

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Dementia: ethical issues* between May 2008 and July 2008. The views expressed are solely those of the respondent(s) and not those of the Council.

Gordon Wilcock

I have looked at your document and don't have a lot to add. You have picked up all the main points.

I would however like to stress that people with dementia, sometimes even quite moderately severe dementia, often have an idea as to whether or not they wish to participate in research, and it is very important that they are consulted as well as those who are their carers or attorney.

It is not appropriate to exclude people from taking part in research if they completely lack the capacity to make this decision for themselves. Family members will often be able to tell you that they believe, or know, that their relative would have wished to have taken part in research if they had been asked earlier in their lives, i.e. before they lacked capacity. This I think is a more realistic way forward than just to make a blanket policy of not including people if they lose capacity.

As far as safeguards are concerned, it is important that everyone who takes part in research in this context has a significant other who can maintain an overview of what is going on, on behalf of the person with dementia. This is a role that is usually subsumed by the next of kin, but under the terms of the Mental Capacity Act it could well be someone else.

I don't have any further points, and would like to congratulate you on having covered the field so effectively.

Yours sincerely

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