

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.

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QUESTIONS ANSWERED:

Q10

ANSWER:

Unfortunately it has become rather a jargon term and not respected but the concept of individualised bespoke care remains essential and is of the essence.

Q14

ANSWER:

Same as question 13

Q13

ANSWER:

Even more effort at inclusion of the person with dementia and their carers in the efforts to achieve consensus on the best interests decisions should be made - though finally the decision maker must make a responsible decision.

Q28

ANSWER:

Decreasing respect for confidentiality seems to be pushing the balance towards too much information being given. The professional should make proper professional balance best interests judgements here.

Q29

ANSWER:

Research should address the cause (basic science and basic mechanisms), cure (approaches to treatment to slow, ameliorate, reverse or prevent) and care (the best approaches to care for the person with dementia (PWD), including evaluation of service provision and including addressing the needs of carers) - as advocated by the Alzheimer's Society. There needs to be more emphasis in research (positive discrimination) into dementia by public authorities (e.g. DH, NIHR, etc) and more encouragement of such funding from charities (e.g. Wellcome etc.), perhaps by incentives such as matched support from Government and/or from industry. Basic neuroscience must not be neglected but otherwise true scientific merit and likelihood of a beneficial knowledge outcomes should weigh heaviest. Evaluation of services and best care provision approaches must be given high priority, with more focus on qualitative study

and systems analysis evaluation in this area, particularly valuing "user/carer" views and involvement.

Q30

ANSWER:

It is essential for the good of all for such research to be encouraged. Significant altruism and wish to benefit society through participation in research have always been marked in the British population and PWD should not be deprived of opportunities to play their part, provided there are proper safeguards. The present safeguards, although slightly messily different and open to variable interpretation, are broadly reasonable and proper safeguards.

Q31

ANSWER:

The ethical justification for change could be achieving a better and more consistently applied balance for the PWD and/or achieving, with proper safeguards for the PWD, more effective research, readily applicable and especially to improve quality service provision and quality of life. There is a contradiction between having a common UK standard for Clinical Trials and differing language for non-clinical trials. This has allowed one independent research ethics committee, for example, effectively to suggest that a doctor could only screen cognitive function in a mildly demented (or possibly demented) individual if the doctor could also swiftly call on specialist old age psychiatry services (via special arrangements) if the subject were to suffer a psychological "catastrophic reaction" in this context - arguably over protective. Most would expect any doctor to be competent to handle such a reaction without extraordinary arrangements. This kind of variable interpretation of what may be "negligible risk" and how it should be handled could impede timely and effective progress of reasonable research. The case should be considered for a central ethical authority on such matters, either to consider projects centrally (UK-wide) or to ensure authoritative guidelines and interpretation, in order to avoid such local idiosyncrasies.