An assessment of the costs of end of life care for people with dementia

Full Technical Report

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1. Key messages

The following key messages emerged from this review of records relating to nine people with dementia in Haringey over the last six months of their lives:

- The average cost of purchasing care over the last six months of life for the nine cases reviewed was estimated at nearly £25,000 per person with dementia
- Costs were higher for people with dementia in care homes and hospitals, than for those living at home
- Accommodation comprised the bulk of costs for people with dementia in care homes or hospitals, whereas formal paid care, hospitalisations and housing modifications made up the majority of costs for people with dementia living at home
- Hospitalisations represented almost 20% of the total average costs of care, and occurred more frequently among people with dementia cared for at home
- In the majority of cases people with dementia were admitted to hospital for ambulatory conditions that could have been treated within the community

2. Objective and background

This case note review aimed to understand both the costs and outcomes for people living with dementia in Haringey over the six months prior to death. In particular, we aimed to understand costs of caring for people with dementia from the perspective of the UK Department of Health and Local Authority Adult Services Departments, in order that this information may be relevant to future commissioning discussions.

Based on Indices of Multiple Deprivation 2007 (IMD 2007) which draw together a number of socio-economic criteria such as education and income, Haringey remains the fifth most deprived borough in London. Most of the deprivation is in the east, particularly the north-east of the borough. Deprivation has had an adverse affect on health, with residents in the east of the borough having a lower life expectancy than those in the west of the borough (Haringey Borough Council, 2008). 15,967 people in Haringey identified themselves as unpaid carers in the 2001 census, with 3,232 providing at least 50 hours per week of care. The carers identified are estimated to save the borough £184.2 million per annum.

This review audits notes from people with dementia who accessed Mental Health Services for Older People in Haringey during 2007-2009. Services in Haringey comprise a memory clinic, consultant-led community mental health team, day hospital, outpatient clinic, admiral nurses, and the inpatient and continuing care wards at St Ann's. People with dementia who had not accessed these services were not included within this review.

3. Methodology

3.1 Data collection

Data was collected on patient demographics and diagnosis, place of care, place of death, carer demographics, care plan, and health and social care services received over the last six months before death (see Audit tool in Appendix). Health and social services received included data on hospital admissions, contacts made with community health and social service providers including formal carers, medications prescribed, and home equipment provided. Data were transcribed from case notes obtained from St Ann's Hospital and Royal Free Hospital notes (both hardcopy and electronic), North Middlesex Hospital, Social Services in Haringey, Kells Nursing Bureau and one GP surgery.

3.2 Unit costs

Two costing perspectives were applied in this analysis: that of the UK Department of Health, and the Local Authority Adult Services Departments, and a societal perspective. Unit costs were taken from NHS HRG tariffs, the 2008 Unit Costs of Health and Social Care (Curtis, 2008), and the British National Formulary and are presented in the Appendix.

Inpatient hospitalisations were costed using HRG tariff payments which reflect the payments made by primary care trusts to hospitals during the 2008/2009 reference period. We have assumed that the tariff applied covers all costs during the spell in hospital, including contacts with consultants and allied health professionals. While HRG tariffs do not reflect the **actual** cost of care, they are relevant for this analysis which seeks to understand costs from a commissioning perspective. Costs for community health and social services were estimated at 2007/8 values, and inflated to 2009 values using a health-specific inflation index (ONS, 2009). Medications were estimated at current 2009 BNF prices (BNF, 2009). Costs of equipment were obtained from Haringey council who reported purchase and installation costs only. Except for housing modifications, we assumed equipment is replaced every three years, and calculated a pro-rata cost for use over the six month study period.

3.3 Calculating cost of care

The financial cost of dementia was estimated for each person over the six months prior to death, and was broken down into the following categories:

Department of Health costs:

- Acute hospital inpatient admissions
- Hospital outpatient services
- Prescribed medications
- Community health services (district nurses, admiral nurses)
- Accommodation: long-stay hospital care (e.g. continuing care ward)

Department of Social Services costs:

- Accommodation: residential care
- Formal care (paid carers, sitters and day care attendance)
- Equipment
- Community social services (social workers, occupational therapists)

Informal costs of care associated with people living at home were included separately to estimate costs from a societal perspective.

Unless otherwise stated, costs of care are presented as weighted averages across all nine people with dementia, regardless of whether or not they accessed the services.

4. Results

4.1 Demographics

- Data were collected for 9 people (6 male, 3 female)
- The age range was 66-84 years
- Ethnicity: 8 white, 1 Caribbean
- People resided in both east and west borough locations, reflecting a mixed socio-economic status profile.
- 5 married, 2 widowed, 1 divorced, 1 single
- Education/occupation/SES unknown in most cases
- Diagnosis: 5 Alzheimer's, 3 Vascular dementia, 1 both
- All but one person was classed as having severe dementia based on MMTS/MMSE scores. End stage dementia was not specifically determined.
- Enteral feeding status: All orally fed
- Co morbidities were common, with records showing some people having in excess of 10 co-morbid conditions (depression, osteoarthritis and hypertension were common).

4.2 Place of care

Six people were cared for in their own home, one in a residential home, one on a continuing care hospital ward, and one unknown. Place of care remained unchanged between six and one month prior to death for all case studies where place of care was recorded at one month prior to death (6/9 patients). 'Family choice' was given as the main reason for people who were cared for at home, whereas 'needing full assistance with activities of daily living (ALD's)' was the reason for one patient being cared for in a residential home; 'unable to manage in a home (agitation)' was the reason given for one person being cared for in a hospital ward. In all cases it was unknown whether this location of care was preferred by the person with dementia.

Of the six people with dementia cared for at home, three attended a day centre a couple of times per week, though only one was still attending one month prior to death. Four of the six people cared for at home used external carers to assist with washing, dressing, transfers etc. Carers came between twice a week and twice a day, though the frequency had increased for many by one month prior to death. Care was provided for one person through a private agency, while the remainder of people accessed care services through a social services care package. One person living at home received full care from his wife, who also used a sitting service a couple of times per week. This was provided through a social service package. The other person living at home was still independent with ADL's. Two people used a hoist, one a stair lift and one a wheelchair, and hospital beds and slide sheets were required in two cases one month prior to death. In most cases, equipment

would have been provided by social services. Three carers were finding it difficult to cope, while in the majority of cases it was not evident from the case notes if carers were coping.

4.3 Care plan

Six people had evidence of a care plan, one did not and details for the other two were unknown. The care plan was most often written by a social worker or staff nurse. Despite having care plans, only one case study showed evidence of having a specific advanced decision not to resuscitate recorded in the care plan.

4.4 Main carer demographics

In five cases the main carer was the person's spouse, in three cases it was the person's son/daughter, and in one case it was the staff at the residential care home. Carers were generally resident with the person if they were the spouse. Two of the three people with a son/daughter as the main carer were cared for on a ward; the other had given up his job as a teacher five years earlier in order to care for his father at home. The degree of input to care was significant for those residing in the same home, including the provision of physical care, emotional support, shopping, cleaning, and control of finances. Most carers residing with the person with dementia reported difficulty in coping, as evidenced from the notes. There was evidence of discussions between carers and nursing staff regarding the person's diagnosis/prognosis.

4.5 Secondary carer details

Secondary carer details were reported for five people. In all cases the secondary carer was the daughter (or daughter-in-law), who was primarily involved in providing emotional support to the main carer.

4.6 The dying phase

Evidence of resuscitation status was found in the hospital medical notes for six of the nine case studies. No record was found of the palliative care team being involved and only one person was on an EOL care pathway. In most cases interventions were not attempted. Advanced care plans and spiritual needs were not assessed. Three patients died in hospital, while the remaining six died in their usual place of care.

4.7 Place of death

From the available case notes reviewed, place of death was only recorded for six patients:

- 2 patients died at home
- 2 died on a continuing care ward at St Ann's Hospital
- 2 died on a general medical ward in an acute hospital?

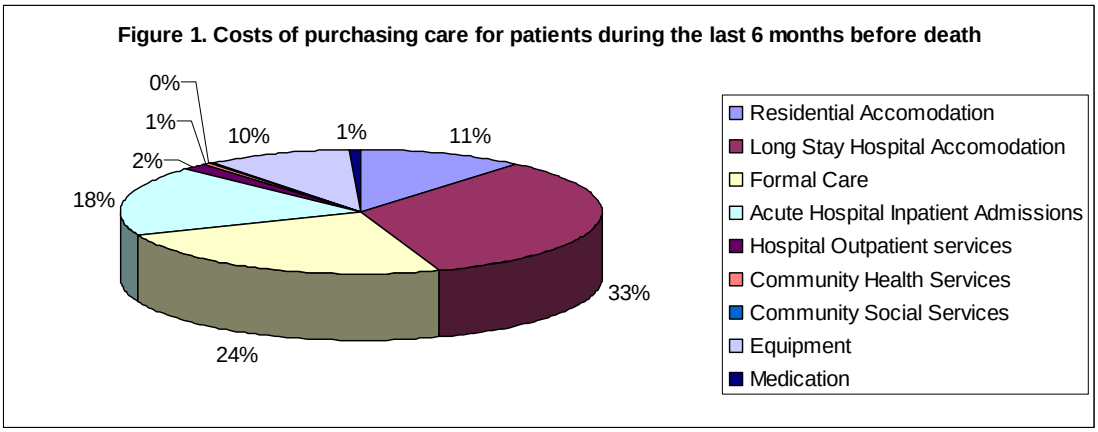
It was unknown whether the relevant location was the person's preferred place of death. Cause of death was recorded for only four people (three died of pneumonia; one died of chronic kidney disease). The cause of death was obtained from the hospital files for those patients who died in hospital. Dementia was mentioned as a secondary cause on one of them.

4.8 Financial cost of dementia

Table 1 shows the estimated cost of care for each person with dementia over the six months before death. The average total cost was £24,278 (range £8,141 - £38,271). These costs are reported from the perspective of the UK Department of Health and the Local Authority Adult Services Departments, and represent the cost of purchasing services.

Figure 1 below shows accommodation and formal care make up the majority of costs (68% of total costs). Following that, acute inpatient admissions account for 18% of the average cost of care in the last six months of life. Costs of care are presented in the Appendix and described below further by commissioning department.

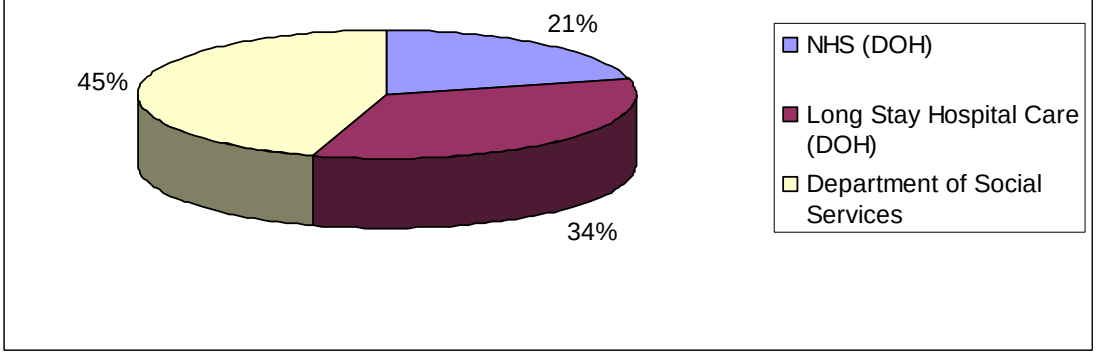
Figure 1. Costs of purchasing care for patients during the last 6 months before death



4.9 Costs of care by commissioning department

Costs of care were divided into those commissioned by the Department of Health and those commissioned by the Local Authority Adult Services Departments. Figure 3 shows 21% (£5,105) of total costs were commissioned by the Department of Health including acute hospital admissions, hospital outpatient services, medication and community health services; a further 34% of total costs (£8,152) were commissioned by the Department of Health toward long stay hospital care; and 45% (£11,021) were commissioned by the council's Adult Services including residential accommodation, formal care, equipment and community social services.

Figure 2. Costs of Care by Commissioning Department



4.9.1 Acute hospital inpatient admissions

Case notes reviewed found evidence that five people were admitted to hospital at least once during the last six months prior to death, three of whom died in hospital. Four people recorded two admissions, and one recorded three admissions. Length of stay ranged from 2 to 40 days, with an average of 12 days. All admissions were unplanned, and required ambulance transport. The average cost of admissions over the last six months of life ranged from £5,651 to £9,956. The weighted average was £4,356 which allows for people without any known admissions, and accounts for 18% of the total costs of care in the last six months of life.

Reasons for admission were varied and are listed in the table below, with the corresponding treatment received in hospital. In the majority of case studies reviewed, patients were treated for conditions that could also have been treated within the community.

Reason for Admission	**Treatment Received**
Not eating or drinking	IV fluids; abdominal ultrasound; catheterised
Constipation, lower abdominal pain, no mobility	IV fluids
Shortness of breath, cough, drowsiness - pneumonia	IV antibiotics and fluids
Acute on chronic confusion	Antibiotics
Poor oral intake, chesty, shaky	SALT assessment, IV antibiotics.
Pale, unresponsive, chesty cough, found unconscious	Nebuliser, IV fluids
Shortness of breath, confusion, pneumonia	IV antibiotics, nebuliser, CT head and neck
Shortness of breath, chest infection	IV antibiotics
Fall/Head injury	CT head; IV fluids
Right leg swollen	Ultrasound and CT abdomen; Warfarin
Vaginal bleeding and reduced appetite	IV fluids; renal ultrasound

4.9.2 Hospital outpatient services

Six patients had seen consultants as a hospital outpatient in the last six months of life. The average weighted cost of hospital outpatient services was £401 in the last six months of life, accounting for 2% of the total costs of care over the last six months of life. Most patients had consulted a psychiatrist once in the last six months before death, and two patient had consulted other specialists (cardiologist, endocrinologist) on an outpatient basis. No contacts were recorded with palliative care services.

4.9.3 Medications

Prescribed medications numbered up to 21 per patient in the six months prior to death (minimum five). The majority were ongoing prescriptions, spanning at least the last six months prior to death. Antidepressants, Proton Pump Inhibitors, analgesics, hypnotics, anti-hypertensives, beta-blocker, statins and laxatives were the most commonly prescribed medications. During the dying phase evidence was mixed over whether all non-essential

medications were stopped, and whether analgesics, sedatives and anti-secretory drugs were prescribed. The average weighted cost of prescribed medications over the last 6 months of life was £189 per patient (range £34 - £551), and accounted for just 1% of the total costs of care.

4.9.4 Community health services

The main community health services accessed by people were district nurses (two people), community mental health nurses (one person) and admiral nurses (two people). The average weighted cost of community health services was £159, again comprising just 1% of total costs. We were not able to access all the evidence relating to contacts with health and social service providers, and equally contacts may not always have been recorded, and as a consequence it must be assumed that this figure is an underestimate.

4.9.5 Accommodation

The cost of accommodation provided in residential care or a continuing care hospital ward over the last six months of life ranged from £24,570 to £36,683. Only three of the nine patients in the review were living in cared accommodation, two of whom were cared for on a continuing care hospital ward. The average weighted cost of accommodation was £10,882, and accounted for 44% of the total costs of care in the last six months of life. Unfortunately we did not have access to information regarding whether part of these costs were met by the patients or their families, and therefore for the purposes of this study it was assumed that the full cost was paid by the Local Authority Adult Service Departments or the Department of Health.

4.9.6 Formal care

The cost of formal paid care for persons at home was estimated to range between £1,433 and £16,811 depending on the frequency of visits. For the three persons who had regular daily carers, the cost for each of their formal care was approximately £15,000 over the last six months of life. The weighted mean cost of formal care was calculated at £5,844 over the last six months of life, and accounted for 24% of the total costs of care. Again, we did not have access to information regarding whether part of these costs were met by the persons with dementia or their families, and therefore it was assumed the full cost was paid by the Local Authority Adult Service Departments and the Department of Health.

4.9.7 Equipment

A variety of equipment was used to assist with caring for people at home, including hoists, sliding sheets, transfer boards, a wheelchair, stair lift, hospital beds, over-bed tables, pressure relieving mattresses, and two families installed ground floor showers. Five of the six people living at home reported at least one item of equipment that was supplied to assist them.

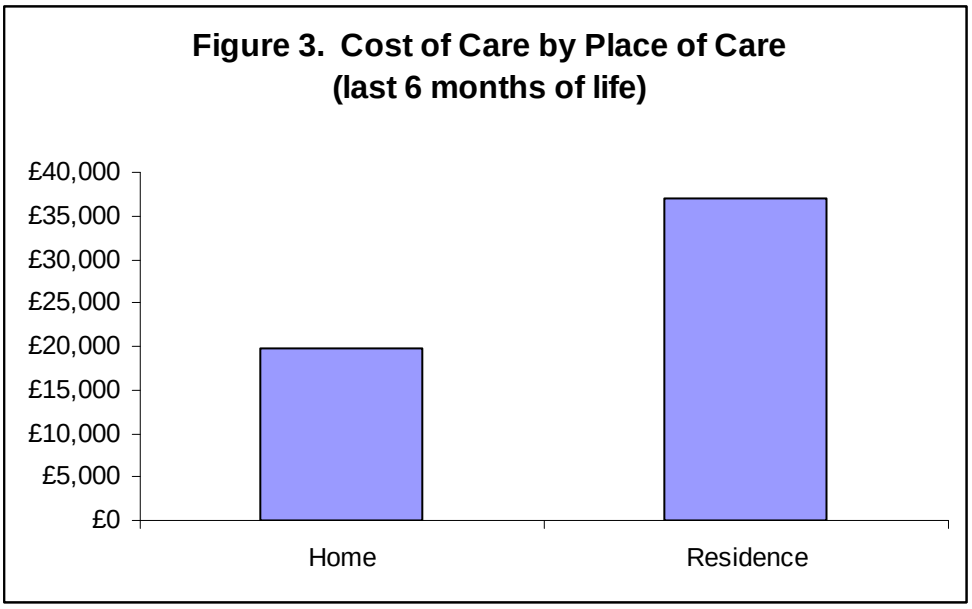
In most cases, the costs of equipment were met by social services, though we did not have access to this information. We have estimated the costs of equipment to range between £148 and £13,000 (median £253; mean £2,400, accounting for 10% of total costs). The cost was dependent on whether structural modifications were made to housing. Some carers installed ground floor showers, stair lifts and built extensions to accommodate the person at home.

4.9.8 Community social services

The main social services accessed by people with dementia were social workers and occupational therapists. Home assessments were conducted for four people, and care packages and arrangements were reviewed by social workers for three people. The average weighted costs of community social services was just £47 in the last six months of life. There was no evidence of contacts with social workers, occupational therapists or community mental health nurses for five people, and therefore we assume this cost is an underestimate.

4.10 Total costs of care by place of care

The average cost of purchasing care for people living at home was £19,854 over the last six months of life, whereas the average cost of purchasing care for people living in a residence or hospital was £37,029. For people cared for in a residential home or hospital, the majority of costs related to accommodation which included 24 hour formal care. For people cared for at home, formal care and acute hospitalisations accounted for the bulk of costs.



4.11 Informal care costs

While the costs associated with informal care may not be relevant from a commissioning perspective, they do represent a significant financial and emotional burden to carers. Based on a conservative estimate of 50 hours of care per week at a rate of £14.50 per hour (Carers UK), we estimate an average cost of £18,850 is associated with the provision of informal care for people living at home.

If costs associated with informal care were incorporated into the analysis, the average cost of care would be £36,844. Informal care would account for approximately 50% of the total cost of care over the last six months of life. Recognition of informal care costs made reduced the difference between costs of care for patients living at home (£38,704), and people in supported residential or continuing care (£37,029).

5. Discussion

5.1 Summary of findings

This audit of nine case notes has highlighted that the cost of purchasing care for people with dementia is substantial. All cases in this review had a diagnosis of severe dementia, and the average cost of their care over the six months prior to death was estimated at nearly £25,000 per person. This represents the cost to the UK Department's of Health and Local Authority Adult Services for purchasing goods and services for these people. By recognising the costs associated with informal care provided to people living at home, average costs of care are estimated at £36,844 over the last six months of life.

Costs of purchasing care were shown to vary by the place of care, with average costs being higher for people in residential homes or continuing care wards, than for people living at home. For people residing in care homes or continuing care wards, the bulk of the cost was related to their accommodation; whereas for patients residing at home, the majority of the cost was comprised of formal paid care, acute hospitalisations and in some cases housing modifications. Acute hospitalisations represented almost 20% of the total average costs of care, and occurred more frequently among people cared for at home. In the majority of cases people could have been treated within the community, which would be more cost-effective than hospital treatment.

5.2 How the results fit with other research

These results are comparable with those reported by the Alzheimer's Society in 2007 (Knapp et al, 2007). They estimated the total annual cost per person with severe dementia in the community was £37,473, and £31,296 for people in care homes (2005/2006 values). Although this estimate is made over a year, we expect the bulk of the cost is incurred in the last six months of life, given that care requirements and hospitalisations may often increase in the months prior to death. These costs were estimated from a societal perspective, and included medication, inpatient care, outpatient care, day hospitals, day centres, community health services, social care, respite care, informal care and lost employment costs. Estimates were based on data collected in another study using the Client Service Receipt Inventory. Accommodation accounted for 41% of total societal costs, and over a third of the total (36%) was due to informal care inputs by family members and other unpaid carers.

Previous research was also reviewed within the same report, and showed that the majority of past studies included informal care as a cost component. Informal care and accommodation tended to make up the bulk of total costs, as shown in our analysis.

5.3 Limitations

These findings must be interpreted with caution given they are based on a very small group of patients. Nevertheless, they do give us some indication over the nature and degree of costs associated with purchasing care for people with dementia.

We also cannot be confident that all the services accessed by each person with dementia have been recorded in the case notes reviewed. In particular, it is anticipated that counts of community health and social services are underestimated.

A number of challenges and obstacles were encountered in undertaking this audit:

- GP notes – despite gaining support for the project and its methodology, we were not granted access to individual GP notes in the majority of cases. We expect these would have been a comprehensive source of information.
- Hospitals – gaining access to case records from hospitals outside Haringey took up to 40 days.
- Within the St Ann's service we could not locate medical records for one case study.
- Obtaining notes through Social Services required going through additional clinical governance procedures.

5.4 Recommendations for future audits

This case note review has enabled us to pilot an audit tool and make recommendations for the collection of data in future audits. One of the largest obstacles faced in this review was obtaining the patient notes from GP surgeries. Future audits should prepare to obtain carer consent upfront in the study in order to access GP notes for deceased patients. Future audits should also record whether a patient died during a particular inpatient admission, ambulance call outs not resulting in admissions, and care package details from social services. These recommendations have been incorporated into the revised data collection form. Future analysis needs to take into account that many accommodation and social care costs are means tested with a financial contribution coming from the family or person with dementia. These costs have not been taken into account in this analysis.

Future audits may also wish to consider using unit costs from local hospitals to reflect the actual cost of hospitalisations, as opposed to the cost of purchasing care from a commissioning perspective.

5.5 Conclusions

This case note review has identified the main costs associated with caring for patients with dementia during the last six months of life. Costs of purchasing care are significant and attempts to avoid unnecessary costs should be of interest to commissioners. While accommodation and formal care comprise the bulk of costs and are generally unavoidable, this review has highlighted a number of cases where costly inpatient hospitalisations could have been avoided if decisions had been made to treat these conditions within the community. Methods aimed at supporting the treatment of such conditions within the community would be a more cost-effective strategy and could reduce total costs of care, as well as maximise health and well-being.

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Appendix

Table 1. Cost of care over the last six months prior to death

Place of care	Residential Accommodation	Long Stay Hospital Accommodation	Formal Care	Acute Hospital Inpatient Admissions	Hospital Outpatient services	Community Health Services	Community Social Services	Equipment	Medication	Total Cost
Home			£15,690			£139		£165	£132	£16,126
Home			£16,811	£5,651	£108	£311	£39	£8,033	£64	£31,017
Continuing care ward		£36,683			£868				£174	£37,724
Continuing care ward		£36,683			£1,457				£131	£38,271
Home			£1,433	£7,791		£262	£77	£148	£34	£9,744
Home			£14,882	£8,766		£459	£77	£253	£166	£24,601
Residential home	£24,570			£9,956	£251				£315	£35,092
Home			£3,779		£376	£262	£231	£13,000	£134	£17,782
Home				£7,040	£550				£551	£8,141
Weighted average	£2,730	£8,152	£5,844	£4,356	£401	£159	£47	£2,400	£189	**£24,278**

Table 2. Range of costs

	Residential Accommodation	Long Stay Hospital Accommodation	Formal care	Hospital Inpatient Admissions	Hospital Outpatient services	Community Health Services	Community Social Services	Equipment	Medication	Total Cost
MIN	£24,570	£36,683	£1,433	£5,651	£108	£139	£39	£139	£34	£8,141
MAX	£24,570	£36,683	£16,811	£9,956	£1,457	£459	£231	£459	£551	£38,271

Table 3. Unit costs

Service	2008	2009	Source	Notes
Local authority residential care for older people	£945	£967	PPSRU, 2008	Care package costs per permanent resident week
Local authority day care for older people	£35	£36	PPSRU, 2008	Cost per morning or afternoon session
24 hours of private home nursing service	£504	£516	PPSRU, 2008	
Cost per hour	£21	£21		
Local authority home care per hour	£18	£18	PPSRU, 2008	
NHS community mental health worker	£38	£39	PPSRU, 2008	per hour client related work
GP per surgery consult of 11.7 mins	£36	£37	PPSRU, 2008	
GP per telephone consultation	£22	£23	PPSRU, 2008	
District nurse	£64	£66	PPSRU, 2008	Per hour spent on home visits
Social worker	£37	£38	PPSRU, 2008	
Hospital OT	£38	£39	PPSRU, 2008	
Hospital Dietician	£30	£31	PPSRU, 2008	
Consultant: Psychiatric	£207	£212	PPSRU, 2008	
Consultant: Psychiatric	£106	£108	PPSRU, 2008	Per contract hour
Continuing care ward St Anns	£201	£206	PPSRU, 2008	Long-stay NHS hospital services for people with mental health problems (cost per inpatient day)

Sitting Service	£10	£10	Estimated cost per hour	
Speech and Language therapist	£38	£39	PPSRU, 2008	Per hour client contact
Informal care (per week)	£725	£742	Carer's UK, 2007	Assume 50 hours of care per week @ £14.50 per hour
Cardiologist	£160	£164	National Schedule of Reference Costs 2007-08	
Endocrinologist	£188	£193	National Schedule of Reference Costs 2007-08	

Cost of equipment	**Cost for 3 years**	**Cost for 6 months ***	
Level access shower	£8,000	£8,000	Haringey Council, Installation cost
Stair lift	£5,000	£5,000	Haringey Council, Installation cost
Hoist (mobile)	£900	£150	Purchase cost Haringey Council
Sliding sheet	£45	£8	Purchase cost Haringey Council
Transfer board	£45	£8	Purchase cost Haringey Council
Hospital bed	£545	£91	Purchase cost Haringey Council
Overbed table	£25	£4	Purchase cost Haringey Council
Pressure relieving mattress (overlay)	£270	£45	Purchase cost Haringey Council
Wheelchair	£200	£33	Estimated

* assumes equipment is replaced after 3 years and spreads the cost over this time