

AMRC Response to House of Lords Science and Technology Committee: Genomic Medicine

The Association of Medical Research Charities (AMRC) welcomes the opportunity to submit evidence to the House of Lords Science and Technology sub-Committee on genomic medicine.

Established in 1987, AMRC is a membership organisation of the leading medical and health research charities in the UK. Its 115 member charities fund research to tackle diseases including heart disease, diabetes, and rarer conditions like cystic fibrosis and motor neurone disease. In developing our response we have consulted with our member charities and their comments have been incorporated. A number will have made their own representation, given their experience in this field as funders.

It may be of interest to the committee to know that AMRC holds data on all research activity conducted by our members. Our data shows that 16 of our member charities have or are funding genomic –type research totalling £80m between 1995 and 2006, of which £43m was spent on specific programmes and projects. Separately, the Wellcome Trust – AMRC’s largest member charity - spends a significant amount on genetic and genomic research alone.

We would like to make the following general comments in response to the questions and issues raised by the committee.

1. Policy Framework

- 1.1. In general AMRC and its member charities believe that the policy framework for Genomic Medicine in the UK is inadequate.
- 1.2. There is a lack of cohesion around policies relating to the area and poor communication generally on the emerging policy approach.
- 1.3. More specifically, the current regulatory framework on issues such as ‘consent’ is in danger of having a negative impact on research in this area and hamper progress in a number of areas by hindering the use of existing samples, lowering recruitment rates, and increasing the cost and complexity of studies.

2. Research and Scientific Development

- 2.1. Genomic medicine is in its infancy compared to other areas of scientific inquiry. Nonetheless it is important that the right balance is struck between advancing the basic science agenda while ensuring that this is focused on ultimately delivering benefits in the greatest areas of patient need.
- 2.2. Some of our members have expressed the view that there is a strong case for developing a proper investment framework on genomic medicine to ensure appropriate funding of agreed priorities.

3. Data Use and Interpretation

- 3.1. Although there would seem to be some value in developing a common, public database which is publically funded and linked to similar initiatives in other countries, it is important that appropriate safeguards are in place to protect against abuse of such a database.
- 3.2. It is critical that any data is known to be reliable and credible before a safe and effective database is established for wider use. This is not the case currently: medical information is often not recorded in a suitable format, due to confidentiality issues and difficulties in accessing medical information.

4. Biomarkers and Epidemiology

- 4.1. In general we believe that it is too early to tell in what way genome-wide association studies might contribute to the identification of biomarkers.
- 4.2. A number of charities are working to address this issue through directional research funding for identification and to obtain the necessary evidence of clinical evaluation of new and complex biomarkers, working with the Department of Health, MRC and industry.

5. Use of genomic information in a health care setting

- 5.1. AMRC and its member charities believe that genomic medicine has the potential to be useful as part of individualised medical advice. However, provisions for ensuring that the individual will be able to understand and manage genomic information will need to be put into place. Thus, use of genomic information would be currently unregulated and therefore opportunistic. Once appropriate guidelines and parameters are in place this will help doctors and individuals decide how meaningful genetic tests are.

AMRC and its member charities welcome the Committee's investigation into genomic medicine and look forward to its conclusions and recommendations. AMRC believes that the Committee's inquiry will be useful in establishing an agenda for the future action that could be pursued in a collaborative way by all interested parties.