Liberty’s Response to the Human Genetics Commission’s discussion document on the storage, protection and use of personal genetic information
March 2001

Liberty also welcomes the prominence given by the Human Genetics Commission to the important international documents that have grappled with reconciling human genetics and human rights: the United Nations’ Universal Declaration on the Human Genome and Human Rights and the Council of Europe’s Convention on Human Rights and Biomedicine. With reference to those documents and the established international human rights law that they draw on, Liberty identifies the following (overlapping) principles that should guide the approach to regulating human genetic information:

- protection of the individual: the presumption should be that the interests, autonomy and welfare of the individual should have primacy over the interests of society and science
- consent: free and informed consent by the individual should be a condition for obtaining and use of human genetic information, including legal protection for those unable to give such free and informed consent
- privacy: the individual’s right to privacy includes all use of their genetic information
- subject access: an individual should have the right to know what personal genetic information about them is being held
- non-discrimination: discrimination against a person on the grounds of their genetic heritage should be forbidden, including the right to legal protection against discrimination in access to basic resources such as healthcare and social or universally-required insurance
- enforcement: individuals should have ready access to effective mechanisms to enforce their rights and get redress for infringements of those rights.
This response paper aims to respond to the human rights issues raised in the questions asked by the Human Genetics Commission.

**What is personal genetic information?**

2.2 **Do you have different concerns over the use of the three different sources of genetic information (family history, external observable characteristics, analysis of blood or bodily tissue) outlined above, and if so, why?**

Liberty considers that different concerns do arise over the use of different sources of genetic information for a number of reasons. Different processes of obtaining each type of information give rise to varying degrees of intrusion into privacy and the increasing degree of specificity of the different sources give rise to increasing intrusion into privacy.

An individual's right to personal autonomy should be seen to extend to personal samples (even those inadvertently left behind) and personal information derived from them. That autonomy should only be compromised under strict regulation, and under the guiding principle that there should be overwhelming evidence of substantial benefit to society or to other individuals if personal autonomy is to be overridden.

Liberty therefore has no doubt that the new ready availability of such personal information derived from personal samples presents society with a unique challenge to the rights of individuals within it. The urge to maximise the use of information derived from such samples for society’s good is ostensibly laudable, but must be approached on a precautionary basis.

2.3 **Should HGC be concerned with all sources of personal genetic information or should it mainly focus on the new DNA technologies?**

The HGC should be mainly concerned with and should mainly focus on the new DNA technologies but should also refer to all practice relating to all sources of personal genetic information in the course of its deliberations.

**Is genetic information special?**

3.2 **Do you think that existing legislation and codes of professional conduct provide a sound basis for the protection of human genetic information?**

Liberty considers that it is possible that existing legislation and codes of professional conduct provide a sound basis for the protection of human genetic information, but this should not be assumed. The reality is that existing legislation and codes of professional conduct have not been drafted with an eye to protecting human genetic information, and it would be foolish to rely upon them to do so. Liberty considers that both legislation to give individuals enforceable protection and professional codes of conduct are necessary. The better approach is to consider what is necessary to meet the challenge of human genetic information and then consider what more needs to be added to current legislation and professional codes of conduct to achieve that. Liberty considers the best course would be to introduce statute and delegated legislation dealing particularly with this area, under the control of an independent regulatory authority. The best working model for such a regulatory authority is the HFEA.

3.3 **Does the protection of the confidentiality of genetic information require special consideration, or should it be treated in the same way as any other form of personal medical information?**

Liberty agrees with the reasons put forward by the HGC why this requires special consideration. We would add:

i. genetic information has a peculiar intimacy to the individual, and this seems intuitively to make it right that it should receive special consideration and protection.
ii. genetic has much greater commercial value than other personal medical information giving a powerful incentive for the misuse of information. Voluntary self-regulation cannot be relied upon. Special consideration must therefore be given to preventing misuse.

iii. genetic information is in general more determinative than other forms of medical data.

Liberty believes that there is an urgent need for legislation to protect genetic information in medical, research and all other contexts. The considerations that apply to the confidentiality of personal genetic information within families, are also of general application. In broad terms, a regulatory scheme is needed that fulfills the following requirements:

- **Separation**: highly sensitive medical data, such as genetic data, should be kept separately from other data
- **Security and controlled access**: genetic data should be subject to a high degree of security and access to it should be controlled and limited to appropriately trained persons requiring the data
- **Recording**: specific consent should be required for access to and use of genetic data, the fact and purpose of the access and use should be recorded
- **Limited use**: genetic data should only be used for the purposes for which it was given and for the purposes for which consent has been given
- **Destruction**: genetic data should be destroyed when it is no longer needed for the purpose for which it was obtained
- **Accountability**: this comprises not only a localised system of control but also a suitable body to police all institutions and bodies holding genetic data
- **Transnational protection**: genetic data must not be exported to countries where similar standards of data protection are not in place
- **Enforcement**: any use, release or other dealings with genetic data in the medical sphere contrary to the regulations should be unlawful and subject to appropriate sanctions, possibly including criminal offences. Individuals should have access to a tribunal to enforce any misuse of information affecting them and that tribunal should be empowered not only to order compliance with the regulatory scheme and compensation but also, where necessary, destruction of other consequential data obtained by misuse of genetic data.

As stated in above, an independent regulatory body covering all those holding personal genetic information will be necessary to enforce any scheme.

**Consent to genetic testing**

5.2 How much information do you think is required for the informed consent of an adult in the following cases:

(i) diagnostic testing;
(ii) carrier testing;
(iii) presymptomatic genetic testing;
(iv) testing carried out in pregnancy?

The issue of consent must be approached by understanding the legal background relating to what constitutes a valid consent. In the Sidaway case, the House of Lords decided in favour of applying a "reasonable doctor" test to determine how much information should be given to a patient in order to obtain consent to carry out an operation. The US doctrine of "informed consent" was rejected. That decision increasingly seems at odds with the expectations of patients in modern society.

Liberty therefore approaches consent on the basis that medical consent in law should mean informed consent as judged by the standard of what information a prudent patient would want. In any case, Liberty considers that the specific nature and implications of human genetic information justifies a high test of what information a patient should be given in order to give valid consent to genetic testing.

In specific terms, Liberty considers that the law should require the following elements to be
present in order for consent to genetic testing to be recognised as valid:

(1) **diagnostic testing**
The individual should be informed of the purpose of the test, for example this would usually be to confirm or exclude a particular condition or set of conditions. The individual must also be told the other information that may foreseeably be obtained. The tester should be in a position to discuss the implications of the possible results that might be obtained, at least in broad terms, before the test is undertaken, and the individual should have a reasonable opportunity (if circumstances permit) to reflect and obtain further advice or ask further questions before any test is undertaken. Information given about the implications of the test should include information about when, if ever, the test results would be disclosed to a third party without the patient's consent. Written consent should ordinarily be obtained to confirm that all stages of that process have genuinely been carried out to the individual's satisfaction.

(2) **carrier testing**
The same approach to carrier testing should apply as for diagnostic testing.

(3) **pre-symptomatic genetic testing**
The same approach to pre-symptomatic genetic testing should apply as for diagnostic testing. But note the ability to provide information about the implications of particular results must in this case, probably to a greater extent than for diagnostic testing, also include information derived from some background knowledge of insurance and (possibly) other areas of law and social practice. Thus, for example, if the test may turn up results which could affect an individual's ability to obtain insurance or employment a doctor or health care worker providing information prior to obtaining consent must be in a position to advise as necessary (or at least to inform the individual that they need to take other advice).

(4) **testing carried out in pregnancy**
Testing carried out in pregnancy is peculiarly difficult. The test and its implications may impact upon the parents and the child (even to the extent of resulting in termination of the pregnancy). Difficulties are foreseeable here, particularly if the concept of foetal rights develops, as it may well do under the Human Rights Act. However, Liberty currently believes that the broad principles are the same as those for diagnostic testing. If the concept of foetal rights develops, it may be necessary for this area to be re-thought.

5.3 **Is it acceptable for family linkage studies to be carried out on:**
(1) **children with consent from a person with parental responsibility and if so, under what conditions?**
(2) **Adults not capable of giving consent for the benefit of other family members and if so, under what conditions?**

(1) The parents and/or the person with parental responsibility should have the right to give consent for family linkage studies to be carried out on a child, unless the child is Gillick competent, which should exclude the parent's ordinary right to give or withhold consent. This should be subject to the overriding supervision of the courts who should apply a test of what is in the best interests of the child concerned as under existing law in other situations.

(2) Carrying out family linkage studies on adults not capable of giving consent should be approached with great caution. Liberty considers that such testing should not be carried without specific permission being obtained from an appropriate judicial tribunal where the interests of the incapable adult are represented and decision maker has considered the interests of the incapable adult applying a test of what is in that person's best interests.

5.4 **If testing techniques give information on many genes or diseases, then should all the results be communicated to the patient, or only those to which the patient had explicitly consented?**
A process of informed consent should be carried out in all instances of testing in which all foreseeable information to be obtained by testing is discussed, as set out in our answer to question 5.2 above. Use testing techniques giving multiple results must be justified clinically. If testing technology is developed that gives information on many genes and diseases, Liberty considers that only information obtained with the specific consent of the patient should be available to the clinicians.

Therefore, multiple test results should only arise where the patient has given consent to this information being obtained. In that case, all the results should be available to the patient, and all should be communicated unless the patient had indicated in the consent process that s/he did not wish to be informed of specific matters. If the patient changes his or her mind prior to the communication of test results his or her revised wishes should be respected.

5.5 Would the carrying out of a DNA analysis on a sample, for example a tumour biopsy, require the specific consent of the patient or would general consent for medical tests to be conducted be sufficient?

Specific consent should always be required for the carrying out of a DNA analysis of a sample. This is a matter of principle in order to respect individual autonomy.

It is also the correct practice. Requiring consent will maintain high standards and develop a respect within the professions for individual autonomy in this area. Individual's rights protected by law should be the appropriate standard for medical practice. The development of proper practice in this area cannot be solely entrusted to the medical profession.

5.6 How can the principle of informed consent be applied for paternity testing or other testing conducted by organisations based outside the UK?

It is obviously impossible for UK law to prevent genetic testing being carried out in breach of the principle of informed consent outside the UK. However, it is not only legitimate for UK law to require that testing information derived from outside the UK can only be used within the UK where it has been obtained with informed consent but a necessary part of the positive obligation on states to protect privacy. Accordingly, UK law should ban the use of such information by in healthcare, official decision making, criminal justice, civil justice, employment and insurance except where such information has been obtained with informed consent in accordance with the standards of UK law.

Where the genetic information is to be used as evidence, courts themselves will be able to ensure that the information is only admissible in evidence if it is obtained in accordance with the standards of UK law. For other uses of genetic information, an independent authority empowered to regulate genetic data privacy could provide permission.

The principle of requiring permission should only be subject to limited exceptions: where all parties affected by the use of such information, necessarily including the donee, give informed consent to its use or where there is a risk of serious medical harm resulting from waiting for permission to be obtained in the field of health care.

Confidentiality of genetic information within families

6.2 In what, if any, circumstances, should the non-consensual disclosure of genetic information be allowed within a family setting?

Non-consensual disclosure of genetic information should be approached with extreme caution and only be allowed subject to strict legal regulation. Confidentiality is particularly important in the context of data as sensitive as genetic information. However, Liberty believes that there are a very limited range of circumstances where the right of confidentiality may be qualified in the interests of protecting another person from very serious harm. Liberty is, however, concerned that allowing this decision to be made by doctors or researchers is too open to abuse and to a practice of disclosure in wider
circumstances developing. Therefore, Liberty believes that specific permission ought to be obtained from a judge or similar judicial body before any disclosure takes place. Further, permission should only be granted where the court is satisfied that the appropriate criteria are met.

Liberty considers that the appropriate test for the exceptional circumstances in which non-consensual disclosure within a family setting could take place are where:

- disclosure will protect another person from very serious harm
- consent for disclosure has been sought
- the harm caused by the non-disclosure outweighs the harm caused by disclosure
- Permission should be limited to disclosure of the information strictly necessary to prevent the very serious harm.

Liberty believes that this test is appropriate with necessary modifications for non-Gillick competent children.

6.3 Does the current framework of law against the unauthorised disclosure of medical information provide adequate protection for genetic information?

Liberty believes that the current framework does not provide adequate protection for genetic information. Viewed from the patient’s point of view, the difficulty with the present law is that there are a variety of possible remedies but an individual’s legal position is likely to be unclear in many specific cases of unauthorised disclosure. For example, the law would plainly prevent Y being told that his brother X already had a particular disease unless X consented to the disclosure of such information. However, consider a situation in which the brothers X and Y have the same general practitioner. Suppose that X has been genetically tested and been found to have a susceptibility to a disease that has, as yet, had no impact upon him, but whose impact can be ameliorated by, say lifestyle changes before the disease becomes symptomatic. The GP then plainly has a reason (even, perhaps, a duty) to encourage Y to undergo genetic testing. If Y was then urged by their common general practitioner to undergo genetic testing "just in case something turned up", with the GP knowing full-well that it is likely to "turn up" the same susceptibility as that suffered by X, that would be a plainly risks being a breach of X’s right to protection of his own genetic information. Both the right to privacy guaranteed by Article 8 of the European Convention on Human Rights and breach of confidence contain a defence for disclosure in the public interest and it is unclear how it would operate in this setting.

Liberty accepts that the law cannot provide for every factual situation. However, the law could and should go further than it currently does to set the boundaries of unauthorised disclosure of genetic information so that individuals can be aware of what their rights are with some certainty.

Liberty is also concerned that the law should prevent unauthorised disclosure of genetic information within families when it is used in other areas, such as insurance.

6.4 What further measures, if any, should be considered to give particular protection to the confidentiality of genetic information in this context?

As set out in the answer to question 3.3 above, Liberty believes there is an urgent need for legislation in this area. Particular risks in respect of confidentiality arise in the family context. The issue in this context is ensuring that professionals, and family members, are aware of individual’s rights and that effective mechanisms are in place to ensure that these are protected in practice. Professional codes, monitoring and auditing, and education all have a role to play.

6.5 In the family context, should there be a “right not to know”? If so, should this right be absolute, or could it be breached in certain circumstances? If it could, what should the circumstances be?
Liberty recognises that difficult issues are raised by the 'right not to know', both in principle and in practice. A supposed 'right not to know' has in the past been coupled with the assumption that a particular patient does not wish to know adverse medical information and used excuse for paternalist non-communication by medical practitioners of invidious kind: the patient, their relatives and healthcare professionals have been aware that the patient has a serious illness but healthcare professionals have hidden behind the comforting, but entirely fictional notion, that the patient would rather not know. This historical practice amounts to a breach of the patients rights and may lead to the "right not to know" being treated with a certain amount of caution.

Liberty however believes that the right not to know should be recognised. Article 5 of the Universal Declaration on Human Genome and Human Rights and Article 10(2) of the European Convention on Human Rights and Biomedicine both correctly recognise the right not to know. There is considerable force in such an idea in a society where it is likely that at least some insurance may permissibly ask for the results of genetic tests where these are known. If a proper informed consent has been obtained to the genetic test then the individual upon whom the test was performed will be known either to want to know or not, and that should be adhered to in respect of that person.

Liberty does not however believe that this right may be qualified in very exceptional circumstances where disclosure to others will protect some other person from very serious harm. As in the case of non-consensual disclosure of information known to a person, disclosure should only be possible pursuant to specific permission from a judge or judicial body. In the limited circumstances where disclosure will not affect the person concerned, Liberty believes that the court ought to grant disclosure without overriding the right not to know. It will be for the court to be satisfied that these circumstances do exist. In other cases, it will be necessary to inform the person concerned and seek their consent for disclosure. Thereafter, the test for whether permission for disclosure should be given is as outlined in our answer to question 6.2, namely:

- disclosure will protect another person from very serious harm
- consent for disclosure has been sought
- the harm caused by the non-disclosure outweighs the harm caused by disclosure

As where the information is known, disclosure should be strictly limited to what data is necessary to prevent that serious harm. Guarantees of non-disclosure should be sought where possible.

**Personal genetic information in research**

Researchers are amassing large amounts of genetic information currently. This is one important source DNA databases for biotechnology companies. This gives rise to real concerns about control of data. Research in the UK is significantly regulated, by for example ethics committees, operating high ethical standards. Liberty, however, agrees with the conclusion of the HGC’s research into international approaches to protection of genetic information, where it is stated that:

’The key issue with regard to research into human genetics is not, therefore, what ethical standards should apply, but rather how these standards are applied in practice...In short, it is not sufficient to have ethical guidelines or codes of conduct governing human genetics research if these guidelines cannot be, or are not, enforced effectively.’

A number of issues also arise out of the use of information on these databases by private companies to commercial objectives, particularly since these will frequently combine genetic information and personal medical information. Liberty therefore believes that as with other areas where genetic information is held there is a strong argument for introducing legislation to control the use of genetic information in and arising out of scientific research. This was the approach taken in the Australian Genetic Privacy and Non-discrimination Bill in 1998.

7.2 What types of information need to be given to someone donating tissue for use in a genetic research project?
Researchers must provide a person who is considering donating tissue to a genetic research subject all the information a prudent person would want before so that informed consent is given. This means:

- the person should be informed of the nature of the specific research being undertaken, its aims, objectives, expected duration, procedures and how it is being supervised
- the person should be informed how the information is to be stored and at what point the information would be destroyed (ordinarily completion of research)
- the person should be informed how the information gained in the research may affect her or him, this should include information about the later implications of the test information and implications of the test information to others such as family members
- the person should be informed of what circumstances would lead to the information being disclosed to others without her or his consent
- the person should be informed that their participation is voluntary and that they have the right to withdraw from the research at any time and that information about them will then be destroyed
- the person should be informed about any genetic counselling that is available for them
- where the research has specific or foreseeable commercial purposes the person should be informed of them and of the extent (if any) that they will benefit from that commercial use

7.3 For future research on the same sample, is specific consent to particular types of genetic research (e.g. research on heart disease or cancer) adequate?

A sample should not be retained for any future research without specific consent relating to the nature of that future research e.g. research on heart disease, the institution where the research will be conducted and the uses to which the research information were put. Thus, for example, if it is intended to take a tissue sample not just for an immediate research project but for storage for research perhaps many years or decades away, the institution obtaining the sample and storing it should make it absolutely clear to the individuals donating the tissue whether or not the institution will directly profit from any information obtained from research. If it intends to profit by the research (i.e.: sell the research results or information derived from them to commercial organisations) it must have specific consent for that purpose.

7.4 Alternatively, would an "opt-out" system be acceptable and if so on what basis?

No.

7.5 It is acceptable to use material left-over from surgical operations in general?

No, not without specific consent.

7.6 Is it acceptable to use material left-over from surgical operations in genetic research?

No, not without specific consent.

Should there be a different approach for anonymised and for identifiable material?

Liberty is not persuaded that a different approach to apply to consent for use of a genetic material that is anonymised as for other sorts of genetic information. The issue is not whether an individual can be traced, which anonymisation would prevent, but whether the individual’s autonomy has been properly respected. In Liberty's view, a breach of that autonomy is no less a breach just because the person whose autonomy has been breached can no longer be traced.

The question whether material should be anonymised in any event when used in research is a quite separate question. Liberty’s position is that the use of anonymised samples and anonymised information breaches the autonomy of the individual to whom the tissue and the information belongs even though both the tissue and the information are anonymised,
and, accordingly, the starting position and the norm should be that samples and information must not be used without the consent of the person from whom the sample has been taken. If any departure is made from that norm, it should be exceptional, only in accordance with regulations, and with the express consent of a regulatory authority.

7.7 What types of information do patients need concerning the potential use in medical research of tissue removed during an operation?

The question of what type of information patients should be given concerning potential use in medical research of tissue removed during an operation is a consent issue. No use should be made of tissue removed during an operation without the patient’s consent to that use, and the information that should be provided to gain consent is discussed above. If the information is to be used in research all the information given in our answer to question 7.2 should be given.

Should unexpected findings from genetic research be fed back to the donors of the sample:
(1) if the sample was given specifically for research;
(2) if the sample was left-over tissue from an operation;
(3) only if the person had given consent to such feedback; and
(4) if the findings could enable the person to take action to prevent damage to their health, even if the person had not asked to receive this information?

Liberty believes that the comparable standards should apply to consent and testing in the research field as for clinical genetic testing. Informed consent should be given for all types of information foreseeable obtained by the test. Similarly, an individual’s right not to know should be respected.

Liberty doubts whether a proper process of obtaining consent would ever result in wholly unexpected findings. Liberty envisage that, as well as discussing anticipated results, the person obtaining the consent will always give an explanation to the effect that not all possible results can be predicted, and ascertain whether the patient or research participant wishes to results even if they have not been specifically discussed.

Making commercial use of personal genetic information

8.2 In what circumstances, if any, should the genetic information of NHS patients be made available to commercial companies engaged in medical research? Should bodily samples taken by the NHS for diagnosis or as a result of surgery be used for commercial research? Liberty believes that issues about the availability of genetic information derived from health care for commercial exploitation should be approached by reference to paramountcy of individuals rights. A person or institution should not be able to sell genetic information about an individual without their specific and informed consent.

The same principles should apply to private patients as NHS patients.

8.3 Should specific consent to the use of genetic information for the purposes of commercially-driven medical research be necessary before information is used for such purposes?
Yes.

8.4 Should the person who is the source of a tissue sample which is detached from his or her body in the course of medical treatment have any rights over what is done with that sample or with the DNA which it contains? If so, what should these rights be?

Liberty believes that a person who is the source of a tissue sample which is detached from his or her body does have rights over that sample and the DNA it contains. Liberty does not consider that these rights need necessarily derive from proprietor rights in the sense of property law. Liberty considers that a persons rights over a sample of their own body derive from their right to autonomy over their body and to privacy. Therefore, a person ought to
be able to compel another person to use that sample only to the extent that consent has been given. The law should also protect people from the export of their tissue samples and/or genetic information to third countries where proper protection on the use and storage of that information does not exist.

8.5 The HGC will be monitoring the area of human genetic databases in the future. Are there any particular issues you would like to draw to the Commission’s attention?

Liberty is concerned at the growth of large number of genetic databases, whose information is frequently the public sector research, genetic services, routine pathology, clinical trials and existing sample collections. These will usually integrate genetic information with other personal medical information. Liberty is concerned that there is no clear statutory framework governing commercial use of genetic information. Current regulation in this area has been described by one commentator who has studied the area as "incoherent, piecemeal and poorly developed". The situation needs to be addressed as a matter of some urgency and clear oversight mechanism for commercial storage and use of genetic information must be introduced.

**Personal genetic information and insurance**

Insurance plays an important role in all of our lives. It is for this reason that genetic discrimination in insurance poses a significant threat.

As the correctly HGC state (page 37), there is a general consensus internationally that it is inappropriate to permit insurers to require applicants to undergo genetic testing. Liberty considers that this is an important principle and protection for individuals and should be enacted into law.

Liberty is concerned that the current system of self-regulation is not working and not sufficient to protect individuals from discrimination. It is not clear that genetic testing results are not being used prior to consent being given by the Genetics and Insurance Committee (GAIC), the body convened to this. It is also not clear that the policy of the Association of British Insurers that no other use of genetic testing information is being complied with or that there is practical redress for individuals who suffer from this.

9.2 Should insurance companies be required to consider personal genetic information differently from other medical information or family history. If so, why?

Liberty considers that genetic information may be considered to be different from other medical information for a number of reasons. First, genetic information may be considered to have predictive value, rightly or wrongly, with a particular consequent risk of discrimination on grounds of genetic heritage. Second, it is highly personal information. Thirdly, we believe that social policy considerations dictate that it should be treated differently: if testing may give rise to exclusion from insurance necessary to full participation in society, this will amount to unlawful discrimination and will hinder the appropriate use of genetic information in medicine. Historically, the use of personal, medical and familial information by insurance companies has simply been allowed to develop in the UK, no doubt partly because insurance is not the method of funding healthcare. It may be that the use of family information also needs to be reconsidered in the context of some insurance. However, it is clear that there is an urgent need for legislation to regulate the use, if any, of genetic information by the insurance industry.

9.3 In the light of the above questions, what principles should govern the way insurance companies may or may not use pre-existing personal genetic information?

9.4 Should any such principles draw distinctions between:

1. different types of insurance (e.g. life/health)?
2. different types of condition (treatable/untreatable)?
3. the value of the policy to be insured?

Liberty considers that three principles of protection should govern the use the insurance companies make of personal genetic information. They are:
• genetic information should not be used where insurance is compulsory (eg. car insurance) or is meeting basic social needs (eg. life insurance necessary to obtain insurance)
• genetic testing information should not be used unless it is accurate and necessary to assess a relevant risk should be regarded as discrimination on the grounds genetic heritage, this requires a regulatory body to give specific permission for individual tests and set appropriate standards which those tests must comply with for use on individuals
• the principles should be protected by law giving individuals against any other use of genetic information

Liberty believes that approach of using an 'enquiry limit' to set a sum insured below which no personal genetic information can be used in decision making may be of considerable value. Currently, this system appears to be successfully operated in relation to life insurance for mortgages where no inquiry is made for insurance below £100,000. This figure would have to be monitored to ensure that it is high enough to cover average house prices.

Liberty believes that the best approach to protecting individuals from unauthorised uses of genetic information would be to make this unlawful discrimination, either under a specific statute or by amendment of the Disability Discrimination Act 1995. This was the approach adopted in the Australian Genetic Privacy and Non-discrimination Bill in 1998.

9.5 The HGC will be separately considering other aspects of the use of genetic test results in insurance. Are there any particular issues you would like to draw to the Commission's attention?

Liberty has very great concerns about the use and storage of genetic information by insurance companies or others for actuarial use. Strict regulation and oversight are necessary to ensure that there is adequate protection for individuals against misuse of their personal information.

Personal genetic information and employment
9.6 Do you have any comments on the proposed principles which should govern the way employers use genetic information?

The Human Genetics Commission's paper asks for view on common set of policy principles on genetic testing in employment proposed by the Human Genetics Advisory Committee's ('HGAC') report The Implications of Genetic Testing for Employment (1999). These are:

(1) an individual should not be required to take a genetic test for employment purposes - an individual's "right not to know" their genetic constitution should be upheld;
(2) an individual should not be required to disclose the results of a previous genetic test unless there is clear evidence that the information it provides is needed to assess either current ability to perform a job safely or susceptibility to harm from doing a certain job;
(3) employers should offer a genetic test (where available) if it is known that a specific working environment or practice, while meeting health and safety requirements, might pose specific risks to individuals with particular genetic variations. For certain jobs where issues of public safety arise, an employer should be able to refuse to employ a person who refuses to take a relevant genetic test;
(4) any genetic test used for employment purposes must be subject to assured levels of accuracy and reliability; ... and,
(5) if multiple genetic tests were to be performed simultaneously, then each test should meet the standards set out in (2), (3) and (4).

Liberty is broadly in agreement with these principles. Liberty is, however, concerned that individuals should only be required to disclose the results of a previous genetic test under principle (2) where there is clear evidence that the information it may provide is needed to assess the susceptibility to harm from doing a certain job. Liberty is concerned that principle (2) of HGAC's proposals as currently worded may be though to allow fishing expeditions by
employers. Liberty also considers that where information concerns issues of risk of future disease employers should be required to make reasonable adjustments for employees either to prevent or accommodate that genetic condition.

Liberty considers that two measures are necessary to give effect to HGAC's principles. First, individual employees require legal protection against the use of or attempted usage of genetic information outside these principles. This can be achieved by ensuring that the law recognises such abuse as unlawful discrimination. In Australia, the Genetic Privacy and Non-Discrimination Bill introduced in 1998 sensibly proposed that abuse would be contrary to existing disability discrimination law. Liberty considers that a failure to make reasonable adjustment to a genetic condition should itself be considered unlawful discrimination as under the current UK Disability Discrimination Act.

Second, a regulatory authority would be needed to give guidance and enforce the requirement on employers both to assist employers to comply with the requirements of these principles and to assist employees subject to employers who do not comply. Here again, the existing anti-discrimination commissions are a useful precedent.

**Personal genetic information in forensic databases**

DNA matching evidence can be an important tool in the detection of crime. However, Liberty believes that the forensic use of personal genetic information should be approached with caution and has serious concerns about recent legislation that has drifted towards ever more permissive police powers to obtain and retain genetic information. Liberty is especially concerned about the recent decision of the House of Lords in Attorney General's Reference (No. 3 of 1999) that has permitted the use of information derived from a sample stored on the DNA database that should have been destroyed, contrary to an apparently clear statutory prohibition on such use.

Obtaining and retaining genetic information for storage on databases interferes with individuals rights to privacy. The need to detect criminals may justify a different approach to storage of genetic information for medical or scientific research. But a balance still needs to be struck.

10.2 For what type of criminal offence, if any, should it be allowable to include a person's bodily sample and DNA profile on a forensic database?

and

10.3 Should a person’s bodily sample and/or DNA profile remain on the database indefinitely once he or she has been convicted of a relevant criminal offence, or should continued inclusion be subject to review?

The HGC's consultation paper rightly remarks that: 'Overall, the scope for sample collection under UK law, the growing number of situation in which bodily samples are being taken and recent proposals to seek consent to retain more samples, could lead to the suspicion that a comprehensive DNA database is being built up by stealth.'

In this respect, UK law and practice is more permissive than anywhere else in Europe and the US and Canada. Liberty considers that it is time to stop and consider what kind of DNA database is actually necessary to further the interests of efficient crime detection. The taking and storage of samples without consent necessarily involves breaches of individual’s the right to privacy and physical integrity. Liberty believes that the current increasingly permissive environment does not achieve a proportionate balance between those breaches and the needs of the police.

Liberty considers that profiling for the DNA database should only be taken after conviction. If DNA profiles are to be taken earlier then these should be destroyed where a person is acquitted, as is the case with fingerprints. DNA profiles should only be held for a limited time, in accordance with the seriousness of the offence. Liberty believes that DNA profiles
should be removed and destroyed where a conviction is 'spent' within the meaning of the Rehabilitation of Offenders Act.

Liberty is concerned by the lack of effective oversight of DNA databases held for forensic use. There may be a strong argument for moving the operation of the DNA database away from the Forensic Science Service, which remains effectively a scientific services provider to criminal prosecution agencies, and to a properly independent body. In any case, the case for an independent regulatory authority is very strong. This was recommended by the Royal Commission on Criminal Justice in 1994 for all the forensic databases but has yet to be done.

10.4 In what circumstances, if any, should genetic information from a person's medical records be given to the police?

Currently, genetic information may be disclosed to the police where the criteria in Department of Health guidance (HSG(96)18) are satisfied. These are that:

i. without disclosure, the task of preventing, detecting or prosecuting a serious crime would be seriously prejudiced or delayed
ii. information is limited to what is strictly relevant to a specific investigation; and
iii. there are satisfactory undertakings that the information will not be passed on or used for any purpose other than the investigation in hand.

The guidance also seems to advise that more justification is needed where information on more than one person is sought, in order to prevent fishing expeditions.

The contents Department of Health guidance (HSG(96)18) is generally satisfactory. Liberty believes that there should be independent oversight mechanisms to ensure compliance with the criteria. It is also necessary to ensure that the information is treated as highly sensitive once it has been disclosed to the police and that protections on the storage and disclosure of the information still apply.

10.5 Should third party researchers have access to a forensic DNA database for research purposes?

Liberty is not persuaded that any sufficient justification has been put forward for allowing research on the database when balanced against the arguments against such access.

Firstly, the information will not have been supplied with consent for that purpose so that such research amounts to a large breach of the privacy and autonomy of the subjects. This is not justified by the mere fact of conviction of a criminal offence.

Secondly, there are real concerns that research from criminal sample group will lead to far more prejudice and discrimination than any useful information.