

1st October 2009

Christine Salmon Percival
Clerk of Science and Technology Committee
House of Lords
London SW1A 0PW

Dear Ms Salmon Percival

House of Lords Science and Technology Select Committee call for evidence: Setting science and technology research funding priorities

I am pleased to attach a response from the Nuffield Council on Bioethics to the above call for evidence.

We focus in the response on relevant findings from the Council's report *Dementia: ethical issues*, published on 1st October 2009, a copy of which has been enclosed with this letter. The report can be downloaded at: www.nuffieldbioethics.org/dementia

The report was prepared by a Working Party established in November 2007 to examine the ethical issues raised by dementia. To inform its deliberations, the Council held a public consultation and spoke to people with direct experience of living with dementia and those working in the field. Although our conclusions on research are made in the context dementia, we believe these to be relevant to a more general discussion on research funding priorities.

I hope that this is a helpful contribution to the inquiry. Please let us know if we can be of further assistance.

Yours sincerely



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Extracts from *Dementia: ethical issues* Executive Summary

[Paragraph numbers correspond with paragraph numbers in the report]

Introduction

2. About 700,000 people in the UK currently have dementia, and this is likely to increase to 1.7 million by 2051. Its prevalence increases rapidly with age, affecting about one in five of us by the age of 85. In addition to its profound personal and social impact, dementia has significant financial implications for those with dementia, for their families and carers, and for our health care and social care systems. In the UK the overall annual economic cost of late-onset dementia is estimated at over £17 billion.

How should research be prioritised?

59. The levels of funding available for dementia research have been strongly criticised, given both the prevalence and burden of dementia. The priority given to different forms of research within dementia (such as basic research, development of treatments, prevention, social science research and research into the quality of care) is also a key issue, especially as different types of research have the capacity to benefit quite different groups. Prevention and cure, for example, both seek primarily to benefit future generations, while research focused on quality of care has the potential to benefit people with dementia in the near future.

60. We are aware of the difficulties inherent in making comparisons between the funding available for research into dementia and funding available for other conditions. Nevertheless, we are struck by the fact that the major research funding bodies within the UK do not appear to have explicit policies according to which they allocate funds between different conditions, focusing rather on research excellence and the 'importance' of the topic. While it is clearly appropriate that funding bodies support important and high quality research, criteria such as these do not, alone, ensure a just distribution between the needs of different parts of the population. **We believe that major research funders should be more explicit as to how they divide their research funds between areas of research that have the capacity to benefit very different groups of the population. Given the social and economic impact of dementia, we believe that a more explicit approach to research priorities would be likely to lead to significant increases in research funding for dementia. If such an increase were not to be matched by research applications of the necessary high standard,**

then active steps should be taken to develop and promote research capacity in the relevant areas (paragraph 8.17).

Recommendation 15: We recommend that the major research funders develop, and articulate, a reasoned basis for the division of their research funds between areas of research which have the capacity to benefit very different groups of the population. We further recommend that, if necessary, they take active steps to promote and sustain the creation of research communities capable of carrying out high-quality research. (Paragraph 8.17)

61. On the question of how funding should be prioritised *within* dementia research, we recognise that it is difficult to give one type of research priority over others. We would, however, make the following observations:

- Research into the effectiveness and transferability of different models of care and support for people with dementia is relatively neglected. Yet research into these areas is crucial if people are to be supported to live well with dementia. This is particularly important given that the prospect of a real cure for dementia is highly elusive.
- There are widespread concerns about the outcome measures used when assessing the effectiveness or cost-effectiveness of a particular treatment or service.
- It is crucial to understand better how people with dementia and their carers live with dementia, how dementia affects them throughout the course of the disease, and how their quality of life could be improved throughout those stages. Social research in this area is an essential starting point for both the research into care models and the development of sensitive outcome measures described above. More research into the effects of stigma and how stigma can best be challenged would also be highly valuable.
- All those involved in caring for people with dementia need better access to education and support in order to respond to the ethical problems they encounter on a daily basis. Further research is required on how best to achieve this aim.
- Research into non-Alzheimer's dementias lags far behind that into Alzheimer's disease.
- Research into preventative strategies appears to receive too low a priority.

Recommendation 16: We recommend that relevant research funders consider ways in which the level of funding for dementia research could be increased in the following areas: health services research into how people with dementia and their carers can best be supported to live well, how mainstream services can best be adapted to their needs, and how good practice can more readily be implemented; more meaningful outcome measures for assessing the effect of particular forms of treatment or service; research into how best to improve the provision of support for ethical decision

making; all forms of research for the non-Alzheimer's dementias; and research into preventative strategies.

Recommendation 17: We particularly highlight the importance of social research in providing an evidence base to underpin better ways of supporting people with dementia and their carers. We recommend that funding bodies such as the Economic and Social Research Council, in partnership with others, take active steps to encourage further research into issues such as how people live with dementia, the nature of their experience and the quality of their lives; how stigma can best be challenged; and how those working in health and social care can best be supported in providing care which genuinely respects the personhood of everyone with dementia. (Paragraph 8.18)