critical intervention in reducing (child) mortality and tackling 'diseases of poverty', for the communities where it is being used, it is also evidently a source of new problems, prompting widespread anxiety and distrust. The latter must be addressed if the former is to work.

In addition to questions of public health and policy, it is clear that perceptions of science and technology may affect how members of different communities participate in the development of science and technology: whether they pursue science and technology education or training; whether and how they have access to technical decision-making and/or the design of programmes and public policy.

In this way, the projects in this theme of the Science in Society Programme reveal both some of the questions that accompany the production and dissemination of science and technology, and, at the same time, indicate how scientists and policymakers might address some of those questions. They provide unequivocal evidence of the role played by identity in society's interaction with science and technology, and vice versa, and the myriad influences that play a role in shaping those identities. They show the importance of taking this into account in designing every kind of public engagement with new technology, from debate, to regulation, to specific programmes and policies. As scientists and policymakers come to recognise the crucial importance of increasing engagement with the public, they must also understand that this must be rooted in an understanding of the diversity of that public, taking account of how different identities shape different ways of seeing the world.

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Research projects listed under topical themes

The Science in Society Programme is one of the ESRC's major investments and is a six year commitment running from 2002 to 2007. The Programme, originally conceived following a parliamentary report on science and technology, is both broad in scope and diverse in its research focus and has been host to 45 different research projects during its lifetime. The Programme is separated into six themes, each one acting as an umbrella for a variety of projects, all of which consider a different aspect of the science-society relationship.

Science in Governance and the Governance of Science

Social and Human Rights Impact Assessment and the Governance of Technology Dr Andrew Barry, research undertaken at Goldsmiths College, London – now based at the University of Oxford andrew.barry@ouce.ox.ac.uk

Interdisciplinarity and Society: A Critical Comparative Study Dr Andrew Barry, University of Oxford andrew.barry@ouce.ox.ac.uk

Using Public Environmental Knowledge in Industry Dr Kate Burningham, University of Surrey *k.burningham@surrey.ac.uk*

Childhood Cancer Tissue Donations: A Gift Relationship? Dr Mary Dixon-Woods, University of Leicester *md* I @le.ac.uk

Contesting Environmental Science: Business and Environmentalist NGOs Dr Sally Eden, University of Hull s.e.eden@hull.ac.uk

Credibility Claims as Scientific Commodities Dr Sally Eden, University of Hull s.e.eden@hull.ac.uk

Inside or Outside the Bio-science Tent? The Presentation of the Laboratory-self Dr Lena Eriksson, research undertaken at Cardiff University – now at the University of York *le502@york.ac.uk*

Caught Between Science and Society: Foot and Mouth Disease Dr Brigitte Nerlich, University of Nottingham *brigitte.nerlich@nottingham.ac.uk*

Public Perceptions of Risk, Science and Governance Professor Nick Pidgeon, research undertaken at the University of East Anglia – now at Cardiff University pidgeonn@cardiff.ac.uk

Accountability and the Governance of Expertise: Anticipating Genetic Bioweapons Dr Brian Rappert, University of Exeter *b:rappert@exeter.ac.uk*

Simulation Modelling of Contentious Scientific Knowledge Claims in Society Dr Simon Shackley, University of Manchester *simon.shackley@manchester.ac.uk* **Resolving Conflicts in Selecting a Programme of Fisheries Science Investigation** Professor Jonathan Side, Heriot-Watt University *j.c.side@hw.ac.uk*

Reproducing the Centre: Performing Innovation at Xerox PARC Professor Lucy Suchman, Lancaster University I.suchman@lancaster.ac.uk

Governance and Accountability Relations in Mundane Techno-Scientific Solutions to Public Problems Prof Steve Woolgar, University of Oxford steve.woolgar@sbs.ox.ac.uk

Re-modelling Science Communication

Deliberating the Environment: Scientists and the Socially Excluded in Dialogue Dr Derek Bell, University of Newcastle derek.bell@ncl.ac.uk

Spinning Science: The Nanotech Industry and Financial News Ms Mary Ebeling, University of Surrey *m.ebeling@surrey.ac.uk*

Public Involvement, Environment and Health: Evaluating GIS for Participation Dr John Forrester, University of York *jf* / 1@york.ac.uk

Communicating Science through Novel Exhibits and Exhibitions Prof Christian Heath, King's College London *christian.heath@kcl.ac.uk*

Experiments In Science Communication: A Pilot Study with a Digital TV Channel Dr Richard Hull, University of Newcastle upon Tyne *richard.hull@ncl.ac.uk*

The New Zoos: Science, Media and Culture Dr Nils Lindahl-Elliot, University of the West of England *nils.lindahl-eliot@uwe.ac.uk*

Consultation as Science Communication? The Case of Local Air Quality Management Prof James Longhurst, University of the West of England *james.longhurst@uwe.ac.uk*

Divided we Stand: Bridging Differential Understanding of Environmental Risk Ms Laura Potts, York St John College, York *l.potts@yorksj.ac.uk*

What Does Social Change Mean in the Context of Engineering Education? Dr Jane Pritchard, University of Glasgow *j.pritchard@udcf.gla.ac.uk*

Science in the Economy and the Economics of Science

Mobility and Excellence in Scientific Labour Markets: The Question of Balanced Growth Professor Louise Ackers, University of Leeds *H.L.Ackers@leeds.ac.uk*

The Impact of Enlargement of Scientific Labour Markets Professor Louise Ackers, University of Leeds H.LAckers@leeds.ac.uk

Work Roles and Careers of Academic Scientists in University-Industry Collaboration Prof Alice Lam, Royal Holloway, University of London *alice.lam@rhul.ac.uk*

Making Science History: The Regionalisation of Science Policy Professor Simon Marvin, University of Salford s.marvin@salford.ac.uk

Building Science Regions in the ERA: Governance in the Territorial Agora Ms Beth Perry, University of Salford *b.perry@salford.ac.uk*

Labour Markets and Knowledge Flows in the Chinese National System of Innovation Dr Matias Ramirez, Brunel Business School *matias.ramirez@brunel.ac.uk* Issues Involved in the Diffusion of Knowledge through Migration of Scientific Labour Prof David Wield, Open University d.v.wield@open.ac.uk

The Impact of Gender Innovation on Regional Technology, Economy and Society Professor Pooran Wynarczyk, University of Newcastle *pooran.wynarczyk@ncl.ac.uk*

Science Technology and Globalisation

Institutional Impacts of North-South Partnerships in Agricultural Biotechnology Professor Joanna Chataway, Open University *j.c.chataway@open.ac.uk*

Regulatory Practices and Challenges of the African Crop Biotechnology Sector Professor Joanna Chataway, Open University *j.c.chataway@open.ac.uk*

Science, Technology and Water Scarcity: Investigating the 'Solutions' Dr Lyla Mehta, IDS, University of Sussex *I.mehta@ids.ac.uk*

Childhood Vaccination: Science and Public Engagement in International Perspective Prof James Fairhead, University of Sussex *j.r.fairhead@sussex.ac.uk*

The World Wide Web of Science: Emerging Global Sources of Expertise Dr Ralph Schroeder; University of Oxford *ralph.schroeder@oii.ox.ac.uk*

Databases, Naturalists and the Global Biodiversity Convention Ms Claire Waterton, Lancaster University *c.waterton@lancaster.ac.uk*

Science and Gender, Ethnicity and the Lifecycle

Boundary Work, Normal Ageing and Brain Pathology Prof John Bond, University of Newcastle-upon-Tyne *john.bond@ncl.ac.uk*

Public Perceptions of Gamete Donation in British South Asian Communities Dr Lorraine Culley, De Montfort University *lac@dmu.ac.uk*

Gender Theories and Risk Perception: A Secondary Analysis Prof Nick Pidgeon, Cardiff University pideonn@cardiff.ac.uk

Asbestos Diseases: Scientific Definitions and Gendered Identites Dr Linda Waldman, Institute of Development Studies *l.waldman@ids.ac.uk*

Genomics and Society

Doing Embryo Ethics: Safety and Efficacy in Research and Practice Professor E. Anne Kerr; University of Leeds e.a.kerr@Jeeds.ac.uk

Farmers' Understandings of Genetically Modified Crops within Local Communities Dr Andy Lane, The Open University *a.b.lane@open.ac.uk*

Pharmacogenomics, Diagnostic Tests and Clinician Acceptance Dr Graham Lewis, University of York gl *1 2@york.ac.uk*

Science, Security and Regulation: How Effective are Export Controls? Dr Jeremy Littlewood, University of Southampton j.littlewood@soton.ac.uk

Dual Use Controls and Genomic Research Dr Paul Nightingale, SPRU, University of Sussex p.nightingale@sussex.ac.uk





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