THE ROYAL SOCIETY

Royal Society National Forum for Science 2003
(People's Science Summit)

Genetic Testing – Which Way Forward?

Report of a meeting at Church House, Westminster, London. March 4, 2003.

Excellence in Science

Introduction to the Royal Society and its Science in Society Programme

The Royal Society is the independent UK academy of sciences devoted to promoting excellence in science through a range of programmes which support cutting edge science, provide advice on key issues in science and technology and facilitate the engagement of scientists and the public in enabling science to progress.

The annual Forum or People's Science Summit represents the climax of a year-long programme of science in society activities organised by the Royal Society which aim:

- To help earn public confidence in science
- To develop innovative, widespread and effective ways of communicating with the public
- To ensure that the voice of the public is heard when discussing and shaping science policy
- To take a leading role in promoting national science policy debate

In May 2002, the Prime Minister, the Right Honorable Tony Blair MP delivered a speech at the Royal Society outlining the importance of science to the country's continued future prosperity. He spoke, in particular, of the relevance of science to society saying "We need better, stronger, clearer ways of science and people communicating. We need to re-establish trust and confidence in the way that science can demonstrate new opportunities, and offer new solutions".

This approach is fully embodied by the Royal Society's Science in Society programme which is now at the end of its second year. We are committed to our ongoing series of regional and national dialogue meetings, designed to promote an open exchange of views among members of society on issues of concern. We are also promoting dialogue and understanding between scientists and politicians through our MP-Scientist Pairing Scheme.

The Science in Society programme is steered by a Royal Society committee chaired by Sir Paul Nurse FRS Nobel Prize Winner and Chief Executive of Cancer Research UK. It is generously funded by the Kohn Foundation.

For full details of the Royal Society's Science in Society Programme, visit:
www.royalsoc.ac.uk/scienceinsociety
To contact us, send an e-mail message to: dialogue@royalsoc.ac.uk

Summary

The Second National Forum for Science, also styled the People's Science Summit, provided an opportunity for general members of the public, scientists and representatives of other groups to discuss and make joint recommendations concerning government policy on genetic testing.

Genetic testing had been chosen because it was known that the government had plans to issue a major policy paper in this area and because it relates to a key concern expressed at the Society's 2002 Forum, *Who controls science?* With 250 people taking part in a day long structured debate, this was consultation on a large scale and followed in the footsteps of a series of regional meetings.

The debate, most of which occurred in small groups, took into account outputs from the regional meetings and a scenario which stated that within 20 years all children could have their genome profiled at birth. Twenty 'information providers' representing advisory bodies, pressure groups, government, industry, consumer groups and others helped stimulate a balanced discussion. The principal recommendations which resulted from the day's proceedings were:

1. That a regulatory body be set up to oversee legislative and other issues surrounding genetic testing

2. That the profiling of the genomes of children at birth should not proceed because as many people were against the idea as were in favour

3. That a strong effort be made to increase education about genetics for both the public and healthcare professionals

4. That the impact of environmental and lifestyle factors on health continues to be considered alongside genetic factors.

A commitment was made by the Royal Society to bring these recommendations to the attention of the Department of Health and the Human Genetics Commission.

1. Introduction

1.1. To find out what people think about science, you could just ask them. But that might not get you very far. On most issues relating to science and its applications, most of us need help getting a fix on what we are thinking about - and that applies just as much to scientists when thinking about subjects other than their own. We don't immediately know what questions we should like to ask. And if, once we have found out about a particular subject, we want to bend the ear of government or someone else, how do we go about this?

1.2. These are some of the reasons why the Royal Society has made a commitment to finding ways for scientists and non scientists to talk to each other and to policy makers more fruitfully than is usually possible. The People's Science Summit is an important part of this effort, bringing together people from all walks of life to debate a notable potential scientific development with help from expert informants. The idea is both to explore how such debates can be enhanced, and to give the public a voice in science policy matters.

1.3. It is also hoped that these meetings can improve understanding between the public and scientists and develop a growing sense of mutual trust.

1.4. **This year's Forum, the second in the series, was devoted to genetic testing. 250 people attended.**

Genetic testing had been chosen because it was known that the government was developing policy in this area, with plans to issue a Green Paper, because it is a subject in which there is considerable interest and because it relates directly to a key concern expressed at the Society's 2002 Forum, *Who controls science?*

1.5. The day was organized by the Royal Society's Science in Society Secretariat in partnership with PEALS (Policy, Ethics and Life Sciences) at the International Centre for Life, Newcastle. Evaluation was carried out by a team from the School of Environmental Sciences of the University of East Anglia.

2. The Scenario

To focus the discussion, participants were asked to consider a possible future in which every newborn child routinely has his/her genome sequenced. This "DNA birth certificate" or genetic identity card could then be used in various ways – for immediate testing for medical risks, for testing later in life, for deposit in a national databank for research or forensic use, and perhaps for health planning.

2.1. This prediction - *an output from a Royal Society/Wellcome Trust "horizon scan" meeting** - was made for the year 2023, suggesting that it is not too soon to start planning to deal with all these possibilities. As Sir Paul Nurse, chairman of the summit, pointed out at the start of the day, gene sequencing technology has advanced remarkably rapidly in the last 20 years, and there is every reason to believe it will go on doing so. Anyone with $700,000 to spend can buy their own, or their child's, genome sequence now, and the US company which offers this service already envisages bringing the cost down to $1,000 in future years. So there is little doubt that the universal genetic identify card will be possible. "This scenario is not science fiction", said Sir Paul.

2.2. If it comes about, there could be benefits for medical diagnosis, treatment, and prevention, but also costs – personal costs in relation to employment or insurance, for example, and perhaps social costs if certain genetic variations became the object of discrimination; we could see the creation of a genetic underclass . There would also be real costs in terms of the hard cash needed for increased counseling services and education. This is why discussion of how best to make use of this information needs to start now.

2.3. But besides the scenario, participants were also given the opportunity to debate questions which had arisen from a series of regional *"Speaking out"* workshops, in Leeds, Newcastle, Norwich and Edinburgh. These had considered a range of other possibilities for genetics-based health technologies, and raised questions from the wide-reaching, such as whether we should tamper with nature or how we know we can trust decision-makers, to the more specific, like how the quality and validity of genetic tests can be assured or their possible impact on health inequalities. From all these, ten key questions were identified for those who came to the London summit.

(* the summarised report of this meeting which took place on 3 February 2003 accompanies this report)

3. Questions referred to the Summit by Regional Workshops

- Could genetic tests tell you (and your close family members) more than you might want to know?
- What legislation or regulations need to be in place to prevent the misuse of genetic information?
- How do you get to know what you need to know about the implications of genetic testing?
- Should health services be prioritising health and well-being through improving living conditions, access to healthy food and exercise, rather than focusing on genetic predispositions?
- How do we deal with the uncertainties and limitations of genetic tests? Is it useful to test for conditions where there are currently no cures available?
- What are the wider consequences (social, political, environmental, economic) of a genetics-driven health system?
- Who is driving the agenda? Why? Should we trust them? Who decides what the priorities are for public debate, scientific research, policy decision making?
- What is the potential for discrimination based on your genetic make-up? What safeguards should be put in place?
- In a health service increasingly driven by genetics, could disparities in income, education and access to healthy food be overlooked?
- How would an increasing focus on genetics impact on NHS and health resources?

4. The people

4.1. This range of questions was matched by the diversity of the debaters. Some of those who came to the Forum had been to one of the regional workshops, but newcomers were added to the mix, recruited through networks of interest and advertising. The result was a widely varied group – pressure groups, patient groups and scientists were there, people with urgent interests in genetics and people who were just interested. The distribution was approximately 57% general public, 13% patient groups, 13% scientists and health professionals, 10% policy makers and 7% special interest groups, all taking part equally in the discussions and the drawing up and voting on recommendations.

5. The recommendations and discussion

5.1. Three hours of lively debate in working groups generated thirty recommendations which were reduced to eleven at a meeting of group representatives. These eleven were offered for discussion by the whole meeting in the closing session (detailed below).

5.2. Some of these recommendations were designed to point up particular alternatives, some to offer general headings with a few details. All were open to interpretation, but they provided a basis for general comment. For each recommendation, participants were invited to discuss the issues raised and to add any further comments that they felt had been missed during the summarisation process – some of the key points made are highlighted below. Immediately after the discussion, participants were asked to express their support or otherwise for each recommendation by displaying a red or green card.

5.3. The full set of thirty recommendations with their full wording, which records a wealth of thought about the future of this technology, is given in Appendix 1.

1. Legal and ethical framework

Recommendations:

- A national independent regulatory body should be set up to oversee health, employment and insurance aspects of genetic testing
- Discrimination on gene profiles should be made illegal
- Information should be anonymous/confidential

Discussion

Most groups agreed that there should be a clear legislative framework established "before the fact", and that this should be supported by a national regulatory body which should be independent and include lay members. Its roles should include maintaining confidentiality of information in medical contexts, and ensuring that it be anonymised if stored in other databases for statistical review.

Voting

Supported

2. Genetics should be kept in perspective

Recommendations:

- Other public health research should be maintained
- Environmental factors should be taken into account

Discussion

This suggestion was relatively non-controversial, although it was pointed out that there is already substantial research focusing on gene-environment interactions.

During the discussion, participants pointed out that genetics has been slow to deliver the benefits promised and that other factors such as lifestyle has as powerful an impact on health and should therefore continue to be considered as significant, albeit alongside genetics.

Voting
Supported

3 & 4 Right to know
Recommendations:
for the child

- There should be an age of consent when children have the right to know the results of genetic tests.

for the parents/guardians

- Parents should have the right to know (or not to know) about their children's genes

Discussion
This pair of proposals gave rise to a good deal of discussion. There was widespread sympathy both for the idea that children would have the right to access their own genetic information after some agreed age of consent (or it they satisfied existing criteria of "competence" which do not turn exclusively on age), and for parents' rights to know about their children's genetic information – or to decline to know.

These recommendations as expressed above were reduced from more extensive suggestions such as: "we recommend that parents deserve the right to know if their child is at risk of a serious genetic condition. The decision to inform resides with a qualified third party who makes decisions on the merits of each case. Ownership transfers to the child at a suitable age. If symptoms surface before this age of consent further consultation is required."

Voting
Both recommendations were accepted, although (ii) was accepted by a smaller majority than other recommendations.

Education
Recommendations:

- Both formal and informal education about genetics and environmental factors is needed
- This education will enable greater involvement in the debate
- A healthier lifestyle should be encouraged. (Better school dinners)

Discussion
Education was a high priority for almost everyone, with a range of tactics recommended, and much concern for the education and updating of doctors and other health service staff.

Again, there were much more elaborate recommendations emerging from the groups, for example:

"We believe that education in this area should be based on honest and reliable sources, be broad in nature, including not only medical genetics information, but conveying the influence of environment and lifestyle choices, as well as related skills such as problem solving, decision-making, values clarification and information evaluation; using both formal and informal channels of information and education; which would be accountable to national standards and measures of success; taking into account principles of universal accessibility and the importance of local and cultural differences and individual and special needs. This should be resourced across all providers of information and education, including all the disciplines of health and social care, education and government."

Voting
Supported

6 & 7 Access to genetic information
Recommendation 1:

- Only health professionals should have access to genetic information

This recommendation was amended during the discussion and the precise wording voted on was:

- Any genetic information is confidential between the health professional and that human being

Recommendation 2:

- Employers should be allowed access but only for health and safety reasons

Another pair of recommendations, designed to capture a difference of opinion between those who felt that only health professionals should be able to get hold of personal genetic information, and that they should keep it confidential, and those who argued that, under certain conditions, employers should have the right to be aware of certain genetic variants. But under what conditions should the latter apply? The person would need to be uniquely at risk, or likely to create risk for others, it was suggested, and the few relevant conditions were better diagnosed by non-genetic means.

Voting
Recommendation 1 – supported
Recommendation 2 – not supported
There was agreement that where there was enhanced risk of more common workplace-related conditions, these would be better dealt with by improving health and safety provision for all.

A separate concern was that drawing access conditions so tightly would impede use of the data for research, and that it should be made available to bona-fide researchers, with suitable safeguards.

8. When should tests be carried out?

Recommendation:

- Tests should only be carried out in order to prevent, counsel, treat, cure

This was amended during the discussion (see below) to include research, so the recommendation voted on was:

- Tests should only be carried out in order to prevent, counsel, treat, cure and conduct research.

Discussion

The point of this formulation was to emphasise that people should only be tested if there was some action which might follow a positive result. However, it appeared to some that casting the action so widely effectively meant that no tests would be excluded, as counseling, at least, could be offered for pretty much anything. Nevertheless, it reflected a fairly widespread view that testing, as it were, for its own sake was undesirable.

Voting

Both recommendations received majority support.

The inclusion of research should be considered alongside '1 Legal and Ethical Framework' above, which states that information collected for research should be anonymised.

9. Cost and resource implications

Recommendations:

- Cost-benefit analysis needed
- More funding for research on gene-environment interactions is needed

Discussion

There were complex concerns about the costs of genetic testing. One obvious area was the implication for health care costs, both of the testing and of any subsequent treatment. It was suggested that cost-benefit analysis was needed, although this was hard to do prospectively, and it also mattered who bore the costs and who benefited. Some were sceptical about any kind of future-oriented technology assessment. A science and society forum looking at electricity in the nineteenth century, it was said, would have concluded that it was far too hazardous for general domestic use.

Voting

Supported

(Comment on the second recommendation is given under '2. Genetics should be kept in perspective'**,** above)

10. Delivery

Recommendations

- Tests should be delivered only by an informed professional who is able to counsel individuals
- Counselling should be widely available

Discussion

Again, there were wide ranging concerns about delivery. They included how to maintain the quality of any tests, and the provision for checking the validity of individual results. And aside from technical competence, those dealing with the tests would need to be capable of explaining the results properly to parents and families. Specific suggestions focused on changes in the medical school curriculum and provision of more genetic counsellors.

Voting

Supported

11. The scenario

Recommendation

- Routine issuing of genetic identity cards at birth should be prevented

Discussion

This outright challenge to the desirability of the future envisaged in the scenario drew a very mixed response. Some felt that, if we really believed that all children were going to have all their 30,000 or so genes read at birth in 20 years time, then few of the measures suggested were adequate to the situation. There was scepticism about the suggested benefits of having the information, on the grounds that many find it easier to ignore existing advice about health. But others felt that there were important benefits in prospect.

Voting

The split was 50:50 amongst those who felt the scenario should be allowed to become a reality and those who wanted to prevent it.

6. Which was the most important recommendation?

6.1. After endorsing or otherwise the 11 recommendations, participants were asked to choose the single most important recommendation and write it down on a piece of paper distributed throughout the hall.

6.2. The recommendation that mattered most to participants was that there be a carefully drawn legal and regulatory framework with the establishment of an independent regulatory body, attracting 40% of the vote.

6.3. Some way behind, in second place (13%) came education and in third place (11%) *was* preventing the genetic identity card

7. The Day's Procedure

7.1. How was the Forum organised?

7.2. After preliminary scene setting introductions, participants were divided into ten assigned groups (each sub-divided into two - one group predominantly public and the other predominantly scientist/other specialist) each of which heard from two expert information providers. Each group focused on one of the ten questions, without the discussion being limited to that question.

7.3. Each group's task, aided by the information providers (See Appendix 2), facilitators, and self-chosen chairs, scribes and timekeepers was to consider its issue alongside the genetic identity card scenario and frame a set of recommendations. These were arrived at through a tightly structured four hours (including coffee and lunch breaks), which allowed group members to hear briefly from the two assigned information providers, think about what they had said, and then pose further questions to them over a 30 minute period. After this information gathering process, the sub-groups paired up to compare notes and select three priority recommendations, ranked by voting. This produced a total of 30 recommendations from the 10 groups.

7.4. Representatives of each of the ten larger groups came together following the working group sessions to select a final list of composite recommendations for the final discussion. The 30 recommendations from the groups were examined to identify any common themes, eventually reducing the long list to a final set of ten (in fact eleven), which were summarised in order to make them clear for the final plenary discussion.

7.5. The eleventh recommendation – in effect, that we should not implement a universal genetic identity card - does not appear in Appendix 1 as it was included in the surviving set on the basis of a verbal "minority report" along these lines.

8. Conclusions

8.1. So what was the significance of all this? First, the process. The day was certainly demanding, and more discussion would have taken place with more time. The need for wording that could be subject to a collective vote meant that the final recommendations were fairly general but participants in the day were able to engage in sophisticated and complex discussions. Given that 250 people took part in a process that lasted just one day, the depth and importance of the discussions surpassed many people's expectations for such a complex topic.

8.2. And the results? With such a wealth of comment behind them, the specific recommendations are open to some interpretation. The emphasis on legislation and regulation certainly suggests that, if the scenario posed becomes real, people want a good deal of thought about safeguards on confidentiality and quality. They are wary, on the whole about what use might be made of genetic information if people outside the medical professions – notably employers and insurers – get hold of it, and they are strongly opposed to anything which smacks of genetic discrimination. The demand for education appears to imply that everyone (including doctors and scientists) should be helped to get better informed, not only to deal with the provision of personal genetic information, but also to promote their further involvement in discussions like this which seeks to influence policy and decision-making.

8.3. Finally, and perhaps the most important thing to note for genetics researchers and health policy analysts, while the day was based on the premise that widespread genetic testing could happen in the future in order to involve people in setting the agenda, there was significant support for the view that universal provision of genetic information should not happen i.e. views were polarised. One way to put it is that a substantial number welcomed the chance to offer opinions about the best way to manage the scenario offered for debate, but also wanted to say: "we wouldn't start from here."

8.4. Sir Paul Nurse closed the proceedings by giving participants an undertaking that these recommendations would be conveyed to the Department of Health, the Human Genetics Commission and other relevant bodies but not before Ms Hilary Newiss a member of the HGC had publicly welcomed the output of the meeting and agreed on behalf of the Commission that the recommendations would be considered fully.

Appendix 1

The names given alongside the Group themes are those of the expert information providers.

Working Group Recommendations

Group 1 – Individual choice: Ms Suzi Leather (Chair, Human Fertilisation and Embryology Authority) and Ms Wendy Watson (National Hereditary Breast Cancer Care Helpline)

Access to information must be strictly confidential and tightly controlled to protect the privacy of the individual, and testing must be based on consent	Very important
We believe that there should be a national independent regulatory body with fixed terms of reference to protect both individuals and society from unethical practices	Important
Discrimination based on genetic profiles should be illegal (as is race, sex…)	Important
Education should be improved to ensure public are kept up to date and in the know on the subject of genetics, benefits and risks. Everyone needs to know/have more information about DNA profiling and genetic testing. This information has to be easily accessible, multi-media, at different levels. Facts – benefits/risks – choices.	Important
Only specific and appropriate tests (at any time)	Important
More discussion is required – issues are complex	Quite important
Complete profile of DNA at birth (with parental consent)	Quite important
No compulsory testing	Quite important
This generation is responsible for ensuring accessible public information on genetics and medical applications	Quite important

Group 2 – Legislation/regulation of genetic information: Dr Ian Gibson MP (Chair, House of Commons Science and Technology Select Committee) and Dr Mark Bale (Secretariat, Human Genetics Commission)

We believe that individuals could be unnecessarily discriminated against if genetic information was openly made available to potential employers. We therefore recommend access to genetic information by employers should be allowed only if the employer can identify specific conditions which would render it unsafe for a person with that condition to perform the job to satisfactory health and safety standards. The information provided should be limited to positive confirmation or denial that an individual has a specific condition. Consideration of genetic information should not be permitted merely to identify future health characteristics of the employee. Transparency required throughout.	Important
We believe that advantages of at birth DNA profiling outweigh the disadvantages. Genetic information should be disclosed at birth only if it is in the interest of the child and allows immediate medical treatment. Otherwise the individual should at age of responsibility be able to request further disclosure of results.	Important
Where genetic information could contribute to or enable improved treatment of recognised medical conditions, genetic screening programmes should be developed and implemented. This must be supported by easily accessible and accurate information.	Important
We recommend that genetic testing should be subject to individual consent. Those who consent (or parents who consent for their children) should be assured that their information is protected by special legislation and access to that information is only on the basis of identified health need and consent obtained at point of request	Quite important
Monitor whether existing legislation is applicable to genetic information and human rights protection is duly taken into account	Quite important
We recommend that a minimum level of counselling be provided in respect of all genetic tests	Quite important

We recommend that the government devise minimum standards of reliability for all genetic tests and regulates all such tests	Quite important

Group 3 – Education: Reverend Michael Reiss (Professor of Education, Institute of Education) and Ms Nikki Ratcliff (Senior Researcher – Health, Consumers Association)

Central to education should be the right to choice –whether to receive more or less information, when and whether to receive the results of the test	Important
We recommend that accurate, unbiased varied access to both formal and informal education supported by counselling, discussion and rationalisation is accessible and available to all to create the opportunity for informed choice and individual empowerment. The government should give this priority and allocate the appropriate resources	Important
We believe that education in this area should be based on honest and reliable sources, be broad in nature, including not only medical genetics information, but conveying the influence of environment and lifestyle choices, as well as related skills such as problem solving, decision-making, values clarification and information evaluation; using both formal and informal channels of information and education; which would be accountable to national standards and measures of success; taking into account principles of universal accessibility and the importance of local and cultural differences and individual and special needs. This should be resourced across all providers of information and education, including all the disciplines of health and social care, education and government.	Important
State to accept: a. moral obligation of proactive support systems and best practice advice b. to ensure equal basic level of access to facilities and services	Quite important

Group 4 – Health and well-being: Mr Gerry Hanon (Public Health Programme Manager, Swindon Primary Care Trust) and Mr Chris Martin (Chief Executive, Sciona)

Increase funding to raise awareness about existing knowledge of interactions between environmental and genetic factors (implement moves towards public understanding and better health). Devise incentives to apply what is known already.	Very important
National Institute of Health to evaluate all research	Important
We recommend and organisation to take responsibility to search out all published data from different fields which impact on health and well-being to: Provide pointers to further research Disseminate effective and achievable educational programmes.	Important
Despite knowledge that good nutrition is a key factor for good health, children are given too much choice of unhealthy options. We recommend restricting non healthy options in schools	Important
Include health education in the curriculum	Quite Important
Public sports facilities for all	Quite important
Coordinated health information policy across government departments with cabinet seat	Quite important
There is a lack of information about local sporting facilities. We recommend that is local promotion of the availability of facilities. Funding should be made available to support this.	Quite important

Group 5 – Quality, validity and accuracy of tests, limitations of tests: Dr Helen Wallace (Deputy Director, GeneWatch) and Dr Ian Frayling (Specialist Registrar in Genetic Pathology, Addenbrookes Hospital)

We recommend that very clear government guidelines be formulated to deal with the following issues. How is the information to be: 1. accessed (ownership) 2. checked 3. corrected 4. scaled up (epidemiology) 5. ownership	Important
We are concerned that the lay public has insufficient understanding of genetics to allow informed choices to be made. We recommend that testing and interpretation is only performed by qualified independent professionals who are able to relay this information in such a way as to allow an informed choice to be made	Important
The government/NHS needs to plan for the cost and resource implications of genetic testing and the criteria for complex cost-benefit analysis	Important
We believe that there is merit in genetic testing. We recommend that (1) there should be introduced a research database in order to identify and potentially treat genetic disorders leading to an improvement in world health and (2) an independent body examine the potential uses, costs and benefits of a DNA birth certificate for all new born babies	Quite important
Regulation is required for consent, procedure of testing, access of information	Quite important
Research should continue to be funded to find cures for diseases which have been identified as being caused by specific genes (without jeopardising other medical research). The direction of the research should be determined following involved, informed public debate. Individuals should be able to request a blood test to identify any conditions they may have from a private/independent body and should then be able to act on their results.	Quite important

Group 6 – Ethics of genetic testing (is it ethical to do it at all?): Dr David King (Editor, Human Genetics Alert) and Dr Ainsley Newson (London IDEAS Genetics Knowledge Park and Medical Ethics Unit Imperial College)

Recognising that we live in an environment that does not necessarily promote good health, we each of us have a unique and precious genetic code that's differentially affected by external factors and in this context we wish to maximise our potential whatever it is. We wish laws and strategies to be developed to ensure that individuality is not compromised by lack of informed and appropriate access to knowledge, in particular genetic information. So that individuals and their families can understand the issues fully so that they can make sensible decisions	Important
Education: 1. increase awareness of medical professionals 2. specialised advisors for families 3. centres of excellence 4. advisor to health insurance companies	important
The ownership of all information arising from genetic testing should reside with the individual or the parent/guardian of the individual until the age of understanding	important
We recommend that a regulatory body should be established, including representatives of all stakeholder groups – including the lay public, to oversee the genetic birth certificates and set limits on access and use of genetic information	Important
The Royal Society should continue to arrange further wide public participation in debates about the issues raised by genetic innovation as a check to the power of commercial and sectional interests	Important

Right to know/not to know: We recommend that parents deserve the right to know if their child is at risk to a serious genetic condition. The decision to inform resides with a qualified third party who makes decisions on the merits of each case. Ownership transfers to the child at a suitable age. If symptoms surface before this age of consent further consultation is required.	Important
Funding: 1. 1st degree relative to proband NHS free 2. Other relatives pay	Quite important
Recognising that there is a right to know and to choose not to know about genetic information, we recommend that although a DNA profile may be collected at birth, information should only be accessed at appropriate to times when there is an IMMEDIATE BENEFIT for treatment or health, and this access should only be with the APPROPRIATE CONSENT, either from the individual or those empowered to consent on their behalf (parents/guardians)	Quite important
Security of information: It is imperative that measures are taken to protect individuals' genetic data. Access to the database should be strictly regulated by an independent working committee	Quite important
Ownership: 1. Individual at 16 years (or Gillick competent) 2. Legal guardian 3. Health advisor (to assist 2)	Quite important
Recommendation to government agency responsible for genetic and insurance committee – add a member (not an MP!) to represent categories that might be discriminated against.	Quite important
The government should retain control of all aspects of genetic testing including: 1. Commercial exploitation 2. Discrimination	Quite important
Recommend that resource availability and allocation be established by economic and medical authorities	Quite important
We believe that everyone has the right to ownership of their genetic information. They, the individual can choose when to access this information in consultation with health care professions and in the light of their family consent (Recommendation to Dept Health and Social Services	Quite important
Recommend that right to know and right not to know be covered by clear rules prepared by legislative and medical authorities.	Quite important
Recommend access to and use of DNA information by third parties be covered by legislation	Quite important

Group 7 – Driving the agenda (research and decision making, trust): Professor Brian Wynne (Research Director, University of Lancaster) and Dr Gill Samuels (Senior Director Science Policy and Scientific Affairs, Pfizer)

Regulation – within an existing body of law by impartial, informed referees with lay members. This group to establish a mechanism for consulting and involving the public	Important
We believe that genetic counselling should be significantly expanded to help patients deal with the implications of genetic traits	Important
We believe that the widespread dissemination of information about the limitations, implications and significance of genetic data will facilitate informed choices	Important
Blanket exclusion or inclusion – opt in or out – choice, geddit?	Important
We need a mechanism for people to change, or complain about, what is happening if there is a problem	Quite important
Enough time is set aside to do the process of introduction properly before the test is introduced	Quite important

Group 8 – New genetic inequality and discrimination: Mr Peter Purton (Disability Policy Officer, Trade Union Congress) and Mr Richard Walsh (Head of Health, Association of British Insurers)

If the testing and collating of genetic information is compulsory then it should be coded and made anonymous and only be decrypted by the parents or individuals except only in extreme conditions when special permission should be obtained (crime/forensic)	Important
Discrimination: Government should undertake legislation in the three key areas: employment, healthcare and insurance, to cover: Consent and security (who has access to genetic information) Who sets the standards (independent body overseeing)	Important
Code of ethics to be drawn up regarding handling of genetic testing information by the medical profession for health care	Important
No access by employers to genetic testing results of potential employees	Important
A need of independent genetics advocate for advice on health and legal issues	Quite important
Fair treatment across the nation and not only constricted to particular areas	Quite important
There may be a problem with compulsory testing, we recommend that pre-test counselling and parental consent should take place	Quite important
For life cover only over a certain level it is legitimate for insurers to request access to genetic test results	Quite important
Discrimination – we would like the Royal Society to investigate the validity and reliability of any genetic testing	Quite important
Counselling and support: we recommend that the government funds adequate counselling support programmes to run adjacent to genetic testing	Quite important
Public awareness of pros and cons to initiate the DNA birth certificate – followed by a referendum	Quite important

Group 9 – Inequality: Ms Sue Dibb (Senior Policy Officer, National Consumer Council) and Dr Eric Brunner (Department of Epidemiology and Public Health, University College London)

Clear legal framework before the fact, making it clear who owns the information and who can do what with it	Important
Maintain research in other areas of public health	Important
Need a strong ethical framework first, before the fact. Need to know what people believe is right and not do it because it's possible.	Important
DNA passport/birth certificate optional	important
Need accessible educational programme to inform	Important
Testing all babies	Quite important
Individual must own their DNA information	Quite important
Make sure benefits on DNA testing applied to whole world	Quite important
All DNA test/research to be publicly funded	Quite important
Genetic profile should not lead to patenting that makes a profit	Quite important
DNA passport mandatory	Quite important
Information for health reasons should not be used for forensics	Quite important
Only test adults	Quite important
No DNA test/research to be publicly funded	Quite important
This proposal is a waste of money	Quite important

Group 10 – Cost – what are the costs and who pays?: Dr Naomi Brecker (Department of Health) and Ms Joy Akehurst (Research and Development Manager/Facilitator, Newcastle Primary Care Trust)

Education of health workers and public – protection of individuals: a. increase specialist genetic counsellors within health services b. alterations to nursing/midwifery/health visiting curriculum – to improve knowledge within the health service c. alteration to national curriculum in schools (science teachers – incentives) d. government driven public education campaigns Increase in support networks and aftercare provision. All publicly funded through taxation.	Very important
We recommend that the use of genetic information be strictly restricted to use by the health service alone	Important
We recommend that the health service aims to prevent, counsel, treat or cure illnesses that are in whole or in part attributable to a genetic condition, and by doing so prolong and improve the quality of life for the population as a whole.	Important
Quantify benefits to health service planning	Important
Our recommendation is that funding should be clear and jargon-free and there should be transparency from all parties involved such as the NHS, research organisations and other drug companies. The benefits should in some way outweigh the cost.	Important
Insurance worries: Personal genetic information should not be used by organisations to discriminate against people with higher risks when they may not go on to develop the condition that they have been tested for. Government legislation should be produced to ensure that this does not happen.	Important
If risk is unknown there should be disclosure of this information (litigation) (even no cure/treatment)	Important
Yes it's useful in helping to target services to those particularly at risk of developing a particular condition in the future	Important
Improve health of society as a whole	Important
Insurance companies should set up special pools of similarly affected people so real risks can be assessed and fair premiums charged	important

Appendix 2

Workshop group subjects and Information Providers

Group	Key issue	Information providers
1	Individual choice (relatives, paternity, knowledge, etc) *Can genetic tests tell you (and your close family members) more than you might want to know?*	• Ms Wendy Watson (National Hereditary Breast Cancer Helpline) • Ms Suzi Leather (Chair, Human Fertilisation and Embryology Authority)
2	Legislation/regulation of genetic information *What legislation or regulations need to be in place to prevent the misuse of genetic information?*	• Dr Mark Bale (Secretariat, Human Genetics Commission) • Dr Ian Gibson MP (Chair, House of Commons Science & Technology Select Committee)
3	Education (formal, less formal, counselling, options re health and genetics) *How do you get to know what you need to know about the implications of genetic testing?*	• Reverend Michael Reiss (Professor of Education, Institute of Education) • Ms Nikki Ratcliff (Senior Researcher - Health, Consumers Association)
4	Health & well-being (environment, food, non-medical intervention) *Should health services be prioritising health & well-being through improving the environment, better diets and more exercise, rather than focusing on genetic predispositions?*	• Mr Gerry Hannon (Public Health Programme Manager, Swindon Primary Care Trust) • Mr Chris Martin (Chief Executive, Sciona)
5	Quality, validity and accuracy of test. Limitations of tests *How do we deal with the uncertainties and limitations of genetic tests? Is it useful to test for conditions where there are currently no cures available?*	• Dr Helen Wallace (Deputy Director, GeneWatch) • Dr Ian Frayling (Specialist Registrar in Genetic Pathology, Addenbroke's Hospital)
6	Ethics of genetic testing (is it ethical to do it at all? Use? Tampering with nature) *What are the wider consequences (social, political, environmental etc) of a genetically-driven health system?*	• Dr David King (Editor, Human Genetics Alert) • Dr Ainsley Newson (London IDEAS Genetics Knowledge Park and Medical Ethics Unit Imperial College)
7	Driving the agenda (research & decision-making, trust) *Who is driving the agenda? Why? Should we trust them? Who decides what the priorities are for public debate, scientific research, policy decision making?*	• Professor Brian Wynne (Research Director, University of Lancaster) • Dr Gill Samuels (Senior Director Scientific Policy and Scientific Affairs, Pfizer)
8	New genetic inequality and discrimination *What is the potential for discrimination based on your genetic make-up? What safeguards should be put in place?*	• Mr Peter Purton (Disability Policy Officer, Trade Union Congress) • Mr Richard Walsh (Head of Health, Association of British Insurers)
9	Inequality (of access to health services, information, ability to change; and risk, exposure to ill-health) *In a health service increasingly driven by genetics, will disparities in income, education and access to healthy food be overlooked?*	• Dr Eric Brunner (Department of Epidemiology and Public Health, University College London) • Ms Sue Dibb (Senior Policy Officer, National Consumer Council)
10	Cost – what are the costs, and who pays? *How would an increasing focus on genetics impact on NHS resources?*	• Dr Naomi Brecker (Department of Health) • Ms Joy Akehurst (Research and Development Manager/Facilitator, Newcastle Primary Care Trust)