Chapter 10

Conclusions

10.1 We set out our conclusions against the background of the following points established earlier in the report:-

(i) screening for **some** defective genes has become a practical possibility;

(ii) medical knowledge about genetic **susceptibility** to common multifactorial conditions (for example, some heart disease and some cancers) is still developing. Even with increased medical knowledge, the individual's risk may be difficult to evaluate;

(iii) many of the ethical issues associated with genetic screening arise from the inescapable involvement of families (both blood relations and spouses);

(iv) the benefits and disadvantages of screening programmes - for individuals, families and society in general - will need to be carefully assessed for each proposed screening programme. Factors to be taken into account include:-

(a) the predictive power and accuracy of the genetic test;

(b) the benefits of informed personal choice in reproductive decisions and their consequences;

(c) the psychological impact of the outcome of screening for both individuals and families;

(d) therapeutic possibilities;

(e) possible social and economic disadvantage relating for example, to insurance and stigma; and

(f) the resource costs and the relative priority, in view of limited resources, of establishing a screening programme.

10.2 Against this background our recommendations fall under six main headings. In making these recommendations we are conscious that no-one can lay down fixed and immutable guidelines for the future of genetic screening. Medical and scientific knowledge is developing rapidly : some of that development may alter the shape and the nature of some of the ethical issues discussed in this report. Nevertheless, certain ethical principles will remain unchanged and certain ethical responses will be required from the health professions, from health administrators, from the insurance industry, from employers and from Government.

What is not covered in this report

10.3 We emphasise once more that this report has covered genetic screening for **serious disease**. (We have explained our views on what constitutes serious disease in paragraph 3.10. Distinguishing between serious disease and other medical conditions would be a task that would fall naturally to the central coordinating body envisaged in paragraph 10.20.) We recognise that there is a whole area of serious concern about genetic screening for human traits that are in no sense diseases. These issues have been brought to the fore by recent controversies about gender choice, and about the so-called 'homosexuality gene'. We do not dismiss these issues. They call for discussion by professionals with skills other than those represented in our Working Party.

I : Providing information and obtaining consent

10.4 **We recommend that adequately informed consent should be a requirement for all genetic screening programmes.** The voluntary nature of the screening process must be emphasised. Adequate information must be provided for all those being invited to enter a genetic screening programme and should include information about the implications for other family members. Information for all genetic screening programmes is best delivered in both written and oral form. (Paragraph 4.29 summarising paragraphs 4.6 - 4.16)

10.5 **We recommend that counselling should be readily available for those being genetically screened, as well as for those being tested on account of a family history of a genetic disorder.** Counselling should be available at all stages of the screening process. This will require the diffusion of an understanding of genetics (at present mainly confined to genetic

counsellors) in particular among those engaged in primary health care. The resource implications, including the need to train large numbers of practice nurses and health visitors in the subject matter and the basic principles of counselling, need to be assessed within the broader context of the expansion and extension of primary care. (Paragraph 4.30 summarising paragraphs 4.17 - 4.22)

10.6 Screening of individuals who are unable to give properly informed consent (minors, the mentally ill and those with severe learning difficulties) require special safeguards (paragraphs 4.24 - 4.26).

II : The results of genetic screening and confidentiality

10.7 The family implications of genetic screening and genetic testing will sometimes require health professionals to review the application of the current principles governing the confidentiality of medical information. We have in Chapter 5 made a start at examining the implications. This work will need to be carried further by the health professional bodies responsible for producing guidelines that govern the conduct of their members as experience is gained from the screening programmes now being introduced.

10.8 We regard it as axiomatic that:-

(i) individuals should normally be fully informed of the results of genetic screening, and in particular of the implications of those results for the family; and

(ii) the accepted standards of the confidentiality of medical information should be followed as far as possible.

10.9 When genetic screening reveals information that may have serious implications for relatives of those who have been screened, health professionals should explain why the information should be communicated to other family members. **We recommend that in such circumstances health professionals should seek to persuade individuals, if persuasion should be necessary, to allow the disclosure of relevant genetic information to other family members.** They should also seek to ensure that treatment, counselling and other appropriate support are made available to those to whom such unsought information is disclosed. (Paragraph 5.41 summarising paragraphs 5.23 - 5.31)

10.10 We note that both the law and professional guidelines provide for exceptional circumstances, when an individual cannot be persuaded to inform family members with a legitimate right to know. In such exceptional circumstances the individual's desire for confidentiality may be overridden. The decision can only be made case by case. **We recommend that the appropriate professional bodies prepare guidelines to help with these difficult decisions.** (Paragraph 5.42 summarising paragraphs 5.23 and 5.29 - 5.31)

10.11 **We recommend that the Department of Health should consider with health authorities and the appropriate professional bodies effective arrangements for the preservation of confidentiality, particularly in relation to genetic registers, and should issue the necessary guidance.** (Paragraph 5.43 summarising paragraphs 5.32 - 5.39)

III : Employment

10.12 At present, the use of genetic screening by employers in the UK does not appear to be a cause for concern. We have found evidence of only one existing screening programme : that programme can be justified quite readily on the grounds of safety, not only of those being screened but also of third parties. Nevertheless we recognise that the matter needs to be kept under review. **We recommend that the Department of Employment keeps under review the potential use of genetic screening by employers.** (Paragraph 6.27 summarising paragraphs 6.24 - 6.26)

10.13 Subject to prior consultation with workplace representatives, and with, as necessary, the Health and Safety Commission, **we recommend that genetic screening of employees for increased occupational risks ought only to be contemplated where:-**

(i) there is strong evidence of a clear connection between the working environment and the development of the condition for which genetic screening can be conducted;

(ii) the condition in question is one which seriously endangers the health of the employee or is one in which an affected employee is likely to present a serious danger to third parties;

(iii) the condition is one for which the dangers cannot be eliminated or significantly reduced by reasonable measures taken by the employer to modify or respond to the environmental risks.

Although it may be appropriate to introduce a genetic screening programme on these limited grounds, it should only be done if accompanied by safeguards for the employee, and after consultation with the coordinating body recommended in paragraph 10.20. (Paragraph 6.28 summarising paragraphs 6.20 - 6.23)

IV : Insurance

10.14 Our recommendations about the use of genetic screening and genetic tests by insurance companies follow from the following considerations:-

(i) the difficulty of assessing what may be slender evidence on the genetic susceptibility of individuals to develop polygenic and multifactorial diseases (for example, some cancers and some heart disease);

(ii) an awareness that ordinary commercial practice will lead companies to be over-cautious in their assessment of the risks derived from medical data; and

(iii) the possibility of abuse.

10.15 **We recommend that British insurance companies should adhere to their current policy of not requiring any genetic tests as a prerequisite of obtaining insurance.** (Paragraph 7.37 summarising paragraphs 7.22 - 7.25)

10.16 **We recommend that there should be early discussions between the Government and the British insurance industry about the future use of genetic data, and that pending the outcome, the companies should accept a temporary moratorium on requiring the disclosure of genetic data.** There should, however, be two exceptions:-

(i) first, in the case of those individuals where there is a known family history of genetic disease that can be established by the conventional questions about proposers' families, then individuals may be asked to disclose the results of any relevant genetic tests (paragraph 7.28); and

(ii) the moratorium should apply only to policies of moderate size. The limit would be a matter to be settled between the Government and the industry in the context of arranging the moratorium.

The importance of the discussions that are recommended is highlighted by the considerations set out in paragraphs 7.7 and 7.8. (Paragraph 7.38 summarising paragraphs 7.26 - 7.35)

V : Public policy

10.17 The threat of eugenic abuse of genetic screening requires safeguards. In a democracy, public understanding of human genetics should serve to create awareness of the dangers of eugenics, and of the possible stigmatisation of those carrying or suffering from genetic disorders. **We recommend the need for improving public understanding of human genetics should be borne in mind in any review of the National Curriculum and in the work of all public bodies concerned with the public understanding of science.** (Paragraph 8.23 summarising paragraphs 8.4 - 8.7)

10.18 We recognise that there are limits to the effects of educational work, however good. We, therefore, regard as essential to the safeguards against eugenic abuse our recommendations on **adequately informed consent, confidentiality** and the **central coordination and monitoring** of genetic screening programmes. (Paragraph 8.24 summarising paragraphs 8.20 - 8.22)

VI : Implementation of screening programmes

10.19 Further consideration needs to be given to the process whereby genetic screening programmes might be introduced into routine practice. As we have emphasised, existing screening programmes are largely pilot programmes. Pilot programmes should be governed by the ethical codes applying to research procedures.

10.20 **We recommend that the Department of Health in consultation with the appropriate professional bodies formulate detailed criteria for introducing genetic screening programmes, and establish a central coordinating body to review genetic screening programmes and monitor their implementation and outcome.** (Paragraph 9.7 summarising paragraphs 9.1 - 9.4)

10.21 As a contribution to the discussion of criteria for screening programmes, we suggest they should include the following:-

(i) the aims and purposes of the entire programme;

(ii) the predictive power and level of accuracy of the particular screening test;

(iii) the value to those being screened of the knowledge gained. For each programme this should have been researched as an integral part of the follow-up to the pilot programme;

(iv) the availability of therapy for the particular condition, accepting that lack of treatment does not necessarily mean that screening is not worthwhile;

(v) the potential social implications; and

(vi) the resource costs.