



# People, Technology and Health

Highlights of the  
Innovative Health Technologies Programme



In collaboration with  
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# Innovative Health Technologies Programme

## Preface

*The ESRC/MRC research programme on Innovative Health Technologies, supporting over 140 researchers across the UK, has produced a wealth of findings and results that are difficult to disseminate in a systematic, comprehensive yet still digestible way. Despite this, we invited Jon Turney, well known as a science editor, academic and now Director of a new creative non-fiction writing course, to use his skills to capture some of the major findings that have emerged from across the 31 projects. We are sure that you will share our view that he has done an excellent job.*

*There will be various publications based on the projects that will be appearing over the next few years published by Palgrave Macmillan to form a major new series **Health, Technology and Society**. These will provide a much richer sense of the importance of this research, and readers are directed especially to the book that covers the whole Programme, A. Webster (ed.) **New Technologies in Health Care: Challenge, Change and Innovation** (Palgrave, 2006).*

*Developments and debate in UK health policy make this research especially timely. The establishing in July 2005 of the NHS Institute, the new 'Connecting for Health' ICT programme, the recent White Papers on genetics and on public health, the move towards more context-sensitive evaluation techniques, all raise questions with respect to the implementation of new technologies in health care. We hope the IHT Programme will provide a lasting contribution towards these policy debates and to our understanding of the relationship between 'people, technology and health'.*

*Professor Andrew Webster, Programme Director  
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Luana Pritchard, Programme Secretary*

*October 2005*

## People, Technology and Health

### Highlights of the Innovative Health Technologies Programme

#### Jon Turney

#### 1. Introduction

***“If I were a medical student... I would be apprehensive that my real job, caring for sick people, might soon be taken away, leaving me with the quite different occupation of looking after machines”.***

When the American doctor Lewis Thomas wrote this in 1983, he was recalling a transformation in medical care in his lifetime, first in his father's practice and then his own. It began with a stethoscope, a collection of largely ineffective medicines, an occasional X-ray and, for a few, anaesthetics and surgery. But it mostly consisted of doctors talking to their patients while their diseases took their course.

By the end of his career, we had a panoply of new health technologies, from antibiotics and antidepressants, CAT scans and kidney dialysis, to hip replacements and heart transplants, genetically engineered insulin and in vitro fertilisation. And in the decades since he wrote the pace of development has accelerated. Old technologies are continually refined and more and more new ones are on offer. Medicine has become immeasurably more effective, but also more complex, and harder to understand. New technologies bring benefits, but also pose new challenges for doctors, health workers, patients, and society at large. Understanding those challenges, and how to meet them, is a study in itself. It is one in which the social sciences have a crucial part to play.

With this in mind, the Economic and Social Research Council (ESRC) and the Medical Research Council (MRC) launched the £5 million programme of research on Innovative Health Technologies in the year 2000. As the programme draws to a close, this brochure summarises some key findings from the later phases of the 31 projects the Councils funded, involving over 140 researchers. Among other things, it shows how there are many more, and subtler, questions to ask about new health technologies than Thomas's query about whether doctors care for the sick or become machine minders. But that one is certainly still worth bearing in mind.

#### 2. Technology everywhere?

One of the remarkable things about modern health care is that there is so much innovative technology in use or under development, and the term covers many different things. There is what you might call dedicated health technology, a drug for lowering your blood pressure, say, or a dialysis machine. Then there are more general technologies which find important applications in health care, like computers and information technology.

Along another dimension, some medical technologies are used by medical staff, and either remain unseen - like a lab test - or a patient may encounter them directly once or twice, as with a CAT scanner. There are others with which you might have a long-term, personal relationship, whether it is with a drug, a heart pacemaker, or a wheelchair. And perhaps there are significant differences between technologies which simply give someone diagnostic or other information about an individual, like that lab test, and those actually used in treatment.

Then again, access to some technologies, or the information they yield, depends on doctors, and the rest of us rely on doctors' diagnoses and their interpretations of a panoply of tests. But then there are medical uses of transformative technologies like the internet, which can give lay users medical information and advice which used to be much harder to get hold of, or even let you order a genetic test yourself at the click of a mouse.

So with all these differences, what do the whole array of medical technologies, present and future, have in common? Not, obviously, any one simple thing. Perhaps it is that they raise similar kinds of questions. If they are to be adopted how can they find their place in a complex system of health care, and in a society in which managing health is a continuing political and personal preoccupation? How can we understand the ways in which every medical innovation is also a social innovation? How are they likely to alter key relationships, whether just between health workers and equipment suppliers, between doctors and other specialists, or most importantly doctors and patients?

Moreover, we need to ask how technologies which give us new information about some aspect of a disease alter our ideas about what the disease is. And how do those which give information about our state of health, or about risks we face, change our ideas about what it means to be well? How do both contribute to redefinitions of health and illness, of what can be done about them, and who should do it?

***In short, we wonder not just what medical technologies do for us, but what they are doing to us? And we need to know how we in turn can adapt or reshape them.***

What follows does not offer conclusive or comprehensive answers to all these questions. But it highlights a selection of the much larger body of findings from the IHT Programme which indicate how some of them may be answered. It begins with a look at some studies of new genetic technologies, moves on to the use of other kinds of information, and then considers views of the whole process of innovation, and of policy-making and regulation. Finally, there is a brief comment about what comes next.

### 3. What's in a gene?

New genetic discoveries are constantly in the headlines, and in their wake come many new applications in medicine. These often involve screening or testing for particular conditions or risk factors, and how people respond to the information such tests offer varies from case to case. Sometimes, the information is important because it relates to decisions about a pregnancy, or whether to try and get pregnant. Sometimes, it seems important because people have come to believe that information about variations in the genes carries special weight. Either way, reactions are hard to predict, but are often marked by ambivalence about the technology and its consequences, and by various kinds of uncertainty.

People are often said to find it hard to deal with the uncertainties which mark tests of genetic risk, as well as other kinds of risk, and we will mention some examples later where they and their doctors seem to strive for additional certainty. However, there are clear exceptions to this and, indeed, in some cases emphasising uncertainty elicits a positive response from

patients. Preimplantation genetic diagnosis (PGD), for example, tries to identify embryos which may be affected by particular conditions before they are selected for use after *in vitro* fertilisation. It is a delicate procedure, still in its early days, and couples considering it appreciated being told about the difficulties. The effort to explain what might go wrong and to reduce their expectations of a clear result made them trust their doctors and genetic counsellors more, precisely because it went against expectation. One couple who were given all these cautions responded approvingly that the people running their clinic were "not really like doctors at all".



People discuss decisions like those surrounding PGD intensively, and perhaps one reason these doctors' approach was appreciated was because it was easier to fit into a wider set of conversations. A separate study of

pregnant women who were offered screening for Down's syndrome showed that they were typically given information about the test, but not about the condition, or what it might be like raising a child with Down's. However, most felt fairly well informed from other sources whether friends, the media, or personal experience and had well-developed views on how to decide whether to have the test, and what to do about the result.

In fact, as another IHT project showed, quite a few people already have a view about the acceptability of pre-natal testing for conditions which cannot be tested for yet. An important finding here for organisation of future services was that it is hard to categorise the many conditions for which testing is likely to become available. There was reasonable agreement among the subjects of this study (all women) about both testing and termination for catastrophic conditions like being born without a brain or with total paralysis though that did not mean that all would seek a termination after a positive test.



But attitudes to testing for a wide range of other conditions, which might be seen as less serious, varied a good deal – in fact there was little agreement about what *counted* as less serious. Perceptions of the quality of life of children with particular conditions, experience of family and friends, religious convictions and media images all played a part in engendering a wide range of views.

Other genetic tests, of course, give results which relate not to reproductive decision-making but to future health prospects for adults. They, too, generate uncertainties which can produce unexpected responses. For example, consider people who are found to carry a genetic susceptibility to haemochromatosis - a condition in which people retain harmful quantities of iron in their bodies but show no symptoms of disease. They have discovered they may at some point suffer from a condition which is treatable, though no-one can really tell them how likely this is. This is in line with often-repeated predictions that genetic tests will create a large new population of the "worried well". But the uncertainty seemed not to trouble most of the people in this study, who simply concluded that this might be something which needed keeping an eye on, but were otherwise largely unmoved by the new information about their genetic status.

But findings among people trying to make sense of a cancer risk assessment were more complex. In this group, some people were classified as high risk on the basis of family history. They were then given a genetic test, and if that in turn was positive, they would be offered further screening and counselling. Some found this more reassuring than alarming. They might be at higher risk than normal of getting, say, breast cancer, but they had already suspected this. But now they were going to be looked after. They had been granted a legitimate claim on more health resources. As one said about their test result:

*"Yeah I am glad. I know that I can say 'Hey, I want some screening now.' And they have to do it too".*

By contrast, some who were labelled as 'low risk' were uneasy about it, and felt excluded or abandoned. They knew there had been cancer deaths in their families, and felt they needed continuing surveillance which the system was not prepared to grant. In such cases the response to the risk judgment was a complex blend of beliefs about health and attitudes to their position in the health care system. These patients, against expectation, wanted a higher risk judgment so that they were included in future monitoring. This has implications for how health policy deals with genetics. It will generate complex responses to risk, which will vary with the condition and the test, and in ways which are hard to predict. The same may also be true of responses to other kinds of information, not just that from genetics tests, and it may well be relevant to reactions to use of innovative health technologies in general.



#### 4. Knowledge and power

Genetic-based risk estimates are only one new kind of information which now has to be dealt with in encounters with medicine. In Lewis Thomas's early days, the main thing a patient learned from their doctor was a name for their disease. Today, there is vastly more information available to the medical professions, in many different forms, and there are new ways of making this available to everyone else. New imaging techniques, new kinds of monitoring, new databases and libraries of reviews, and patients who use phone services, websites or internet chat rooms, all form part of an increasingly complex overlay on more familiar ways of sharing health information or finding out about disease through talking to people or reading the newspapers. Policy-makers hope that better co-ordination of health information through IT systems will increase efficiency and improve patient care, while also suggesting that giving patients better access to information will help them understand their choices and even manage their own care.

Many questions arise as these new networks develop. They do more than simply allow information to be delivered more easily by those who have it to those who do not from medical authorities, say, to patients. They allow new inputs into the system, new sources of information and opinion, and the spread of new definitions of health, illness, and appropriate treatment. And they raise complex issues of co-operation, collaboration, authority and trust.

In some cases, the new ways of communicating allow patient groups to share knowledge in ways which complement

conventional medical management. So, an 11-year-old girl with diabetes reckoned that:

***"I can control my diabetes more now than when I was younger cos I didn't understand much when I was younger. But now I'm older I'm getting to learn more and more about it, cos mam's found all these websites and everything on the computer about diabetes. And you can ask people questions how they cope with it and everything and they just reply back and everything".***

This fits a fairly straightforward model of patients being empowered to help one another. But contrast this with a study of websites and chatrooms for anorexics. Some of these sites adopt a "pro ana" stance, which directly challenges the medical view that the condition needs to be overcome. They are written by people who are extremely knowledgeable about anorexia and recognise that it is a disease. But they also recognise that some people are strongly wedded to a life built around rituals associated with food and food avoidance. As one contributor to web chat put it:

*"Maybe one day I will be "ready" for recovery but I certainly am not yet - and I am sick and I like to know there are people out there who feel the same way as me".*

So while the motivation is in some respects similar to that of the girl with diabetes, the context and the outcome are very different.

As this suggests, this new realm of health information and communication is a complex and rapidly evolving landscape, and this may be one reason why the effects are sometimes less dramatic than policy-makers may be aiming for. For example, internet and telephone-based health advice can reach people who find it hard to get to the doctor, so young parents tend to use it to help work through the anxieties of childcare. One mother described how the computer was "here at home and you just click and away you go" instead of "making an appointment and traipsing into the doctors". But it still takes its place alongside all the things they might have done before, like using books and magazines or asking friends and relatives.

So the internet or NHS Direct might reduce visits to the doctor's surgery for this group. But for others new sources of information would also be used to inform a visit to the doctor, which would not be changed all that much but might still produce a more satisfactory outcome in terms of understanding. As one woman put it:

*"I discussed what I'd read [on the Internet] with my sister, and it helped me when I talked to the doctor to understand a bit more what the doctor was saying. It gave me a much better understanding of the prognosis and the likely outcome having read it. More so than I got from the medical staff. I mean eventually they did say 'its not looking good', but I'd already realised that."*

Individual strategies for using the new media vary widely. But overall it seems that internet sources and services like NHS Direct are not yet leading to self-management of health care by clients or patients, in the sense of dispensing with advice from their doctor. Rather, they tend to be one more way of getting information which informs their transaction with the doctor.

It may help people feel justified in seeking a consultation, by reassuring them that they are “not wasting the doctor's time”. Or it helps them make sense of what was said afterwards. But if there is an overall effect it seems that users are better informed, but still want to trust their doctors and the National Health Service - as the best source of advice, and most reliable validators of diagnosis and treatment. This was partly a response to the sheer diversity of new sources, and the awareness that they might not be reliable. More broadly, the web or phone advice appear to enhance, but do not replace, the traditional medical consultation. And although the patient may come through the door armed with more information, this does not necessarily lead to challenging the doctor's verdict.



The complexity of the new information landscape, both in terms of the range of sources and the kinds of information on offer, means that the effects for patients or clients are not simple, and the benefits are not always easy to discern. Increasingly often, people will get different kinds of medical information from different sources. A case where this is already found is a woman's decision whether or not to use hormone replacement therapy (HRT) after the menopause. For some, the strongest influence is a test of bone density – using dual energy X-ray absorptiometry (DEXA) – which may give an indication of the chances of developing osteoporosis. The test simply gives an indication whether bone mass is within the normal range, and needs to be interpreted in terms of future risks, rather like some of the genetic tests already discussed. However, in the group studied, women commonly heard a doctor's interpretation of their personal scan as giving a firm prognosis. The bone density graph seemed like a window into the body, and was treated as a diagnosis. One subject who was informed by her doctor that her scan was normal nonetheless concluded that she had osteoporosis from all that she heard about the reasons for doing the test. Not surprisingly, the researchers found that the test result loomed large when deciding to use HRT.



Health information from the internet, by contrast, had a weaker impact on women's thinking about whether to use HRT. Some avoided looking up the subject because they did not want to complicate their relationship with their doctor. Some looked but found conflicting sources, or no sources relevant to their particular symptoms or hormone formulation. Yet others used it as one information source among many which they drew on when discussing the best course of action with their doctor. But there was no general effect like making the whole issue less uncertain or more straightforward.

Finally, one general question which also tended to make people turn back to their doctors for advice was the quality of information from the wide range of sources that the internet grants access to, and the possibility of bias. This can be present even when people are discussing in apparently open fora. In a study of health discussion groups, part of a larger project on collaborative knowledge systems in health care, the researchers found that on one website a significant fraction of the traffic came from two contributors who were plugging a particular manufacturer's brand of weight reduction products.

## 5. Innovation: Context and Meaning

Social science can illuminate many aspects of the development and use of new medical technologies. It is not just that health systems are complex, and the application of new technology has social aspects which need to be understood. The conception, design, testing, refinement and deployment of new technologies – the whole process of innovation – are also brought about through social processes.

Moreover, the social involvement may be broader in many new medical technologies and procedures than it is with other technologies. Sometimes, innovations are generated inside a single, research intensive organisation, typically a company. But medical innovations seem more often to emerge from more widely distributed efforts, involving collaborations between many different disciplines and people working in different settings.

For example, the lengthy histories of what have now become extremely widely used artificial replacements for hip joints and for cataract clouded lenses in the eye both demonstrate this. Shifting combinations of surgeons, designers, materials experts and, eventually, companies and regulators, explored what worked in patients and what did not in areas where results were a better guide than theory. Both these IHT projects help show how technology needs to be studied not simply as a realised set of possibilities, which have “effects”, but as the choices which fix the forms of particular innovations as they emerge.

A good way to appreciate this is to look at a technology whose clinical use is not quite established, like the new generation of brain scans. These now show not just the structure of parts of the brain, but give a picture of activity in terms of increased blood flow to particular regions in the brain. But what do the images actually mean, and what use might they be to doctors? This is not yet clear, but they are already powerful exhibits for patients. They may perceive a PET scan as a picture of their disease, an image of depression or schizophrenia, say. Some even take them home and have them framed. We do not yet know what role these kinds of images will play in altering medical management of mental illness, as this is still being worked out between technologists, neurologists, and psychiatrists. But they may already be changing how some patients see their condition literally as well as figuratively.

Another way of opening up innovation processes to inspection is to study what happens when the assumptions built into a particular technology change. Take something as mundane (to the able-bodied) as a wheelchair. Up to the 1940s, they were mostly made of wood, and weighed as much as 100 lbs. And they almost all had castors at the rear with the wheels the user pushed at the front. This made them handy for doorways inside a building, but unmanageable outdoors. The path from there to ultra-light, metal-framed, folding chairs that weigh less than 10 lbs, or chairs with their own power, which can use new ramps on buildings or get on and off buses and trains when these are properly equipped was marked by lengthy campaigns from users determined to redefine their relationship with the device.

The wheelchair was to become a technology of independence, not dependence, but it needed a complex combination of activism, design modification and legislation to achieve this, even imperfectly. In the



process, new definitions of technology and need became built into design assumptions, so that disability access is now often seen simply as wheelchair access.

Another set of projects comment on innovative technologies which are designed to affect the fine grain of the social organisation of health care, but often encounter unexpected difficulties because that organisation leads people to respond in ways which were not well understood at the planning stage.

For example, computerised decision support systems to help manage the response to foetal distress in labour were conceived as a way of reducing the risks of the delivery room. They were based on the notion that such decisions are made by individuals, who were imagined to be weighing all the evidence and making a rational judgment. However, real-life decision-making during labour depends on complex interactions between midwives who are normally present throughout delivery and doctors who appear intermittently, and is hard to track back onto individuals. Introducing a continual monitoring system alters assessments of risk and well-being in unpredictable ways, and changes relationships between health workers. It may achieve better outcomes for some babies, but there are complex costs to take into account as well.

A further area where new IT-based systems have been implemented in ways which have had mixed results is “telemedicine”, the use of remote viewing of images and health information to allow remote diagnosis and management of patients. A detailed case study of use of telemedicine in dermatology indicated that making it work required a recognition that the innovation was not so much technical as organisational. And although once touted as transformative, use of electronic systems to view photos of skin problems and details of a clinical history tended to take their place alongside “conventional” consultations.

As with many other applications of new computerised information systems, they have the potential to radically alter relationships between people negotiating or managing health care, but the way they fit into the systems which already exist can mean that big changes do not immediately follow.

## 6. Policy, Regulation and Evaluation

If innovation takes place in a social system, important roles in that system are played by policy-makers and regulators. In health, they are concerned with an enormous range of outcomes, which they try and steer in the direction of improving health while containing costs. And there are an overlapping set of concerns about risks and how they can be understood and dealt with. New technologies constantly challenge the regulatory system. They can improve efficiency, but may also increase costs because they enable doctors to do new things for patients. They may not fit into existing regulatory regimes, and have to be dealt with as those regimes struggle to adapt. And they pose new questions for evaluators, who must recognise that what counts as a good outcome is not a technical question. In all these ways, innovative health technologies help shape policy and regulatory worlds, at the same time as those worlds attempt to influence the development and deployment of the technologies.

In the life sciences, the technologies which derive from new research can pose particular challenges for regulators because they create new kinds of things which don't fit established categories. The emerging uses of transgenic organisms, xenotransplantation and tissue engineering are a case in point.

For example, a few years ago the US Food and Drug Administration had to change its definition of xenotransplantation normally focused on transferring organs or parts of organs. But then how to treat a method for culturing human skin for burn treatment already in use which grew human cells on a base layer of cultured mouse cells?

The same problem troubled officials in other countries. As an interviewee from the UK Department of Health put it:

***“the mice who provided the cells were long dead. Years and years ago, so it's an established cell line that's being used, really without people thinking about it as being particularly mousy”.***

The point is that it is hard to make distinctions which stick when the technology changes so fast, and therapeutic products may involve new mixtures of artificial, human and other material. Even well-established regulatory machinery like that for pharmaceuticals is constantly being modified to meet shifting pressures from the need to harmonise controls in different countries, to contain costs, to ensure drugs are available to the needy, or to take account of changing information and attitudes about particular risks. Those operating regulation for more novel biotechnology have an even more complex job. Yet this kind of regulation is perhaps the leading mechanism for social oversight of the deployment and use of innovative health technologies.

More broadly, as the pace of technological change has quickened over the past decades, so the climate for introducing innovative health technologies has changed. Once, patients were recruited to try new things by enthusiastic pioneers. Now ethical, legal, economic and bureaucratic restraints mean that people cannot just be “guinea-pigged” by well-meaning doctors.

At the same time, evaluation, and the use of performance indicators, have become an essential part of the management of health care, whether the concern is quality, cost or risk. For new treatments and techniques, the staged, randomised clinical trial became the main requirement for adoption. The obvious bottom line is preventing death, but that quickly raises subtle questions about the life which is saved. Some can be answered on biomedical criteria, like lowering blood pressure. Others relate to more subjective aspects of the life as it is lived.

Trying to answer those questions has led to measures of “quality of life”. These, too, are in part a means of giving patients' perceptions of outcomes more weight than hitherto. To be usable in decision-making, though, they need to be formulated in ways which produce agreed measures of the results, which distance them again from the way people would describe their own experience. As the general shift toward “evidence based medicine” has come to shape the introduction of new treatments and procedures, quality of life measures have become standardised, but in ways that are always contestable, despite their being a routine component within the evaluation of innovative. At the same time, they themselves can be seen as a new technology, but one on which successful introduction of the others depends.

## 7. General policy implications

Together, the various IHT studies suggest a number of implications for policy in different areas. The ones which have been highlighted here relate to genetics, the use of new sources of health information, and of more sophisticated information systems, and to regulation.

In genetics, the research results indicate both that some people who are healthy may become anxious about their health after testing, while others may be reassured that someone is keeping an eye on them, even though they are at high risk of disease. Overall, it is clear that there is no simple response to genetic risks, but the effects can be explained if we understand the social context more clearly.

The new sources of health information and advice like the internet or NHS Direct have important effects, but perhaps not as important as some forecasts envisaged. They do not necessarily replace visits to the doctor, but seem more often to be used as supplementary sources, either to prepare for a consultation or to help someone understand what the doctor said.

Other sophisticated applications of computer and information systems can also be powerful influences on behaviour, but again not always in the way which was expected. They can alter relations between professionals in complex social systems, but those same systems may react in unpredictable ways.

Finally, in all these areas, and others, regulation and regulatory structures find it difficult to keep up with novel and rapidly changing technologies, particularly with biomedical technologies which challenge established categories and definitions.

## 8. What next?

This is only a small selection of findings from the 31 separate projects (see appendix on back page). The various project reports, papers and books describe them in much more detail, and discuss the theoretical and practical issues they raise at greater length too. But these are far from the only outputs from the IHT Programme. Social science researchers have forged new relationships with clinicians and health administrators. Individual projects have been taken up by a wide range of groups interested in particular conditions, treatments, or problems, from African Aids support groups to designers of websites.



There have also been informal and formal contributions to a wide range of health policy deliberations, advisory committees and inquiries. They include various Department of Health

committees and expert panels, the NHS Confederation, a number of Select Committee Inquiries, notably the House of Commons Health Committee inquiry into Introduction of New Medical Technologies into the NHS. Internationally, the Health Technology Assessment International meeting in 2005 hosted a workshop devoted to the IHT Programme, and there is strong interest in the Programme in Australia and Canada.

Although the Programme is now formally complete, it is feeding into future research plans for work on health service delivery, informatics and, in particular, the ESRC's new Stem Cell Initiative. One current trend where the Programme's results raise a series of concerns is the push towards more use of near-patient technologies, and of monitoring systems which permit patients to manage aspects of chronic illness. This tends to go along with shifting care into the home or the community. Unintended effects of these changes include new responsibilities being placed on carers. And there are further concerns about whether the technologies can be adapted by patients, and how medical oversight can be maintained from a distance.

Innovative health technologies are invariably the product of a great deal of ingenuity and effort, aimed at saving life or improving it. What the projects in the IHT Programme show vividly is how complex it is to make use of them, understand their effects, and think through how the people who may benefit can become involved in the innovation process, and so help shape the technology. In fact these all require just as much ingenuity and effort as the technical challenges of health care. And that effort will continue.

## Appendix (List of Projects)

### Regulation of Innovative Pharmaceuticals in the EU and US: a Comparative Analysis

Project Leader: Professor John Abraham

### Reforming the Governance of Human Genetics: The Politics of Public Trust

Project Leader: Professor Brian Salter

### A Historical Sociology of the Wheelchair

Project Leader: Dr Brian Woods

### Quality of Life as an Innovative Health Technology

Project Leader: Dr David Armstrong

### Genetic Screening for Susceptibility to Disease: The Case of Haemochromatosis

Project Leader: Professor Paul Atkinson

### The Challenge of Recent Advances in Brain Scanning (Neuro-Imaging) to Ideas of Mental and Physical Illness

Project Leader: Dr Simon Cohn

### Transitions in HIV Management: The Role of Innovative Health Technologies

Project Leader: Dr Paul Flowers

### Social and Ethnic Differences in Attitudes and Consent to Prenatal Testing

Project Leader: Professor Jenny Hewison

### NHS Direct: Patient Empowerment or Dependency?

Project Leader: Professor Gerard Hanlon

### Technology and Time: Home Care Regimes and Technology-Dependent Children

Project Leader: Janet Heaton

### Definitions of Genetic Knowledge and Pre-Implantation Genetic Diagnosis: an Ethnographic Study

Project Leader: Professor Sarah Franklin

### IHT's at Women's Midlife: Theory and Diversity Among Women and "Experts"

Project Leader: Dr Frances Griffiths

### Presenting and Interpreting Health Risks and Benefits: the Role of the Internet

Project Leader: Dr Flis Henwood

### Social Implications of One Stop First Trimester Prenatal Screening

Project Leader: Professor Gillian Lewando-Hundt

### The Technological Management of Childbirth: Risk, Empowerment and Professional Accountability

Project Leader: Professor David Mason

### Xenotransplantation: Risk Identities and The Human/Non Human Interface

Project Leaders: Professor Mike Michael

### Innovation, Assessment and the Hip Prosthesis

Project Leader: Professor John Pickstone

### The Construction of Risk Estimates in a Cancer Genetics Clinic

Project Leader: Professor Lindsay Prior

### Technology and Natural Death: a Study of Older People

Project Leader: Professor Jane Seymour

### Inclusive Internet Technologies for People With Communication Impairment

Project Leader: Dr Susie Parr

### The Mediation of CAM In and By Cancer User Groups, Charities and Informal Networks in the UK & Pakistan

Project Leader: Dr Philip Tovey

### Innovations in Cancer Pain Relief: Technologies, Ethics and Practices

Project Leader: Professor David Clark

### Distributed Innovation Processes and the Uneven Growth of Medical Knowledge

Project Leader: Professor Stanley Metcalfe

### Consumerism, Information and Drug Prescribing Governance

Project Leader: Dr Nicholas Fox

### Medical Device Governance: Regulation of Tissue Engineering in the UK and EU

Project Leader: Dr Alex Faulkner

### Transformations in Genetic Subjecthood

Project Leader: Dr Anne Kerr

### Children, Parents and the Management of Chronic Illness in the Information Age

Project Leader: Dr Sarah Nettleton

### The Role and Effectiveness of Collaborative Knowledge Systems in Health Promotion and Health Support

Project Leader: Dr Joseph Cullen

### Telemedicine and the "Future Patient"? Risk, Governance and Innovation

Project Leader: Professor Carl May

### Neuroscience Promises: Current and Future Application of Brain Imaging Technology

Project Leader: Dr Simon Cohn

### The Impact of Genomics on Innovation in the Pharmaceutical Industry

Project Leader: Dr Paul Martin

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Complete 'Findings' from each of the projects can be found on the IHT web site

[www.york.ac.uk/res/iht](http://www.york.ac.uk/res/iht)

For all other outputs from the Programme and similar research visit the ESRC web site

[www.esrcsocietytoday.ac.uk](http://www.esrcsocietytoday.ac.uk)