Editorial – a personal view

Ethics of genetic screening: the first report of the Nuffield Council on Bioethics

Raanan Gillon  Imperial College Health Service and St Mary’s Hospital Medical School, London University

The first report of the UK’s nearest equivalent to a national bioethics committee was published at the end of last year. In the report – on ethical issues in genetic screening (1) – the Nuffield Council on Bioethics, through its working party, makes recommendations concerning informed consent, disclosure of results and confidentiality, employment, insurance, public policy and the implementation of screening programmes. The recommendations – summarised briefly below – are liberal, commonsensical and humane. The report disappoints, however, by the relative lack of academic rigour of its argument and justification for its conclusions.

Adequately informed consent, states the Nuffield Council, should be a requirement for all genetic screening programmes, and should include information about the possible implications of screening for other family members. Information should be both oral and written, and counselling, normally ‘non directive’, should be ‘readily available’. Evaluation of the effectiveness of different approaches to provision of information and obtaining of consent ‘should be built into all screening programmes’. The council urges government to acknowledge the considerable resource implications of these recommendations, which include additional training in genetics and genetic counselling of primary care workers.

On disclosure of results of tests and confidentiality the council recommends that individuals being screened should normally be fully informed of the results of tests ‘for the disorder being screened for’. However, ‘Difficulties can arise when the screening process yields results which are unexpected, unwanted and have not been covered by consent’ – for example unsought-for chromosomal abnormalities or non-paternity. Such findings can produce ‘ethical dilemmas for which there are no easy answers, or indeed any correct answers’.

The same applies, says the council, to dilemmas arising when the individual screened refuses to allow other family members to know results of the genetic screening that might be of major importance to them. For example, other members of the family may carry a gene for a severe disorder, knowledge of which might alter their approach to reproduction (for example, cystic fibrosis, thalassaemia or Tay-Sachs disease); or they may themselves be at risk of a severe genetic disorder whose manifestations may be fatal and preventable (for example, familial colon cancer or breast cancer) or fatal and unpreventable (for example, Huntington’s disease).

Where screened individuals are reluctant to pass on important genetic information to family members the council believes it is the responsibility of the health professional concerned to ‘seek to persuade individuals, if persuasion should be necessary, to allow the disclosure of relevant genetic information to other family members’. Where such persuasion is unsuccessful, and where the information ‘may have serious implications for relatives’, exceptionally ‘the individual’s desire for confidentiality may be overridden’. Such decisions can only be made case by case, and the council recommends ‘that the appropriate professional bodies prepare guidelines to help with these difficult decisions’.

In the context of employment the council states: ‘We see no reason why people should be required by employers to undergo genetic screening unless the illness or condition will present a serious danger to third parties. Where the concern is limited to the health of the employee it should be a matter for the individual employee to decide whether or not to participate in the screening programme’.

The council envisages the introduction of justified genetic screening programmes by employers, and recommends that the Department of Employment keeps under review the potential uses of such screening. Conditions recommended by the council for the introduction by employers of any genetic screening are: strong evidence of a clear causal connection between the working environment and the development of the condition being screened for; a serious risk to the health of the employee or a serious risk to third parties resulting from the employee’s condition; a condition for which the dangers cannot be significantly reduced by reasonable measures on the employer’s part; safeguards to the employee (including the right to refuse to participate in screening for conditions where the health of the employee is endangered but others are not; and including procedures to ensure fair treatment, and assistance
in the event of the need for redeployment). In addition the council recommends prior consultation with workplace representatives and, as necessary, with the Health and Safety Executive, and with a national co-ordinating body on genetic screening which the council recommends should be set up, before any genetic screening programme is introduced.

On insurance the council recommends a 'temporary moratorium on requiring the disclosure of genetic data' – with two exceptions. The first is in cases where there is already a known family history of genetic disease, establishable by straightforward questions as at present. The second is where policies are for large sums of money (here the council gives as an example the level of £65,000 set for a similar moratorium in the Netherlands – which would exclude a large number of house-buyers in the UK who are likely to need life insurance for considerably more than this sum).

In the area of public policy the council states that: 'The threat of eugenic abuse of genetic screening requires safeguards'. To provide them the council recommends better education in schools about human genetics and awareness by all public bodies concerned with the public understanding of science of the need for better public understanding of human genetics.

In addition to emphasising its recommendations concerning adequately informed consent and confidentiality, the council recommends that government should establish a central co-ordinating and monitoring body to review genetic screening programmes, including pilot programmes, and to monitor their implementation and outcomes.

The council’s report is packed with good common sense. None the less, compared to the 'gold standard' for reports from national bioethics commissions, notably those of the US president’s commission on bioethics (2), there is a relative inadequacy in this publication of thorough, sustained argument. In ethics particularly, justification based on argument in the context of the strongest available counterarguments is a sine qua non. The president’s commission reports combined both the brief civil service type of argumentation characteristic of the Nuffield Council’s present report and extensive, rigorous and sustained ethical, jurisprudential, sociological, religious and other argument, stemming from stated moral premises, and taking into account strong counterarguments to their own positions. In addition, several of the president’s commission reports were published with substantial supplementary appendices containing background papers, sometimes including empirical as well as theoretical work commissioned or prepared by the commission, on the issues considered. And their referencing, academic and non-academic (as well as their indexing) was considerably superior to that of the present report.

As examples of the relative lack of argument in the present report it is sufficient to consider the issue of release of genetic information to potentially seriously affected family members. The council hardly acknowledges the existence of arguments in favour of maintaining absolute confidentiality of patients’ genetic test results (unless the patient allows them to be divulged). And at the other end of the spectrum it dismisses both legislation to require sharing of such test results with family members in limited circumstances and it also dismisses the possibility that prior agreement to such sharing should be a condition for obtaining genetic screening within national health services.

The council’s minimal argument against legislation is stated in a few lines; and it presents no argument at all against making appropriate sharing with family members a condition of screening, other than: 'Inevitably some individuals will refuse to allow disclosure and this can present the doctor or health professional with an ethical dilemma'. A potential national bioethics commission can reasonably be expected to provide more thorough counterarguments to the proposals it rejects – and perhaps especially so in relation to proposals argued for by other national bioethics commissions.

To be fair to the new council, it has a tiny permanent staff (the US president’s commission had a large multidisciplinary academic staff) and the councillors themselves are all eminent and thus very busy professionals. None the less, if the Nuffield Council on Bioethics is to fulfil its potential of becoming the equivalent of Britain’s national bioethics commission it surely needs to support the summary and in many ways admirably commonsensical arguments characteristic of the present report with more rigorous ethical argument. This, preferably, should be summarised in the main body of the report and provided more extensively in appendices, fully referenced (and indexed), and with genuine efforts to present as strongly as possible arguments opposed to their conclusions.

As a start, the many submissions presented to the council on the subject under report could in future be published, in whole or in rigorous summary of their contained arguments, with explicit counterarguments being provided against those arguments which the council rejects. In addition, full summaries of relevant arguments from the existing literature might be published, and academic papers giving all the relevant arguments, and their assumptions, in the various relevant disciplines, could either be prepared by an extended academic staff of the council, and or be commissioned from some of the many academic centres now specialising in bioethics as well as in medical law, medical sociology, religion, medical economics and other academic disciplines, as all these disciplines impinge on bioethics. And the council’s own ethical assumptions should at least be...
We believe that both the Californian courts and the drafters of the HFEA have failed to recognise the two important elements of maternity. A child with separate birth and genetic mothers has two mothers. It may be in its best interests that custody and perhaps also visiting rights are only given to one of them. If so such decisions should be made on relevant criteria, such as the best interests of the child or review of the contractual state of the parties. The problem cannot be sidestepped by arguing that only birth or genetic motherhood is significant since, as we have shown, people seem to regard them as approximately equally important.

J G Thornton, MD, MR CoG, DT MoH, is Senior Lecturer/Honorary Consultant in Obstetrics and Gynaecology at the University of Leeds. H M McNamara, MB, D Ch, DObs, is Registrar in Obstetrics and Gynaecology, Barrington's Hospital, George's Quay, Limerick, Ireland. I A Montague, MB, is Registrar in Obstetrics and Gynaecology at Bradford Royal Infirmary. All correspondence to Dr Thornton at the Institute of Epidemiology and Health Services Research, Leeds University.

References

News and notes
Medical law journal launched

Medical Law Monitor, a new journal, was launched in January with an introductory issue which summarises 'some of the most important developments in medical law in the last year'. The journal aims to inform readers as to significant case law, legislative and procedural changes and also to 'analyse the implications of these changes for the providers of healthcare'.

The journal will be published ten times a year by Monitor Press, Rectory Road, Great Waldingfield, Sudbury, Suffolk CO10 0TL. The editor is Julie Stone.

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explained and where possible justified. What, for example, does the council mean by 'solidarity' and by 'equity'? These ethical terms are open to widely disparate interpretations.

Of course, had the council carried out such an exercise for the current report its conclusions may well have remained unchanged. However, it is the justification of conclusions in the light of the strongest available counterarguments that is at the heart of bioethics. From that perspective the Nuffield Council on Bioethics has not - in its first report - yet measured up to, let alone surpassed, the 'gold standard' of such reports provided by the US president's commission on bioethics over ten years ago.

References