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From the Biological Secretary and Vice-President Professor PPG Bateson FRS
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Dear Mr Farrar

The Genetics and Insurance Inquiry

The Royal Society welcomes the opportunity to comment on this important subject. First I should like to highlight the main issues that we believe ought to be addressed by Government

- To what extent should insurance companies' access to test results be balanced against the need to protect individuals? If the insurance industry does have access then special provisions should be available to the public to cope with any consequences.
- If the insurance industry are allowed to demand access to test results are we abandoning the principle of medical confidentiality? If yes, what are the wider implications of this?
- There is a clear need to separate the implications for health from life insurance. The National Health Service provides satisfactory cover to all individuals with diseases such as cystic fibrosis and we believe it is extremely important to maintain such universal coverage.
- Not all genetic tests are suitable for use by the insurance industry. In many cases genetic tests that will determine surgery or treatment should be totally irrelevant to insurers because the condition can be treated. Genetic tests should be considered on case-by-case basis.
- To protect research in this area the public needs to be confident if and how test results will be used.
- Self-regulation is not an adequate regulatory system.

In answer to the questions outlined in the enquiry

1. What effect could the use of test results by insurance companies have on research in the UK?

The real problem is not so much the "use" of test data but the requirement to disclose all test results, even though insurers are not in a position to use them. Without some move by the insurance industry to allay public fears, the effect could be, and maybe already is, to make it significantly more difficult to recruit research subjects. This may be a particular problem for the proposed large-scale population-based studies, where people do not necessarily have the motivation provided by having a genetic disease in the family. Research ethics committees may want to include warnings about insurance risks in consent forms.

The problem lies in the public perception rather than in real disadvantage, because:

- (a) the question only arises when research subjects are told their test results, which in most cases they are not. However, it may be difficult to refuse information if requested by the individual, and this may then impose the obligation on the individual to reveal the information to an insurance company. In our view this should be prevented.
- (b) insurers should use only tests approved by Genetics and Insurance Committee (GAIC) to adjust premiums;
- (c) GAIC is very unlikely to approve tests that are not already fully researched;
- (d) it is hard to imagine a research project that would use a fully validated test, communicate the results back to subjects, but not do the actual testing within a service framework (typical projects would explore psychosocial effects of diagnostic testing).

People exaggerate the predictive power of genetic data, and they don't trust insurance companies. A statement from the Association of British Insurers (ABI) that research results **will not be used**, and **need not be declared**, would be very helpful. "Research" would need careful definition, but discussion among geneticists suggests this is not an insuperable problem.

2. To your knowledge, what scientific evidence have those involved in the area (Government, insurers, regulatory bodies etc) based their decisions upon, and how reliable is it?

There is a widespread belief that **insurance companies** often make decisions based on inadequate scientific data (Low, King & Wilkie, *BMJ* **117**:1632-5;1998; for a US perspective see Wertz, *Health Law Review* **7**: 7-8). The ABI Code of Practice should prevent this, and most alleged examples are undocumented. The ABI has agreed among themselves a list of 7 conditions for which test results could be used to modify premiums; this selection appears arbitrary. Any decision on which diseases should be considered must be left to a body independent of the industry and indeed at arms length of Government.

As regards **regulatory bodies**, GAIC requires very detailed scientific justification for all proposals, which are then subject to thorough external review (though they may well need to

pay reviewers professional fees to keep up this level of reviewing). The example of Huntington disease, which involves the most clear-cut scientific issues, shows just how demanding a proper review of complex subjects like cancer susceptibility will be. It is doubtful that collecting data on low-penetrance (susceptibility) genes will be approved by GAIC.

Multifactorial diseases, where a gene confers an increased susceptibility to a disease (but is not the only component), are of little if any relevance for life insurance. Screening for such diseases will only be undertaken where there is evidence for a clear beneficial 'treatment' of those at risk e.g. diet or blood pressure reducing drugs for heart disease. In such cases the increased risk of those individuals identified as genetically susceptible can be brought down to more or less normal level. Since the insurance industry is interested in a 50% increased risk or greater, any genetically identified component of multifactorial disease susceptibility should, especially if targeted with prevention, be of no interest for life insurance.

3. How effective do you feel the current regulatory system is?

Being voluntary, it depends on the continuing vigilance and goodwill of all players. The following questions need to be considered:-

- Are the ABI's systems of self-regulation and appeals procedure effective?
- What are non-ABI insurance companies doing?
- The ABI's refusal to observe a moratorium on their 7 tests when the GAIC mechanism was set up suggests that the system is not powerful. At the moment the most effective deterrent to abuse is the large number of people who have a hopefully exaggerated view of the wickedness of insurance companies, and who would dearly like to name and shame companies that do anything wrong.
- In our view voluntary agreement amongst the insurance companies is not enough and a regulatory framework is required.

In addition, a quite separate and very important political question is raised. To what extent should life's uncertainties be covered by mutuality-based insurance, and what extent do they require protection by a state run scheme?

This is of particular relevance when considering what does one do about life insurance for the severe, later-onset, simply inherited diseases such as Huntington's disease. Should there be legislation which proscribes the use of genetic information for the calculation of life insurance premiums, except in the case of an approved list of such diseases? The approved list of diseases would accumulate by case law and that solidarity may then be achieved by a variety of mechanisms including reimbursement, by the Government, of insurance companies for providing normal cover notwithstanding the altered risk, and also by appropriate social services cover for special care.

Please do not hesitate to contact me if you require any further information
Yours sincerely

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