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Mental Disorders & Genetics: The Ethical Context

Response to the Nuffield Council on Bioethics Inquiry

This submission was prepared by a group of Fellows and other experts under the Chairmanship of Professor P.J. Lachmann. The other members were: Dr B.M. Cattanach, Professor the Reverend G.R. Dunstan, Professor M.A. Ferguson-Smith, Professor P.A. Jacobs, Professor J.M. Newsom-Davis, Sir Michael Rutter and Sir David Weatherall. It has been endorsed by the Council of the Royal Society.

We note that many of the issues raised in the scope of the study of the Nuffield Council on Bioethics Working Party are of general ethical concern, and could be applied equally to diseases with a genetic component unrelated to mental health. We feel that the general issues have been adequately dealt with in Nuffield's earlier report on Genetic Testing, the majority of whose recommendations we broadly endorse. The Royal Society has in the past also commented on the general issues related to human genetics in two submissions to the House of Commons Select Committee on Science and Technology. They are enclosed for your information.

In this submission our comments extend to a few suggestions on the scope of the study, and some general comments that we feel are worth raising in the current context, but are mainly limited to issues that we feel are particularly relevant to genetics and mental disorders.

SCOPE OF THE STUDY

We largely concur with the boundaries set for the study, and would endorse the view that social deviance should be excluded from the definition of mental disorder, but would suggest some modifications as follows.

Regarding section 3.5 of the "Scope of the Study": we would suggest that the list of "techniques used in genetic research" (at Annex A) might usefully include cytogenetics and high through-put analyses of gene expression.

Regarding section 3.6: we agree that the interactions of the genetic and environmental influences on mental disease should be clearly recognised.

Regarding section 4.1: we believe that it is inevitable that genetic information will be used to identify sub types of disorders, even though genetic information will not necessarily provide a sufficient basis for diagnosing and classifying mental disorders. Although molecular genetics may clarify the boundaries between different conditions with similar symptoms, a single gene defect can also produce diverse phenotypes.

Regarding section 5.1: Given the current difficulty in interpreting the complex of interacting factors, including genes, that lead to mental disorders, we do not

consider that attempts to link genetic markers with characteristics such as crime are likely to be productive. However, it may be possible to make inferences between genetically influenced personality attributes and the risk of a number of consequences arising from them.

GENERAL POINTS

Regulation

The current paucity of information on genetics and mental disorders suggests that it is too early to try to develop detailed ethical frameworks. Nonetheless it is important to identify the issues that may arise. We see no good reason to discourage research into links between genetics and mental disorders but recognise that the application of the results of such research may give rise to ethical questions and require regulation. It is in the application of research that moral responsibility must be applied.

Material Held in Databases

Although no really new issues have been raised by the ability to sequence DNA some unresolved issues remain. One such relates to material held in databases and the consent that was given for collection of that material. Opportunities now exist to attempt to answer questions by revisiting stored material armed with new techniques. This material will however have been collected for a specific purpose and consent will have been granted on that basis. We recognise that the rights of the patient must be protected but realise that if specific consents were required for each additional use valuable databanks might become unusable. We suggest that the problem of consent is not acute in anonymised databases when no interest of patients is threatened. However, re-examination of banked material should require the approval of an independent ethics committee. We would stress that researchers proposing a study should not judge their own case.

Genetic Counselling for Mental Disorders

We believe that the principles governing counselling for genetics and mental disorders are no different from those for other disorders. Judging risks and benefits, gauging competence to understand and act, and assessing any broader ramifications of imparting the information are all a question of applying good practice. We would stress, however, clinical tests should be carried out only when there is a sufficient knowledge base to recognise the significance of the data.

Emphasis must be placed on understanding the probabilistic nature of genetic information. It is particularly important that a predisposition to a disease of late onset in adult life be interpreted for what it is - as representing a risk of suffering some level of incapacitation towards the end of what otherwise may be a normally healthy and productive life.

We also consider that counselling must be provided for individuals and not populations as characteristics related to life style or race may also influence the consequences of harbouring a particular trait. A necessary condition is, therefore, that counsellors be adequately trained to tailor their advice to the particular needs of the individual. In addition to counsellors, those professionals whose duty it is to care for and advise patients (e.g. clinical psychologists, psychiatrists and psychotherapists) should be made aware of the implications of genetic research.

A further point is related to resources. Ideally each individual involved in a screening programme should be fully appraised of its purpose and counselled on the possible consequences of its outcomes. However, because the results for most individuals will give no cause for concern, this "preparation" counselling may not be the best use of resources, especially in conditions where medical resources are scarce. Careful consideration should therefore be given to appropriate counselling for the activity in question.

ISSUES OF PARTICULAR IMPORTANCE TO GENETICS & MENTAL DISORDERS

Competence

Competence to judge the implications of taking part in research or to deal with the information and the consequences that may stem from it is an issue for all areas of research. However, an issue peculiar to genetic research is that results obtained from one family member may be directly applicable to other family members. The competence of the person agreeing to the test therefore becomes of greater significance.

We concur with the Nuffield Council's view of the importance of safeguards for individuals deemed incompetent, but feel that the statement that "it is important that individuals are not excluded from research by virtue of impaired competence when the research is of specific relevance to them" also should be stressed. Researchers should be required to justify the selection or exclusion of participants in their studies to independent ethics committees.

Disclosure of Information

There is a danger of confusing the emotional feelings of individuals with "rights". We believe that all genetic information arising from research should be scrutinised and the benefits and disadvantages of patients having access to it should be carefully considered. Information should not be passed on unless it can be properly interpreted and explained - and if it is to be made available to patients the probabilistic nature of genetic information must be stressed.

Withholding clinically significant information from the patient concerned is probably unlawful, although in the UK informing the subject's General Practitioner is a proper alternative. An individual becoming aware of such information at a later date may have grounds to take legal action against the physician/researcher should they feel disadvantaged by not having known the result of a particular test. Problems of non-disclosure would not arise if experimental data were anonymised. However, this process entails the risk of not being able to attribute information that might be beneficial to participants.

Of prime importance is that clinical discretion can be exercised to choose the best course of action. Patients' confidence in the ability of those in the medical profession to make sound ethical decisions has been eroded. To enable the effective management of sensitive information for the benefit of the patient will require the urgent restoration of public confidence in clinical discretion.

Implications of the Use of Genetic Findings

Regarding access to insurance, employment, education and healthcare: we would suggest that in most cases the issues are not substantially different from those for other diseases. The distinctive issue may be the difficulty of purchasing insurance for chronic care. With the increase in incidence of diseases of later life accompanying greater longevity the

ability to identify risk by genetic testing makes insurance in this area especially problematic. The Royal Society recently hosted a discussion meeting jointly with the Faculty and the Institute of Actuaries where the implications of the use of genetic findings were discussed. The proceedings of that meeting will be published in *Philosophical Transactions of the Royal Society Biological Sciences* in August 1997.

The possibility of stigmatisation, as a result of being at risk of a certain condition, should be kept under review. Much information related to susceptibility to certain diseases is already available, although little use has been made of it and it has not incurred special attention. If, however, certain genetic information were to start carrying with it a stigma then the correct response would be via education of the public of the true nature of the information and its consequences.

In conclusion we would like to emphasise the widening gap between genetic knowledge concerning disease and susceptibility to certain diseases, and the ability to do anything about them. Disclosure of information to individuals without being able to act upon it could be very damaging. In the short term, and until appropriate treatments become available, there is a real danger of knowledge of some types of genetic information being more worrying than beneficial.