

Commentary¹ on the DoH White Paper:

Our Inheritance, Our Future: Realising the potential of genetics in the NHS, 2003

1. The recently published White Paper, *Our Inheritance, Our Future: Realising the potential of genetics in the NHS* deals with a vital issue, the ways in which genetic research and its results might be incorporated in the NHS. While there are some very clear proposals being made, it is also the case that the Paper invites suggestions from Trusts and others with regard to the way in which these are to be implemented in detail. A cautious approach is appropriate, since much of the science base relating to genetics is still to be developed, and it is well known that the current use of genetics (as screening, diagnostics or testing) is often highly provisional, uncertain and open to diverse interpretations among genetic scientists, clinicians and patients and their families. This is especially so as researchers recognise the multigenic nature of disease and pathologies. In addition, the economic calculation of the cost effectiveness of new (or simply incremental) genetic technologies is in its infancy since the multidimensional methodologies that need to be deployed are themselves underdeveloped in this area.

2. The IHT Programme (www.york.ac.uk/res/iht) supports various projects that are exploring genetics within the health care system (in the UK and overseas), including diagnostics, screening, and testing at the level of the clinic as well as related innovation in fields such as pharmacogenomics, biotechnology and xenotransplantation. This commentary is based on discussion of the White Paper across the IHT Programme as a whole and special contributions made by colleagues working on genetics-based projects. In addition, the ESRC also supports a number of Genomics social science research centres, and one of these CESaGen has provided some additional observations that are incorporated in this paper.

2.1 In the following discussion, we offer a number of observations about the Paper and its framing of genetics, its proposals and go on to make some, we hope valuable, suggestions for policy within the Department of Health. We do not comment on the Paper in its entirety, a document that covers a very broad range of issues that it recognises as both complex and in need of careful handling. We recognise that the Department still regards genetics science in need of further development before any implementation strategy relating to fields such as gene therapy and pharmacogenetics can be put in place. We hope that the following will make a contribution towards developing such a strategy in the medium term.

3. There are at least three areas deserving comment. These relate to:

- the general context within which genetics is developed
- specific issues relating to the main science-based areas covered in the Paper, viz. diagnostics/testing, gene therapy and pharmacogenetics

¹ This paper is based on commentary and feedback provided by a number of participants in the Innovative Health Technologies Programme: the views and statements expressed do not necessarily reflect those of the ESRC or MRC

- public engagement with genetics.

4. First, in regard to the general context, as various IHT projects demonstrate, the ‘realisation’ of the potential of genetics is not straightforward. There is no simple strategy that would deliver *the* genetics ‘promise’, and indeed we can say at present that there is no single clinical, business or regulatory model in place to help define and deliver the potential the field might have. The Paper itself is, of course, part of a broad and complex policy process through which the various potential roles of genetics are mobilised such that they might be made workable in the NHS. But as one moves from country to country – say from the US, through Germany to the UK - what ‘the potential’ means is defined quite differently, more ambitiously in some, more conservatively in others. To the extent that this is the case, there is no single ‘future’ but multiple ones, and therefore no single benchmark that would allow us to determine how the UK might be ‘left trailing’ (p 23) behind other health systems. Such systems are based on quite distinct innovation networks that combine scientific, organisational and broader cultural drivers in different ways, such that the deployment and interpretation of a genetic test is highly varied, affecting its perceived utility for the clinic and patient.

The approach the White Paper takes is, at least indirectly, cognizant of the need to build gradually ‘from below’ – through its support for new initiatives in integrating clinical care services (3.16) and PCTs (3.25).

4.1 To this extent, the virtue of the document’s origin as a Green Paper is that it has avoided too strong a steer from the centre, and allows diverse groups to define what will be a complex, heterogeneous and exceedingly demanding role for genetics in the health service. It will be important along the way to try to determine the opportunity costs as well as benefits of investing in genetics, an issue that will be of keen interest to PCT managers. This more cautious tone in the Paper is an important ‘voice’ to sustain over the period ahead, especially given the (current) scepticism about the therapeutic value of some genetic predictions. Moreover, investment in different areas is likely to have uneven returns for public/personal health: for example, the Paper discusses possible developments in understanding the relationship between genes and diet and the implications for the future role of nutritionists in health service delivery, but the relative merits of nutrigenomics as compared with pharmacogenomics are still unclear.

4.2 The move towards developing an evidence-based but also efficient system across the NHS is very strong across all clinical services, not just genetics. Managing the demand for genetics services in an efficient and effective way will be a complex matter, since it will have to cope with the tendency towards an over-investment in genetic ‘solutions’ to conditions, patients and doctors’ anxieties over managing highly provisional genetic diagnostics and, possibly in the longer term, insurance companies’ position once their moratorium on testing is at an end.

4.3 The White Paper’s approach here is to draw on existing models of clinical information management, linked to the recent restructuring of the Pathology (public health lab) service, with a strong emphasis on integration and centralised services in labs around the country. Indeed, the Paper invites bids to develop services informed by the Pathology approach that seek to integrate genetics with pathology, which should help to add value to both forms of information. The proposal to include genetics in the Integrated Care Records Service as part of the NHS Information Strategy should help in

the long term at the point of clinical delivery. Again, however, it will be important that the way genetics records are configured allows their meaning to be open to reconsideration as the science-base gains a better understanding of gene-gene, gene-environment, and genotype/phenotype relationships.

5. There are a number of specific areas relating to clinical research and delivery that are worth commenting on, drawing on research conducted within the IHT Programme.

5.1 *Screening, Diagnostics and Tests*

5.1.1 The Paper discusses various ways in which more extensive genetic screening might be introduced within the NHS. However, while there is some consideration of screening in the antenatal setting, there are issues that the IHT-based research can help address in more detail, such as consent to genetic testing. For example, Down's syndrome (DS) meets the stated criteria of a 'high impact' genetic test. Therefore written consent should be given, following the giving of 'appropriate' information. Although the Paper acknowledges that the question of what constitutes appropriate information is particularly complex in genetics, its focus here is more on issues such as a person's employment prospects being affected, issues that relate much more to genetic tests offered *outside* the antenatal setting. In the antenatal setting with Down's syndrome there is a need to recognise the variability of the condition, and the difficulty that practitioners have in conveying this aspect of it when trying to give appropriate information. This relates more generally to data the Programme has via a number of projects on the continuing difficulty that staff have in conveying risk information in a meaningful way.

5.1.2 On a more organisational question the commissioning of DS screening needs to be addressed, to dovetail with planning being undertaken by the National Screening Committee: is it, for example, going to happen at PCT level or SHA level? The Paper also seems to move towards DS screening as a requirement for all women: "All pregnant women are offered antenatal screening and then counselled by midwives to help them make an informed choice". This implies that all women will be expected to have the test and counselling only follows the result. This changes DS screening from an 'opt in' process to an 'opt out' one, and may raise new ethical as well as managerial difficulties.

5.1.3 The Paper discusses the part that midwives are playing in antenatal screening and information giving. Although it notes the extra genetic counselling posts that have been funded (p.25), it makes no mention of how midwives are supposed to manage this extra work, although later it reiterates that 'by 2004/5, all pregnant women are offered antenatal screening for Down's syndrome and then counselled by midwives to help them to make an informed choice' (p 46). There are two issues here at least - the first is that to help women make an informed choice more time needs to be allocated within an already very stretched system.

5.1.3.1 The way that maternity care is organised is currently designed to process a large number of women as efficiently as possible through a 'default' pathway. This results in many decisions being routinised and thus non-problematised. It also raises the question of the meaning of 'informed compliance' in different contexts, from home birth to screening, to choice of care provider and subsequent interventions. Thus the problem is not just about training or indeed on-going training of midwives and doctors, but around

the social and organisational context within which maternity care is provided. Even if training were provided, it would not tackle the above problem. Currently, the way care is organised, there is inadequate time within a booking session to discuss such issues, with many Trusts allocating 30 minutes for a first visit in pregnancy.

The NSF maternity group has recognised this problem and is advising that early antenatal care needs to be reorganised in order to give more time to discuss these issues. However, the path from recommendation to policy guidance and implementation is a long one.

5.1.3.2 The second issue is that recent work in the IHT programme and beyond shows how many midwives struggle to provide an informed choice for women.

The training of the midwifery workforce is, therefore, a key area for policy, and the time that providing additional information will take, in the light of the current shortage of midwives and poor track record of providing informed choice in maternity care. In many places what occurs is 'informed compliance' around a range of issues. There are a number of fellowships for GPs and genetic nurses announced in the Paper, but none for midwives, yet it is these who are being appointed as screening co-ordinators in most Trusts.

5.1.4. In short, the proposed investments in specialist genetic services are very welcome, but the new genetic developments will have huge implications for the wider primary care workforce and these professionals will be dealing with the more difficult issues of screening uncertainties and explaining probabilities and risk. The Paper quite rightly announces support for various training initiatives (3.25 and 3.27) to foster specialist skills in genetics at the primary care level, but in the medium term this should be extended for midwives especially through the planned NHS Genetics Education and Development Centre. We suggest then that ***consideration be given to invest in the broader training of antenatal nursing staff, especially midwives, and at the same time delimit where responsibilities for counselling lie.***

5.1.5 Screening for babies at birth raises important policy issues: how will this information be stored, used, and who will have access? This is very easy to do logistically, as it can be incorporated into the existing neonatal newborn screening blood spot test at 7 days but will need very careful regulation of what would become a mass DNA database. The Paper is aware of this issue (para 3.38) and calls for the HGC to consider the implications of genetic profiling at birth. This is a very sensible strategy to adopt and we would hope to be able ***to contribute to the HGC work drawing on information from the screening-related projects funded by the Programme, especially in regard to the wider social implications of profiling at birth.***

5.1.6 Work elsewhere in the Programme beyond the antenatal setting has explored screening for wider genetic conditions, such as the blood disorder haemochromatosis. Even when the fact of such a genetic disease running in the family is openly shared across and between generations people do not always take pre-emptive measures to manage it. This is not to suggest that they suffer from some kind of fatalism (as the White Paper speculates some may do [3.35]) or feel some kind of powerlessness in the face of an 'inevitable bad genetic outcome' but rather the clear absence of any symptoms, signs and general sense of well being on a day to day basis informs their actions. Individuals undergoing active screening and surveillance, IHT research further suggests, tend to remain nonchalant about their genetic make up. This work is especially important as it

examines a form of disorder that is likely to be typical of that to be dealt with by the NHS – that is, a disorder to which many are susceptible as carriers but who do not necessarily express the disease itself. The data emerging from this type of study are important for the NHS especially in regard to debates over the merits of screening ‘given that risk or susceptibility information to healthy individuals can become a potential source of anxiety and distress’.

5.1.6.1 While it is possible to screen individuals with the view to predicting their personal susceptibility to developing genetic conditions, such risk prognostications are often tentative. Testing positive for the mutation only identifies an otherwise healthy individual as susceptible. There is as yet no clinical basis to predicting with any certainty just when and how a healthy susceptible individual develops frank disease or overt iron overload as in the case of haemochromatosis. Research in the Programme has identified three forms or levels of uncertainty: uncertainty over the category of the ‘disease’ itself; how doctors and others draw a distinction between healthy carriers and those expressing the disorder and the gradations between these two; and the personal sense of uncertainty about the future generated by the disorder. Crucially, these three do not add up to produce a *unified* risk measure or risk algorithm that can be used by clinicians or genetic counsellors. In light of this, ***consideration might be given to drawing on this research to develop more nuanced risk measurement instruments or guidelines to advise service users attending for counselling.***

5.1.7 Apart from these three general recommendations there are some more specific practical suggestions that have been made by members of the IHT Programme who have a particularly strong focus on screening as part of their research. The various suggestions made below derive from work that has focused on Down's Syndrome, but we suggest that they are of general utility across a range of other conditions where screening might be deployed.

5.1.7.1 With regard to first trimester prenatal screening for Down's syndrome it seems relatively simple to install a benchtop analyser in an antenatal clinic, and a computer link between the analyser and the ultrasound machine. It is also relatively simple to install a computer with the software to calculate probabilities. However, the IHT work points to the importance of understanding the experience of women undergoing screening and the danger of decontextualising this from the complex health system in which they sit, as is often the case with technological devices. There are many specific issues being explored here via IHT projects, but one example illustrates our concerns. At present there is no standard training for professionals who do scans: midwives, obstetricians, sonographers all scan with varying degrees of training and expertise and there is inadequate information about who is doing NT scanning at the moment. The way this is organised is different in each NHS trust and again no-one knows what happens in private practice, which is an important player here.

5.2 *Diagnostics*

5.2.1 Diagnoses in genetics are highly complex, such that where, how and what diagnoses are made can have an affect on the actual diagnoses made. Typically, such diagnoses happen in the face-to-face immediacy of a clinical setting, but there are other routes through which information of a more general nature might be given to patients. One of these identified in the Paper is NHS Direct, which, as is noted, already provides information via its Online service regarding genetic conditions.

5.2.2 NHS Direct has been subject to review and analysis with the IHT Programme, and while the specific question of the provision of advice in regard to genetic conditions has not been explored, there are some generic findings that should be taken into consideration if phone-mediated advice is to become more commonplace. One of the most important findings is that the nurse handler/inquirer engage in a transaction process where mutual sense-making of the symptoms/diagnoses has to take place. This can often be difficult and require a number of separate calls or recourse by other clinical advisors (such as GPs). More importantly, data suggest that there are various areas of misunderstanding that may well prevail in regard to genetic counselling too. The three that have been especially apparent are:

- Callers' expectations being at odds with what is formally on offer and/or the expectations of particular nurses. Thus, for example, callers may expect a diagnosis, whereas nurses restrict themselves to triage
- Problems may arise regarding the character, location or effects of service users' symptoms, such that nurses and users may experience difficulties achieving mutual understanding
- When nurses offer/relay advice or information the question arises as to whether users understand the advice/information and its implications

We might also ask whether NHS Direct will be able to prepare sufficiently sensitive algorithms and standardised advice in giving the sort of information one needs to determine genetic risk? One suggestion is to *explore what are perceived to be effective counselling strategies within face-to-face clinical settings using social science techniques such as Conversation Analysis to help build more sensitive yet effective communication patterns in phone-mediated genetics advice.*

5.2.3 Within the clinical setting itself, work on pre-implantation genetic diagnostics (PGD) in the IHT programme shows how users rather surprisingly *valued* uncertainty in the context of treatment, and expressed a preference for managing their own uncertainties, rather than having them managed by others. If there is a 'gap' between a 'strictly clinical' account of genetic diagnosis and the users' 'more intimate and emotive relationship to such information' the more likely will the results of clinical tests be regarded as meaningless by patients. In light of this, in some settings we would recommend that *encounters between clinicians and service users are not framed by an attempt to reduce or manage uncertainty*, often the approach adopted by an expert-led biomedical model.

5.3 Tests

Susceptibility or predispositional tests are increasingly common across the NHS. In this regard, in a study of breast cancer genetics clinics, IHT research shows that while decision support technologies can assist clinical decision making, these will be interpreted and modified such that levels of risk (high, moderate, low) are locally determined according to experience, circumstance and case. In other words, as genetic testing is rolled out through the NHS, careful consideration will need to be given to the balance between national instruments and measures, the quality of life assumptions that inform them, and their local interpretation. This will be an important issue for Trusts who have

been invited to take the lead here: we would very strongly *recommend that in sharing good practice across the network of genetics services the relationship between tests, risk calculation and local circumstances (such as ethnic profile of the local population, household and family patterns, availability of support services) needs to be considered.*

One of the key issues informing practice will be the ways in which clinicians, counsellors and patients respond to the new *pace* that genetics will encourage in clinical-patient decision-making. The White Paper understandably seeks to encourage speedy and early tests. However, as IHT research on the introduction of first trimester genetic screening and testing for Downs reports, the new tests may create difficulties for clients in regard to the provision of adequate information giving and informed choice. A first trimester, one stop screening process does not inevitably need to hasten the speed at which decisions must be taken, but the way that it is implemented may do this because of the underlying assumption that earlier and faster is better for women; as a result information and choice are compressed not only in time but also in *meaning*. Analysis of genetic testing by social scientists outside of the IHT programme indicates that the meaning of tests and the management of the conditions to which they relate should take into account the ways in which patients often deploy wider culturally anchored strategies commonly used to manage illness. This finding has important implications for both the organisation and delivery of antenatal tests and care: we would suggest that *more consideration is given to developing a balance between the clinically-defined timeliness for interventions and the user's personal timelines for managing, making sense of and making a decision about an extremely difficult set of circumstances.*

6. Gene therapy

6.1 The White Paper makes various proposals in relation to fostering gene therapy research and implementation in the UK. The paper seems particularly optimistic about the prospects for this technology in the medium term, despite there being a track record of major safety problems with the technology in clinical trials in, for example, both the US and France. Moreover, data indicate that there has been large-scale disinvestment in the field by both the biotechnology and pharmaceutical industry. Research by members of the IHT programme show that there are very few (<5) well-funded gene therapy firms in the world and almost no commitment from large companies, while the industry has spent over \$3 billion on gene therapy with little real return.

Although it is correct to say, as the White paper does, that private sector firms are not interested in single gene disorders and that the public sector should fill this gap, given their failure despite substantial investment in this area by firms, there is at least considerable caution needed in making high levels of public investment here. There may be other diseases where it might be easier to make progress. The proposed investment in vector manufacturing on the other hand seems sensible and builds on earlier investment in basic science here, and the problems that public sector investigators are having getting industrial sponsorship.

6.2 In conclusion, *the £9million spending on gene therapy perhaps needs reviewing in the context of the other priorities and needs being addressed by the White Paper.*

7. Pharmacogenetics

7.1 The White Paper calls for more research on pharmacogenetics (PGx) and especially on generic drugs that are commonly used with the NHS whose ADRs might be, via PGx, both more predictable and so containable. This focus on safety/toxicity with drugs that have a narrow therapeutic index makes sense and will be welcomed by the clinical researchers working in pharmacology/medical genetics. As the focus moves in the longer term towards efficacy there may be a need for the Department and regulatory agencies, such as the new MHRA, and the CSM to develop new approaches toward pharmacovigilance and the oversight of chronic disease management.

There are also resource-related issues surrounding the medium term development of PGx tests: would, for example, the public sector (NHS PCTs) need to secure the technical equipment to undertaken near-patient tests, or could this be offered centrally and in collaboration with not-for-profit agencies. Genetic screening for a *predisposition* towards a PGx-related response (in regard to safety and efficacy) may be too costly and too difficult to interpret, especially at the level of the GP. Clearly, ***the Paper's proposal to support training here is crucial, but this needs to be done in light of the likely context and pattern of use of PGx test. Moreover, special attention here needs to be given to the notions of sensitivity and specificity of drug response.***

7.2 PGx testing should be part of a wider review of testing, especially one that explores the way in which phenotypic information is understood and used by clinicians – such as blood counts, hepatic/renal function, known drug-drug interaction etc. The ***relative costs of testing need to be considered against the health care costs of ADRs, and in this regard further work within the field of health economics would be invaluable.***

8. Public engagement with and confidence in genetics

8.1 Finally, the White Paper concludes (in section 6) with a discussion of policy relating to public perceptions of and anxieties over genetics. There are some inevitable policy worries. These relate to the need to control the NHS resourcing of tests and counselling, and a concern that it could prove difficult to determine what might be expected to be met by public good provision and what by private sector services. One of the problems will be in trying to guess what is likely to be the demand from the 'worried well'. Again, work on the IHT Programme offers both assistance as well as challenge here: research is examining the notion of 'genetic subjecthood' that people have and how this shapes their perceptions of and engagement with genetics. People may hold different notions of genetic subjecthood simultaneously and deploy these according to context and circumstance: this can create a range of responses such that the scale of the 'worried well' might be better seen not in terms of possible gross numbers, but in terms of an uneven and contingent distribution across the population. ***More robust, but as sensitive, measures of lay persons' engagement with genetics may well allow for a much clearer sense of how best to anticipate and deploy health resources in the NHS.***

8.2 Section 6 'Ensuring Public Confidence' deals mainly with the government's formal apparatus of regulation. Work on the Programme suggests that public confidence is likely to depend equally on measures taken in the sphere of the *private governance* of genetics.

The main areas of private governance are:

research funding agencies - the government's research councils (the MRC and the BBSRC), and major charities such as the Wellcome Trust, the Cancer Research Campaign and the Imperial Cancer Research Fund. Both the MRC and the Wellcome Trust have been active in producing guidance in the genetics field.

the medical profession - it is a moot point as to whether government or the medical profession oversees the NHS's ethics committees (the new coordinating body is the Central Office for Research Ethics Committees (COREC). <http://www.corec.org.uk>). Relevant national medical bodies include the Academy of Medical Sciences, the Royal College of Physicians, the BMA's Ethics Committee and Science Board, the GMC's Ethics Committee, and the Joint Committee on Medical Genetics. The key point is that in effect, ethics committees are going to be critical instruments for translating general principles into research practice (e.g. on consent, on use of genetic data etc.).

industry - the insurance industry and the moratorium on genetic tests is included in the White Paper. This is a clear example of self-regulation responding to government pressure. As important is the unmentioned arena of the pharmaceutical industry which is developing its own guidance through bodies such as the BioIndustry Association and the ABPI.

In light of these important constituencies, consideration should be given to *reviewing the boundaries and networks of interaction between the state and the private governance mechanisms, to determine where these might be enhanced and where clarified and made more precise.*

9. Conclusion

9.1 This brief overview of some of the key issues appearing in the White Paper is provided in order to help address some of the likely problems that a deepening of genetics provision in the NHS will have to confront. These are of a clinical, organisational, resource and wider cultural nature. The IHT projects that are focusing on genetics in particular along with all other projects on the Programme are producing results that this brief commentary has drawn on, though only in a very abbreviated and condensed fashion.

9.2 The various suggestions and recommendations relating to further research, policy and clinical practice made above are, we hope, useful contributions to the wider debate within the Department. We are anxious that the response to the White Paper will include much greater consideration to the long term economic and clinical effectiveness of genetics in the NHS compared with other therapies and approaches. The anticipated 'savings' and therapeutic value that genetics delivers are at present more a hope than reality.

Programme Director: Professor Andrew Webster
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Appendix

Projects funded by the Programme (2000-2005)

Phase 1:

Professor JW Abraham

University Of Sussex

Regulation Of Innovative Pharmaceuticals In The EU And US: A Comparative Analysis

Professor B Salter

University Of East Anglia

Reforming The Governance Of Human Genetics: The Politics Of Public Trust

Dr B Woods, Mr N Watson & Professor D Mackenzie

University of York & University Of Edinburgh

A Historical Sociology Of The Wheelchair

Dr D Armstrong, Dr J Ogden, Professor S Wessley & Professor R Lilford

Kings College London & Birmingham University

Quality Of Life As An Innovative Health Technology

Professor PA Atkinson, Dr A Bharadway, Dr AJ Clarke, Dr M Worwood, Dr R Hutton & Dr R

Ravine, Cardiff University & University Of Wales College Of Medicine

Genetic Screening For Susceptibility To Disease: The Case Of Haemochromatosis

Dr S Cohn, J Bichard

London: Goldsmith's College

The Challenge Of Recent Neurology To Conceptions Of Mental And Physical Illness

Dr P Flowers, Mr JCG Imrie, Professor GJ Hart & Mr M Davis

Glasgow Caledonian University & Royal Free University

Transitions In HIV Management: The Role Of Innovative Health Technologies

Professor J Hewison, Dr J Green, Professor HS Cuckle, Professor RF Mueller & Mr J Thornton

Leeds University & St James' University Hospital

Social And Ethnic Differences In Attitudes And Consent To Prenatal Testing

Professor G Hanlon, Dr A O'Cathain, Dr D Luff, Dr D Greatbatch & Dr T Strangleman

University Of Leicester, University Of Sheffield & London: King's College

NHS Direct: Patient Empowerment Or Dependency

Ms J Heaton, Ms J Noyes, Professor P Sloper, Dr R Shah

University Of York

Technology And Time: Home Care Regimes And Technology-Dependent Children

Professor S Franklin, Dr Celia Roberts, Professor A Rutherford & Professor P Baude

Lancaster University & Guy's King's & St Thomas'

Definitions Of Genetic Knowledge & Pre-Implantation Genetic Diagnosis: An Ethnography

Dr FE Griffiths, Professor E Green, Dr GA Bendelow & Dr KC Backett-Milburn

University Of Warwick, University Of Teeside & University Of Edinburgh

IHT's At Women's Midlife: Theory And Diversity Among Women And 'Experts'

Dr FJ Henwood, & Dr A Hart, University Of Brighton, Dr SME Wyatt, University of Amsterdam

Presenting And Interpreting Health Risks And Benefits: The Role Of The Internet

Professor GA Lewando-Hundt, Professor J Sandall, Dr K Spencer, Professor R Heyman, Dr C Williams & Mr R Grellier

University of Warwick, City University & Institute Of Education

Social Implications Of One Stop First Trimester Prenatal Screening

Professor DJ Mason, Professor EM Ettorre, Dr GJ Lankshear & Professor KR Greene

University Of Plymouth

The Technological Management Of Childbirth: Risk, Empowerment And Accountability

Professor M Michael & Dr N Brown

Goldsmith's College & University Of York

Xenotransplantation: Risk Identities And The Human / Non Human Interface

Professor JV Pickstone, Dr Julie Anderson, Dr Francis Neary, & Dr DJ Cantor

Manchester University

Innovation, Assessment And The Hip Prosthesis

Professor LF Prior, Dr J Gray, Professor D Hughes & Dr R Pill

Cardiff University, University Of Wales College Of Medicine And University Of Wales: Swansea

The Construction Of Risk Estimates In A Cancer Genetics Clinic

Dr JE Seymour, Dr CM Gott, Professor D Clark, Professor SH Ahmedzai & Dr G Bellamy

University Of Sheffield

Technology And Natural Death: A Study Of Older People

Dr SP Parr, Dr BL Petheram & Professor SC Byng

City University & University Of The West Of England

Inclusive Internet Technologies For People With Communication Impairment

Phase 2

Dr P Tovey, Dr J Chatwin, Dr S Mason, Dr K Atkin - University of Leeds

Mediation of CAM in and by Cancer User Groups and Charities: UK and Pakistan

Professor D Clark, Dr JE Seymour, Dr W Noble, Dr M Winslow - University of Sheffield

Innovations in Cancer Pain Relief: Technologies, Ethics and Practices

Professor JS Metcalfe, Mr AD James, Dr A McMeekin - University of Manchester

Distributed Innovation Processes and the Uneven Growth of Medical Knowledge

Dr NJ Fox, Dr K Ward, Dr AJ O'Rourke - University of Sheffield

Consumerism, Information and Drug Prescribing Governance

Mr AC Faulkner, Professor M Bloor - University of Wales, Cardiff

Dr JA Kent - University of the West of England, Dr D Fitzpatrick - University College Dublin

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

Dr EA Kerr, Dr Richard Tutton - University of York, Dr S Cunningham-Burley - University of Edinburgh

Transformations in Genetic Subjecthood

Dr SJ Nettleton, Mr RJ Burrows, L O'Malley, Professor I Watt - University of York

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

Dr JD Cullen - The Tavistock Institute

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

Professor C May, Dr Tracey Finch - University of Newcastle upon Tyne

Dr M Mort - University of Lancaster, Dr F.S. Mair - University of Liverpool

Telemedicine and the 'Future Patient'? Risk, Governance and Innovation

Dr S Cohn, J Bichard - University of London

Neuroscience Promises: Current and Future Application of Brain Imaging Technology

Dr PA Martin, Professor H Rothman - University of Nottingham

Dr P Nightingale - University of Sussex

Impact of Genomics on Innovation in the Pharmaceutical Industry