The response reproduced below was submitted further to a consultation held by the Nuffield Council on Bioethics on its Report: Pharmacogenetics- ethical issues, during November 2002 – February 2003. The views expressed are solely those of the respondent(s) and not those of the Council.

Alzheimer's Society, UK

The use of genetic information raises important public, social and ethical issues and the Alzheimer's Society welcomes the Council's enquiry into pharmacogenetics.

The Alzheimer's Society is the leading care and research charity for people with dementia and their carers. It was founded in 1979 as the Alzheimer's Disease Society. It provides information and education, support for carers, and quality day and home care. It funds medical and scientific research and campaigns for improved health and social services and greater public understanding of dementia.

The Society has over 24,000 members and operates through a partnership between some 250 branches and support groups and the national organisation in England, Wales and Northern Ireland. The Society brings together carers, family members, health and social care professionals, researchers, scientists and politicians through shared concern for people with dementia and those who care for them.

There are over 700,000 people with dementia in the UK. Dementia affects one person in 20 aged over 65 and one person in five as they reach 80 years of age. As the population ages so the number of people with dementia will grow. There are over 18,000 people with dementia aged under 65 years of age in the UK.

I have enclosed the Society's response to the Human Genetics Commission's consultation on the use and storage of genetic information. It outlines the Society's position on a number of related issues, such as why insurance companies should not have access to genetic information. In addition, it explains why genetic information should be treated differently to other types of personal health information.

The Society has long campaigned against genetic discrimination. People with all forms of dementia are vulnerable to genetic discrimination – both perceived and real. Moreover, the Society remains concerned that the Association of British Insurers is still applying for the genetic tests for Alzheimer's disease to be approved by the Genetics and Insurance Committee.

There are now four drug treatments licensed for the treatment of Alzheimer's disease in the UK. About half those who try these drugs do gain some benefit, but there is no way of predicting who will benefit in advance. The potential of pharmacogenetics remains an active area of research in treatments for Alzheimer's disease and other dementias. However, to date, this has not been a fruitful area of research. The Society anticipates that this situation will continue for the immediate future.

The consultation document points out that pharmacogenetics is likely to predict probability of response, for example it may tell you that you have a 30% chance

of the drug working, rather than anything more definitive in terms of a treatment effect for an individual. As a result, it is likely that people affected by a condition such as a dementia, with little alternative treatment available, will still want to try a drug treatment – even if they know that the rate of success might be low.

People with dementia already experience high levels of discrimination in terms of access to drug treatments. This is a result of discrimination on the grounds of age as well of negative attitudes towards dementia. Exaggerated claims about the cost of the treatments for dementia have led to strict prescribing guidelines that restrict access to drugs on a scale not seen with drugs of similar cost and efficacy.

Pharmacogenetics may, in the future, provide additional information to help make an informed decision. In the short term, we believe that this is unlikely and may only lead to further discrimination. The Alzheimer's Society believes that it is also likely to restrict access to medicines and would not support any further moves to limit the numbers of people who have the opportunity to try drug treatments. Dementia care is subject to very high levels of privatisation at the moment. People with dementia have to pay for substantial amounts of health care, as well as access to drugs via private prescriptions.

Given the current context with regards to access to genetic information, the Society is not convinced that people should only have access to genetic information through health professionals as part of a decision about the use of a prescribed medicine. While it is beneficial for everyone to have access to appropriate genetic counseling and information, there may be financial implications of accessing information through medical professionals. As a result, the Society understands that some people with dementia may wish to prevent wider access to personal genetic information.

The Society believes that the Government's decision to allow insurers to take into account the results of genetic tests will have adverse consequences for people with Alzheimer's disease. It will increase social exclusion, fail to protect consumers and contribute little to improving public health.

The Society would support a position that patients should be able to refuse a genetic test to determine response to medicines and still expect to receive a prescription. Patients should be given full information as to the adverse side effects and make a decision on that basis.

The Society supports the use of anonymised data as part of research. If a particular genetic test with clinical relevance was identified, participants should be offered the opportunity to be re-tested in a clinical setting as opposed to a research setting.

Full consent should be given for the collection of genetic material. The issue of consent has wider implications for people with dementia. The Society believes

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that new legislation is needed urgently to protect people who do not have capacity to consent. The Society is campaigning for the introduction of continuing powers of attorney which would enable a person with dementia to nominate a health proxy to make decisions about participation in research on their behalf when they are no longer able to do so.