

Social care and hospital use at the end of life

Care of the dying can be seen as an indicator of the quality of care provided for all sick and vulnerable people.¹ About half a million people in the UK die each year, and the quality of care they receive also affects a much larger number of relatives, carers and friends. Although the costs of this care are also high, there is a shortage of information about the care people receive at the end of life and major gaps in our understanding of what services are appropriate.

This briefing summarises a Nuffield Trust report to investigate the use and estimated costs of hospital and social care services for large groups of individuals at the end of their lives. We believe that this is the first time that such an estimate has been derived for large populations.

Key points

- This study extracted and linked anonymous health and social care data to examine the care history of 16,479 individuals who died in 2007 in three primary care trust (PCT)/local authority areas. The research found that on average 30 per cent of the group used some form of local authority-funded social care service in the 12 months prior to death. Uptake was higher in older age groups.
- Use of local authority-funded social care increased gradually in the last year of life, whereas NHS-funded inpatient hospital care increased sharply, particularly in the final two months. There were marked differences between the three PCT/local authority areas studied in terms of the balance of health and social care costs.
- The use of social care also differed according to the presence of some long-term conditions. For example people with mental health problems, falls and injury, stroke, diabetes and asthma tended to use more; those with cancer appeared to use less.
- The balance of total hospital inpatient and social care costs shifted dramatically with increasing age. After age 60, hospital costs in the final year of life declined, while social care costs increased. A crossover occurs in people aged 90 and over, when estimated social care costs in the last year of life exceed the hospital inpatient costs.
- There is some evidence across all age groups that higher social care costs at the end of life tend to be associated with lower inpatient costs. While a direct causal link between high social care use and lower hospital use cannot be confirmed, it does suggest that any reductions in the availability of local authority-funded social care might increase demand for hospital services.
- The Nuffield Trust has been commissioned by the National End of Life Care Intelligence Network to conduct a more detailed follow-up study. This will involve a wider range of local authorities, and an extended number of datasets.

Introduction

Supporting people at the end of their lives is a complex task – often requiring a patchwork of different services to be delivered. Information about care is important to help us assess how health and social services can be better coordinated in ways that translate into higher-quality and more efficient care. Yet there is a shortage of information about the care that people receive at this critical time and there are major gaps in our understanding of what services are appropriate. There are also concerns that too often people are dying in hospitals when they would rather be at home.

Background

Care of the dying can be seen as an indicator of the quality of care provided for all sick and vulnerable people.¹ About half a million people die each year in the UK, and the care of this group also impacts upon the much larger number of relatives, carers and friends.¹ It has been estimated that the number of people who die in any one year is set to rise by 17 per cent between 2012 and 2030.² Despite the fact that surveys strongly suggest the majority of people would prefer to die at home, many end up doing so in hospital without a medical need.³ An essential element of good commissioning for end-of-life care is to ensure that there are appropriate alternatives to hospital care that can both reflect a person's wishes and be less costly to the system.⁴

Care at the end of life has been recognised as making up a significant proportion of all health care expenditure in the NHS. Given the need to increase the quality and efficiency of care as demand rises, there are renewed searches for areas of avoidable expenditure and potentially wasteful duplication of care.⁵ This means even greater effort to coordinate planning and commissioning across care sectors. The Wanless review into funding for long-term care pointed to the vacuum in information about the overlaps between health and social care.⁶ One of the key gaps is the availability of information on local authority-funded social care. The recent Government Spending Review largely protected NHS spending, but did not do the same for social care.⁷

This report describes an innovative study to shed light on this area using anonymous record linkage that brought together information on the use of health care and social care by people in the last months of life. The analysis focused on 16,479 people who died across three PCT/local authority areas in England in 2007. Datasets

from local areas were linked in ways that protected an individual's identity. The main objective of the work was to describe patterns in use of health and social care by individuals and more specifically to consider:

- What proportion of patients used social care services in the months/year before death?
- How did use of social care vary in the months before death and relative to use of health care?
- What is the cost of the use of social care relative to the cost of health care?
- Which patients were most likely to use social care?

Findings

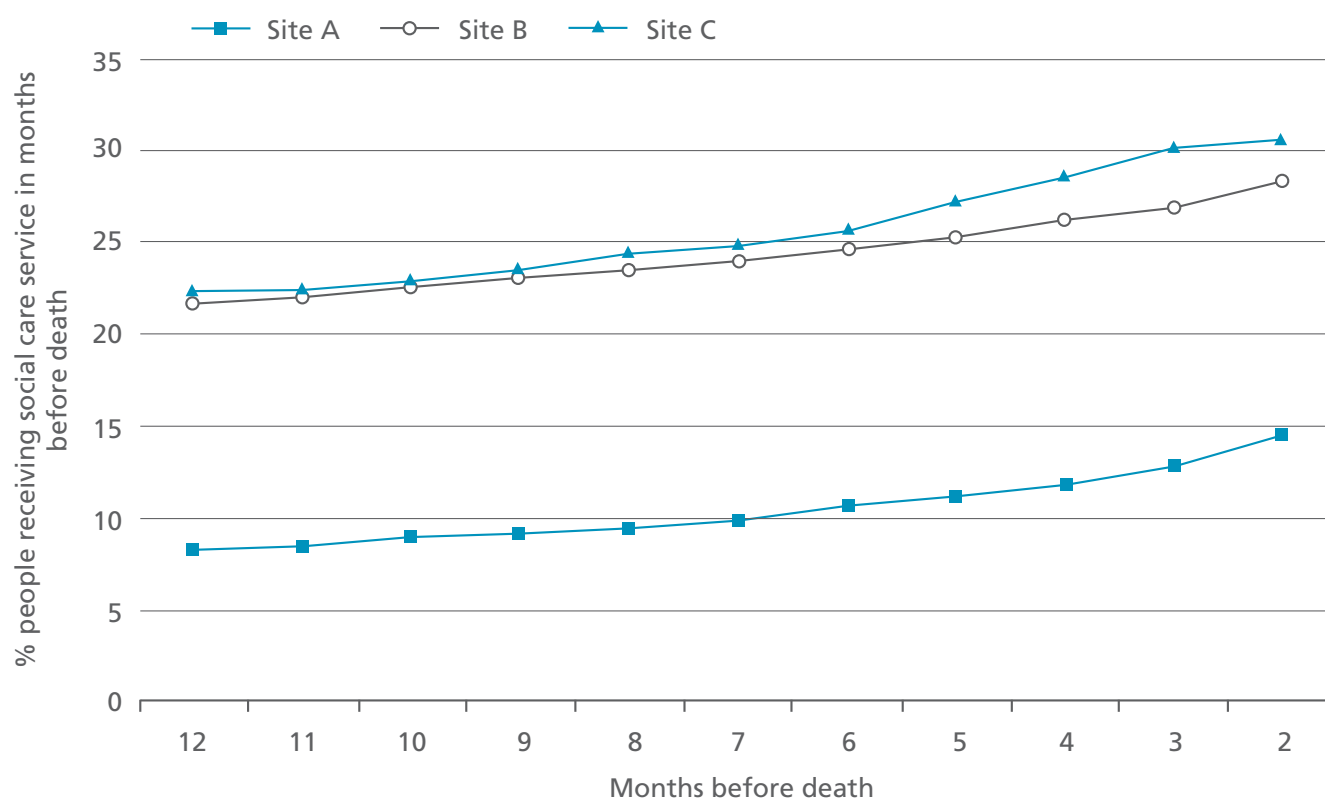
Level of uptake of social care

For the 16,479 who died, we began by identifying how many had any record of local authority social care services in the last months of life. In the first instance this was for any social care service identified by the local authority information systems, so could include anything from meals services to nursing home care. Figure 1 summarises the proportion of people who were recorded as accessing local authority-funded care for each month in the period before death. On average across all ages and all sites, we found that 30 per cent of the people who died had some form of local authority-funded social care service in the 12 months prior to death. For older people this proportion exceeded 40 per cent. A large proportion of the increase in social services used in the last twelve months can be attributed to increases in the use of care homes and medium-intensity home care services.

This graph also demonstrates two other features of the care provided:

- There were marked differences in the use of local authority-funded social care between the three study PCT/local authority areas.
- The numbers of people accessing local authority-funded social care in any one month gradually increased over the last 12 months of life. The proportion of the group accessing any social care in any one given month increased from 15 per cent to 30 per cent during this period. This steady rise is in contrast to the sharp increase seen in hospital care.

Figure 1: Percentage of people receiving local authority-funded social care in months before death, by site



Costs of hospital and social care

Of the 16,479 people in the study group, in the last year of life 7.2 per cent accessed only social care, 49 per cent accessed hospital inpatient care and 23 per cent used both types of services. For the whole group, the costs associated with inpatient care (£102.6m) were about twice as high as those for social care (£49.6m). The

costs per user for those accessing services are shown in Table 1. For the groups using both social and inpatient care, the costs in the last 12 months of life averaged over £17,000. Note, these costs are approximate and underestimates as they do not include some major elements of care such as primary and community care, hospice care and self-funded social care.

Table 1. Average costs per user in last 12 months of life

	Number of people	Social care cost per user	Inpatient cost per user	Social care plus inpatient cost per user
Inpatient care only	8,085	–	£8,017	–
Social care only	1,188	£16,921	–	–
Both inpatient and social care	3,786	£7,791	£9,998	£17,790

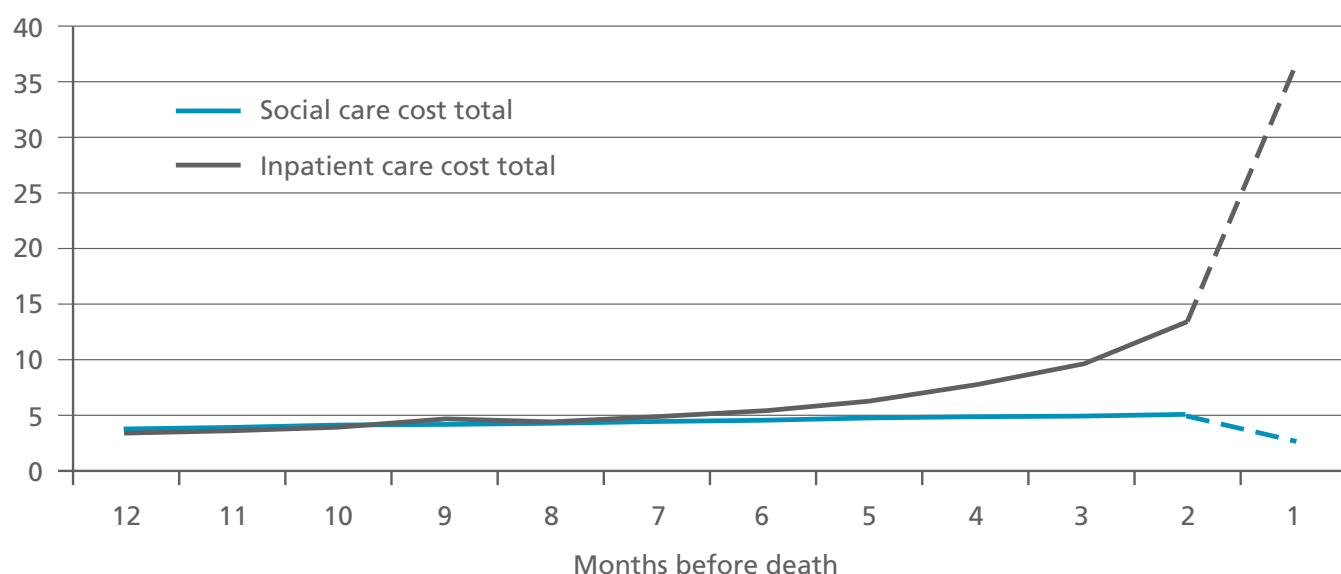
Table 2. Hospital inpatient and social care costs per user and cost per death by site

	Site A	Site B	Site C	Across all sites
IP costs per user	£8,526	£9,395	£4,848	£8,649
SC costs per user	£5,895	£10,818	£10,055	£9,972
IP costs per death	£6,220	£6,790	£3,349	£8,649
SC costs per death	£1,138	£3,554	£3,689	£3,010

Figure 2 shows the average cost per month of inpatient and social care costs respectively, for the whole cohort of 16,497 people who died. The figure shows a small but steady growth in costs for health and social care, with little difference between them up to six months before death. After that time the costs of inpatient care

for the group began to rise more steeply before rising very steeply in the final two months. The social care costs continue on the same steady slight growth until death (the values for the final month are underestimates due to limitations in the data).

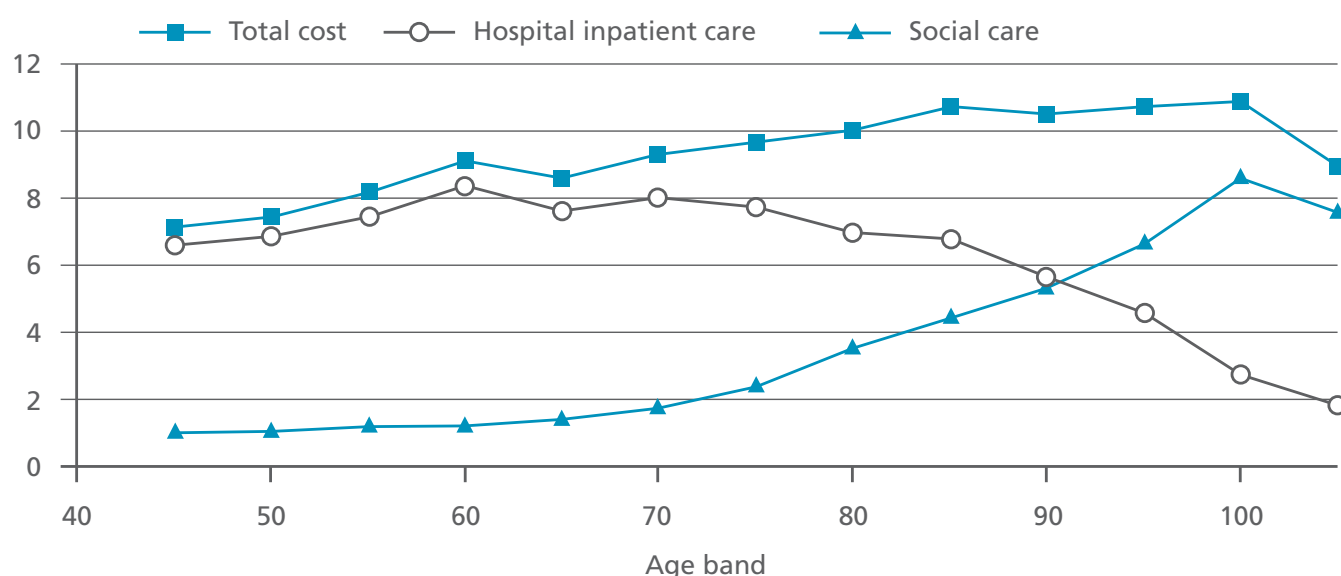
Figure 2: Average inpatient and social care cost per month (£m) in 12 months before death



The balance of hospital inpatient and social care costs shifted dramatically with increasing age (Figure 3). When measured over a 12-month period (as opposed to single months), after age 60 hospital costs at the end of

life declined with increasing age, while social care costs increased. A crossover occurs in people aged over 90, when estimated social care costs in the last year of life exceed the hospital inpatient costs.

Figure 3: Average cost per person (£000s) by age group in last 12 months



There is some evidence across all age groups that higher social care costs at the end of life tend to be associated with lower inpatient costs. This difference is associated with the use of residential and nursing home care. There are a number of possible explanations for this. Hospital admission may be being avoided by care in a residential setting – or people can be made to feel better able or better supported to cope with an acute crisis without the need for hospital. Alternatively it may be that in some cases people cannot access appropriate hospital care.

Long-term conditions

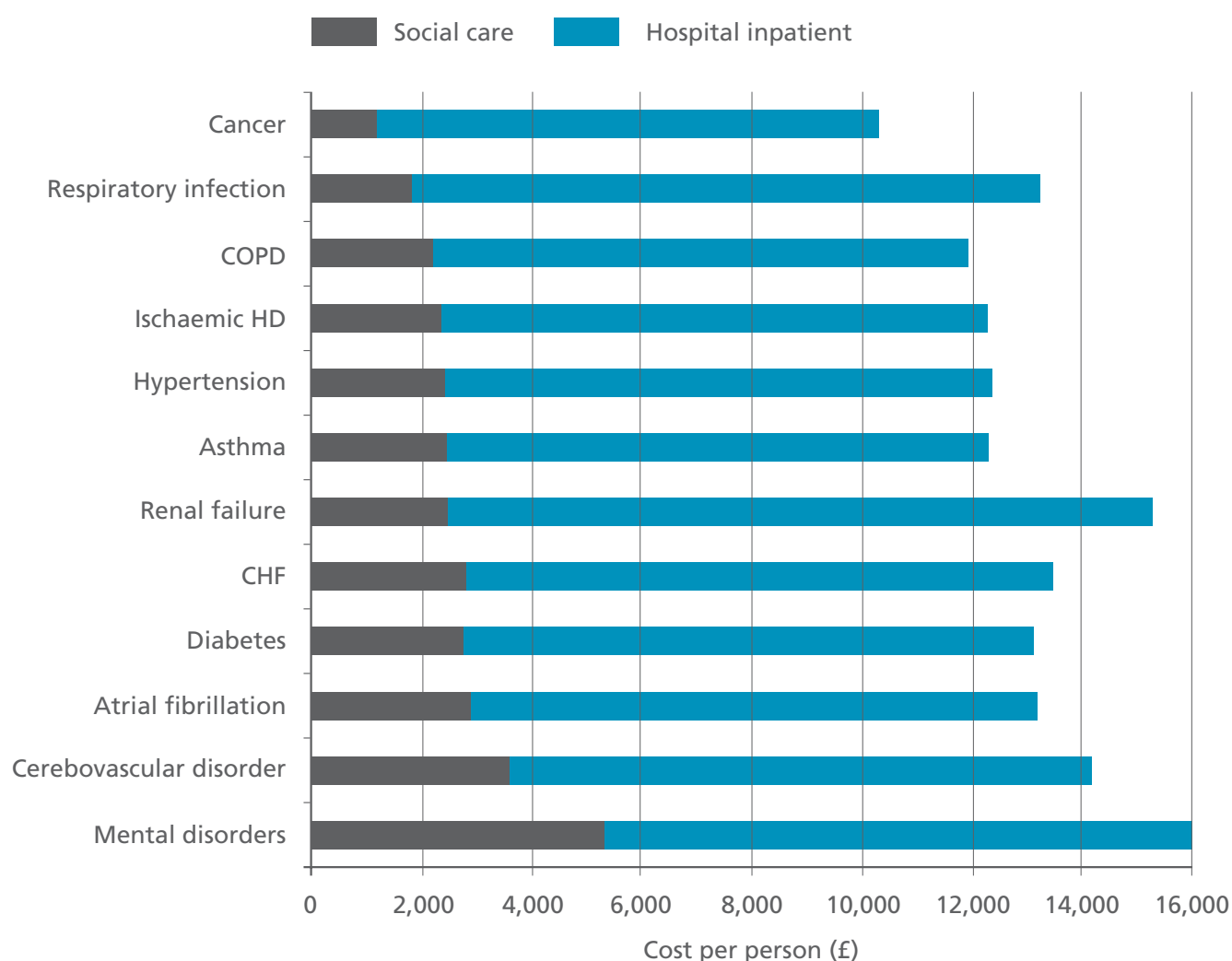
By linking health and social care data it is possible to look at some details of a person's prior health history

and see how that relates to the uptake of social care.

This study looked for the presence of selected long-term conditions in the previous two years and compared the relative use of social care and hospital costs.

The use of social care differs according to the presence of certain long-term conditions; people with mental health problems, falls and injury, stroke, diabetes and asthma tended to use more services. People with cancer appeared to use local authority-funded social care the least – an effect not simply due to the younger age profile of these cases. Though the number of long-term conditions a person has is related to higher hospital costs, it appears to be unrelated to social care costs (see Figure 4).

Figure 4: Average costs per person in the last 12 months of life, by diagnostic group



Discussion

Social care is an important support for people in the last year of their lives, especially for older people. Though the data studied in this analysis had limitations, we were able to estimate that in the three study areas total expenditure on social care for the 16,479 individuals who died in 2007 was just under £50m, and inpatient hospital care £102m. Projections of future population changes suggest both an increase in the numbers dying in any one year and a larger proportion of older people dying. This could mean significant cost pressures for both health and social care services.

The balance of hospital inpatient and social care costs shifted dramatically with increasing age. After age 60 hospital costs at the end of life declined, while social care costs increased. A crossover occurs in people aged 90 and over, when estimated social care costs in the last year of life exceed the hospital inpatient costs. In this age group, social care may be substituting for inpatient care. The key question is whether reduced access to social care may lead to knock-on effects on demand for hospital care.

The 'right' mix of health and social care use is not possible to define in the absence of information on the quality of care; what may be appropriate given the circumstances of the patient or the type of illness experienced, or on the availability of other sources of care not analysed here (for example, charitable domiciliary or hospice care, or privately-funded social care). But this analysis prompts further questions about whether social care options are being used sufficiently (or are sufficiently available) by people younger than 90 to help support them at home at the very end of life. Alternatively, it may be that inpatient care is inappropriately underused by those over 90 years of age.

This study looked at an opportunistic sample of three local authority/PCT areas, and marked differences in use of social care were found between these. More work is needed to understand better the nature of these variations for patients, users and commissioners of care services. This work would also be usefully augmented through the additional analysis of other services used for care at the end of life, as well as by linking the findings with more detailed studies of the quality of care delivered.

The national End of Life Care Strategy and the recent White Paper⁸ advocate greater joint commissioning of health and social care by the NHS (soon to be GP commissioning consortia) and local authorities to help achieve more integrated and efficient care. It will be

critical to develop analysis of the type presented in this paper for this aim to be realised.

Suggestions for further research

The approach which underlies this study – that of extracting and linking health and social care data – seems to offer great scope for a range of new analyses. The use of existing operational data offers significant advantages in that costly new data collection is not required, and it is possible to study the full range of service users not just a pre-specified subset or client group.⁹ While bringing these data together is a significant step forward in terms of a better understanding of the full picture of care for people at the end of life – it is still partial, particularly in respect of the data concerning use of health services in the community, and (to a lesser degree) outpatients and A&E.

It is, therefore, important that the analyses in this report be extended. We suggest that the two most important ways to achieve this are as follows.

- Repeat these studies with a wider range of local authorities and ones that represent a broader spectrum of the UK population.
- Extend the range of datasets that are used to construct person-level care histories. Many of the people receiving care at the end of their lives (particularly those not in institutional care and specifically those with cancer) will be accessing much of their care from NHS generalists (district nursing and GPs). Though linking more datasets presents a challenge, we believe it is an important direction for future research.

Finally, the type of analysis described in this report can inform a number of key policy areas. This includes ways to evaluate better the impact of new services – especially community-based care strategies designed to improve quality and satisfaction for patients, and also avoid expensive hospital or institutional care. Given the financial climate, now more than ever this type of analysis is critical if more value is to be extracted from public funds.

The techniques used in this analysis mark a significant step forward in terms of providing a better understanding of health and social care services used by people at the end of life. However, the analysis is partial. The Nuffield Trust has therefore been commissioned by the National End of Life Care Intelligence Network to conduct a more detailed follow-up study. This study, which will report in 2011, involves a wider range of local authorities, and an extended number of datasets.

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Dr Martin Bardsley is Head of Research at the Nuffield Trust and has over 20 years' experience in health services research and analysis. Before joining the Trust he worked for the Healthcare Commission, leading a team developing and implementing new approaches to the use of information for risk-based regulation. He has also a research background in public health and the development of case mix and outcome measurement.

Theo Georghiou

Theo Georghiou joined the Trust in Autumn 2008 from The King's Fund. During his time at the Fund he gained wide experience of linking and analysing large health care datasets including English inpatient and outpatient hospital episode statistics and nationwide GP registrations data.

Theo was also involved in the initial development of a 'person-based resource allocation' model for use in the allocation of NHS funds. Theo has also worked as an analyst at the Healthcare Commission and the Commission for Health Improvement.

Jennifer Dixon

Dr Jennifer Dixon has researched and written widely on health care reform in the UK and internationally. She trained originally in medicine, practising mainly paediatric medicine, before a career in policy analysis. Before joining the Nuffield Trust in 2008, she was Director of Policy at the King's Fund, London. She is a former Harkness Fellow and was the policy adviser to the Chief Executive of the National Health Service between 1998 and 2000. She is currently a board member of the Audit Commission. Jennifer is a visiting professor at both the London School of Economics and at Imperial College, London; in 2009 she was elected as a Fellow of the Royal College of Physicians.

About the Nuffield Trust

The Nuffield Trust is a charitable trust carrying out research and health policy analysis on health services. Our focus is on the reform of health services to improve the efficiency, effectiveness, equity and responsiveness of care.

Key current work themes include:

- the future organisation and delivery of care
- commissioning
- efficiency
- UK and international comparisons
- competition.

This briefing forms part of the Trust's work on the commissioning of health care. The full report *Social care and hospital use at the end of life* is available at:

www.nuffieldtrust.org.uk/publications

The report authors are Martin Bardsley, Theo Georghiou and Jennifer Dixon.

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