

15 February 2010

Ms Emma Benson
Age Equality Team
Room 602, Richmond House
Department of Health
London
SW1A 2NS

Dear Ms Benson,

Age equality in health and social care

I am writing in response to your call for feedback on the non-legislative recommendations of the South West Review on the issue of age equality in health and social care.

Drawing on the recently published report of the Nuffield Council on Bioethics on *Dementia: ethical issues*, I would like to comment on two points in the Department of Health's consultation document.

1. Paragraph 5.10 – further research on ageing

The Review states "we therefore call upon the Department of Health through the NHS National Institute for Health Research and its school for social care research to review the relevant guidance to ensure it is compliant with the Equality Bill, and promote further research on ageing".

The Council welcomes this recommendation. The amount of funding available for dementia research appears low, given both the number of people with dementia and the effect dementia has on people's lives. As such, the Council recommends:

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.

Recommendation 15, *Dementia: ethical issues*

Chair
Professor Albert Weale FBA

Deputy Chairman
Professor Hugh Perry FMedSci

Members
Professor Steve Brown FMedSci
Professor Roger Brownsword
Dr Amanda Buris
Professor Robin Gill
Professor Sian Harding FAHA FESC
Professor Peter Harper
Professor Ray Hill FMedSci
Professor Søren Holm
Professor Christopher Hood FBA
Dr Rhona Knight FRCGP
Professor Graeme Laurie FRSE
Dr Tim Lewens
Professor Ottoline Leyser CBE FRS
Professor Anneke Lucassen
Professor Alison Murdoch FRCOG
Dr Bronwyn Parry
Professor Nikolas Rose
Professor Dame Marilyn Strathern DBE FBA
Professor Joyce Tait
Geoff Watts
Professor Jonathan Wolff

Director
Hugh Whittall

Assistant Directors
Dr Alena Buyx
Katharine Wright

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 16, *Dementia: ethical issues*

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.

Recommendation 17, *Dementia: ethical issues*

2. Paragraph 7.14 – education and training

The Review recommends that “all organisations responsible for education and training in health and social care will need to ensure that their curricula and programmes enable staff and trainees to apply the law effectively in time for its commencement. We recommend that the providers of education develop ways of involving older people in the delivery of education programmes, especially to trainees at an early stage in their learning”.

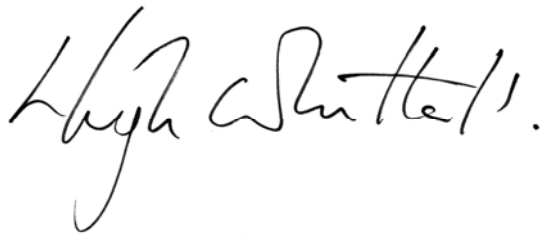
The ethical framework of our report highlights the value and individuality of each person with dementia, and that the nature of dementia creates dilemmas for all those involved in day-to-day care in how best to promote the person's autonomy and well-being in difficult circumstances. Accordingly, we recommend that all those involved in the direct care of a person with dementia – carers, care workers, health and social care professionals, and volunteers – should have access to the ongoing education needed to equip them to respond appropriately to ethical problems, and should also have access to forums for sharing and receiving support in making ethical decisions (paragraph 6.3, *Dementia: ethical issues*).

Complementing this conclusion, we also recommend that “the UK Departments of Health consider, as part of their dementia strategies and workforce planning, how all those involved in direct care of people with dementia can access appropriate education and support in ethical decision making” (recommendation 9, paragraph 6.3, *Dementia: ethical issues*).

The Nuffield Council’s report is available to download from the Council’s website at www.nuffieldbioethics.org/dementia. A copy will also be posted to you, along with a hard copy of this response.

Please do not hesitate to contact me if you would like further information or assistance.

Yours sincerely

A handwritten signature in black ink that reads "Hugh Whittall". The signature is written in a cursive style with a large, sweeping initial 'H'.

Hugh Whittall
Director