National Audit Office

2007

Web Forum Survey Results

Improving Services and Support for People with Dementia

HELPING THE NATION SPEND WISELY

The National Audit Office scrutinises public spending on behalf of Parliament.

The Comptroller and Auditor General, Sir John Bourn, is an Officer of the House of Commons. He is the head of the National Audit Office, which employs some 800 staff. He, and the National Audit Office, are totally independent of Government. He certifies the accounts of all Government departments and a wide range of other public sector bodies; and he has statutory authority to report to Parliament on the economy, efficiency and effectiveness with which departments and other bodies have used their resources.

Our work saves the taxpayer millions of pounds every year, at least £8 for every £1 spent running the Office.

For further information please contact:
Karen Taylor
Director ,
National Audit Office
157-197 Buckingham Palace Road,
Victoria, London, SW1W 9SP

020 7798 7161
Email: Karen.Taylor@nao.gsi.gov.uk

CONTENTS PAGE

National Audit Office Web Forum Survey

November 2007 Reference:

National Audit Office Web Forum

The National Audit Office undertook a web-based survey for people with dementia and unpaid carers, asking them to tell us "what you would like Parliament to know about services for people with dementia" regarding a series of questions. The overall findings are presented in the National Audit Office report *Improving Services and Support for People with Dementia*. A summary of the quantitative results from the survey is presented here.

The National Audit Office received 174 responses to the web-based survey. The closing date for the survey was 31 December 2006.

All percentages shown are the "valid percentages" i.e. they exclude blank and not applicable responses.

General Information

Seventy-nine per cent of people completing the survey were carers, seven per cent were people with dementia and two per cent were both who completed the survey together. Twelve per cent described themselves as "other".

Figure 1 shows the time since formal diagnosis of the person with dementia.

Figure 1: Over half of responses related to a person who had been formally diagnosed with dementia over 3 years ago.

Time since diagnosis	**Percentage**
Under 6 months	7
7-18 months	20
19 months to 3 years	19
More than 3 years	53

Figure 2 breaks down the age of the person with dementia.

Figure 2: 75-84 years was the most common age group of people with dementia

Age group	**Percentage**
Under 55 years	2
56-64 years	10
65-74 years	27
75-84 years	43
85 years and over	18

Assessment process and development of care package

The NAO asked a series of questions asking respondents to rate their experience of the assessment process and development of the care package, illustrated in Figures 3, 4 and 5 below.

Figure 3: Sixty-one per cent of respondents rated their overall experience of the assessment process as satisfactory or better.

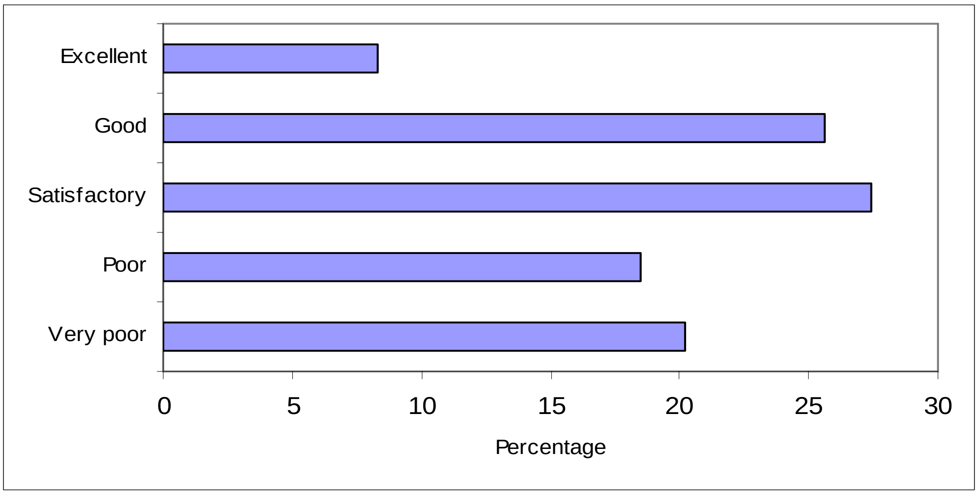


Figure 4: Forty-five per cent of respondents felt the assessment process had a poor or very poor understanding of their needs.

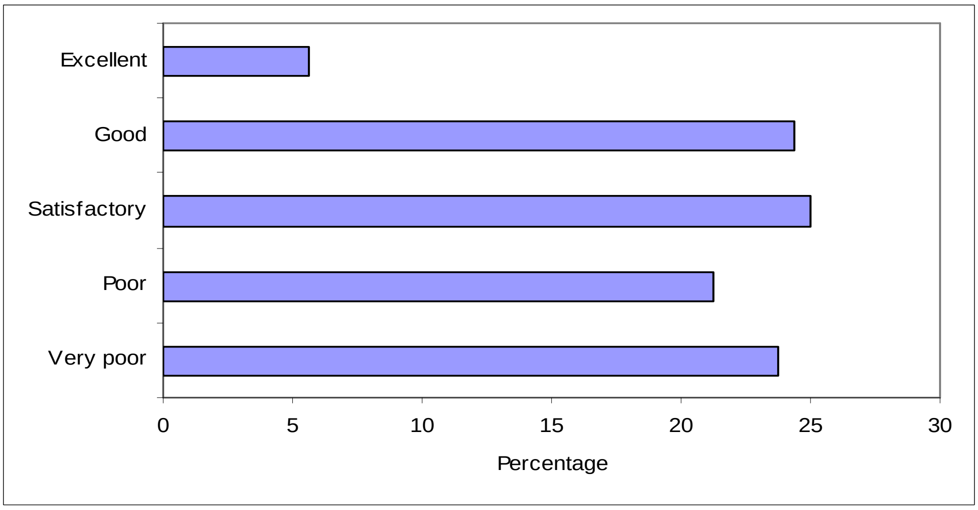
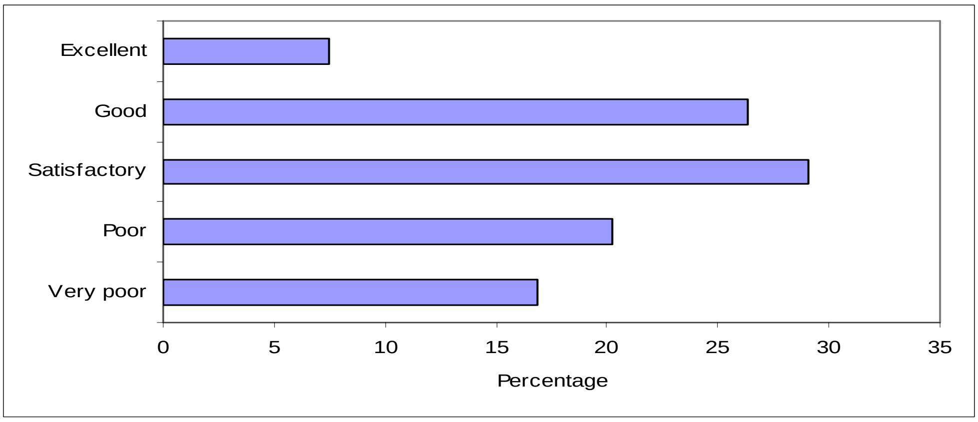


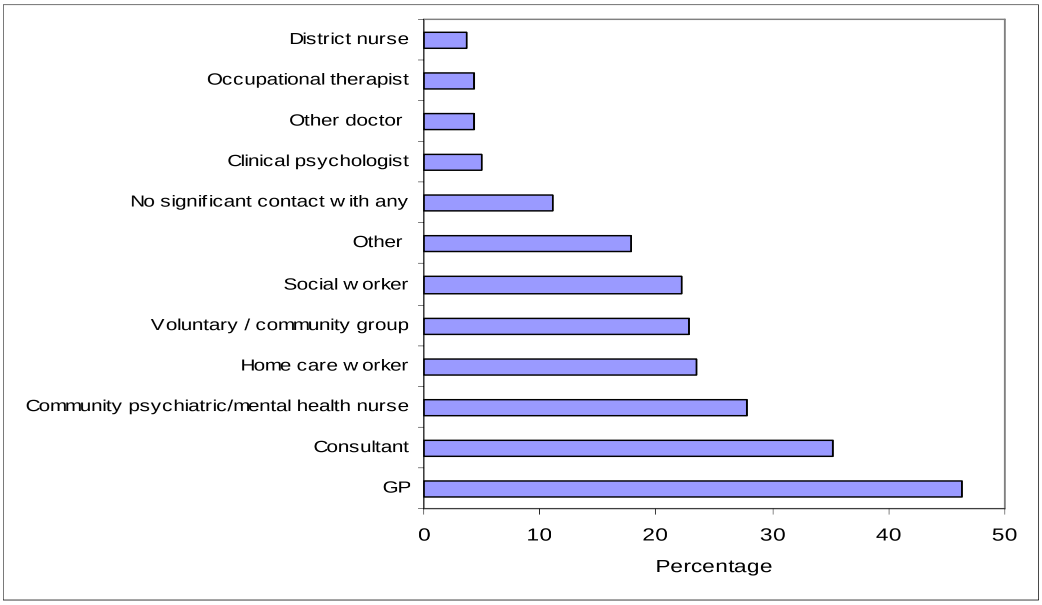
Figure 5: Over one-third of respondents rated their involvement in the development of the care package as less than satisfactory.



Provision of support and satisfaction with services

People with dementia and their carers are in contact with a number of health and social care professionals as shown in Figure 6.

Figure 6: The GP is one of many health and social care professionals involved in caring for and supporting people with dementia and their carers.



The same services may be provided by different organisations/providers, depending on local arrangements as Figure 7 shows.

Figure 7: Social services and the charitable/voluntary sector seem to provide the bulk of non-health services.

Service	Social Services (%)	NHS (%)	Charity / Voluntary Organisations (%)
Day care in a day centre	71	19	22
Respite Care	75	11	20
A care assistant comes in to help	81	2	25
Carer support group	25	15	65
Alzheimer's cafe	21	16	68
Day hospital	17	67	17

Note: Percentages will not total 100% as more than one answered was allowed.

The NAO asked people with dementia and carers to rate how well they felt they had been supported by the NHS, Social Services and charitable/voluntary organisations. Generally there was much praise for charitable and voluntary organisations, with over 80 per cent of respondents feeling support provided to both the person with dementia and the carer was satisfactory or better. Half of respondents felt the support provided to both the person with dementia and the carer by social services and the NHS was satisfactory or better, and half felt it was poor or very poor. See Figures 8 and 9.

Figure 8: Over 80 per cent of respondents felt the support provided by charitable or voluntary organisations to the person with dementia had been satisfactory or better.

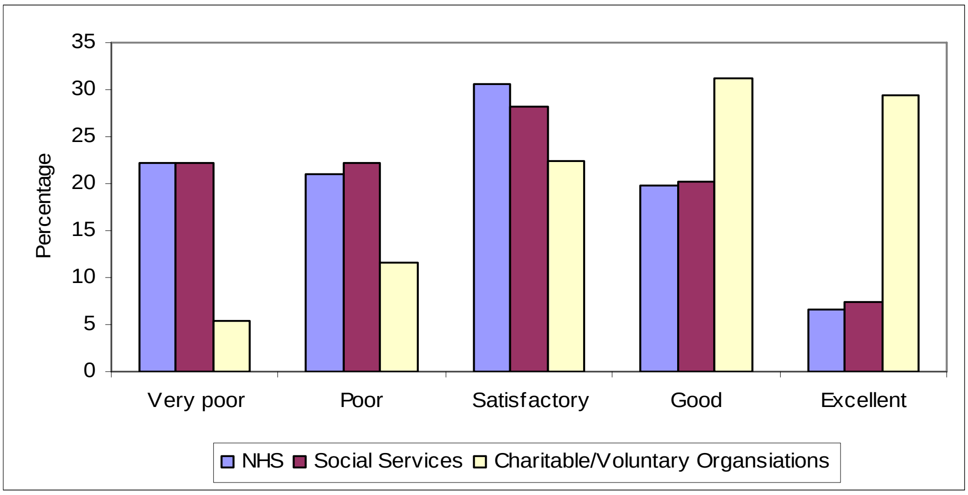
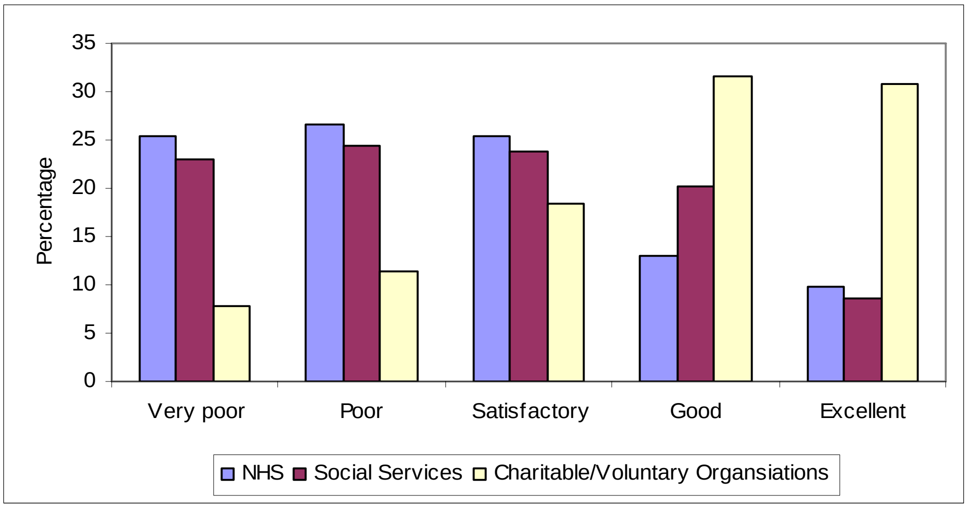


Figure 9: Around half of carers felt the support provided to them by the NHS and social services had been poor or very poor.



Meeting needs

The NAO asked if people with dementia and carers had opportunities to explain what their needs are and whether these needs were being met by health and social care services. See Figure 10.

Figure 10: Over half of respondents felt that few of the needs of the person with dementia were being met and over 60 per cent felt that few carers' needs were being met.

Statement	Needs of person with dementia (%)	Needs of carer (%)
All needs are met	10	7
Most needs are met	38	32
Few needs are met, even when I explain what is needed	30	37
Few needs are met and there is no opportunity to tell anyone	23	25

Day care and other non-residential care

The NAO asked about levels of day care or other non-residential care received and asked respondents to state whether the levels being received were enough. We also asked respondents to provide information on by whom the care was provided. See Figures 11, 12 and 13. We also asked about availability of respite care, see Figure 14.

Figure 11: Over one-third of people with dementia attend a day centre or other non-residential care setting once a week or less.

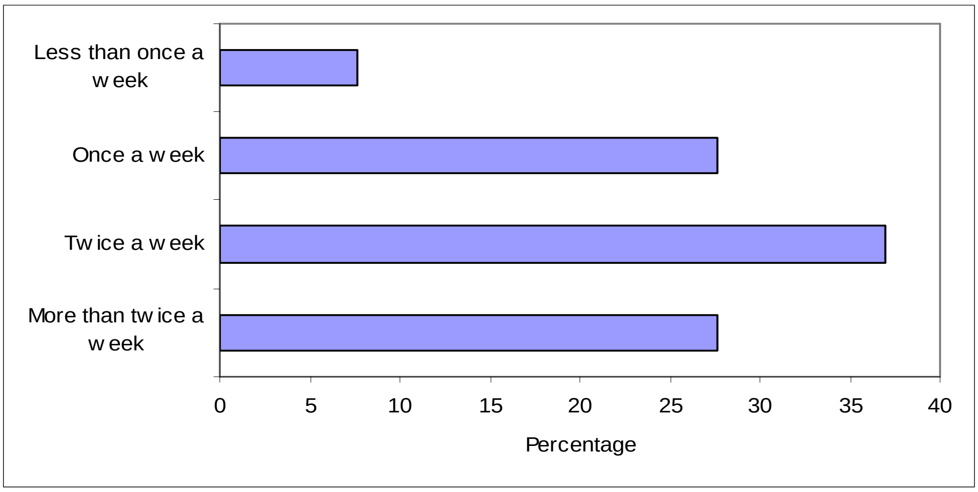


Figure 12: Just over half of respondents felt that the amount of day care or other non-residential care provided was too little.

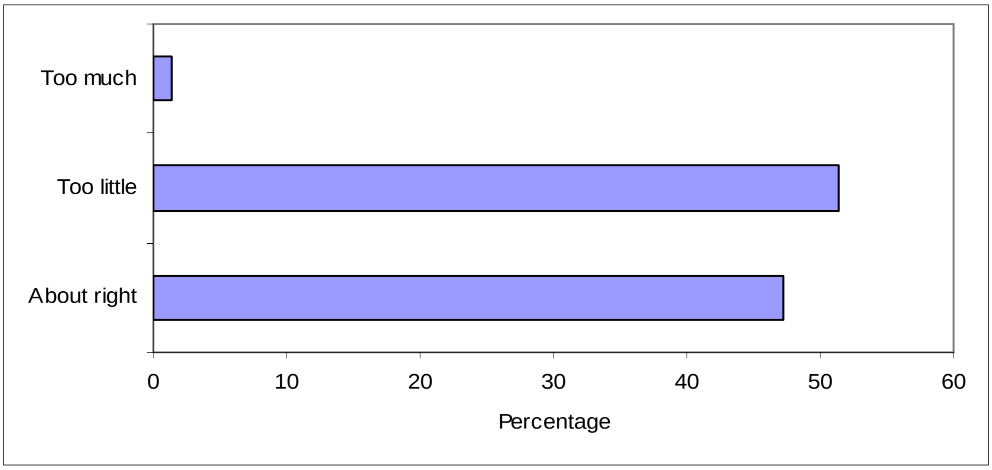


Figure 13: Over half of day care or other non-residential care is provided by social services.

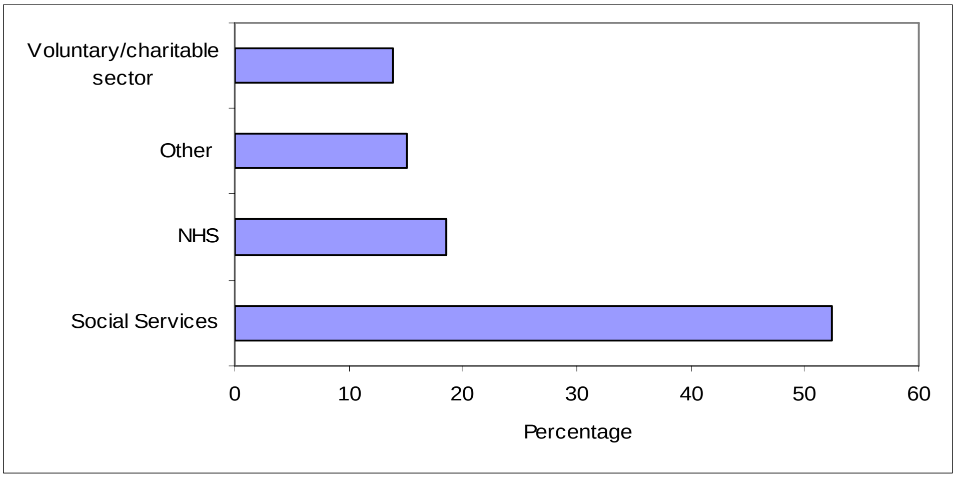
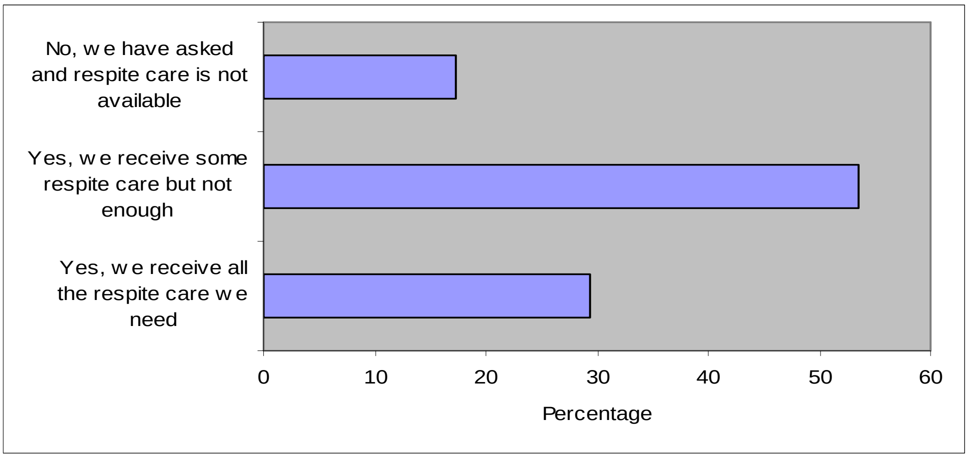


Figure 14: Over 70 per cent of respondents said no respite care, or not enough respite care, was available.



Residential / nursing home care

The NAO asked whether the person spent any time in residential / nursing home care, how this care was funded and who had explained any entitlements to the person with dementia and/or their carer. See Figures 15, 16 and 17.

Figure 15: Most respondents to the survey stated the person with dementia did not stay in residential or nursing home care.

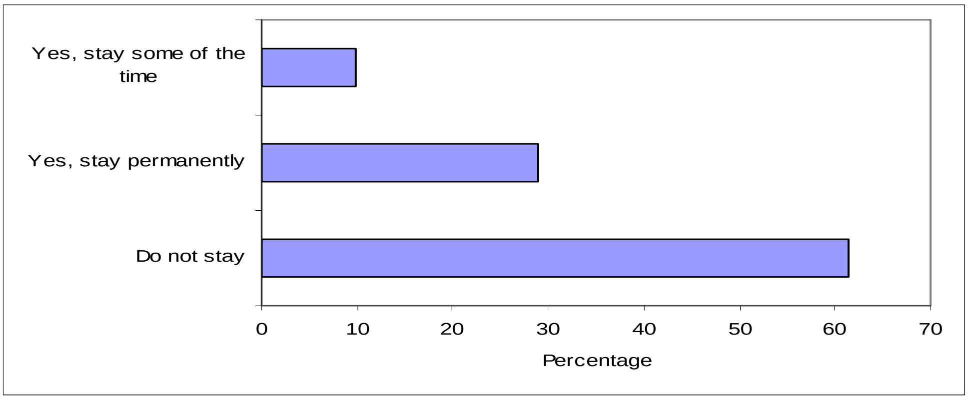


Figure 16: For those people with dementia in receipt of residential/nursing home care, three-quarters had care funded in part or in full either by the NHS or social services.

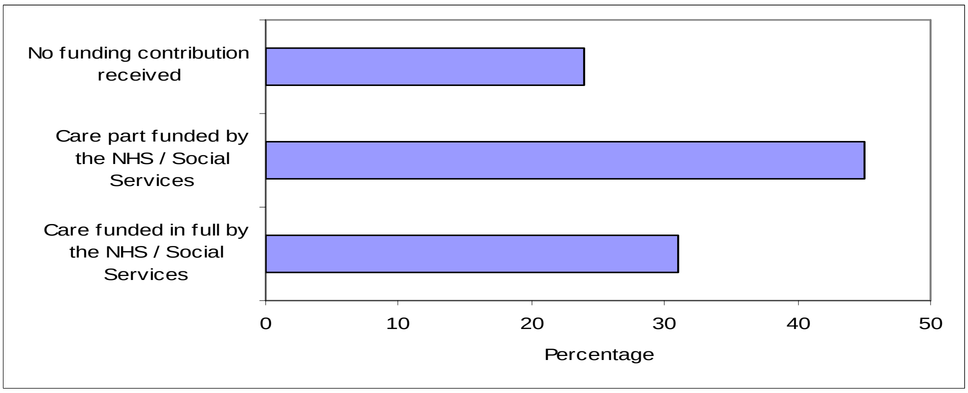
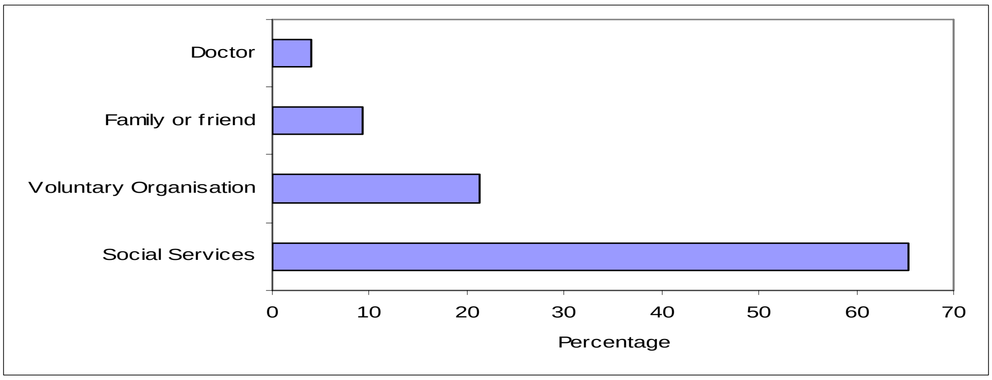


Figure 17: Two-thirds of respondents in receipt of funding had their entitlement explained to them by social services.



Knowledge and understanding of dementia

The NAO asked respondents to compare their level of knowledge about dementia before and after they were affected by the disease, and also to give their views on whether they feel health and social care professionals have a good understanding of dementia. See Figures 18, 19 and 20.

Figure 18: Over 85 per cent of respondents had no knowledge, or only basic awareness of dementia before being affected by it.

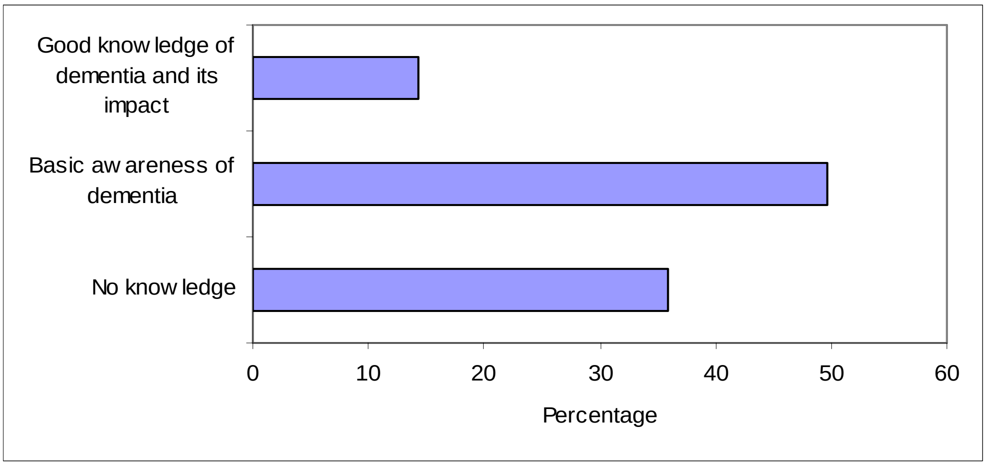


Figure 19: Almost 80 per cent had good knowledge of dementia after being affected by it, but only 18 per cent attributed this knowledge to health and social care services.

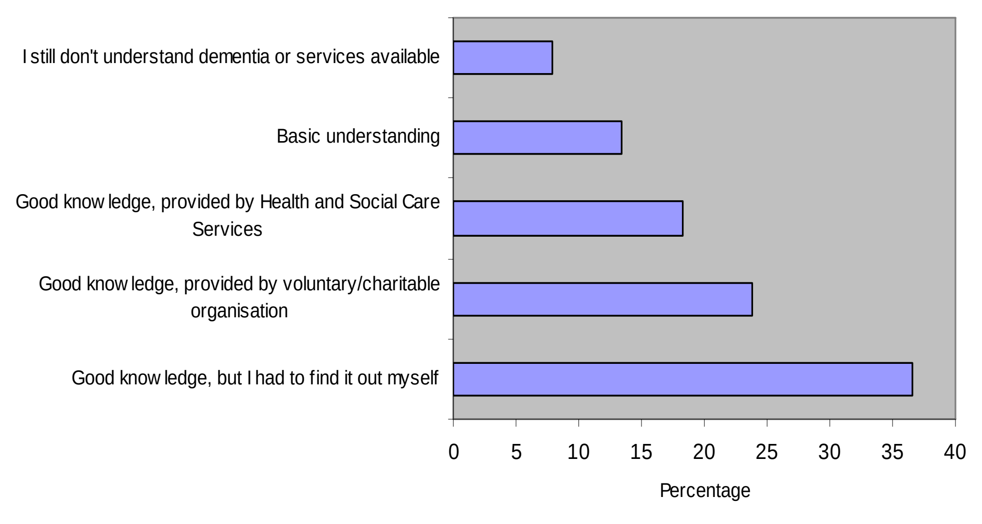


Figure 20: Almost one fifth of respondents felt that not many health and social care staff have a good understanding of dementia.