

ence their local research strategy as the bulk of NHS research funding is allocated, without reference to them, to secondary care organisations.⁶

Similarly, the financial support for primary care research is also a cause for concern. The 2002-3 allocation for primary care research was only a small proportion of the £540m NHS budget.⁷ In addition, the recent annual research and development report from the NHS ranked the primary care focus of current NHS research programmes poorly, with about one quarter ranking weak.⁸

The key to supporting primary care research lies in successful partnerships between primary care trusts and the academic sector. Because many primary care trusts do not currently have expertise in research, primary care research networks and academic departments ought to be natural partners for primary care trusts. The development of sites for the national network for the management and governance of primary care trust research offers a location for the coexistence of management, capacity building, and partnership.

Since the 1980s primary care research networks, which are multidisciplinary networks of general practices active in research, have formed an important part of the backbone of primary care research.⁹ Primary care research networks are unique in that they also offer a wealth of experience in research capacity building in community settings, which is precisely the need faced by primary care trusts.¹⁰

Many academic departments of primary care are keen to build partnerships with primary care trusts.¹¹ Such linkages would help universities build research capacity and enable primary care trusts to meet their education and research objectives. However, some medical schools fear that small scale, local health services research will not be highly rated in the impending research assessment exercise that will take place in 2007 and thus may be dissuaded from working with primary care trusts.

Many opportunities exist for primary care research and primary care trusts to have a central role in improving the quality of primary care in the NHS.¹² The new general practice contract has provisions that offer further opportunities for primary care trust leadership and collaboration in research and service development. Specifically, the new framework for the measurement of quality of care, requires substantial input and participation by primary care trusts. They will be responsible for developing data systems to track

and monitor performance of general practitioners and ensure that the quality framework functions.

Over the next few years, the National Programme for Information Technology will also be rolled out, leading to the eventual creation of integrated health records across primary and secondary care. The existence of these data, alongside data from the new general practitioner contract, creates major opportunities for primary care research.

An essential prerequisite to taking advantage of these opportunities is clear guidance on national and local research and development priorities for primary care. This in turn needs to be combined with adequate levels of funding, both centrally from the Department of Health and locally from primary care trusts. Evidence suggests that this is happening, for example, through the requirement that the new clinical research networks have strong input from primary care. However, if this does not occur, primary care research may decline further, leading to major long term adverse consequences for the NHS and healthcare systems overseas that rely on the NHS to provide evidence to support their own reforms.

Frederick Chen *Atlantic fellow in public policy*

Public Health Policy Unit, School of Public Policy, University College London, London WC1H 9QU
(fchen@u.washington.edu)

Azeem Majeed *professor of primary care*

Department of Primary Care and Social Medicine, Imperial College, London W6 8RP

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Specialist palliative care in dementia

Specialised units with outreach and liaison are needed

In its latest report on palliative care, the health committee of the House of Commons recorded the Department of Health's admission that the lack of palliative care for patients without cancer was the greatest inequity of all.¹ In the United Kingdom, people die in hospices almost solely from cancer, although it accounts for only 25% of all deaths.^{1 w1} Yet patients

dying from dementia have been shown to have health-care needs comparable to those of cancer patients.²

The palliative care approach provides appropriate control of symptoms, emphasises overall quality of life,

 Additional references w1-w18 are on bmj.com

takes a holistic approach, involves the patient and the family in decisions, and fosters good supportive communication between all concerned.^{w2} Hence, it equates to person centred care in dementia.^{w3 w4} Evidence suggests a palliative care approach in dementia is favoured by formal and informal carers.³ The wishes of patients themselves, however, are hardly known—although preliminary results show high rates of satisfaction when a palliative care approach is adopted.⁴

Palliative care in dementia would facilitate discussion about the diagnosis and thus allow subsequent care to be based on previously agreed goals, which could be modified periodically.^{w5 w6} Good communication would also involve families, where bereavement around dementia is different to bereavement following cancer.⁵

The palliative care approach should be integral to the management of all non-curative diseases, so this is hardly a controversial idea in connection with dementia. However, it is still worth voicing, given the evidence that the quality of care for people with advanced dementia is so poor.^{w7} The select committee commended the use of care pathways for palliative care.^{w8} A more controversial suggestion is that people with dementia require specialist palliative care. What might this entail?

Specialist hospices for people with advanced dementia, focusing on terminal care, have existed in the United States for some time. When compared with usual nursing care, patients with dementia experienced less discomfort in a palliative care unit, which was also cheaper.⁶ Specialist hospice dementia units tend to limit medical interventions, including both tube feeding and cardiopulmonary resuscitation,^{w9 w10} that inflict discomfort and do not provide unequivocal benefit.

Such units make the control of symptoms a priority. Research into whether or not antibiotics relieve distress in advanced dementia continues.^{7 w11} Some evidence exists that conservative management does not seem to hasten death.⁸ Despite instruments to detect it, pain is undertreated in people with Alzheimer's disease.^{9 w12} Adequate analgesia may help to combat behavioural disturbances in dementia.¹⁰ Research into these issues would be encouraged by specialist dementia palliative care units. But is this model all that is required?

The model would certainly serve a function, particularly in those people who die with dementia but from some other cause. Yet there are problems. Firstly, 41% of people with dementia die in nursing or residential care.² To move them in the terminal phase to a hospice might be deleterious. Secondly, identifying the terminal phase in dementia can be problematic.^{w13} Thirdly, most hospice staff feel undertrained to care for people with dementia.³ Finally, we do not know whether this model would be the one chosen by people with dementia and their carers.

Is there a need, therefore, for some alternative form of specialised palliative care in dementia? Firstly, a need exists for the palliative care approach to be pursued in all community and hospital settings. Dedicated teams would help to improve the skills in delivering palliative care more broadly to patients in the community.¹¹ Such teams could also support existing hospice personnel in managing people with dementia.

Secondly, the specialist expertise of such teams might focus on the management of behavioural and psychological signs in dementia (BPSD), which are ubiquitous.^{w14} Palliative care fosters a holistic view, with attention to the psychological, social, and spiritual needs of people with dementia. Psychosocial interventions, which may incorporate alternative therapies,^{w15} are now recommended as the first line of treatment for BPSD.^{w16} By encouraging an empathic approach, a facilitating social environment and meaningful activities, with the judicious use of medication, specialist teams might nurture a better quality of life for people with dementia.^{w17 w18}

The evidence shows that specialist palliative care would be beneficial in dementia.¹² The select committee was also concerned about the use of NHS facilities for long term care.¹ Conceivably, a more positive philosophy for continuing care units for people with dementia might come from looking on them as specialist palliative care units. Through outreach and liaison they could foster broad palliative care for people with dementia in the community, including in nursing and residential homes, as well as supporting hospitals and hospices. They could continue to provide inpatient care for people with complex needs, while encouraging research and enabling a more flexible, holistic, and person centred approach to the difficulties that arise for people with advanced dementia.

Julian C Hughes *consultant in old age psychiatry*

North Tyneside General Hospital, Rake Lane, North Shields, Tyne and Wear NE29 8NH
(j.c.hughes@ncl.ac.uk)

Louise Robinson *clinical senior lecturer in dementia and ageing research*

Centre for Health Services Research, 21 Claremont Place, Newcastle upon Tyne NE2 4AA

Ladislav Volicer *courtesy full professor*

School of Aging Studies, University of South Florida, 4202 E Fowler Ave, MHC 1342, Tampa, FL 33620, USA

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