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Costs of care for people with dementia aged 75 and over

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PSSRU discussion paper 1303/2 March 1997

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The **PERSONAL SOCIAL SERVICES RESEARCH UNIT** undertakes social and health care research, supported mainly by the United Kingdom Department of Health, and focusing particularly on policy research and analysis of equity and efficiency in community care, long-term care and related areas — including services for elderly people, people with mental health problems and children in care. The PSSRU was established at the University of Kent at Canterbury in 1974, and from 1996 it has operated from three sites:

This work was undertaken by the PSSRU, which receives support from the Department of Health. The views expressed in this publication are those of the authors and not necessarily those of the Department of Health.

Costs of Care for People With Dementia Aged 75 and Over

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PSSRU Discussion Paper 1303/2

SUMMARY

This report is based on analysis of data from the Cambridge cohort study of elderly people with dementia (Ely et al, 1995), utilising re-analyses performed by Economists Advisory Group (EAG), on behalf of Pfizer Ltd. The clinical data has been combined with costing figures from a programme of work based at the PSSRU (Kavanagh et al, 1993; Schneider et al, 1993; Kavanagh et al, 1995).

The report evaluates the changing average cost of care as the cognitive level of a given person changes. The Cambridge study provides figures for cumulative distributions of scores that have been used to map from MMSE to OPCS SEVINT scores. This facilitates the use of Kavanagh (1995) figures to establish a distribution of locations and types of care at given levels of severity. The proportions are combined with costs to give an average cost. All estimates are restricted to direct costs of health and social care and do not reflect variations in informal care and indirect costs.

The costs show a variation, with a general upwards trend matching the upward trend in severity. This rate of change of severity is not uniform, with variations between different sectors of the population, dependent on age and severity of dementia.

Annual rates of change are used as the basis for extrapolation of the data over a period of eight years, showing longer term changes in severity for any given individual. These long term changes have some apparently anomalous effects on the pattern and distribution of costs.

A set of more complex models will be developed, based on the work within this report.

INTRODUCTION

This report is a summary of part of a programme of work aimed at reviewing and assessing economic aspects of the impact of Alzheimer's Disease. The area has received much attention (see Stewart, 1996, for a review) but little of this has actually focused on evaluating the impact of therapies. In this exercise, basic factors of costs and disease progression are reviewed and evaluated for an important comparator group for any study of treatments in this area: elderly persons with dementia but not receiving any active treatment. This group will be used in subsequent work as the most valid comparator group. They are not subject to some of the biases that may be inherent in the results obtained from evaluation of placebo treatment groups.

METHODS AND DATA

This analysis brings together data from two main sources.

- 1. Cambridge cohort study of frail elderly people. This is an epidemiological study of a local population aged over 75 years of age (Ely et al, 1995). Data on this population is used as a basis for estimates of progression of dementia related cognitive impairment. The sample of persons in the study show a series of annual progression rates. Data highlighting these rates has been extracted from reanalysis of the original data, performed by EAG for Pfizer Ltd.
- 2. PSSRU analysis of OPCS Disability Survey. A series of series have been produced by the PSSRU (Kavanagh et al., 1993; Kavanagh et al., 1995; Schneider et al., 1993) examining OPCS data sets to establish the location and type of care received by elderly persons with dementia. The work also estimated costs of care for persons in each location receiving different types of care. In this report direct costs of formal health and social care are evaluated. There are significant costs associated with informal care, but these are not included in the calculations.

The above two sets of research both utilise measures of severity of cognitive impairment, but actually use different measures. The Cambridge study, as developed by EAG, uses a variety of measures including CAMDEX, Blessed and MMSE. In contrast, the PSSRU studies are based on the same measure as the Disability Survey uses, the OPCS SEVINT scale. This report required use of the Cambridge information on illness progression in conjunction with the PSSRU estimates on costs, therefore a method was needed to map the SEVINT scores onto MMSE figures. This was performed by using estimates, from both sources of cumulative incidence of levels of severity. These levels were mapped across between the scales to establish the nearest equivalents between each point on the two scales. The comparisons can be seen in Table 1.

MMSE So	core D	Distrib	ution in (Cambridg	ge City	OPCS SE	VINT Sco	re GB
Freq		%	Cum%	MMSE	SEVINT	No of	Cum %	%
				Score	Score	Items		
	75	2.9	2.9	-1	13.0	11	1.6	1.6
	6	0.2	3.1	0				
	1	0.0	3.1	1	12.0	10	3.0	1.4
	2	0.1	3.2	3				
	4	0.2	3.4	4				
	5	0.2	3.6	5				
	3	0.1	3.7	6				
	4	0.2	3.8	7				
	9	0.3	4.2	8	10.5	9	4.2	1.2
	7	0.3	4.4	9				
	12	0.5	4.9	10				
	11	0.4	5.3	11	9.5	8	5.4	1.1
	13	0.5	5.8	12				
	14	0.5	6.4	13				
	16	0.6	7.0	14	8.0	7	6.8	1.5
	22	0.8	7.8	15				
	32	1.2	9.0	16	7.0	6	8.5	1.6
	41	1.6	10.6	17	6.0	5	9.9	1.5
	44	1.7	12.3	18	4.5	4	11.4	1.5
	65	2.5	14.8	19	3.5	3	14.2	2.7
	83	3.2	18.0	20	2.0	2	15.2	1.0
	97	3.7	21.7	21	1.0	1	15.9	0.7
	127	4.9	26.6	22				
	155	5.9	32.5	23				
	210	8.0	40.6	24				
	256	9.8	50.4	25				
	260	10.0	60.3	26	0.0	0	59.9	44.0
	313	12.0	72.3	27				
	315	12.1	84.4	28				
	278	10.7	95.1	29				
	129	4.9	100.0	30		non	100.0	40.1
						disabled		

Table 1 MMSE / OPCS SEVINT Scores: Mapping via Cambridge City

The study was thus able to use Cambridge EAG data on changes in MMSE scores to provide equivalent positions on the spectrum of SEVINT scores used by the PSSRU work. All of the costs have been updated to 1996 levels, using Hospital and Community Health Services (HCHS) and Personal Social Services (PSS) Indices (Netten and Dennett, 1996).

A figure has been set for the average annual costs of care for a person at each different level of the SEVINT score. It has been established by combining the figures for costs of care in different locations with the figures for proportions resident in different locations at each level of severity, as in Figure 2. The cost is then calculated as:

$$Cj = \sum PijCi$$

 $i = 1$

where:

Pij = proportion in care location \$\phi\$ at severity level j;
Ci = average costs of care for a person at location i;
Cj = average costs of care for a person at severity level j.

The set of states used were:

- 1. Living alone in private household;
- 2. Living with others in private household;
- 3. Residential accommodation (weighted average of Local Authority residential homes, Independent Sector residential homes, Independent Sector nursing homes and NHS hospital).

The proportions in each location were as shown in Table 2.

Table 2	Lo	cation :	at differ	rent levels of s	everity							
OPCS M	MSE	Home		Home	Residential(1)				LA	Ind	Ind	SHN
SEVINT		Alone		With Others					Resi	id Resid	Nursing	Hospital
		000,	%	000,	%	000,	%					
0	26	1133	39.57	1621.4	56.63	109	3.81	100	43.4	28.3	23.5	13.8
1		28.3	29.51	38.8	40.46	28.8	30.03	100	6.2	2.9	5.2	14.5
2		40.6	38.78	40.6	38.78	23.5	22.45	100	9.6	6.2	5.1	2.3
3.5	19	27.4	34.25	38.1	47.63	14.5	18.13	100	5.9	2.1	2.9	3.6
4.5	18	25.5	33.42	34.8	45.61	16	20.97	100	6.6	3.7	2.8	2.9
9	17	24	28.88	37.5	45.13	21.6	25.99	100	8.8	4.5	ю	5.3
L	16	16.4	21.38	36.4	47.46	23.9	31.16	100	9.1	3.9	4.9	6
8	14	. 10.7	13.54	38.9	49.24	29.4	37.22	100	11.1	4	5.2	9.1
9.5	11	10.2	20.48	23.4	46.99	16.2	32.53	100	6.5	ю	3.4	3.3
10.5	8	3.1	7.28	25.9	60.80	13.6	31.92	100	5.6	1.7	3.1	3.2
12	1	1.7	3.11	33.4	61.06	19.6	35.83	100	6.9	1.5	4	7.2
13		2.2	8.43	8.9	34.10	15	57.47	100	6.1	1.3	2.2	5.4
					(1) = Sum of L	A/Ind Resid, Ind Nursing	g, NHS H	lospita	П			

The updated base costs for each care location were as below:

1. Living alone in private household	£12,331.63
2. Living with others in private household	£14,132.60
3. Residential accommodation	£24,801.05

Note that due to changes in NHS and Social Services provision the number of NHS hospital beds for long-stay elderly persons has declined dramatically. It was therefore assumed that all persons resident in residential accommodation would be located in NHS nursing homes.

These sets of figures combined to produce estimated average costs of care at the levels shown in Table 3.

In the main analysis these figures have been applied over an eight year time span, to model the expected progression of a person suffering from a dementia type of illness, such as Alzheimer's Disease. For subsequent modelling work, this assumption on time span may be varied. The results show the expected outcomes of following patients over this period of time, as measured by SEVINT, MMSE and expected costs of care.

The analysis follows the set of patient categories used by the EAG re-analysis of the Cambridge study:

- 1. 75-79 years old, mild illness;
- 2. 75-79 years old, moderate illness,
- 3. 80-84 years old, mild illness;
- 4. 80-84 years old, moderate illness;
- 5. 85+ years old, mild illness;
- 6. 85+ years old, moderate illness.

The definition of mild, moderate and severe follows that used in the Cambridge study, i.e. it is based on Blessed classifications, with estimates of correspondence to MMSE scores..

Table 3Costs at different levels of set	severity
---	----------

MMSE	Cost	
	One Year	One Week
26	13826.1	265.887
	16805.0	323.173
	15828.8	304.399
19	15449.4	297.104
18	15767.9	303.228
17	16385.5	315.106
16	17071.8	328.305
14	17859.0	343.441
11	17234.2	331.427
8	17407.4	334.758
1	17899.3	344.218
	20112.1	386.771
	MMSE 26 19 18 17 16 14 11 8 1	MMSE Cost 26 One Year 26 13826.1 16805.0 15828.8 19 15449.4 18 15767.9 17 16385.5 16 17071.8 14 17859.0 11 17234.2 8 17407.4 1 17899.3 20112.1

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Moderate

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<u>Chart 1</u>

This takes figures directly from the EAG/Cambridge data. A mean start point is evaluated for each group and the EAG re-analysis then provides the annualised rate of change in MMSE score, applied over eight years. These rates of change are shown, for each sub-group, in Table 4 and the extrapolated MMSE scores are shown in Table 5.

Table 4 Annual Rate of Change

Patient Sub-group	Annual Decline MMSE
75/79 mild	-0.9
75/79 moderate	-2.92
80/84 mild	-0.2
80/84 moderate	-3.29
85+ mild	-1.6
85+ moderate	-0.79

Table 5 MMSE Scores Over Eight Years

	0	1	2	3	4	5	6	7	8
75/79 mild	19.71	18.81	17.91	17.01	16.11	15.21	14.31	13.41	12.51
75/79 moderate	12.88	9.96	7.04	4.12	1.2	-1.72	-4.64	-7.56	-10.48
80/84 mild	19.05	18.85	18.65	18.45	18.25	18.05	17.85	17.65	17.45
80/84 moderate	14.85	11.56	8.27	4.98	1.69	-1.6	-4.89	-8.18	-11.47
85+ mild	19.69	18.09	16.49	14.89	13.29	11.69	10.09	8.49	6.89
85+ moderate	10.6	9.81	9.02	8.23	7.44	6.65	5.86	5.07	4.28

Years From Start

Note that scores of less than -1 are not actually measurable by the MMSE scale, they are just notional results. Patients have actually reached their maximum level of measurable decline at -1. As the chart illustrates there is a steady decline across all groups.

Chart 2

These tables and chart illustrate the same process of decline as shown through changes in SEVINT scores. Each point on MMSE change has been mapped to the equivalent SEVINT score, producing the set of annual projections shown in Table 6.

Table 6 SEVINT Scores Over Eight Years

	0	1	2	3	4	5	6	7	8
75/79 mild	3.5	3.5	4.5	6	7	7	8	8	8
75/79 moderate	9.5	9.5	10.5	10.5	12	13	13	13	13
80/84 mild	3.5	3.5	3.5	4.5	4.5	4.5	4.5	4.5	6
80/84 moderate	8	9.5	10.5	10.5	12	13	13	13	13
85+ mild	3.5	4.5	7	8	8	9.5	9.5	10.5	10.5
85+ moderate	9.5	9.5	10.5	10.5	10.5	10.5	10.5	10.5	12



IST79 moderate ■ 80/84 moderate ■ 85+ moderate ∞ Chart 2: Cognitive Decline SEVINT Over 8 Years Straight Line Extrapolation 9 Ś Years From Start Г 4 \mathcal{C} Ħ 2 0 SEVINT⁸ 9 12 10 4 2 4 0 Score

□ 75/79 mild

□ 80/84 mild

85+ mild

Chart 3

The previous figures for the decline of SEVINT were transformed into annual costs of care, via the process described earlier. Table 7 shows actual figures for costs.

The figures show the expected average annual costs at each yearly interval from the point of the EAG analysis. A general upwards trend is evident, but it shows a different slope to that for changes in cognitive ability. As the measured cognitive ability declines, the balance of locations changes, leading to changes in costs. However, there may be some apparent anomalies in the shifts occurring at individual levels. In some cases, as patients decline, they move from living alone and receiving high levels of formal care to living with others, usually close relatives, and receiving high levels of informal care, but low levels of formal care.

Costs
spected
nual Ex
5 7 An
Table

Years From Start

	0	-	N	ო	4	ъ 2	9	7	8
75/79 mild	15449.4	15449.43	15767.86	16385.49	17071.84	17071.84	17858.96	17858.96	17858.96
75/79 moderate	17234.19	17234.19	17407.43	17407.43	17899.33	20112.09	20112.09	20112.09	20112.09
80/84 mild	15449.43	15449.43	15449.43	15767.86	15767.86	15767.86	15767.86	15767.86	16385.49
80/84 moderate	17858.96	17234.19	17407.43	17407.43	17899.33	20112.09	20112.09	20112.09	20112.09
85+ mild	15449.43	15767.86	17071.84	17858.96	17858.96	17234.19	17234.19	17407.43	17407.43
85+ moderate	17234.19	17234.19	17407.43	17407.43	17407.43	17407.43	17407.43	17407.43	17899.33



Charts 4-7

The first three charts, and accompanying Tables, assume that the annual rate of change is set at the start and remains fixed over the following eight years, depending on age group and illness severity group. In Charts 4-7 this process of extrapolating annual rates is refined. As the process of decline causes cognitive scores to pass through the thresholds separating mild, moderate and severe, the annual rate of decline is adjusted to match the new severity group. This leads to a change in projected levels of cognitive ability at successive points in time, as shown in Table 8 (MMSE scores) and Table 9 (SEVINT scores).

Table 8 Adjusted Decline, MMSE

					I cui s	1 I UIII	Start		
	0	1	2	3	4	5	6	7	8
75/79 mild	19.71	18.81	17.91	14.99	12.07	9.15	6.23	3.31	0.39
75/79 moderate	12.88	9.96	7.04	4.12	1.2	-1.72	-4.64	-7.56	-10.48
80/84 mild	19.05	18.85	18.65	18.45	18.25	18.05	17.85	14.56	11.27
80/84 moderate	14.85	11.56	8.27	4.98	1.69	-1.6	-4.89	-8.18	-11.47
85+ mild	19.69	18.09	16.49	15.7	14.91	14.12	13.33	12.54	11.75
85+ moderate	10.6	9.81	9.02	8.23	7.44	6.65	5.86	5.07	4.28

Vears From Start

Vears From Start

Table 9 Adjusted Decline, SEVINT

					1 0111	o vai v			
	0	1	2	3	4	5	6	7	8
75/79 mild	3.5	3.5	4.5	8	9.5	10.5	10.5	12	12
75/79 moderate	8	9.5	10.5	12	12	13	13	13	13
80/84 mild	3.5	3.5	3.5	4.5	4.5	4.5	4.5	8	9.5
80/84 moderate	8	9.5	10.5	10.5	12	13	13	13	13
85+ mild	3.5	4.5	7	7	8	8	8	8	9.5
85+ moderate	9.5	9.5	10.5	10.5	10.5	10.5	10.5	10.5	12

Charts 4 and 6 show this adjusted decline for the whole population, for MMSE and SEVINT respectively. In Charts 5 and 7 clarity is enhanced by removing those over 85 years, as there are only a small number of cases. This allows a clearer focus on the key age groups, 75-79 years of age and 80-84 years of age. One point of interest

emerges from Chart 7. Measured by SEVINT scores, the 'moderate' groups in both categories appear to change at a fairly similar rate. However, the mild groups differ, with the 80-84 age group apparently changing far less than those aged 75-79. It is possible that this apparent anomaly is a sampling problem, generated by the reltively small numbers of persons in each sub-group.











<u>Charts 8-15</u>

This next set of charts takes the data for adjusted levels of cognitive decline and combines this with the data on costs of care, as used in Chart 3. The first example, Chart 8, shows the costs at each point for each of the age and severity sub-groups, using revised figures for cognitive decline. Costs figures are shown in Table 10.

Chart 9 removes the 85+ age group to highlight the key groups of 75-79 years old and 80-84 years old. Chart 10 then picks out the group rated as of mild severity. This shows some apparent anomalies in the progression of costs levels, as discussed earlier. These anomalies are seen more sharply in Chart 11, which concentrates on the 75-79 age group and separates out different bands of annual costs. That is, it shows where the increase in severity leads to the crossing of a threshold where a different mix of care is provided. The annual costs show a gradual trend upwards, but with a sharp rise in year three followed by a fall in year four, with a subsequent resumption in the upward trend. If one examines Table 2, showing the relative location of patients (from Kavanagh et al, 1995) this data can be matched with the change in costs at Year 3. This shows that the shift from SEVINT of 4.5 at Year 2 to SEVINT of 8 at Year 3 results in a shift to a more costly mix of care locations.

In Chart 12, covering the 80-84 age group, a similar general upward trend can be seen. However in this case, the anomalies shift is seen at Year 7, with the same underlying reasons.

Decline
Adjusted
Costs:
xpected
10 E
Table

Years From Start

	0	-	2	3	4	5	9	L	8
75/79 mild	15449.43	15449.43	15767.86	17858.96	17234.19	17407.43	17407.43	17899.33	17899.33
75/79 moderate	17858.96	17234.19	17407.43	17899.33	17899.33	20112.09	20112.09	20112.09	20112.09
80/84 mild	15449.43	15449.43	15449.43	15767.86	15767.86	15767.86	15767.86	17858.96	17234.19
80/84 moderate	17858.96	17234.19	17407.43	17407.43	17899.33	20112.09	20112.09	20112.09	20112.09
85+ mild	15449.43	15767.86	17071.84	17071.84	17858.96	17858.96	17858.96	17858.96	17234.19
85+ moderate	17234.19	17234.19	17407.43	17407.43	17407.43	17407.43	17407.43	17407.43	17899.33







□ 75/79 mild blim 48/08

Chart11: Annual Costs Bands 75-79 Mild



Annual

Costs (£)





Chart 12: Annual Costs Bands 80-84 Mild

Annual Costs (£)

Charts 13-15 repeat this process for the groups defined as 'moderately ill'. In Charts 14 and 15 the bands of annual costs are shown, illustrating how both groups show an immediate dip in the level of expected costs. Both age groups (75-79 and 80-84) reach their highest point early on, by Year 5. As they are more severely ill at the onset of the analysis, it appears intuitive that they should reach a peak of costs faster than those defined as 'mild'.





■ 75/79 moderate 80/84 moderate





Charts 16-19

This set of charts follows the expected costs of care, as calculated previously, and applies the principle of discounting to reflect the lower present value of future costs. Table 11 shows the discounted values of costs in each year f the eight year period.

As shown in Chart 16, discounting of future values results in an observable reduction in the current value of future costs. This gives a set of figures for the present value (PV) of the costs of eight years of care.

 $PVi = Ci / (1+r)^i$

where PVi = Present value of costs of care in year i
Ci = Total costs of care in year i, at current price levels in year i
r = Discount rate.

Chart 17 removes the 85+ age group to focus on the key groups, the 75-79 and 80-84 age groups. Charts 18 and 19 take this further and separate out the mild and moderate age groups.

Future Value of Costs, Discounted at 6% Per Year

Table 11

Years From Start

75/79 mild 15449	,	-	N	ო	4	ŋ	9	7	ω
	19.43	14574.93	14033.34	14994.72	13651.09	13007.85	12271.55	11904.07	11230.26
75/79 moderate 16848	18.07	16258.67	15492.55	15028.62	14177.94	15930.66	15028.92	14178.23	12618.57
80/84 mild 1457 ⁴	74.93	14574.93	13749.93	13239	12489.62	11782.66	11115.72	11877.23	10812.94
80/84 moderate 17858	58.96	16258.67	15492.55	14615.62	14177.94	15930.66	15028.92	14178.23	12618.57
85+ mild 15445	19.43	14875.34	15193.88	14333.85	14145.97	13345.25	12589.86	11877.23	10812.94
85+ moderate 1723 ⁴	34.19	16258.67	15492.55	14615.62	13788.32	13007.85	12271.55	11576.94	11230.26



Chart 16: Annual Costs Discounted @6%

Chart 17: Annual Costs Discounted @ 6% 75-84 Only





■ 75/79 mild □ 80/84 mild



Chart 20

The previous analysis showed the discounted values of future cost in any given year. By aggregating these figures we arrive at the net present value (NPV) of costs over the eight year time span. This can be expressed as:

NPV =
$$\sum_{i=1}^{N} Ci / (1+r)^{i}$$

where

N = Time span, in years

Ci = Costs of care in year i

r = Discount rate

Table 12 NPV of all groups

	Total NPV (£)
75/79 mild	105,667.80
75/79 moderate	118,714.20
80/84 mild	99,642.04
80/84 moderate	118,301.20
85+ mild	107,174.30
85+ moderate	108,241.80

This shows clearly that costs will be higher for patients initially in the 'moderate' group, as opposed to those in the 'mild' group, albeit with some apparent anomalies.



Chart 20: NPV of Costs Over 8 Years

Charts 21-24

The discounting of future costs, to produce NPV, is in line with economic theory and with standard financial theory. However, for service providers and planners costs of care are paid for at current prices, irrespective of the point in time that is being examined. Hence, such persons may be more interested in projected costs, measured at future levels of current prices. Therefore, this next set of analyses takes all projected annual costs and applies an estimate of future costs inflation. A rate of 3% has been used. There are no available forecasts of HCHS or PSS for the next eight years, therefore this figure is just hypothesis. It is in line with recent trends (Netten and Dennett, 1996) and provides some guidance. If actual inflation is higher then future costs will of course be higher, and vice versa.

As can be seen from Table 13, the value of yearly costs rises steadily, peaking in the range of \pounds 22,000 to \pounds 26,000 per annum. This is an approximate indication of the cash sums that will be required at future points to provide care for those currently at given levels of cognitive impairment.

nflation
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Costs
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				Year	s From Star	t			
	0	-	0	က	4	ъ	9	7	ω
75/79 mild	15449.43	15912.91	16728.13	19514.96	19397.23	20179.99	20785.39	22013.91	22674.33
75/79 moderate	17858.96	17751.21	18467.55	19559.08	20145.85	22636.33	23315.42	24014.88	25477.39
80/84 mild	15449.43	15912.91	16390.3	17229.97	17746.87	18279.27	18827.65	21964.26	21831.75
80/84 moderate	17858.96	17751.21	18467.55	19021.57	20145.85	22636.33	23315.42	24014.88	25477.39
85+ mild	15449.43	16240.9	18111.52	18654.87	20100.41	20703.42	21324.53	21964.26	21831.75
85+ moderate	17234.19	17751.21	18467.55	19021.57	19592.22	20179.99	20785.39	21408.95	22674.33







Annual

Costs (£)







CONCLUSIONS

The general conclusions from this work are in line with intuitive expectations. After diagnosis of dementia there is a progressive decline in cognitive ability, as measured by either SEVINT or MMSE.

Over an eight year period this decline leads to a gradual increase in costs of care, as people move away from living at home towards residential care and other more costly interventions. There are some anomalies, so the change is not a smooth upward slope. However, it does appear that if people were prevented from moving along the slope of cognitive decline there would be a beneficial effect on levels of expected costs. They would be held down as people remain at lower points on the spectrum of cognitive disability and impose fewer demands on providers of health and social services.

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