Survey of Admissions to Residential and Nursing Home Care

Final report of the 42 month follow-up

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Summary

Chapter 1: Introduction

- This report describes findings from the final follow-up of individuals included in the 1995 PSSRU Survey of Admissions to Residential and Nursing Homes, three and a half years after admission. The survey provides a unique perspective on what happens to publicly funded residents after admission, allowing us to relate characteristics on admission to subsequent events. The introductory chapter describes the structure of the report and details the methodology and development of the longitudinal database. It includes a description of the outcome of a special exercise with the Office for National Statistics to track mortality of people who had been lost to the survey.

Chapter 2: Moves within Residential and Nursing Home Care

- Approximately 10 per cent of the individuals included in the admissions survey were recorded as having moved to a different home and 7.4 per cent were recorded as having moved to a different type of bed. Including individuals who were admitted to a nursing bed from a residential home suggests that approximately 18 per cent of individuals admitted to a residential bed subsequently move to a different type of bed. (This figure does not include moves from a residential bed via hospital and moves later than 42 months after admission.)

- Individuals admitted to a residential bed were more likely than those admitted to a nursing bed to have moved to a different home or to a different type of bed. Individuals admitted to dual registered homes were less likely to have moved to another home but more likely to have moved to a different type of bed than individuals in the survey as a whole, and the majority moved from a residential to a nursing bed.

- Individuals who moved to a different home or type of bed were more likely to have survived to the 42 month follow-up than those who remained in the same home or type of bed, an unexpected finding for those who moved from a residential bed to a nursing bed.

- Individuals who moved from a nursing bed to a residential bed had lower levels of dependency on admission than those who remained in the same type of bed or who left nursing home care. People who moved from a residential bed to a nursing bed had slightly lower levels of dependency on admission than those who remained in the same type of bed,

but the difference was not statistically significant. Individuals who left residential care tended to have lower levels of dependency than those who remained in residential or nursing home care.

- Individuals who moved to a different type of bed were more likely to have been predicted to have been admitted to that type of bed than those who remained in the original type of bed. However, the association between the predicted location and the destination was much weaker for those admitted to a residential bed than for those admitted to a nursing bed.

- Levels of dependency on admission of those who moved from a nursing bed to a residential bed and the association between their predicted location and their destination suggest that these moves were likely to have resulted from initial misplacement. However, changes in health states appear to be more likely factors precipitating moves from residential to nursing beds. Such individuals were more likely to have had a higher level of dependency following the move than on admission, compared with those who remained in a residential bed.

Chapter 3: Length of Stay and Mortality

- The median survival for the whole sample is 19.6 months (± 0.9 months). For those originally admitted to nursing homes it is 11.9 months (± 0.9 months), and for residential care it is 26.8 months (± 1.0 months).

- The factors at admission that significantly raise subsequent mortality are, in order of their statistical significance:
  - having a malignancy (cancer);
  - having a low Barthel score (high disability);
  - old age;
  - being a man;
  - being admitted to a nursing home;
  - being admitted from a hospital;
  - having a respiratory illness;
  - being cognitively impaired on admission.

- There are no significant differences between local authorities in survival outcomes, after taking into account factors such as dependency on admission.

- As a few residents will live for a long while, the average length of survival is much greater than the median. Although this average cannot be calculated precisely until all have died, our best estimate is 29.7 months and almost certainly in the range 28.9–30.7 months.

Chapter 4: Dependency and Mental Health Outcomes

- With regard to both dependency and cognitive function, survivors at six months may, on average, be a little better than at the time of admission, but thereafter there will be a slow but steady decline. The improvement by six months is most marked in those activities of daily living that might relate to being in a better controlled environment, rather than any real indication that people have recovered in a way that might make them more fit to return to private households.

- People who are comparatively independent at the time of admission improve most. People with specific health diagnoses on admission are the ones most likely to improve. Surprisingly, however, these are not people discharged from hospital. More of the people admitted from private households improve.

- This suggests that it is not premature discharge from hospital that provides the greatest missed opportunities for possible rehabilitation. Rather it is among people admitted from private households with chronic diseases. Possibly these are diseases that may undergo remission, and thus enable the person to be more independent, at least for a while.

- Expectation of life at different states of health differs considerably depending on health at the outset. A person with very severe dependency on admission is likely to spend most of their remaining life in that state. A person with low dependency will live perhaps four times as long, and half of their remaining life will be at low dependency.

- Though some people seem quite independent and mentally alert at each stage of the survey, only one per cent of all those admitted were in this condition at every wave of the survey. The implication is that there is not an obvious group for whom such a placement is clearly inappropriate.

Chapter 5: Lifetime Costs within a Care Home

- The average gross lifetime cost to social services of a placement is £32,000 for a nursing bed and £38,000 for a residential bed (1996 prices). There is tremendous variation in lifetime costs and about 10 per cent will cost more than £100,000. These estimates depend on survival beyond 42 months, but are likely to be within 5 per cent of these figures.

- Net lifetime costs are harder to judge because of problems establishing the client contribution. The cost is much higher in local authority residential homes compared with other types of accommodation. Given the central forecast of survival it likely to be £30,000-£34,000 for a placement in a local authority home, £18,000-£23,000 in other residential homes, and £19,000-£22,000 in a nursing home.

- We recommend that the most appropriate way to estimate the gross lifetime cost of a new client is from the initial weekly cost multiplied by expected survival, given by the prediction model from chapter 3.

- Those factors which raise weekly costs, for example by leading to nursing rather than residential care, are precisely those that lower expected survival. The consequence is that while lifetime cost may be predicted prior to a placement decision, the great variation means such estimates cannot be expected to be very accurate in individual cases.

- An example is given of how to calculate expected gross lifetime costs, using the prediction formula.

Chapter 1
Introduction

1.1 Introduction

This is the final report of the follow-ups to the 1995 PSSRU Survey of Admissions to Residential and Nursing Homes (Bebbington et al., 1996), and reports on the status of users in the first three and a half years following admission. The survey provides a unique perspective on what happens to publicly funded residents, allowing their characteristics on admission to be related to subsequent events.

The final stage of the survey was intended primarily as a check on results reported after 30 months (Bebbington et al., 2000), and this report brings those results up to date. In general, the assumptions at 30 months have proved correct, and so the broad sweep of conclusions is not greatly changed. What was innovative at this final stage was a check with the Office for National Statistics (ONS) on the death registrations of members of the original survey, particularly those with whom contact had been lost. This means that the evidence on survival is almost complete. One consequence is that lifetime survival appears to be slightly longer than previously estimated, as a result of which the estimated lifetime costs of care are a little higher than before.

The present report covers only some of the issues with which the survey has been concerned. Previous reports and papers have described the characteristics of people being admitted and how they differed from the general elderly population, the circumstances surrounding admission, the risk of admission, what influences placement and the initial cost, ethnicity, and what happens subsequently to people who leave care homes. These themes are not repeated here.

The present report begins in this chapter with a complete description of the tracking process and the locations of residents at each of the stages of the longitudinal study. A new appendix has been added describing the results of the ONS enquiry, which will be of methodological interest to other researchers. Chapter 2 explores the degree to which people move once they have been admitted: between homes, out of homes and between types of bed. Chapter 3 updates an analysis predicting length of stay and mortality among residents, key factors in predicting long-term costs, with a method of predicting survival given circumstances on admission. Chapter 4 considers how health states change during the first few years after admission, and the consequences for healthy (or unhealthy) life expectancy while in care homes. Finally, chapter 5

brings together information about care careers and mortality to predict lifetime costs after admission to a care home.

1.2 The Survey

The survey included 2,629 individuals who were admitted from 18 local authorities to residential and nursing home care during a three-month period in the autumn of 1995, as long-stay, local authority supported residents aged 65 or over. The follow-ups were conducted six months, 18 months, 30 months and 42 months after admission.

1.2.1 Selection of local authorities

An initial sample of 20 local authorities, stratified by type of authority (London borough, metropolitan district, and county), was selected and approached to discuss participation in the survey. It had been estimated on the basis of available statistics that this number of local authorities would yield 2,200 new long-term admissions to residential and nursing homes over a period of three months. Within authority type, local authorities were subdivided by a further geographical stratification and then classified according to the following additional factors: socio-economic group (Craig, 1985), population sparsity (Chartered Institute of Public Finance and Accountancy, 1994) and migration rate (1991 Population Census data). The migration rate measured the influx of people aged over 45 years and was included as an indicator of retirement areas. London boroughs were divided into inner and outer London boroughs, and were then selected to represent different socio-economic groups and, secondly, different migration rates. Metropolitan districts were selected to represent different socio-economic groups and, secondly, different levels of population sparsity, within the constraint that one metropolitan district be selected from each of the six former metropolitan counties. Counties were divided into two geographical groups corresponding to the North and Central and to the Southern Policy and Business Regions used by the Social Services Inspectorate. They were then selected according to migration rate and population sparsity and, within these, total population, in order to ensure the inclusion of a sufficient number of large local authorities. Where there were alternatives within these subgroups, authorities were selected at random. The information on socio-economic groupings was only available for the 1981 Population Census figures at the time of the selection of the sample, and was not used in the selection of county councils because it was only available at district level. The local authorities included in a concurrent PSSRU project, 'Evaluating Community Care for Elderly People' (Bauld et al., 2000), were excluded from the sampling frame. The 20 selected authorities included six London boroughs, six metropolitan districts and eight counties.

Some of the original 20 selected local authorities were not able to participate in the admissions survey, and authorities with similar characteristics from the same type of authority, and inner or outer London, where relevant, were approached as potential replacements. Five additional authorities were approached as potential replacements. Uncertainties about the definite agreement to participate and some delays by authorities in advising of their withdrawal resulted in a final group of 18 local authorities, including 14 of the original 20 selected and four of the five approached as replacements. This group included five London boroughs (Haringey, Harrow, Newham, Southwark and Sutton), eight metropolitan districts (Doncaster, Leeds, Manchester, Sandwell, Sefton, South Tyneside, Stockport and Tameside) and five counties (Cheshire, Hertfordshire, Kent, Norfolk and Warwickshire).

Comparisons of the final sample of authorities for the admissions survey with national socio-demographic indicators and statistics of residential provision suggested that the selected authorities were not atypical, either as a whole or within authority type. However, the final sample was rather unbalanced in terms of the number of authorities selected from each authority type. Comparisons of the number of supported residents, at 31st March 1995, indicated that the selected London boroughs covered 14 per cent of elderly residents supported by local authorities in residential and nursing homes, and the selected counties covered 13 per cent, whereas the figure for metropolitan districts was 24 per cent. In the analyses of the admissions survey for Standard Spending Assessment calculations, the data were reweighted to represent the proportions of supported elderly residents in the three types of authority (Bebbington et al., 1996).

1.2.2 Fieldwork procedure for the follow-up surveys

The information collected in the admissions survey was provided by social services staff in the 18 participating local authorities. In the follow-ups, home managers were asked to complete a questionnaire to record the location of the elderly person and, if they were still resident in the home, information on their level of dependency. The information on dependency was designed to correspond to the information recorded in the admissions survey. For those elderly people who were no longer in the home, respondents were asked to record their destination and the date of departure or death. If an elderly person had moved to another residential or nursing home, the new home was contacted and asked to complete the same questionnaire. Separate exercises were conducted in parallel to each of the follow-ups, to follow up those elderly people who left the home to return to a private household or who were discharged to hospital without their bed in the home being kept open. Information about these cases was obtained from the local authority which made the original assessment for admission and, except for the 42 month follow-up, included information on dependency for individuals who were still alive and who had not returned to residential or nursing home care. Those re-admitted to a residential or nursing

home were then included in the main series of follow-up studies. Following the 42 month follow-up, arrangements were made with the Office for National Statistics to undertake a flagging exercise to obtain dates of death for individuals who had been reported as having died, but with no date of death, and for individuals for whom follow-up information was missing. The flagging exercise was undertaken for 226 individuals, of whom 103 were reported as having died, 99 were reported as still alive and 24 could not be traced. As our experience may be of interest to other social science researchers wishing to obtain information from this source, further details of this exercise are contained in an appendix to this chapter.

The results from the first three follow-ups, including information about those elderly people who returned to a private household or who were discharged to hospital, have been presented in four previous papers (Darton and Brown, 1997; Bebbington et al., 1998, 1999, 2000).

1.3 Development of the Database

The full database for the admissions survey included 2,629 individuals. However, the survey included two groups of individuals who were included at the request of two of the participating local authorities: 66 individuals in the first local authority were on a waiting list for admission; and three individuals in the second local authority were receiving alternative packages of care to residential or nursing home care. In addition, 15 individuals were aged under 65 years, including one of the waiting list cases, and four were found to be short-term admissions, including one individual aged under 65 years. A further three cases were found to be duplicates.

This chapter is based on 2,540 cases, excluding the 89 out-of-scope cases. Previous reports on the results of the six month, 18 month and 30 month follow-ups were based on slightly different numbers of cases, depending upon the availability of information on out-of-scope cases. As in the previous reports, the cases have not been weighted for the purposes of the analyses presented in this chapter.

1.3.1 Data on location one month after admission

The original survey in autumn 1995 included a check on the location of the elderly people one month after admission. One hundred and seventy two individuals were reported to have died and 64 individuals were reported as having moved to another location within one month of admission. In addition, separate information was obtained on the death of 28 individuals, of whom four had moved to another location within one month of admission.

1.3.2 Six month follow-up data

At the six month follow-up, information was obtained for 1,917 of the 2,540 individuals included in the analysis of the admissions survey, including two cases reported to have died within one month of admission, although the information on location at the six month follow-up was incomplete for three cases. No information was obtained at the six month follow-up for 42 of the 60 individuals who were reported as having moved to another location within one month of admission, but who were not reported to have died, and the information obtained on the location of these cases one month after admission was used as the location at six months. As a result of these adjustments, information was available for 2,154 cases, 85 per cent of the 2,540 individuals included in the analysis of the admissions survey. However, separate information was also obtained on deaths within the first six months and, in addition, further information on deaths by six months was obtained at the subsequent follow-ups and in the flagging exercise. This accounted for a further 207 deaths. For 132 of these individuals their location at six months was previously classified as unknown. Thus the information on location at six months presented below is based on 2,286 cases. The cases who were not followed up at six months included 44 individuals who refused to be included in the follow-up and eight cases who were untraceable. For 32 of the 754 deaths recorded at the six month follow-up, the date of death occurred more than six months after admission. However, this problem was largely overcome in the questionnaires used for the subsequent follow-ups by improving the instructions on the questionnaires.

1.3.3 18 month follow-up data

The 18 month follow-up included individuals who were alive, traceable and who had not previously refused to take part in the study. One thousand, eight hundred and thirty-one of the 2,629 cases in the full database remained after excluding cases who were recorded as having died at the time of the six month follow-up, those who refused and those who were untraceable. Additional information obtained from homes and local authorities between the six month and 18 month follow-ups, together with information from the six month follow-up, identified a further 431 cases who had died, or who had moved to a private household or who had been discharged to hospital. Excluding these cases, and the three individuals included in the admissions survey who were receiving alternative packages of care, resulted in a total of 1,397 individuals for whom an 18 month follow-up questionnaire was sent to home managers. Information was obtained for 1,161 of the 1,397 individuals covered by the 18 month follow-up (83 per cent), of whom 1,125 were included among the 2,540 cases used in the analyses presented in this report. The cases who were not followed up at 18 months included 32 individuals who refused to be included in the follow-up and eight cases who were untraceable or ineligible, for example those who were self financing. Among the 1,125 cases for whom information was obtained at the 18

month follow-up, 120 were recorded as having died, four were recorded as having moved to a private household and 11 were recorded as having been discharged to hospital.

The information obtained at the 18 month follow-up has been combined with information obtained at the six month follow-up, and additional information on deaths, moves to a private household and discharges to hospital, to provide comprehensive information on location at the 18 month follow-up. As for the information presented on the six month follow-up, the information presented on location at 18 months incorporates some separate information on deaths within the first six months and further information obtained at the subsequent follow-ups and in the flagging exercise. The information on location at the 18 month follow-up includes the deaths of 134 individuals whose location was classified as unknown in the 18 month follow-up. The information on location at 18 months presented below is based on 2,266 cases.

1.3.4 30 month follow-up data

The methodology used for the 18 month follow-up was repeated for the 30 month follow-up. Beginning with the 1,831 cases identified for the 18 month follow-up, 1,269 remained after excluding cases who were recorded as having died prior to or during the 18 month follow-up, those who refused, those who were untraceable or ineligible, the three individuals included in the admissions survey who were receiving alternative packages of care, and a duplicate case. Additional information obtained from homes and local authorities between the 18 month and 30 month follow-ups identified a further 296 cases who had died, or who had moved to a private household or who had been discharged to hospital. Excluding these cases resulted in a total of 973 individuals for whom a 30 month follow-up questionnaire was sent to home managers. Information was obtained for 819 of the 973 individuals covered by the 30 month follow-up (84 per cent), of whom 799 were included among the 2,540 cases used in the analyses presented in this chapter. The cases who were not followed up at 30 months included 11 individuals who refused to be included in the follow-up and two cases who were untraceable. Among the 799 cases for whom information was obtained at the 30 month follow-up, 84 were recorded as having died, four were recorded as having moved to a private household and seven were recorded as having been discharged to hospital. As for the previous follow-ups, the information obtained at the 30 month follow-up has been combined with additional information on deaths, moves to a private household and discharges to hospital, to provide comprehensive information on location at the 30 month follow-up. The information on location at 30 months presented below is based on 2,315 cases.

1.3.5 42 month follow-up data

A similar procedure was employed for the 42 month follow-up. Beginning with the 1,269 cases identified for the 30 month follow-up, 879 remained after excluding cases who were recorded as

having died prior to or during the 30 month follow-up, those who refused and those who were untraceable. Two cases which had been removed at previous stages were reinstated because it was uncertain whether they had actually died and two duplicate cases were removed, leaving 879 cases for the follow-up. Additional information obtained from homes and local authorities between the 30 month and 42 month follow-ups identified a further 205 cases who had died, or who had moved to a private household or who had been discharged to hospital. Excluding these cases resulted in a total of 674 individuals for whom a 42 month follow-up questionnaire was sent to home managers. Two cases which had been excluded were subsequently found to be living in residential care, and were included, bringing the total to 676 cases. Information was obtained for 586 of the 676 individuals covered by the 42 month follow-up (87 per cent), of whom 573 were included among the 2,540 cases used in the analyses presented in this chapter. The cases who were not followed up at 42 months included five individuals who refused to be included in the follow-up. Among the 573 cases for whom information was obtained at the 42 month follow-up, 71 were recorded as having died, four were recorded as having moved to a private household and eight were recorded as having been discharged to hospital. As for the previous follow-ups, the information obtained at the 42 month follow-up has been combined with additional information on deaths, moves to a private household and discharges to hospital, to provide comprehensive information on location at the 42 month follow-up. The information on location at 42 months presented below is based on 2,359 cases.

1.4 Location of Elderly People at the Six Month, 18 Month, 30 Month and 42 Month Follow-Ups

Tables 1.1 and 1.2 present information on the location of the elderly people at the six month, 18 month, 30 month and 42 month follow-ups, after incorporating the adjustments to each set of follow-up data described in section 1.3. These adjustments include information on deaths of individuals who had moved to a private household or who had entered hospital. Thus, the proportions of deaths at six, 18 and 30 months are higher than the corresponding figures shown in the reports on these follow-ups (Darton and Brown, 1997; Bebbington et al., 1998, 1999, 2000). The information presented in tables 1.1 and 1.2 also incorporates amendments to the location of individuals obtained in the follow-ups of people who left the home to return to a private household or who were discharged to hospital. The type of bed to which the individuals were originally admitted refers to the type of bed recorded in the admissions survey, and does not necessarily correspond to the type of bed to which individuals who were already in residential or nursing home care were first admitted.

As noted above, information on the location of individuals at six months was obtained for 2,286 of the 2,540 individuals included in the admissions survey (90 per cent). Of these 2,286 cases, 61 per cent were still in the same type of bed as on admission, 33 per cent had died, 2 per cent had moved to a different type of bed, 2 per cent had moved to a private household and one per cent had entered hospital. At 18 months, information was obtained on the location of 2,266 individuals (89 per cent). Of these 2,266 cases, 39 per cent were still in the same type of bed as on admission, 54 per cent had died, 4 per cent had moved to a different type of bed, 2 per cent had moved to a private household and seven individuals had entered hospital. At 30 months, information was obtained on the location of 2,315 individuals (91 per cent). Of these 2,315 cases, 26 per cent were still in the same type of bed as on admission, 68 per cent had died, 4 per cent had moved to a different type of bed, 2 per cent had moved to a private household and ten individuals had entered hospital. At 42 months, information was obtained on the location of 2,359 individuals (93 per cent). Of these 2,359 cases, 18 per cent were still in the same type of bed as on admission, 78 per cent had died, 3 per cent had moved to a different type of bed, one per cent had moved to a private household and ten individuals had entered hospital. A further 45 individuals were reported to have died more than 42 months after admission, including 20 individuals for whom no information was obtained on their location at 42 months. Thus, 1,883 of the 2,540 individuals (74 per cent) are known to have died during a period of approximately four and a half years from the beginning of the admissions survey.

Individuals admitted to a nursing bed in autumn 1995 were more likely than those admitted to a residential bed to have died by the six month follow-up, and less likely to be in the same home or to have moved elsewhere, either to hospital or to a private household. Among the individuals for whom follow-up information was obtained, 45 per cent of those originally admitted to a nursing bed had died, compared with 22 per cent of those originally admitted to a residential bed, while 52 per cent of those originally admitted to a nursing bed and 70 per cent of those originally admitted to a residential bed were still in the same type of bed. By the 18 month follow-up, 67 per cent of those originally admitted to a nursing bed had died, compared with 42 per cent of those originally admitted to a residential bed, while 28 per cent of those originally admitted to a nursing bed and 49 per cent of those originally admitted to a residential bed were still in the same type of bed. By the 30 month follow-up, 78 per cent of those originally admitted to a nursing bed had died, compared with 59 per cent of those originally admitted to a residential bed, while 19 per cent of those originally admitted to a nursing bed and 33 per cent of those originally admitted to a residential bed were still in the same type of bed. By the 42 month follow-up, 85 per cent of those originally admitted to a nursing bed had died, compared with 71 per cent of those originally admitted to a residential bed, while 12 per cent of those originally admitted to a nursing bed and 23 per cent of those originally admitted to a residential bed were still in the same type of bed.

Table 1.3 presents information on the destination of the elderly people who left residential or nursing home care within 42 months of admission, by their location at the 42 month follow-up. A total of 93 individuals (4 per cent of all individuals) were recorded as having moved to a private household and a total of 103 individuals (4 per cent) were recorded as having been discharged to hospital during the 42 months following admission. In addition, two individuals who were recorded as having moved to a private household and five who were recorded as having been discharged to hospital were recorded as having died on the same day. These individuals were included with the 1,701 deaths in table 1.3. Among those who had moved to a private household, 24 per cent were still in a private household at 42 months, 13 per cent had returned to residential or nursing home care or were in hospital, and 57 per cent had died. Among those who had been discharged to hospital, 10 per cent were still in hospital and 82 per cent had died.

Appendix 1: The Follow-Up of Missing Cases via the Office for National Statistics (ONS)

A1.1 The Problem

Commencing in the latter part of 1995, the longitudinal survey of people admitted to residential and nursing home care identified and followed 2629 individuals nationally. Information was obtained at the time of admission, and again after one, six, 18, 30 and 42 months, mainly by postal survey. This information was designed to record the health and survival outcomes of individuals, the pattern of discharge, and the cost consequences of the admission.

One of the key items in relation to health and, as it turned out, to the long-term cost, was the survival of the person following admission. This also affected the conduct of the survey in so far as those who were reported as having died were no longer followed up. For this reason we were concerned that, as far as practicable, accurate information regarding survival was obtained. During the survey, such information was sought from a variety of sources:

- At one month, information was obtained from care managers.
- Prior to the six, 18, 30 and 42 month waves, the local authorities were asked to provide information on deaths and, for 18 months onwards, changes of location.
- At each follow-up, information was obtained from questionnaires returned by home managers, detailing the status of the person.
- Where people had left the care home, a 'tracking' exercise was conducted to contact the care manager or, in some cases, the person's family to discover what had happened.
- Ad hoc information provided by home managers between waves, using a form supplied to report changes of circumstances.

When a person was reported as having died, a date of death was recorded in the database. At all stages of the survey everyone was followed up who had not been reported dead or had requested to be removed from further participation in the survey. Nevertheless, like all surveys of this type, not everyone was successfully traced at all stages. After the 42 month wave, there were still a number who were not reported to have died, but for whom there was no return confirming they were still alive (excluding the small group that had withdrawn from the survey). Moreover, there were a number of cases where death had been reported, but no date given; and some where we had reason to doubt whether the report of death was accurate.

We removed a few cases that should not have been included in the original survey: people under 65, or who were not local authority financed. In total this left 226 such cases unknown.

It was decided that it would be desirable to seek information on this group through the Registration of Deaths, and for this purpose an approach was made to the ONS.

A1.2 Recovery of Data

There were two major practical difficulties with this exercise: first, obtaining permission from the ONS and, second, providing information to the ONS in a suitable format for death notification (if any) to be given.

First, although Death Registrations are public documents, this is not the case for information held on the National Health Service Central Register, which is by far the most convenient source of computerised information on deaths. However, these records are available for bona-fide medical research, with permission.[1] Normally, medical research involves approval by the appropriate ethics committees. However, the study was primarily a local authority survey. The ethics committee of South Thames RHA was approached, but they expressed the view that the study did not require approval, though they had no objection to it. The study did, of course, relate to health care, it was Department of Health funded, we had the approval of all but one of the participating local authorities for this purpose, and individuals had agreed in principle that health information could be forwarded to the survey. Ultimately, on consideration, the ONS gave their approval, though this took a year and the caution they exercised should be noted. Having once agreed, however, the required information was supplied to us within three weeks of the list being sent to the ONS.

Second, the ONS required as much information as possible about individuals in order to trace them. Ideally this would be their NHS number, which was not known to us, but the name, date of birth, and last known address should suffice in most cases. These details were not known to the survey team, IPSOS-RSL, in all cases. There were several variations in the data collection methodology and six of the 18 local authorities had provided a 'client reference number' rather than a name, in order to protect the person's identity. The consequence was that all subsequent contact with or about the individual had to be conducted via the local authority, rather than with home managers.

[1] Office for National Statistics Information and Statistics Division, *Application to use Individual Records for Medical Research.*

The result was that where a name was known the case could be submitted directly to the ONS. Cases with a client reference number could only be sent to the ONS via the relevant local authority. In these latter cases we cannot, in general, be certain whether this was done or whether the information we subsequently received had come from the ONS or from a further local authority search. One local authority refused to participate in this exercise. The results of this were as follows:

- 171 cases were submitted direct to ONS, of which the success rate for obtaining information was 95 per cent - 162 valid results. The summary provided by ONS was not very specific as to why the remainder were untraced, but we must assume that they were untraceable as a result of insufficient information to uniquely identify the person.
- 48 cases were followed up by local authorities, of which the success rate for obtaining information about survival was 83 per cent - 40 valid results. The main reason for a non-valid response from the local authorities was that there was no record of the case appearing on their database. The information had simply been lost.
- Seven cases were not followed up.

Overall, 202 of the 226 cases were successfully followed up, of whom 103 were recorded as having died and 99 were still alive, at the date of the 42 month follow-up (one advantage of the NHS Central Register is that it could positively confirm this). Twenty-four cases were not successfully traced.

Table 1.1: Location of individuals at 6 month, 18 month, 30 month and 42 month follow-ups

Location	*6 months*		*18 months*		*30 months*		*42 months*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Total number of individuals	2540	100.0	2540	100.0	2540	100.0	2540	100.0
Originally admitted to residential bed	885	34.8	652	25.7	467	18.4	338	13.3
Same type of bed	846	33.3	590	23.2	404	15.9	291	11.4
Moved to nursing bed/home	39	1.5	62	2.4	63	2.5	47	1.9
Originally admitted to nursing bed	569	22.4	334	13.1	230	9.1	151	5.9
Same type of bed	558	22.0	299	11.8	207	8.1	135	5.3
Moved to residential bed/home	11	0.4	35	1.4	23	0.9	16	0.6
Elsewhere	78	3.1	62	2.4	45	1.8	32	1.3
In hospital (bed not being kept open)	24	0.9	7	0.3	10	0.4	10	0.4
In private household	54	2.1	55	2.2	35	1.4	22	0.9
Died	754	29.7	1218	48.0	1573	61.9	1838	72.4
No information	254	10.0	274	10.8	225	8.9	181	7.1

Table 1.2: Location of individuals at 6 month, 18 month, 30 month and 42 month follow-ups, by type of bed to which originally admitted

Location	*6 months*				*18 months*				*30 months*				*42 months*			
	Admitted to residential bed		*Admitted to nursing bed*		*Admitted to residential bed*		*Admitted to nursing bed*		*Admitted to residential bed*		*Admitted to nursing bed*		*Admitted to residential bed*		*Admitted to nursing bed*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Total number of individuals	1366	100.0	1174	100.0	1366	100.0	1174	100.0	1366	100.0	1174	100.0	1366	100.0	1174	100.0
In a residential or nursing home	885	64.8	569	48.5	652	47.7	334	28.4	467	34.2	230	19.6	338	24.7	151	12.9
In same type of bed originally admitted to	828	60.6	539	45.9	581	42.5	297	25.3	400	29.3	202	17.2	288	21.1	132	11.2
In another residential bed/home	18	1.3	11	0.9	9	0.7	35	3.0	4	0.3	23	2.0	3	0.2	16	1.4
In another nursing bed/home	39	2.9	19	1.6	62	4.5	2	0.2	63	4.6	5	0.4	47	3.4	3	0.3
Elsewhere	56	4.1	22	1.9	44	3.2	18	1.5	32	2.3	13	1.1	21	1.5	11	0.9
In hospital (bed not being kept open)	16	1.2	8	0.7	6	0.4	1	0.1	7	0.5	3	0.3	7	0.5	3	0.3
In private household	40	2.9	14	1.2	38	2.8	17	1.4	25	1.8	10	0.9	14	1.0	8	0.7
Died	270	19.8	484	41.2	509	37.3	709	60.4	730	53.4	843	71.8	899	65.8	939	80.0
No information	155	11.3	99	8.4	161	11.8	113	9.6	137	10.0	88	7.5	108	7.9	73	6.2

Table 1.3: Destination of individuals who had left residential or nursing home care within 42 months of admission, by location at 42 month follow-up (number of cases)

Destination	*Residential Bed*	*Nursing Bed*	*Hospital*	*Private household*	*Died*	*No information*	*All individuals*
Number of individuals	307	182	10	22	1838	181	2540
Destination							
Residential or nursing bed	295	175	-	-	-	-	470
Hospital	4	3	10	0	84	2	103[1]
Private household	8	4	0	22	53	6	93[2]
Died	-	-	-	-	1701	-	1701
No information	-	-	-	-	-	173	173

Notes: 1. Excluding 5 deaths on the date of discharge.
2. Excluding 2 deaths on the date of discharge.

Chapter 2
Moves within Residential and Nursing Home Care

2.1 Introduction

The examination of moves within residential and nursing home care is of interest both for welfare and for financial reasons. From a review of the literature on the attitudes and aspirations of older people, Boaz et al. (1999) note that older people who have moved into residential care often identify advantages of their new homes, including the safe environment, the care they received and the company of others, but they also do not want to have to move again. Financially, the move from a residential to a nursing home entails considerable extra costs, with the average weekly fee level for private nursing home care being approximately £100 greater than that for private residential home care (Laing and Buisson, 1999). Information from the admissions survey and the three follow-ups up to 30 months on the extent of moving between residential and nursing home care, and on the characteristics of movers, was presented in Bebbington et al. (2000). This chapter updates the information presented in the previous report by including information from the 42 month follow-up. For individuals admitted to dual registered homes, moves between residential and nursing beds may be made within the home, thus avoiding unwanted further moves between homes, and this chapter includes information on moves of those admitted to dual registered homes. This chapter includes information on the number of moves within and out of residential or nursing home care, and it includes some information about the characteristics of those who moved out of residential or nursing home care. Further details of the characteristics of these individuals are given in the report of the 30 month follow-up (Bebbington et al., 2000).

Information is presented in this chapter on moves within residential and nursing home care in terms of moves between types of bed and moves between homes. However, since moves between beds were less likely to be underestimated than moves between homes, as explained below, and also incorporated moves within dual registered homes, the analyses concentrate on moves between beds. The information presented in this chapter is based on 2,540 cases, following the exclusion of 89 out-of-scope cases, as described in chapter 1. The majority (over 98 per cent) of individuals in the admissions survey were admitted from a domestic household, sheltered housing, residential care, nursing home care, or hospital. The remainder were admitted from an unspecified, 'other' location and, in one case, the information was not recorded. Approximately 13 per cent of the individuals in the admissions survey were admitted from a residential or a nursing home, 10 per cent from a residential home and 3 per cent from a nursing home. For the purposes of the analyses below, the sources of admission have been grouped into

four categories, as follows: a private household (including a domestic household, sheltered housing, another location and a missing location); a residential home; a nursing home; and hospital.

2.2 Methodology for Defining Moves

Between the admissions survey and the follow-up of those elderly people who had returned to a private household or who had been discharged to hospital by 42 months, information on the location of the elderly people was obtained on up to 14 occasions, inclusive of the admissions survey and the 42 month follow-up. However, the information collected prior to the six month, 18 month, 30 month and 42 month follow-ups was less detailed than the information collected in the follow-ups themselves. In the admissions survey, individuals were classified according to the type of home (nursing home, residential home, residential bed in a dual registered home, or nursing bed in a dual registered home) and the ownership of the home (local authority, voluntary/not for profit, or private). For those remaining in residential or nursing home care, the information collected one month after admission and in the six month, 18 month, 30 month and 42 month follow-up studies included the type of bed the resident was occupying and whether the resident was in a different home on the relevant follow-up date. Those who had moved to a different type of home were classified in one of the above four categories, and the same classification was used to record the location of individuals who were recorded as being in residential or nursing home care in the follow-ups of those who had returned to a private household or who had been discharged to hospital. However, the information collected prior to the six month follow-up only covered deaths, while the information collected prior to the 18 month, 30 month and 42 month follow-ups covered moves to a different home, but did not include the type of home.

For those remaining in residential or nursing home care, moves may have occurred between homes or, in dual registered homes, from one type of bed to another. The questionnaires used for the follow-ups asked respondents to indicate whether the elderly person was in the same home as they were admitted to in the admissions survey, or whether they were in a different home. However, it is possible that some respondents may have not made the connection with the admissions survey and simply recorded that the elderly person was in a residential or nursing bed, thus leading to an underestimate of the number of moves between homes. Consequently, the recording of moves between types of bed, either between homes or, in the case of dual registered homes, within homes, is likely to be more complete than the recording of moves between homes. As noted above, the information collected prior to the 18 month, 30 month and 42 month follow-ups recorded moves between homes, but did not identify the type of home. For

cases where subsequent follow-up information was obtained, the nature of the move would be clarified, except possibly in the case of moves between the same type of home, and thus the information collected prior to the follow-ups could not be used in determining moves between beds without subsequent follow-up information. However, the information collected prior to the 18 month, 30 month and 42 month follow-ups has been used to estimate the number of moves between homes.

2.3 Destination of Elderly People in the Period up to the 42 Month Follow-Up

Tables 2.1 and 2.2 show the destination of individuals in the period up to the 42 month follow-up, according the type of bed that they were admitted to during the admissions survey, and their source of admission. Table 2.1 does not include moves within homes, that is, moves within dual registered homes, and table 2.2 does not include moves between homes to the same type of bed. Table 2.3 summarises the information shown in table 2.2, and table 2.4 shows the same information for those individuals admitted to residential or nursing beds in dual registered homes. Moves out of residential or nursing home care to a private household or hospital are denoted as moves 'elsewhere' in the tables. Table 2.5 shows the time at which moves to a different home or type of bed were recorded. The tables record the moves of individuals prior to death, and details of deaths are given in table 2.6.

As may be seen from tables 2.1 and 2.2, very few individuals left residential or nursing home care after moving to a different home or to a different type of bed. In addition, few individuals were recorded as having returned to residential or nursing home care after having moved to a private household or hospital. However, moves back into the same type of bed following a move out of residential or nursing home care have not been identified separately, and are included in moves 'elsewhere' in table 2.2. Table 2.3 summarises the information shown in table 2.2. In this table, individuals who left residential or nursing home care after moving to a different type of bed are included with those who moved to a different type of bed. Individuals who left residential or nursing home care and then returned are included with those who were just recorded as having left residential or nursing home care.

As may be seen from table 2.3, 7.4 per cent of individuals were recorded as having moved to a different type of bed (9.7 per cent were recorded as having moved to a different home). Individuals admitted to a residential bed were more likely than those admitted to a nursing bed to have moved to a different type of bed (9.7 per cent compared with 4.8 per cent) or to have moved to a different home (12 per cent compared with 7.5 per cent).

Table 2.4 shows the corresponding information for individuals admitted to dual registered homes to that shown in table 2.3 for all individuals. Individuals admitted to dual registered homes were less likely to have moved to another home than individuals in the survey as a whole (4.5 per cent compared with 9.7 per cent), but they were more likely to have moved to a different type of bed (16 per cent compared with 7.4 per cent). Among those who moved to a different type of bed, the majority (86 per cent) moved from a residential to a nursing bed. Few of those admitted to a dual registered home moved to a private household or hospital, compared with individuals in the survey as a whole. Including those who had moved to a different home or type of bed prior to moving out of residential or nursing home care, 196 individuals (7.7 per cent) were recorded as having moved out of residential or nursing home care. Among those admitted to dual registered homes, eight individuals (4.5 per cent) were recorded as having moved out of residential or nursing home care, including one individual who had moved to a different home and one who had moved to a different type of bed prior to moving out of residential or nursing home care.

The preceding comparisons relate to the type of bed to which the individual was admitted in the admissions survey. Among those admitted to a residential bed, 11 per cent were admitted from another home, the majority (86 per cent) having been admitted from another residential home. For those admitted to a nursing bed, 16 per cent were admitted from another home, the majority (73 per cent) again having been admitted from a residential home. An estimate of the proportion of individuals admitted to residential care who moved to a nursing bed may be derived by including the 134 individuals admitted to a nursing bed from a residential home with the 1,346 individuals admitted to a residential bed from sources other than a nursing home. Among these individuals, 18 per cent were recorded as having moved to a different type of bed, compared with the 9.7 per cent of individuals admitted to a residential bed in the admissions survey who subsequently moved to a different type of bed. Since few individuals in the admissions survey were admitted to a residential bed from a nursing home, the corresponding estimate for individuals admitted to a nursing bed who moved to a residential bed is more similar to the proportion of individuals admitted to a nursing bed in the admissions survey who subsequently moved to a residential bed (6.8 per cent compared with 4.8 per cent).

For individuals who moved to a different type of bed, table 2.5 shows the time at which the move was recorded. The largest proportion of moves (37 per cent) was recorded at the 18 month follow-up. However, individuals admitted to a nursing bed were much more likely to have been recorded as having moved to a different bed at the 18 month follow-up than those admitted to a residential bed (52 per cent compared with 30 per cent).

2.4 Survival of Elderly People in the Period up to the 42 Month Follow-Up

Table 2.6 shows the numbers of individuals who were recorded as having died within 42 months of admission and the number who were recorded as having survived, according to the type of bed that they were admitted to during the admissions survey and their destination, defined in terms of the type of bed they occupied. The percentages given in the table have been calculated after excluding individuals for whom no information was obtained about their destination.

Individuals who were recorded as having moved to a different home or to a different type of bed were more likely to have survived than those who remained in the same home or type of bed, or who left residential or nursing home care. Among those admitted to a residential bed, about 50 per cent of those who moved to a different home or type of bed were recorded as having survived to 42 months following admission, compared with 27 per cent of those who remained in the same home or type of bed. For individuals admitted to a nursing bed, 49 per cent of those who moved to a different home and 52 per cent of those who moved to a different type of bed were recorded as having survived, compared with 12 per cent of those who remained in the same home or type of bed. Although it may be expected that individuals admitted to a nursing bed and moving to residential care would be less frail than those remaining in nursing home care, the greater survival rate among those who moved from a residential bed to nursing home care is unexpected.

The figures shown in table 2.6 include individuals admitted from another home. However, the greater survival rate among those who moved to another home or another type of bed, than among those who remained in the same home or type of bed, was exhibited by individuals admitted from a private household and by those admitted from hospital, and the greater survival rate among those who moved to a different type of home or bed does not appear to be an artefact.

2.5 Dependency Characteristics of Individuals on Admission according to their Destination

Tables 2.7 and 2.8 present information on the dependency characteristics and cognitive functioning of individuals on admission, according to the type of bed that they were admitted to during the admissions survey and their destination, defined in terms of the type of bed they occupied. The discrepancies between the number of individuals admitted to residential or nursing beds shown in these tables and the total number included in the preceding tables (1,366 admissions to residential beds and 1,174 admissions to nursing beds) are due to the exclusion of cases with missing dependency or cognitive impairment data. The percentages given in the

tables have been calculated after excluding individuals for whom no information was obtained about their destination. The measure of dependency presented in table 2.7 is the Barthel Index of Activities of Daily Living (ADL), which is based on ten functions (Collin et al., 1988). For this index, a higher score (maximum 20) corresponds to a lower level of dependency. The scores on the Barthel Index have been grouped into five categories (0-4, 5-8, 9-12, 13-16, 17-20), following Granger et al. (1979), but with an additional subdivision of the group of higher scores. The measure of cognitive functioning presented in table 2.8 is based on a grouping of the seven categories of the MDS Cognitive Performance Scale (CPS) (Morris et al., 1994): 'intact' = code 0; 'mild impairment' = codes 1, 2, 3; 'severe impairment' = codes 4, 5, 6.

Individuals admitted to a residential bed who moved to a private household or to hospital had lower levels of dependency than those who remained in residential or nursing home care. Among those who left residential care, 62 per cent had low or very low levels of dependency on admission (Barthel scores 13-20), compared with 49 per cent of those who remained in the same type of bed and 54 per cent of those who moved to a different type of bed. By contrast, individuals admitted to a nursing home and who moved to a different type of bed were more likely to have had low or very low levels of dependency on admission (30 per cent) than those who remained in the same type of bed (11 per cent) or those who left nursing home care (18 per cent). In both cases, there was a statistically significant association between the level of dependency and the destination, although this was weaker for those admitted to a residential bed: for admissions to a residential bed, $X^2 = 16.2$, 8 df, $p = 0.040$; for admissions to a nursing bed, $X^2 = 33.4$, 8 df, $p < 0.001$. For individuals who were admitted to a nursing bed and who remained in residential or nursing home care, there was a significant association between the level of dependency and whether they remained in a nursing bed or moved to a different type of bed ($X^2 = 27.0$, 4 df, $p < 0.001$). However, it should be noted that only 9.6 per cent of individuals admitted to a nursing bed moved from a nursing bed to a different type of bed or left nursing home care, excluding those for whom no information on their destination was obtained. For individuals who were admitted to a residential bed and who remained in residential or nursing home care, the association between the level of dependency and whether they remained in a residential bed or moved to a different type of bed was not statistically significant ($X^2 = 1.40$, 4 df, $p = 0.844$).

Individuals admitted to a residential bed who moved to a private household or to hospital also tended to have lower levels of cognitive impairment than those who remained in residential or nursing home care, and the same was the case for individuals admitted to a nursing bed. Among those who left residential care, having been admitted to a residential bed, 81 per cent were cognitively intact or suffered mild cognitive impairment (MDS CPS scores 0-3), compared with 73 per cent of those who remained in the same type of bed and 64 per cent of those who moved

to a different type of bed. For those admitted to a nursing bed, 66 per cent of those who left nursing home care were cognitively intact or suffered mild cognitive impairment, compared with 54 per cent of those who remained in the same type of bed and 49 per cent of those who moved to a different type of bed. However, although the association between the level of cognitive impairment and the destination just reached the 5 per cent level of statistical significance for admissions to a residential bed ($X^2 = 9.57$, 4 df, $p = 0.048$), it was not statistically significant for admissions to a nursing bed ($X^2 = 7.17$, 4 df, $p = 0.127$).

The preceding comparisons relate to the type of bed to which the individual was admitted in the admissions survey. Although 54 per cent of those who moved from a residential bed to a different type of bed had low or very low levels of dependency on admission to residential care, and 64 per cent were cognitively intact or suffered mild cognitive impairment, individuals admitted to a nursing bed from a residential home had higher levels of dependency and cognitive impairment on admission. Only 18 per cent of these individuals had low or very low levels of dependency and 48 per cent were cognitively intact or suffered mild cognitive impairment. As noted above, individuals admitted to a nursing bed who moved to a different type of bed had lower levels of dependency than those who remained in the same type of bed or who left nursing home care. Among these individuals, 30 per cent had low or very low levels of dependency on admission and 49 per cent were cognitively intact or suffered mild cognitive impairment. However, 53 per cent of those individuals who were admitted to a residential bed from a nursing home had low or very levels of dependency and 81 per cent were cognitively intact or suffered mild cognitive impairment, although, as noted above, few individuals were admitted to a residential bed from a nursing home.

As explained in section 2.3, above, an estimate of the proportion of individuals admitted to residential care who moved to a nursing bed may be derived by including the individuals admitted to a nursing bed from a residential home with those individuals admitted to a residential bed from sources other than a nursing home, and a similar estimate may be made of the proportion of individuals admitted to nursing home care who moved to a residential bed. Among the individuals admitted to a nursing bed from a residential home or who were admitted to a residential bed from sources other than a nursing home, and who subsequently moved to a different type of bed, 36 per cent had low or very low levels of dependency on admission and 56 per cent were cognitively intact or suffered mild cognitive impairment. Among those who were admitted to a residential bed and who moved to a different type of bed, 54 per cent had low or very low levels of dependency on admission and 64 per cent were cognitively intact or suffered mild cognitive impairment. For individuals admitted to a residential bed from a nursing home or who were admitted to a nursing bed from sources other than a residential home, and who subsequently moved to a different type of bed, 35 per cent had low or very low levels of

dependency on admission and 59 per cent were cognitively intact or suffered mild cognitive impairment. The proportion of individuals with low or very low levels of dependency on admission is similar to that for those who were admitted to a nursing bed and who moved to a different type of bed (30 per cent), whereas the proportion who were cognitively intact or who suffered mild cognitive impairment is somewhat higher than that for those who were admitted to a nursing bed and who moved to a different type of bed (49 per cent). However, few individuals were admitted to a residential bed from a nursing home.

Information on the dependency of individuals who were admitted to a nursing bed from a residential home or to a residential bed from a nursing home was obtained at the time of the re-admission. Thus, combining information on dependency for those admitted to residential or nursing home care for the first time in the admissions survey with that for those who were admitted from another home does not take account of changes in levels of dependency between the original admission and the re-admission. However, incorporating information for those admitted from another home does alter the level of dependency in the expected direction for both admissions to residential and to nursing home care, although the difference is more marked for those who moved from residential to nursing home care since the majority of moves between residential and nursing homes were in this direction.

As noted above, moves out of residential and nursing home care include moves to a private household or to hospital, and it may be expected that individuals who moved to a private household were less dependent than those who moved to hospital. In fact, the proportion of individuals who had low or very low levels of dependency on admission was only slightly higher among those who moved to a private household than those who moved to hospital. Among those admitted to a residential bed, 64 per cent of those who moved to a private household and 60 per cent of those who moved to hospital had low or very low levels of dependency on admission. Among those admitted to a nursing bed, a slightly higher proportion of those who moved to a private household also had low or very low levels of dependency, compared with those who moved to hospital, but there were only a few of these individuals. Ideally, comparisons of levels of dependency of those who moved to different locations should be based on the level of dependency at the time of the move, not the level of dependency on admission. As noted in chapter 1, information on dependency levels was obtained at the time of the move in the six month, 18 month and 30 month follow-ups, but not in the 42 month follow-up. Furthermore, information on dependency levels at the time of the move was obtained for about two-thirds of those who were recorded as having moved to a private household by the 30 month follow-up, but those who moved to hospital were not routinely followed up (Bebbington et al., 2000).

2.6 Predicted Location of Individuals and their Destination

In a previous paper (Netten et al., 1999), logistic regression analysis was used to compare the characteristics of individuals admitted to a nursing home bed with the characteristics of those who were admitted to a residential bed. The variables examined in the analysis related to personal characteristics (age group, sex, Barthel score, cognitive impairment, problem behaviour, need for nursing care, disorders and diseases, and reasons for admission), household composition and source of admission. A model including variables which reached the 5 per cent level of statistical significance produced correct predictions of the type of bed to which the individual was admitted for over 81 per cent of cases. Since 54 per cent of the sample had been admitted to a residential bed and 46 per cent had been admitted to a nursing bed, the minimum proportion of correct predictions, 54 per cent, could be achieved by allocating all cases to residential beds. Thus the model provided a substantial improvement over this. The variables included in the final equation were: the (grouped) Barthel score; the frequency of problem behaviour; whether the individual suffered from malignancy, whether they suffered from arthritis; whether they suffered from deafness; whether they required daily dressings; whether they required bedfast procedures; whether they required other nursing care; whether their admission was due to physical health problems; whether their admission was due to family breakdown; whether their admission was due to a lack of motivation; whether they lived alone or with others; and their source of admission. Individuals who suffered from arthritis or deafness, or whose admission was due to family breakdown or a lack of motivation, or who lived alone, were more likely to be admitted to a residential bed.

Table 2.9 shows the predicted location of individuals based on the logistic regression model, according to the type of bed that they were admitted to during the admissions survey and their destination, defined in terms of the type of bed they occupied. Individuals who were recorded as having assets exceeding the capital limit for public funding (£8,000 at the time of the survey) were not included in the logistic regression analysis, and are excluded from the table. Individuals with a predicted probability of less than 0.5 of being admitted to a nursing bed have been predicted to be admissions to a residential bed, and individuals with a predicted probability of at least 0.5 of being admitted to a nursing bed have been predicted to be admissions to a nursing bed. Predictions cannot be made for individuals with missing information for one or more of the variables in the logistic regression equation, and these individuals have been omitted from the table. The percentages given in the table have been calculated after excluding individuals for whom no information was obtained about their destination.

The logistic regression model predicted that 87 per cent of those admitted to a residential bed would have been admitted to a residential bed and that 75 per cent of those admitted to a nursing

bed would have been admitted to a nursing bed. Individuals admitted to a residential bed and who moved to a nursing bed were only slightly more likely to have been predicted to have been admitted to a nursing bed than those who remained in a residential bed (16 per cent compared with 13 per cent), and the association between the predicted location and the destination was not statistically significant ($X^2 = 0.60$, 1 df, $p = 0.438$). In contrast, individuals admitted to a nursing bed and who moved to a residential bed were substantially more likely to have been predicted to have been admitted to a residential bed than those who remained in a nursing bed (58 per cent compared with 23 per cent), a statistically significant association ($X^2 = 27.4$, 1df, $p < 0.001$). However, it should be noted that the number who moved from a nursing bed to a residential bed was relatively small.

The source of admission was included as a predictor in the logistic regression model, and so it is not necessary for this analysis to adjust the number of individuals admitted to residential or nursing home care to take account of those admitted from another home.

2.7 Change in Dependency of Individuals according to their Destination

As shown in section 2.5, individuals who moved from a nursing bed to a residential bed had lower levels of dependency on admission than those who remained in a nursing bed, although there were relatively few such individuals. On the basis of their characteristics on admission, they were also substantially more likely to have been predicted to have been admitted to a residential bed than those who remained in a nursing bed, as shown in section 2.6. However, individuals who moved from a residential bed to a nursing bed had only slightly higher levels of dependency on admission than those who remained in a residential bed, and the association between the predicted location and the destination was much weaker for those admitted to a residential bed than for those admitted to a nursing bed. Thus, although moves from nursing to residential beds were associated with characteristics on admission and might have been the result of initial misplacement, moves from residential to nursing beds were likely to result from subsequent changes in health state.

Table 2.10 shows changes in the level of dependency between admission and each of the four follow-ups for individuals remaining in residential or nursing home care, according to the type of bed that they were admitted to and whether they were recorded as remaining in the same type of bed or as having moved to a different type of bed. The table includes 178 individuals who were recorded as having moved to a different type of bed at the six month, 18 month, 30 month and 42 month follow-ups, and excludes ten individuals who were recorded as having moved one month after admission, as shown in table 2.5. Individuals with incomplete follow-up

information are reported separately in the table. These cases are those for whom incomplete information on dependency was obtained or, in the case of those remaining in the original type of bed, no response was obtained to the follow-up questionnaire. Changes for individuals can be extremely heterogeneous (Jagger et al., 1993), and the assessment of changes over time is complicated by problems of measurement error, which will reduce the correlation between the separate assessments (the regression towards the mean effect). For the Barthel Index, a difference of four points has been suggested as highly likely to represent a genuine change (Collin et al., 1988), and changes of four or more points have been used to denote changes in dependency in table 2.10. However, it should be noted that the assessments for the admissions survey and at the four follow-ups were undertaken by different personnel, and thus may be subject to additional measurement error. In addition, individuals who were recorded as having moved to a different type of home at a particular follow-up could have moved at any time since the previous follow-up. Thus, the information on dependency does not relate exactly to the level of dependency at the time of the move, and would include any further changes in dependency between the time of the move and the follow-up.

However, despite these caveats, individuals who were admitted to a residential bed and who moved to a different type of bed were more likely than those who remained in a residential bed to have a higher level of dependency at each follow-up. Among those who remained in a residential bed, the proportion recorded as having a higher level of dependency increased from 20 per cent at the six month follow-up to 40 per cent at the 42 month follow-up. However, 73 per cent of those who moved from a residential to a nursing bed were recorded as having a higher level of dependency following the move, the lowest proportion being 63 per cent, at the 18 month follow-up.

Among those who remained in a nursing bed, the proportion recorded as having a higher level of dependency increased from 22 per cent at the six month follow-up to 40 per cent at the 42 month follow-up, and the proportion recorded as having a lower level of dependency decreased from 17 per cent at the six month and 18 month follow-ups to 8 per cent at the 42 month follow-up. Among those who moved from a nursing bed to a residential bed, 29 per cent were recorded as having a higher level of dependency following the move and 26 per cent were recorded as having a lower level of dependency.

Individuals who moved from a residential bed to a nursing bed were also more likely than those who remained in a residential bed to suffer from cognitive impairment at the follow-up. Among those who remained in a residential bed, the proportion recorded as suffering from cognitive impairment, defined as MDS CPS scores 2-6, increased from 58 per cent at the six month follow-up to 68 per cent at the 42 month follow-up. Among those who moved from a residential

bed to a nursing bed, 84 per cent were recorded as suffering from cognitive impairment following the move. However, among individuals admitted to a nursing bed, levels of cognitive impairment among those who moved to a residential bed were similar to levels of cognitive impairment among those who remained in a nursing bed.

Thus, as expected, individuals who moved from a residential bed to a nursing bed were more likely to have a higher level of dependency following the move than on admission, compared with those who remained in a residential bed. Conversely, those who moved from a nursing bed to a residential bed were more likely to have a lower level of dependency than on admission, compared with those who remained in a nursing bed, although the difference was less marked and there were fewer individuals who moved from a nursing to a residential bed.

2.8 Comparisons between the 30 Month and 42 Month Follow-Ups

The incorporation of information from the 42 month follow-up in the analysis of moves within residential and nursing home care has not altered the principal findings presented in the report on the 30 month follow-up (Bebbington et al., 2000).

In the previous report, 167 individuals were recorded as having moved to a different type of bed, and the information collected in the 42 month follow-up increased this figure to 188 individuals. This altered the distribution of the length of stay prior to the move to a different type of bed and reduced the proportion of moves which occurred by each of the previous follow-ups, but the relative proportions of movers at the previous stages were unaffected.

Although the number of individuals who survived to 42 months was inevitably lower than the number who survived to 30 months, the relative proportions of survivors among those who moved to different locations were similar to those recorded at the 30 month follow-up.

Among those admitted to residential care, the relation between their level of physical dependency on admission and their destination, and the association between their predicted location from the logistic regression model and their destination tended to be weaker than in the analyses based on the 30 month follow-up, while the association between cognitive impairment on admission and the destination was slightly stronger. However, the differences between the results from the 30 month and the 42 month follow-ups were small, and the direction of the differences were not changed, with one minor exception. In the analysis based on the 42 month follow-up, the proportion of individuals with low or very low levels of dependency among those who moved from a residential bed to a nursing bed was slightly higher than among those who

remained in a residential bed, whereas in the 30 month follow-up the proportions were the same. However, the difference at the 42 month follow-up was not statistically significant.

Individuals admitted to a residential bed, and who moved to a private household tended to have slightly lower levels of dependency on admission than those who moved to hospital, whereas in the analysis based on the 30 month follow-up the same proportions had low or very low levels of dependency on admission. However, the differences between the 30 month and the 42 month follow-ups were small.

2.9 Conclusions

Approximately 10 per cent of the individuals included in the admissions survey were recorded as having moved to a different home and 7.4 per cent were recorded as having moved to a different type of bed. Individuals admitted to a residential bed were more likely than those admitted to a nursing bed to have moved to a different home or to a different type of bed. Individuals admitted to dual registered homes were less likely to have moved to another home but more likely to have moved to a different type of bed than individuals in the survey as a whole, and the majority moved from a residential to a nursing bed.

Including individuals who were admitted to a nursing bed from a residential home suggests that approximately 18 per cent of individuals admitted to a residential bed subsequently move to a different type of bed. It should be noted, however, that this figure does not include moves from a residential bed via hospital and moves later than 42 months after admission.

Individuals who moved to a different home or type of bed were more likely to have survived to the 42 month follow-up than those who remained in the same home or type of bed, an unexpected finding for those who moved from a residential bed to a nursing bed.

Individuals who moved from a nursing bed to a residential bed had lower levels of dependency on admission than those who remained in the same type of bed or who left nursing home care. However, individuals who moved from a residential bed to a nursing bed had slightly lower levels of dependency on admission than those who remained in the same type of bed, but the difference was not statistically significant. Individuals admitted to a residential bed who moved to a private household or to hospital tended to have lower levels of dependency than those who remained in residential or nursing home care.

Predictions of the type of bed that individuals would be expected to have been admitted to, derived from a logistic regression analysis, have been compared with moves between residential and nursing home care. This showed that individuals who moved to a different type of bed were more likely to have been predicted to be admitted to that type of bed than those who remained in the original type of bed. However, the association between the predicted location and the destination was much weaker for those admitted to a residential bed than for those admitted to a nursing bed. The results suggest that the limited moves from nursing to residential beds were likely to have resulted from initial misplacement. The moves from residential to nursing beds, on the other hand, were less evident from characteristics on admission, suggesting that changes in health state are more likely to be the factors precipitating a move. This is supported by an analysis of changes in levels of dependency among those who moved to a different type of bed. Individuals who moved from a residential bed to a nursing bed were more likely to have had a higher level of dependency following the move than on admission, compared with those who remained in a residential bed. Individuals who moved from a nursing bed to a residential bed were more likely to have had a lower level of dependency than on admission, compared with those who remained in a nursing bed, although the difference was less marked. Chapter 4 of this report discusses changes in health state generally.

Table 2.1: Destination (home) of individuals in period to 42 month follow-up, by type of bed admitted to and source of admission (number of cases)

Type of bed admitted to and source of admission	*Same home that admitted to*	*Different home*	*Different home then elsewhere*	*Elsewhere*	*Elsewhere then returned to a home*	*No information*	*All individuals*
Number of individuals	1960	233	13	141	42	151	2540
Admitted to residential bed	985	150	8	103	34	86	1366
From private household	457	76	2	44	23	35	637
From residential home	92	22	2	4	2	5	127
From nursing home	14	1	0	2	0	3	20
From hospital	422	51	4	53	9	43	582
Admitted to nursing bed	975	83	5	38	8	65	1174
From private household	202	16	1	7	4	19	249
From residential home	112	11	1	2	0	8	134
From nursing home	43	3	0	1	0	2	49
From hospital	618	53	3	28	4	36	742

Table 2.2: Destination (type of bed) of individuals in period to 42 month follow-up, by type of bed admitted to and source of admission (number of cases)

Type of bed admitted to and source of admission	*Same type of bed that admitted to*	*Different type of bed*	*Different type of bed then elsewhere*	*Elsewhere*	*Elsewhere then different type of bed*	*No information*	*All individuals*
Number of individuals	2002	181	7	170	19	161	2540
Admitted to residential bed	1004	126	6	123	16	91	1366
From private household	460	69	1	57	11	39	637
From residential home	98	13	1	6	1	8	127
From nursing home	14	1	1	1	0	3	20
From hospital	432	43	3	59	4	41	582
Admitted to nursing bed	998	55	1	47	3	70	1174
From private household	203	14	1	9	2	20	249
From residential home	118	4	0	3	0	9	134
From nursing home	45	1	0	1	0	2	49
From hospital	632	36	0	34	1	39	742

Table 2.3: Destination (type of bed) of individuals in period to 42 month follow-up, by type of bed admitted to and source of admission

Type of bed admitted to and source of admission	*Same type of bed that admitted to*		*Different type of bed*		*Elsewhere*		*No information*		*All individuals*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Number of individuals	2002	78.8	188	7.4	189	7.4	161	6.3	2540	100.0
Admitted to residential bed	1004	73.5	132	9.7	139	10.2	91	6.7	1366	100.0
From private household	460	72.2	70	11.0	68	10.7	39	6.1	637	100.0
From residential home	98	77.2	14	11.0	7	5.5	8	6.3	127	100.0
From nursing home	14	70.0	2	10.0	1	5.0	3	15.0	20	100.0
From hospital	432	74.2	46	7.9	63	10.8	41	7.0	582	100.0
Admitted to nursing bed	998	85.0	56	4.8	50	4.3	70	6.0	1174	100.0
From private household	203	81.5	15	6.0	11	4.4	20	8.0	249	100.0
From residential home	118	88.1	4	3.0	3	2.2	9	6.7	134	100.0
From nursing home	45	91.8	1	2.0	1	2.0	2	4.1	49	100.0
From hospital	632	85.2	36	4.9	35	4.7	39	5.3	742	100.0

Table 2.4: Destination (type of bed) of individuals admitted to dual registered homes in period to 42 month follow-up, by type of bed admitted to and source of admission

Type of bed admitted to and source of admission	*Same type of bed that admitted to*		*Different type of bed*		*Elsewhere*		*No information*		*All individuals*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Number of individuals	124	69.7	29	16.3	7	3.9	18	10.1	178	100.0
Admitted to residential bed	56	59.6	25	26.6	4	4.3	9	9.6	94	100.0
From private household	23	52.3	15	34.1	2	4.5	4	9.1	44	100.0
From residential home	5	83.3	1	16.7	0	0.0	0	0.0	6	100.0
From nursing home	2	40.0	2	40.0	0	0.0	1	20.0	5	100.0
From hospital	26	66.7	7	17.9	2	5.1	4	10.3	39	100.0
Admitted to nursing bed	68	81.0	4	4.8	3	3.6	9	10.7	84	100.0
From private household	6	50.0	3	25.0	0	0.0	3	25.0	12	100.0
From residential home	11	84.6	0	0.0	0	0.0	2	15.4	13	100.0
From nursing home	2	100.0	0	0.0	0	0.0	0	0.0	2	100.0
From hospital	49	86.0	1	1.8	3	5.3	4	7.0	57	100.0

Table 2.5: Time of move of individuals who moved to a different type of bed in period to 42 month follow-up, by type of bed admitted to and source of admission

Type of bed admitted to and source of admission	*1 month*		*6 months*		*18 months*		*30 months*		*42 months*		*All individuals*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Number of individuals	10	5.3	44	23.4	69	36.7	37	19.7	28	14.9	188	100.0
Admitted to residential bed	9	6.8	33	25.0	40	30.3	27	20.5	23	17.4	132	100.0
From private household	4	5.7	17	24.3	23	32.9	18	25.7	8	11.4	70	100.0
From residential home	0	0.0	5	35.7	5	35.7	2	14.3	2	14.3	14	100.0
From nursing home	0	0.0	0	0.0	0	0.0	1	50.0	1	50.0	2	100.0
From hospital	5	10.9	11	23.9	12	26.1	6	13.0	12	26.1	46	100.0
Admitted to nursing bed	1	1.8	11	19.6	29	51.8	10	17.9	5	8.9	56	100.0
From private household	0	0.0	3	20.0	9	60.0	3	20.0	0	0.0	15	100.0
From residential home	0	0.0	0	0.0	1	25.0	1	25.0	2	50.0	4	100.0
From nursing home	0	0.0	0	0.0	0	0.0	1	100.0	0	0.0	1	100.0
From hospital	1	2.8	8	22.2	19	52.8	5	13.9	3	8.3	36	100.0

Table 2.6: Survival of individuals in 42 months following admission, by destination (type of bed)

Type of bed admitted to and survival to 42 months	*Same type of bed that admitted to*		*Different type of bed*		*Elsewhere*		*No information*		*All individuals*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Number of individuals	2002	84.2	188	7.9	189	7.9	161	-	2540	100.0
Admitted to residential bed	1004	78.7	132	10.4	139	10.9	91	-	1366	100.0
Not recorded died within 42 months	271	72.1	67	17.8	38	10.1	91	-	467	100.0
Died within 42 months	733	81.5	65	7.2	101	11.2	0	-	899	100.0
Admitted to nursing bed	998	90.4	56	5.1	50	4.5	70	-	1174	100.0
Not recorded died within 42 months	120	72.7	29	17.6	16	9.7	70	-	235	100.0
Died within 42 months	878	93.5	27	2.9	34	3.6	0	-	939	100.0

Table 2.7: Destination (type of bed) of individuals in period to 42 month follow-up, by type of bed admitted to and dependency (Barthel Index of ADL) at admission

Type of bed admitted to and dependency at admission	*Same type of bed that admitted to*		*Different type of bed*		*Elsewhere*		*No information*		*All individuals*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Number of individuals	1998	84.1	188	7.9	189	8.0	161	-	2536	100.0
Admitted to residential bed	1004	78.7	132	10.4	139	10.9	91	-	1366	100.0
Very low dependence (Score 17-20)	193	73.1	26	9.8	45	17.0	27	-	291	100.0
Low dependence (Score 13-16)	301	77.8	45	11.6	41	10.6	29	-	416	100.0
Moderate dependence (Score 9-12)	302	81.6	35	9.5	33	8.9	18	-	388	100.0
Severe dependence (Score 5-8)	160	81.6	19	9.7	17	8.7	16	-	212	100.0
Total dependence (Score 0-4)	48	82.8	7	12.1	3	5.2	1	-	59	100.0
Admitted to nursing bed	994	90.4	56	5.1	50	4.5	70	-	1170	100.0
Very low dependence (Score 17-20)	28	82.4	4	11.8	2	5.9	7	-	41	100.0
Low dependence (Score 13-16)	83	80.6	13	12.6	7	6.8	6	-	109	100.0
Moderate dependence (Score 9-12)	185	88.9	12	5.8	11	5.3	12	-	220	100.0
Severe dependence (Score 5-8)	328	91.9	21	5.9	8	2.2	19	-	376	100.0
Total dependence (Score 0-4)	370	93.0	6	1.5	22	5.5	26	-	424	100.0

Table 2.8: Destination (type of bed) of individuals in period to 42 month follow-up, by type of bed admitted to and cognitive impairment (MDS Cognitive Performance Scale) at admission

Type of bed admitted to and cognitive impairment at admission	*Same type of bed that admitted to*		*Different type of bed*		*Elsewhere*		*No information*		*All individuals*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Number of individuals	1876	84.3	172	7.7	178	8.0	153	-	2379	100.0
Admitted to residential bed	967	79.0	123	10.0	134	10.9	90	-	1314	100.0
Intact (Score 0)	204	79.1	23	8.9	31	12.0	26	-	284	100.0
Mild impairment (Score 1-3)	503	79.0	56	8.8	78	12.2	48	-	685	100.0
Severe impairment (Score 4-6)	260	79.0	44	13.4	25	7.6	16	-	345	100.0
Admitted to nursing bed	909	90.7	49	4.9	44	4.4	63	-	1065	100.0
Intact (Score 0)	157	87.2	9	5.0	14	7.8	13	-	193	100.0
Mild impairment (Score 1-3)	338	91.8	15	4.1	15	4.1	18	-	386	100.0
Severe impairment (Score 4-6)	414	91.2	25	5.5	15	3.3	32	-	486	100.0

Table 2.9: Destination (type of bed) of individuals in period to 42 month follow-up, by type of bed admitted to and type of bed predicted from logistic regression model[1]

Type of bed admitted to and type of bed predicted	*Same type of bed that admitted to*		*Different type of bed*		*Elsewhere*		*No information*		*All individuals[2]*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Number of individuals	1800	84.3	166	7.8	170	8.0	143	-	2279	100.0
Admitted to residential bed	928	79.0	121	10.3	126	10.7	84	-	1259	100.0
Predicted residential bed	806	79.2	102	10.0	110	10.8	74	-	1092	100.0
Predicted nursing bed	122	77.7	19	12.1	16	10.2	10	-	167	100.0
Admitted to nursing bed	872	90.7	45	4.7	44	4.6	59	-	1020	100.0
Predicted nursing bed	670	93.2	19	2.6	30	4.2	41	-	760	100.0
Predicted residential bed	202	83.5	26	10.7	14	5.8	18	-	260	100.0

Notes: 1. See Netten et al. (1999).
2. Excluding individuals with assets exceeding £8,000.

Table 2.10: Change in dependency (Barthel Index of ADL) of individuals who stayed in original type of bed or who moved to a different type of bed in period to 42 month follow-up, by type of bed admitted to

Type of bed admitted to and change in dependency from admission[1]	*6 months*				*18 months*				*30 months*				*42 months*			
	Same type of bed		*Different type of bed*		*Same type of bed*		*Different type of bed*		*Same type of bed*		*Different type of bed*		*Same type of bed*		*Different type of bed*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Number of individuals[2]	1098	-	23	-	682	-	54	-	465	-	31	-	378	-	19	-
Admitted to residential bed[2]	648	100.0	16	100.0	447	100.0	32	100.0	319	100.0	22	100.0	260	100.0	15	100.0
Lower dependence (≥ 4 points)	158	24.4	1	6.3	83	18.6	1	3.1	60	18.8	0	0.0	38	14.6	1	6.7
No change (< 4 points)	360	55.6	3	18.8	241	53.9	11	34.4	143	44.8	5	22.7	118	45.4	1	6.7
Higher dependence (≥ 4 points)	130	20.1	12	75.0	123	27.5	20	62.5	116	36.4	17	77.3	104	40.0	13	86.7
Information incomplete	133	-	17	-	120	-	8	-	74	-	5	-	13	-	8	-
Admitted to nursing bed[2]	450	100.0	7	100.0	235	100.0	22	100.0	146	100.0	9	100.0	118	100.0	4	100.0
Lower dependence (≥ 4 points)	76	16.9	3	42.9	41	17.4	5	22.7	21	14.4	1	11.1	9	7.6	2	50.0
No change (< 4 points)	273	60.7	2	28.6	130	55.3	11	50.0	75	51.4	5	55.6	62	52.5	1	25.0
Higher dependence (≥ 4 points)	101	22.4	2	28.6	64	27.2	6	27.3	50	34.2	3	33.3	47	39.8	1	25.0
Information incomplete	102	-	4	-	84	-	7	-	56	-	1	-	3	-	1	-

Notes: 1. A change of 4 or more points on the Barthel Index of ADL is classified as a change in dependency (Collin et al., 1988).
2. Excluding individuals with incomplete information.

Chapter 3
Length of Stay and Mortality

3.1 Introduction

This chapter determines the expected length of stay and survival for someone aged 65+ admitted for the first time to a residential or nursing home as a supported resident.[1] It is based the first 42 months following admission. Life expectancy is examined in relation to circumstances at the time of admission, and an example is given to show how to calculate expected survival from the outset of an admission. This chapter provides necessary background statistics for the following two chapters on changes in health and the costs of care.

3.2 Methodology

3.2.1 The survey

Previous chapters have described the sample and the method of establishing information about residents at each stage of the study. Information on deaths was sought at each stage from the person providing the information. In addition a number of deaths were reported during the preparatory stages of the six, 18, 30 and 42 month follow-ups. Cases for which progress was uncertain during the study or for which information was incomplete were followed up using the ONS Register of Deaths, or in confidential cases (where the local authority restricted information), through the local authority itself. Results from this 'flagging' exercise would provide a confirmed status for the majority of these uncertain cases at 42 months.

Immediately after the 42 month follow up and the flagging exercise, the position was as follows:

Known to be alive	614	24%
Known to be dead	1850	72%
Uncertain	113	4%
Total	2577	100%

The 'uncertain' group includes two categories:

[1] These are people who were assessed by social services departments in the PSSRU admissions survey and who were subsequently admitted to residential or nursing home care on a long-stay basis, on the assumption that part or all of their costs would be met by the social services department.

- 21 cases which do not have a confirmed status at 42 months. These are people for whom we were neither able to trace alive at 42 months nor do we have a definite date of death. This includes cases that could not be traced either through the survey or through the ONS Register of Deaths. Six of these cases had been reported dead during the study with no date of death given, but ONS were unable to confirm death.[2]
- 92 cases had elected not to provide further information to the study at either the six, 18 or 30 month stages. No further attempt was made to obtain information about these people, nor, by agreement with the participating local authorities, did we seek mortality information about them from ONS.

As this analysis is leading towards the total lifetime cost following first admission as a supported resident, some individuals have been excluded from the remaining analysis in this chapter who appear not to be first-time admissions to supported care. This includes people identified in the admissions survey who were in fact transferring between residential and nursing homes, or moving between homes for other personal reasons. However, we have retained those people transferring from a short-term place, those previously admitted on an emergency basis and those previously self funding. This leaves 2386 people who are assumed to be first-time long-stay admissions to supported care, including all people who were living at home at the time of admission or who were admitted direct from hospital.

3.3 Survival

3.3.1 Evidence

The main factor in determining the length of time for which care will be required following admission to a care home is the individual's subsequent mortality. For this report, data corrections have been incorporated into the database following the results of the 42 month follow-up and the flagging exercise.

As is reported above, survival up to 42 months is uncertain for 113 people in the original sample. However, we do have some information about nearly all of these. All but one were tracked for some time beyond the initial point of admission, and we are able to say that each person was known to be alive up to a certain point, for example up to the point at which they had requested not to provide further information. This is of use to the survival models employed in this analysis.

[2] Note that unlike the treatment in previous reports, we do not impute a date of death in such cases, but regard them as lost to the study after the last report alive.

3.3.2 Survival analysis

The remainder of this analysis is based on standard life table methods, now commonly known as survival analysis. The virtue of this approach is that it takes account of information about people for as long as that information is available. The methods commonly centre on the calculation of *hazard rates* which predict the probability of dying in a given time interval after admission, given survival up to that point.

Table 3.1 shows the life table on a month-by-month basis for the 42 months of the survey. This gives, for the combined sample, the cumulative probability of survival and the hazard (life table mortality) rates. The table shows that the median survival is 19.6 months. The general trend appears to be an initially high mortality rate which declines rapidly during the first six months, after which the rate remains fairly steady through fluctuating from month to month. We discuss further below possible explanations for this fluctuation.

The median survival for people admitted to nursing beds is 11.9 months and for residential beds is 26.8 months.[3] Table 3.2 compares the patterns of survival for these two groups. The initial death rate is much higher for people admitted to nursing beds, who suffer particularly high mortality in the first three months following entry. The probability of dying in the first three months is 30 per cent, compared with 12 per cent for people admitted to residential care. In the longer term the hazard rates get closer but generally tend to be higher for people in nursing beds.

3.3.3 Robustness

It is of interest to ask whether the 113 cases lost to follow-up could have greatly affected the above estimates. Two extreme possibilities might be considered. The first is pessimistic: that everyone with whom we lost touch died immediately after the last date on which we had contact. The second is optimistic: that all those lost to follow-up are still alive at 42 months.

[3] Nursing beds includes people admitted to nursing homes and those admitted to nursing beds in dual-registered homes: likewise residential beds. This analysis is by *first* admission, and includes a small number of people subsequently transferred to the other type of bed.

	Median survival for residential bed admissions (months)	*Median survival for nursing bed admissions (months)*
Pessimistic scenario	24.7	10.9
Central estimate	26.8	11.9
Optimistic scenario	27.8	12.1

It is evident from this that our estimates might be a little different if the people for whom we have incomplete information are very atypical in their outcomes.

It is unlikely that the true situation is as extreme as would be implied by either the optimistic or pessimistic scenarios. What evidence we have suggests that any bias will be towards the optimistic scenario. Those people who withdrew from the study were on the whole slightly younger and slightly less disabled than average, both factors which (we shall show) might improve survival.

3.3.4 Factors affecting survival

The hazard rate can be used to provide a means of determining what effect certain factors at admission have on survival. In order to do this we have to assume *proportionality of hazards,* which implies that although the hazard rates for the categories of key explanatory variables, may differ through time, throughout they remain approximately in constant ratio to one another. This assumption was examined in detail at 30 months (Bebbington et al., 1999), and found to be reasonable, though there are some initial differences for residential and nursing homes.

Given that a major use of this analysis is to provide predictions of likely survival following admission, we present two versions, reflecting different stages of the admissions process.

- Table 3.3 shows the results of analysis using a range of risk factors that should be known at the time of admission, but prior to assessment. This may be useful to those wanting to consider likely outcome before a placement decision is reached.
- Table 3.4 shows the results of analysis using a range of risk factors that should be known at the time of admission, but including the decision about which type of bed to provide. As the assessment decision incorporates a careful judgement based on detailed

understanding of the elderly person's circumstances, not surprisingly more accurate estimates of survival can be made if this is taken into account. But the judgement about type of home may also to some extent incorporate local policy or practice styles which may lead to different decisions for people with similar needs. So it would not be appropriate to use this form of analysis as the basis for example, of a comparative evaluation of local authority performance.

The analysis is based on 2191 individuals. The 195 who have been excluded are those with missing information for any of the items in this table.

The final column of tables 3.3 and 3.4 shows the relative risk of each factor. This column may be interpreted as follows (referring to table 3.3):

- Women have a risk rate which is only 74 per cent of men: in any short period they are only three-quarters as likely to die (all else being equal, such as age, health at the outset etc.).
- People admitted with a malignancy have a relative risk rate thereafter which is 2.47: in any short time period they are almost two and a half times more likely to die as those who did not have a malignancy at admission.

And so on. To summarise tables 3.3 and 3.4:

- The factors at admission that significantly raise subsequent mortality are, in order of their statistical significance: having a malignancy (cancer), having a low Barthel score (high disability), old age, admission to a nursing bed, being a man, being admitted from a hospital, having a respiratory illness, cognitive impairment.
- The factors at admission that significantly reduce subsequent mortality are: being younger, being a woman, being admitted to a local authority residential home, having a high Barthel score, being admitted from another care home (many of whom are spend-down cases).
- Factors that make no difference (after other factors are allowed for) include region of residence, being diagnosed with dementia, depression, cardio-vascular disease, or admitted following a stroke, being incontinent.

The models of tables 3.3 and 3.4 can be used to predict the probability of survival up to 42 months of people with particular characteristics on entry. An illustration is given in tables 3.5 and 3.6. For a woman aged 75-84, admitted from a hospital, with a Barthel score below five, mild cognitive impairment, but no diagnosed illnesses in the above list, the probability

that she will survive for at least 12 months after admission is 54 per cent (table 3.5). However, this rises to 65 per cent if we additionally know she was admitted to a residential bed (table 3.6).

The characteristics we have examined mainly reflect the circumstances of the individual immediately prior to the time of first admission. The list does include local authority of origin, which is not a significant factor to outcome. It would also be of considerable interest to use this approach to examine how the home itself, particularly the facilities, staffing levels and regime, influence outcome. This may be possible with some additional research.

The close relationship between dependency and survival among elderly people in institutions echoes the findings of Donaldson et al. (1980). This was the last large-scale longitudinal study of this type in the UK, though that study was not based on admissions and so was unable to estimate life expectancy within institutional care.

3.3.5 Average length of survival

The above analysis gives an indication of the factors at admission that will affect typical length of life, and so length of stay in care homes. However, when planning in aggregate for the cost consequences of admissions, what is important to determine is not the median, but rather the expected, or average survival, given these factors. The average and median length of stay can be considerably different, due to a small proportion of people who may remain many years in a care home, and so who add to overall average life expectancy. In principle, we will not know the actual average until the last person from this cohort has died, which might be as long as 25 years or more. However, as the number of people surviving beyond 42 months is only one quarter of the original, it is possible to make assumptions about what will happen in the future to the remainder, which enables an average to be calculated.

This can be done using a forecasting model. Such a model must make assumptions about the processes affecting future mortality, and the models of tables 3.3 and 3.4 cannot be used for this purpose, because they are non-parametric. Table 3.1 showed that the hazard rate drops quickly during the first six months, but stays fairly level thereafter. We shall, therefore, consider the implications of assuming that after 42 months, the hazard rate will remain at a constant rate for each survivor, corresponding to the average level between 12 and 42 months, but making allowance for the factors at admission which we have already shown influence survival.

This model is similar in concept to that described in the previous section except that it carries the additional assumption that life expectancy from 42 months onwards follows a Poisson

process. Estimation by standard maximum likelihood methods generates the coefficients shown in table 3.4. This model predicts an average death rate of 3 per cent per month among survivors at 42 months (with a standard error of 0.1 per cent), and, on average, another 37 months of life for these survivors. Combined with the data on people already dead, the average length of survival is predicted to be 29.7 months following admission.

This model has been used to microsimulate survival for the 721 people alive, or not known to have died, by the end of the study. Microsimulation is used for the later cost predictions that will be made. Of course it is not possible to say how accurate this model will prove to be. However, when we undertook a similar exercise after the 30 month report, the model forecast that 247 of the 833 survivors at that stage would die by 42 months, compared with an actual figure of 253. This, so far as it goes, provides some confidence in the assumptions we are making. If the death rate beyond 42 months were to be 10 per cent higher than predicted by the above model[4] (average 3.3 per cent per month), the overall average life expectancy would be 28.9 months. If the death rate were to fall by a similar proportion (average 2.7 per cent per month), the average life expectancy would be 30.7 months. These we may regard as the limits of prediction.

Finally, table 3.7 shows how the average life expectancy can be calculated for an individual with particular characteristics on admission. This estimate may be compared with the median calculated in table 3.5B. As the method is somewhat cumbersome, a simplified but slightly less accurate method will be given in a future addendum.

3.4 Conclusion

Information about the expected length of stay for people admitted to residential and nursing home care is an important building block for predicting lifetime costs as well as for planning purposes. Primarily length of stay will be determined by mortality. The analysis of data up to 42 months after admission shows:

- The median survival for the whole sample is 19.6 months (± 0.9 months). For those originally admitted to nursing homes it is 11.9 months (± 0.9 months), and for residential care is 26.8 months (± 1.0 months).
- Mortality rates are high initially, especially in nursing homes, but after about twelve months settle to around 3 per cent per month (for the combined sample).

[4] I.e. higher by three times the standard error of the forecast.

- The factors at admission that significantly raise subsequent mortality are, in order of their significance: having a malignancy (cancer), having a low Barthel score (high disability), old age, being a man, being admitted to a nursing home, being admitted from a hospital, having a respiratory illness, being cognitively impaired.
- There are no significant differences between local authorities in survival outcomes, after taking into account factors such as dependency on admission.
- As a few residents will live for a long while, the average length of survival is much greater than the median. Although this average cannot be calculated precisely until all have died, our best estimate is 29.7 months and almost certainly in the range 28.9-30.7 months.

Table 3.1: Life table for first time admissions to publicly funded residential and nursing homes during the 42 month study

Month	*Number at start of month*	*Number lost to study*	*Number exposed to risk*	*Deaths during month*	*Proportion surviving month*	*Cumulative proportion survivors*	*Hazard rate*
1	2386	2	2385	212	0.9111	0.9111	0.0930
2	2172	3	2170.5	155	0.9286	0.8460	0.0741
3	2014	0	2014	111	0.9449	0.7994	0.0567
4	1903	1	1902.5	72	0.9622	0.7692	0.0386
5	1830	0	1830	68	0.9628	0.7406	0.0379
6	1762	0	1762	51	0.9711	0.7191	0.0294
7	1711	43	1689.5	55	0.9674	0.6957	0.0331
8	1613	0	1613	34	0.9789	0.6811	0.0213
9	1579	1	1578.5	33	0.9791	0.6668	0.0211
10	1545	0	1545	39	0.9748	0.6500	0.0256
11	1506	0	1506	29	0.9807	0.6375	0.0194
12	1477	0	1477	37	0.9749	0.6215	0.0254
13	1440	1	1439.5	51	0.9646	0.5995	0.0361
14	1388	0	1388	47	0.9661	0.5792	0.0344
15	1341	0	1341	45	0.9664	0.5598	0.0341
16	1296	0	1296	36	0.9722	0.5442	0.0282
17	1260	0	1260	32	0.9746	0.5304	0.0257
18	1228	0	1228	18	0.9853	0.5226	0.0148
19	1210	35	1192.5	31	0.9740	0.5090	0.0263
20	1144	0	1144	31	0.9729	0.4952	0.0275
21	1113	0	1113	21	0.9811	0.4859	0.0190
22	1092	0	1092	29	0.9734	0.4730	0.0269
23	1063	0	1063	22	0.9793	0.4632	0.0209
24	1041	0	1041	28	0.9731	0.4507	0.0273
25	1013	0	1013	24	0.9763	0.4401	0.0240
26	989	0	989	29	0.9707	0.4272	0.0298
27	960	0	960	29	0.9698	0.4143	0.0307
28	931	0	931	31	0.9667	0.4005	0.0339
29	900	0	900	34	0.9622	0.3853	0.0385
30	866	0	866	19	0.9781	0.3769	0.0222
31	847	14	840	25	0.9702	0.3657	0.0302
32	808	0	808	22	0.9728	0.3557	0.0276
33	786	0	786	16	0.9796	0.3485	0.0206
34	770	0	770	17	0.9779	0.3408	0.0223
35	753	0	753	23	0.9695	0.3304	0.0310
36	730	0	730	21	0.9712	0.3209	0.0292
37	709	0	709	27	0.9619	0.3086	0.0388
38	682	0	682	23	0.9663	0.2982	0.0343
39	659	0	659	30	0.9545	0.2847	0.0466
40	629	0	629	19	0.9698	0.2761	0.0307
41	610	0	610	16	0.9738	0.2688	0.0266
42	594	0	594	14	0.9764	0.2625	0.0239

Table 3.2: Kaplan-Meier survival probability for people first admitted to residential and nursing beds

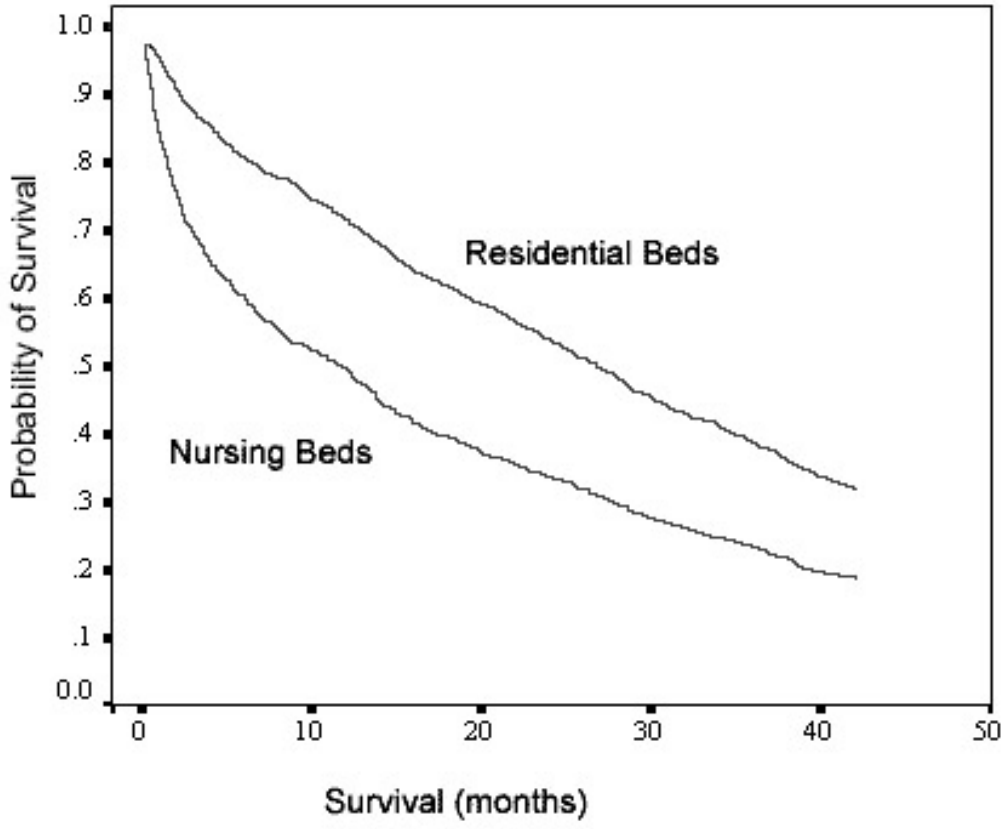

Table 3.3: Proportional hazard model for factors affecting death rates in residential and nursing homes (prior to assessment)

	Model coefficient	*Standard error*	*Wald test statistic*	*Df*	*p*	*Relative risk*
Area of origin			4.0044	2	0.14	
Shire county	0.0000					1.00
Metropolitan district	-0.1050	0.0548				0.90
London	-0.0940	0.0908				0.91
Age at admission			69.2489	2	0.00	
65-74	0.0000					1.00
75-84	0.3466	0.0911				1.41
85+	0.6703	0.0910				1.95
Gender			28.0472	1	0.00	
Male	0.0000					1.00
Female	-0.3048	0.0576				0.74
Diagnosed illness on entry						
Dementia	-0.0369	0.0639	0.3342	1	0.56	0.96
Depression	0.0315	0.0761	0.1714	1	0.68	1.03
Cardiovascular	0.1046	0.0639	2.6816	1	0.10	1.11
Respiratory	0.3416	0.0702	23.6960	1	0.00	1.41
Malignancy	0.9046	0.0851	113.0764	1	0.00	2.47
Stroke	0.0210	0.0639	0.1083	1	0.74	1.02
Incontinent (urine or faeces)	-0.0759	0.0704	1.1632	1	0.28	0.93
Barthel score on entry			76.0148	3	0.00	
0-4	0.8230	0.0945				2.28
5-8	0.3815	0.0758				1.46
9-12	0.2802	0.0697				1.32
13+	0.0000					1.00
MDS Cognitive scale			6.8703	2	0.03	
Intact	0.0000					1.00
Mild impairment	0.1276	0.0725				1.14
Severe impairment	0.2316	0.0884				1.26
Source of admission			10.4980	3	0.02	
Private household	0.0000					1.00
Care home	0.0090	0.1158				1.01
Hospital	0.1669	0.0564				1.18
Other	0.3134	0.2060				1.37

Table 3.4: Proportional hazard model for factors affecting death rates in residential and nursing homes (including assessment of appropriate bed)

	Model coefficient	*Standard error*	*Wald test statistic*	*df*	*P*	*Relative risk*
Area of origin			5.0331	2	0.08	
Shire County	0.0000					1.00
Metropolitan District	-0.1152	0.0549				0.89
London	-0.1175	0.0910				0.89
Age at admission			73.6836	2	0.00	
65-74	0.0000					1.00
75-84	0.3498	0.0910				1.42
85+	0.6891	0.0911				1.99
Gender			26.0965	1	0.00	
Man	0.0000					1.00
Woman	-0.2944	0.0576				0.75
Diagnosed illness on entry						
Dementia	-0.0443	0.0640	0.4793	1	0.49	0.96
Depression	0.0386	0.0763	0.2556	1	0.61	1.04
Cardiovascular	0.0918	0.0641	2.0521	1	0.15	1.10
Respiratory	0.3379	0.0703	23.0917	1	0.00	1.40
Malignancy	0.8507	0.0861	97.7227	1	0.00	2.34
Stroke	0.0189	0.0640	0.0870	1	0.77	1.02
Incontinent (Urine or faeces)	-0.0769	0.0705	1.1891	1	0.28	0.93
Barthel score on entry			39.9674	3	0.00	
0-4	0.6377	0.1026				1.89
5-8	0.2607	0.0802				1.30
9-12	0.2361	0.0704				1.27
13+	0.0000					1.00
MDS Cognitive scale			6.2435	2	0.04	
Intact	0.0000					1.00
Mild Impairment	0.1376	0.0725				1.15
Severe Impairment	0.2198	0.0885				1.25
Source of Admission			5.7511	3	0.12	
Private Household	0.0000					1.00
Care Home	0.0079	0.1158				1.01
Hospital	0.1234	0.0572				1.13
Other	0.2561	0.2065				1.29
Sector			22.3658	2	0.00	
LA home	0.0000					1.00
P/V Residential bed	0.1509	0.0995				1.16
Nursing bed	0.4127	0.1069				1.51

Table 3.5A: Illustrative calculation of life expectancy in publicly funded residential/nursing home care, given circumstances on admission

What is the median expected survival and the probability of surviving 12 months, for a person with the following characteristics?

	Coefficient from table 5.3
Living in shires	0.0000
Woman	-0.3048
Aged 75 – 84	0.3466
No diagnosed medical condition	0.0000
Incontinent	-0.0759
Barthel score 0 – 4	0.8230
Mild cognitive impairment	0.1276
Admitted from hospital	0.1669
Total score	1.0834

Hazard ratio 'r' (compared with general average) = exp(1.0834)/ exp(0.8411) = 1.274 (Note that 0.8411 is the score at the average of all explanatory variables).

Probability of survival 'm' months can be estimated from $\prod(2 - r.h_I) / (2 + r.h_I)$ where the product is over I = 1,…..,m and h_I denotes the monthly hazard rate as given in table 5.1. The following table shows the first 12 months of this calculation:

Month	*Hazard rate (h_I)*	*Specific hazard rate ($r.h_I$)*	*Probability of surviving month $(2–r.h_I)/ (2+r.h_I)$*	*Cumulative probability of survival*
1	0.0930	0.1185	0.8881	0.8881
2	0.0741	0.0944	0.9098	0.8081
3	0.0567	0.0722	0.9303	0.7517
4	0.0386	0.0492	0.9520	0.7156
5	0.0379	0.0483	0.9528	0.6819
6	0.0294	0.0375	0.9632	0.6568
7	0.0331	0.0422	0.9587	0.6297
8	0.0213	0.0271	0.9732	0.6128
9	0.0211	0.0269	0.9735	0.5966
10	0.0256	0.0326	0.9679	0.5774
11	0.0194	0.0247	0.9756	0.5633
12	0.0254	0.0324	0.9682	0.5454
13	0.0361	0.0460	0.9550	0.5209
14	0.0344	0.0438	0.9571	0.4985
Etc				

In this example the probability of surviving 12 months is 55 per cent, and the median survival is 14 months.

Table 3.5B: Illustrative calculation of life expectancy in publicly funded residential/nursing home care, given circumstances on admission and initial placement

What is the median expected survival and the probability of surviving 12 months, for a person with the following characteristics?

	Coefficient from table 5.4
Living in shires	0.0000
Woman	-0.2944
Aged 75 – 84	0.3498
No diagnosed medical condition	0.0000
Incontinent	-0.0769
Barthel score 0 – 4	0.6377
Mild cognitive impairment	0.1376
Admitted from hospital	0.1234
Admitted to nursing bed	0.4127
Total score	1.2899

Hazard ratio 'r' (compared with general average) = exp(1.2899) / exp(0.9930) = 1.3457. (Note that 0.9930 is the score at the average of all explanatory variables).

Probability of survival 'm' months can be estimated from $\mathbf{\Pi}(2 - r.h_I) / (2 + r.h_I)$ where the product is over I = 1,…..,m and h_I denotes the monthly hazard rate as given in table 5.1. The following table shows the first 12 months of this calculation:

Month	*Hazard rate (h_I)*	*Specific hazard rate ($r.h_I$)*	*Probability of surviving month ($2–r.h_I$)/ ($2+r.h_I$)*	*Cumulative probability of survival*
1	0.0930	0.1251	0.8822	0.8822
2	0.0741	0.0997	0.9050	0.7984
3	0.0567	0.0763	0.9265	0.7398
4	0.0386	0.0519	0.9494	0.7023
5	0.0379	0.0510	0.9503	0.6674
6	0.0294	0.0396	0.9612	0.6415
7	0.0331	0.0445	0.9564	0.6135
8	0.0213	0.0287	0.9717	0.5962
9	0.0211	0.0284	0.9720	0.5795
10	0.0256	0.0344	0.9661	0.5599
11	0.0194	0.0261	0.9742	0.5455
12	0.0254	0.0342	0.9664	0.5271
13	0.0361	0.0486	0.9526	0.5021
14	0.0344	0.0463	0.9548	0.4794
Etc				

In this example the probability of surviving 12 months is 53 per cent, and the median survival is 13 months.

Table 3.6: A model for forecasting survival beyond 42 months

Life expectancy in months (given survival to 42 months) = 1/exp(-z), where z is given by the sum of the following:

Constant	6.910
Age at admission	- 0.037 * age
Gender	
Male	0.000
Female	0.236
First placement	
LA home	0.000
Private/ Voluntary Residential home	-0.302
Nursing home	-0.413
Admitted with	
Respiratory/ chest disease	-0.347
Malignancy	-0.566
Barthel score on admission	
0 – 4	-0.317
5 – 8	-0.185
9 – 12	-0.067
13+	0.000

Table 3.7: Illustrative calculation of life expectancy in publicly funded residential/nursing home care, given circumstances on admission

The mean is given by:

Mean = Σ (Mid month) × (Prob. of dying in month)

where the summation is over all months until all are certain to have died. This can use the Cox model of table 5.4 for the first 42 months, and the Poisson model of table 5.6 thereafter. For example using the illustration of table 5.5B assuming age is 80, then:

Month	*Hazard rate* (h_I)	*Specific hazard rate* ($r.h_I$)	*Probability of surviving month* $(2–r.h_I)/(2+r.h_I)$	*Cumulative probability of survival*	*Probability of dying this month,* p_i	$(m-½)*p_i$
1	0.0930	0.1251	0.8822	0.8822	0.1304	0.0652
2	0.0741	0.0997	0.9050	0.7984	0.0916	0.1374
3	0.0567	0.0763	0.9265	0.7398	0.0635	0.1587
4	0.0386	0.0519	0.9494	0.7023	0.0402	0.1407
5	0.0379	0.0510	0.9503	0.6674	0.0373	0.1677
6	0.0294	0.0396	0.9612	0.6415	0.0275	0.1512
7	0.0331	0.0445	0.9564	0.6135	0.0295	0.1920
8	0.0213	0.0287	0.9717	0.5962	0.0182	0.1368
9	0.0211	0.0284	0.9720	0.5795	0.0175	0.1488
10	0.0256	0.0344	0.9661	0.5599	0.0205	0.1948
etc until	…	…	…	…	…	…
41	0.0266		0.9609	0.1393	0.0057	0.2296
42	0.0239		0.9648	0.1344	0.0049	0.2035
Total						10.4362

Beyond 42 months, use table 5.6 to calculate z:

$$z = 6.910 – 0.037 * \text{Age} + 0.236 – 0.413 – 0.317 = 3.456$$

and then:

$$\text{Mean} = \Sigma p_i + (\text{Prob surv 42 months}) \times (42 + 1/\exp(-z)) = 10.4 + 0.1344 \times 73.7$$
$$= 20.3 \text{ months.}$$

Chapter 4
Dependency and Mental Health Outcomes

4.1 Introduction

A major aim of the longitudinal survey has been to establish the outcome of an admission to a care home, in terms of the health and survival for the person who is admitted. There are two applications for this investigation.

- *As a guide to quality.* A concern of care homes is to provide an enabling environment and to support and maintain the health of residents as far as is practicable, and these are criteria by which homes may be judged. Arguably, one home is better than another if residents in similar circumstances on admission live longer, enjoy better health, and are more able to manage basic activities.
- *For planning.* A goal of the work is to investigate the practicality of predicting subsequent health following admission, as a guide to care planning.

This chapter examines changes in the health of survivors in two ways:

- Dependency, measured by the Barthel Index of ADL scale.
- Cognitive state, as measured using the MDS CPS.

There are particular reliability issues with change measures in longitudinal surveys. Appendix 4A summarises these.

4.2 Changes in Dependency

The Barthel scale is a well known and standard scale of dependency covering eight activities. A high score counts as relatively able. Scores run from 0 to 20, and these are often classified into four groups. Table 4.2 shows the distribution at the time of admission.

The key evidence on change is summarised in table 4.3. This shows the transition between disability states, measured by the grouped Barthel scale. Points to note from this table:

- Many people improve as well as get worse.
- Rates of change are greatest in the first six months.
- Rates of change appear to settle down by 30 months.

Table 4.4 summarises these changes, showing the proportion of people who make significant changes between survey waves. This shows clearly that the general trend is towards greater dependency, even though a surprising number improve (by four or more points on the Barthel scale) in the first six months. However, thereafter comparatively few people will improve with regard to physical dependency.

This initial improvement might be due to particular difficulties around the time of admission, which resolve later.[1] It is of interest to ask in what respects are improvements achieved, and conversely, what aspects of dependency are least likely to be improved. This is examined in table 4.5. This table shows that improvements can occur in aspects of dependency, particularly in the first six months; while declines are similar, but the rate of decline continues through time. Initially, the rate of improvement of disabled people is greater than the rate of decline for able people for many aspects of dependency. However, as there are fewer disabled than able people (except for dressing and bathing), overall there is a decline.

- *Feeding* stands out as the area where most improvements are made following admission. Improvements continue to occur later on as well, to a greater extent than any other ability.
- *Continence* likewise shows good gains immediately following admission, and shows low rates of decline throughout. However, if the gains are not made immediately after admission, they are much less likely to occur later. This finding probably reflects improved management of incontinence following admission, rather than any great improvement in the underlying condition.
- *Mobility* also stands out as an ability that is well maintained, and declines are low. Again, this is probably due to the regime in homes providing support to prevent residents becomes wholly bed- or chairbound.

Those people who improve shortly after admission, particularly those who as a result of their improvement then have a moderate or low level of dependency, might seem good candidates for measures to postpone an early long-term admission. We have compared these with the remainder to see if they could have been identified at the time of admission. The criterion for an improvement is a gain of four or more points on the Barthel scale, with a final score exceeding eight. Because individuals with initially high scores may be unable to improve that much (because of the nature of the scale), the analysis is confined to those who scored 14 or less on admission.

[1] It should be noted that at the time of admission, the questionnaire was completed by social workers, while at later stages, by staff of care homes. This may or may not make a difference.

Table 4.6 shows factors that are significantly different between these 'improvers' and others. It turns out to be the people who are comparatively independent at time of admission that improve most. What is particularly noticeable is that it is people with specific health diagnoses on admission that are the most likely to improve. However, perhaps surprisingly, it is not people discharged from hospital (presumably following some acute condition) who are most likely to show subsequent improvement.

So it is not premature discharge from hospital that provides the greatest missed opportunities for possible rehabilitation. Rather, it is among people admitted from private households with chronic diseases. Possibly these are diseases that may undergo remission, and thus enable the person to be more independent, at least for a while.

It would be possible to use the factors that are significant in table 4.6 to generate an equation that predicts, from the circumstances at admission, who is likely to make significant improvements in their dependency by six months. However, the level of prediction turns out to be too small for this to have much practical use. The level of prediction gets even lower at 18 and 30 months.

4.3 Changes in Cognitive Function

Cognitive functioning was measured in this study using the MDS Cognitive Functioning Scale. This scale is based on five items, but combined in a complex manner as shown in table 4.7. It produces seven levels of functioning, but for this analysis we have reduced this to three, by combining levels 0; 1, 2 and 3; 4, 5 and 6.

It should be noted that the questionnaire did not ask whether the resident was 'comatose'. It is assumed that anyone who is in such a state would also be reported as unable to make decisions and dependent with regard to feeding, so would automatically be classified at the highest level anyway. Given that the analysis was based on three broad categories, it is inconceivable that anyone who might be described as comatose would fall into either of the lower two groups.

Table 4.8 shows the situation at the time of admission. The majority were described as showing some degree of problem. The transition rates of table 4.9 show that there were as many recoveries as declines in the first six months, when indeed the majority of survivors were in the 'mildly confused' category.

However, at the next two waves more people decline than improve, so that of those who survived to the end of the study, 42 per cent were severely impaired compared with 34 per cent at the outset.

It is notable that though in the first six months there is only a slight relationship between cognitive functioning and mortality, in subsequent waves death rates were much higher among those who had been severely dysfunctional.

No factors on admission appear to be predictive of subsequent changes in cognitive functioning.

4.4 Healthy Life Expectancy Following Admission

A Markov chain model has been used to estimate healthy life expectancy following admission, based on the transition rates shown in tables 4.3 (Barthel scale) and 4.9 (MDS Cognitive Performance Scale). This model, which is regarded as the best method of estimating healthy life expectancy but has rarely been applied in practice, has been used to estimate the proportion of remaining life that will be lived at various health states, given health state on admission. Like the survival model in chapter 3, it assumes proportionality: that is although the expected length of remaining life may vary depending on age, gender etc, the proportion at different health states will be similar. Details of the model are given in appendix 4B.

Table 4.10 shows the outcomes. From part A, a person who has low dependency on admission can expect to live about half their remaining life at this low level of dependency, while a person at total dependency can expect to live about two-thirds of their remaining life at this level.

Although median survival and subsequent expectation of healthy life are very different depending on life expectancy at the outset, for a typical person the expectation of life in total dependency is about four months regardless of their state of health on admission.

Cognitive functioning is shown in table 4.10 part B. It also appears that those who are admitted with severe dysfunction are likely to spend the greater part of their remaining life in that state. Those who are intact on admission can however expect to decline and will spend more than half their life with some degree of problem.

4.5 People with Low Needs in Care Homes

It has been suggested that significant numbers of people are admitted to care homes though their needs do not seem to warrant it. For this reason we looked at people who had a Barthel score in the low range and no cognitive impairment at the time of admission. Fourteen per cent of admissions are in this group. This rate stayed fairly constant at each wave of the survey. However, of the people who survived through the 42 months, just 14 people, less than one per cent of the original admissions, had always been low dependent with no cognitive impairment. The implication is that there are not large numbers of relatively healthy people supported by local authorities in residential care, though health may fluctuate once in care.

4.6 Conclusion

This chapter has been concerned to provide descriptive information which may help both individuals and organisations plan the future for people admitted to a care home. With regard to both dependency and cognitive function, the evidence suggests that survivors at six months may on average, be a little better off than at the time of admission, but thereafter there will be a slow but steady decline. The improvement by six months is most marked in those activities of daily living that might relate to being in a better controlled environment, rather than any real indication that people have recovered in a way that might make them more fit to return to private households. Though some people seem quite independent and mentally alert at each stage of the survey, only one per cent of all those admitted were in this condition at every wave of the survey. The implication is that there is not an obvious group for whom such a placement is clearly inappropriate.

Appendix 4A: Reliability of Measures

4A.1 Change variables

Change in longitudinal surveys is normally measured by the simple difference between measured health at two points in time. We have followed that convention, though there are some known problems whenever health cannot be measured with perfect reliability. One example is the *end effect*. People who have a perfect score can only get worse. Some will seem to do so merely because of imperfect reliability. So in general it will appear that well people get worse, ill people get better, even if in reality there is no change. This effect actually will occur throughout the range of the health measure, to produce *regression towards the mean.* It has been proposed that changes are better measured by regression adjusted estimates of final health than by difference, in order to allow for this. However, results are less easily interpreted, and we have stuck to the conventional method in this chapter.

A general caveat about analysing changes in health concerns how health state was determined. If it simply reflects the state on the day of the survey, then health changes will be subject to considerable volatility, with the problems mentioned in the previous paragraph. Elderly people in care homes do tend to experience fluctuations in their health. The measures we have used refer to the 'general' rather than the immediate state of health. However this is less precise, and it is likely that the resulting reports will tend to overestimate average levels of health at a point in time. Both the Barthel Index and the MDS CPS are well-established scales that have been well-tested for their reliability, but these problems are not eliminated. The result is that there is inevitably a certain amount of 'noise' in measuring change, which may reduce our ability to predict or explain why changes occur.

4A.2 Missing data

Missing data is a major problem for all longitudinal surveys. It is particularly a problem for health surveys, since there is a likelihood that the ability and willingness to respond will be related in some way to changes in health. The present survey has enjoyed exceptionally low levels of missing data. In relation to survival, almost the only missing data comes from those who stopped co-operating with the survey. Nearly all other missing data can be attributed to failure of completion by the head of home, rather than problems contacting the resident. This means that missing data is less likely to be associated with the person's circumstances than is normal with self completion. Nevertheless, it is sensible to take note of missing data. Tables 4.3 and 4.10 report the health of people who were missing at the next stage. It appears that

people with low initial dependency were more likely to be missing later, but this is not true subsequently. This might imply that the remaining sample are biased towards being more dependent on average, but if so the bias would be a small one. There are no obvious biases with regard to cognitive functioning. On this evidence we have chosen not to make any adjustment for possible bias due to differential missing data.

Appendix 4B: Healthy Life Estimates

The estimates in table 4.10 are constructed as follows.

Construct: $T_x = \{\underset{\sim}{1}\ R_x\}$ x = 1,2,3,4

where R_x denotes the 4 x 5 transition matrix shown in table 4.3 for dependency groups or the 3 x 4 matrix in table 4.10 for cognitive functioning. x=1,2,3,4 corresponds to the matrices for 0→6, 6→18, 18→30, 30→42 months respectively. $\underset{\sim}{1}$ denotes the first column of the identity matrix.

Calculate $P_x = T_x \times P_{x-1}$ *where* $P_0 = I$

Then, using the standard theorem for forward Markov processes, the total expected months spent in each state is then estimated by

$$M = \sum_x \frac{n_x}{2}(P_{x-1} + P_x) \quad , \quad x = 1,2,3,...$$

where n_x denotes the number of months corresponding to x (6,12,12,12,…). As the rates seem to have settled down by 30 months, with similar rates at 42 months, beyond 42 months we assume the transition matrices P_x for x > 4 will be the average of P_3 and P_4. The elements of M corresponding to states other than death converge on summation. This is a 'passage time' problem with a well-known analytic solution in the case of all equal *P*. (e.g. Bartlett, 1962, chapter 3).

This model generates an estimate of the average life expectancy for people in a given health state at the outset. However as it makes simpler assumptions about changes in state from the model of chapter 3, it gives somewhat different and rather less reliable estimates. These estimates are slightly less than given in chapter 3. For this reason, table 4.11 describes the proportion of remaining life at given states of dependency rather than the total. This is given by:

Proportion of remaining life in state 'j' for someone in initial state 'i': = $m_{i,j} \Big/ \sum_j m_{i,j}$

where $m_{i,j}$ denotes the elements of M and the summation excludes j = 1 (death).

Table 4.1: Barthel Index of Activities of Daily Living

The Barthel Index is computed as the sum of the scores for the ten items shown, and ranges from 0 (highest level of dependency) to 20 (lowest level of dependency).

Function	*Score*	*Description*
Bowels	0 1 2	Incontinent (or needs to be given enemata) Occasional accident (once/week) Continent
Bladder	0 1 2	Incontinent, or catheterized & unable to manage Occasional accident (max once per 24 hours) Continent (for over 7 days)
Grooming	0 1	Needs help with personal care Independent face/hair/teeth/shaving (implements provided)
Toilet use	0 1 2	Dependent Needs some help, but can do something alone Independent (on & off, dressing, wiping)
Feeding	0 1 2	Unable Needs help cutting, spreading butter etc Independent (food provided in reach)
Transfer	0 1 2 3	Unable – no sitting balance Major help (1 or 2 people, physical), can sit Minor help (verbal or physical) Independent
Mobility	0 1 2 3	Immobile Wheel chair independent including corners etc Walks with help of 1 person (verbal or physical) Independent (but may use any aid, eg stick)
Dressing	0 1 2	Dependent Needs help, but can do about ½ unaided Independent (including buttons, zips, laces, etc)
Stairs	0 1 2	Unable Needs help (verbal, physical, carrying aid) Independent up & down
Bathing	0 1	Dependent Independent (or in shower)

Table 4.2: Dependency at the time of admission, among people admitted to residential and nursing home care

Barthel dependency score	*%*
Total (0-4)	18
Severe (5-8)	23
Moderate (9-12)	24
Low (13-16)	21
Very low (17+)	13
Base	2349

Table 4.3: Transition rates for levels of disability (Barthel)

At 6 months	*At admission*			
	Total %	*Severe* %	*Moderate* %	*Low* %
Dead	55	35	33	23
Total	27	15	8	3
Severe	11	25	17	5
Moderate	5	13	16	17
Low	2	11	26	52
(Base)	(361)	(460)	(479)	(631)
Missing %	15	17	17	23
(Base)	(427)	(556)	(576)	(821)

At 18 months	*At 6 months*			
	Total %	*Severe* %	*Moderate* %	*Low* %
Dead	53	37	28	20
Total	36	22	9	2
Severe	9	32	25	7
Moderate	2	7	24	15
Low	0	4	14	56
(Base)	(186)	(222)	(215)	(408)
(Missing %)	17	19	18	19
(Base)	(223)	(273)	(262)	(508)

At 30 months	*At 18 months*			
	Total %	*Severe* %	*Moderate* %	*Low* %
Dead	43	36	32	20
Total	49	25	14	4
Severe	8	29	21	6
Moderate	1	7	26	16
Low	0	3	8	55
(Base)	(142)	(162)	(143)	(267)
Missing %	17	15	11	16
(Base)	(170)	(190)	(161)	(319)

Table 4.3 (continued)

At 42 months	*At 30 months*			
	Total %	*Severe* %	*Moderate* %	*Low* %
Dead	48	33	30	15
Total	43	26	12	5
Severe	8	29	23	5
Moderate	1	8	27	15
Low	0	3	8	60
(Base)	(125)	(92)	(86)	(144)
Missing %	11	11	8	10
(Base)	(140)	(103)	(93)	(161)

Interpretation: At six months, 55 per cent of those whose dependency is 'total' on admission were dead (based on 363 people). Of those who scored 'total' on admission, 14 per cent were missing at six months (based on 421 people).

Some of the above tables have been subject to minor alteration since the 30 month analysis. 'Missing' includes those who are known to be alive but with no returned information on the Barthel scale, plus a small number lost to the study (mainly refusers).

Table 4.4 Changes in dependency (summary)

	During first 6 months	*Between 6 and 18 months*	*Between 18 and 30 months*	*Between 30 and 42 months*
Improved	14%	4%	3%	4%
Same	37%	48%	49%	54%
Declined	14%	16%	18%	14%
Died	35%	31%	30%	28%
Base: (Change)	(1934)	(1032)	(714)	(498)

Improved = gain of at least four points on Barthel scale.
Declined = loss of at least four points on Barthel scale.

Table 4.5: Improvement and decline in dependency activities between survey waves

A. Proportion of disabled people who became able (improvement)

	Between admission and 6 months		*Between 6 and 18 months*		*Between 18 and 30 months*		*Between 30 and 42 months*	
	%	*N*	*%*	*N*	*%*	*N*	*%*	*N*
Continence	43	(329)	21	(171)	19	(160)	15	(1133)
Grooming	34	(591)	26	(296)	12	(233)	17	(180)
Using Toilet	35	(572)	18	(281)	12	(233)	10	(175)
Feeding	69	(236)	40	(62)	28	(43)	29	(49)
Transfer	32	(614)	17	(294)	11	(219)	9	(174)
Mobility	30	(368)	20	(230)	12	(164)	11	(148)
Dressing	24	(898)	13	(477)	5	(338)	6	(252)
Climbing Stairs	13	(960)	8	(568)	6	(415)	7	(297)
Bathing	6	(1179)	3	(707)	3	(496)	2	(351)

Table 4.5 (continued)

B. Proportion of able people who became unable (decline)

	Between admission and 6 months		*Between 6 and 18 months*		*Between 18 and 30 months*		*Between 30 and 42 months*	
	%	*N*	*%*	*N*	*%*	*N*	*%*	*N*
Continence	17	(978)	18	(594)	23	(378)	19	(241)
Grooming	30	(26)	29	(478)	30	(310)	26	(199)
Using Toilet	26	(746)	25	(493)	28	(310)	20	(205)
Feeding	8	(1083)	7	(706)	12	(493)	11	(330)
Transfer	23	(706)	21	(478)	26	(321)	22	(207)
Mobility	19	(852)	17	(541)	20	(374)	19	(231)
Dressing	47	(420)	32	(294)	36	(204)	26	(129)
Climbing Stairs	51	(347)	42	(198)	39	(125)	43	(77)
Bathing	80	(143)	62	(68)	60	(48)	61	(28)

Definitions of ability used in above table

	Able	*Unable*
Continence (bowels, bladder)	Levels 1 or 2 (for both)	Level 0 (for either)
Grooming, bathing	Level 1	Level 0
Using toilet, dressing, climbing stairs, feeding	Levels 1 or 2	Level 0
Transfer, mobility	Levels 2 or 3	Levels 0 or 1

Note: 1. Levels are as defined in table 4.1.

Table 4.6 Factors associated with Barthel score improvement in the first six months[1]

	Prop^{n} of Improvers *%*	*Sig different? (1%)*
Area of origin		No
Shire County	23	
Met District	21	
London	27	
Gender		No
Man	24	
Woman	23	
Age at admission		No
65-74	23	
75-84	21	
85+	25	
Diagnosed illness on admission		No
Dementia	23	Yes
Depression	32	Yes
Cardiovascular	34	Yes
Respiratory	32	No
Malignancy	33	No
Stroke	20	
Incontinent (urine or faeces)	20	No
Barthel score on entry		Yes
Total	15	
Severe	25	
Moderate	28	
Low[2]	18	
Confusion		No
Intact	24	
Mild Impairment	24	
Severe Impairment	24	
Source of admission		Yes
Private household	28	
Care home	17	
Hospital	22	

Notes: 1. Analysis based on 929 individuals with an initial Barthel score of 14 or below, who were alive after six months.
2. Score 12-14.

Table 4.7: MDS Cognitive Performance Scale

MDS CPS item	*Level*	*Description*
Comatose	0 1	No Yes
Short-term memory	0 1	Memory OK Memory problem
Decision making	0 1 2 3	Independent Modified independent Moderately independent Severely impaired
Understood	0 1 2 3	Understood Usually understood Sometimes understood Rarely/never understood
Eating	0 1 2 3 4	Independent Supervision Limited assistance Extensive assistance Total dependence

Computation of impairment and severe impairment counts for constructing scale

Impairment/Severe Impairment Counts	*Components*	*Levels*
Impairment count (IC)	Decision making Understood Short-term memory	1,2 1,2,3 1
Severe impairment count (SIC)	Decision making Understood	2 2,3

Table 4.7 (continued)

Decision Rules for Scoring MDS Scale

Score	*MDS CPS Category*	*Decision Rule*
6	Very Severe Impairment	Comatose = 1, Comatose = 0 & Decision making = 3 & Eating = 4
5	Severe Impairment	Comatose = 0 & Decision making = 3 & Eating ≠ 4
4	Moderately Severe Impairment	Comatose = 0 & Decision making ≠ 3 & IC ≥ 2 & SIC = 2
3	Moderate Impairment	Comatose = 0 & Decision making ≠ 3 & IC ≥ 2 & SIC = 1
2	Mild Impairment	Comatose = 0 & Decision making ≠ 3 & IC ≥ 2 & SIC = 0
1	Borderline Intact	Comatose = 0 & Decision making ≠ 3 & IC = 1
0	Intact	Comatose = 0 & Decision making ≠ 3 & IC = 0

Note that the longitudinal survey excluded the item describing 'comatose state'**.**

Table 4.8: Cognitive functioning at the time of admission, among people admitted to residential and nursing home care

MDS Cognitive Functioning level	*%*
Severe confusion (levels 4,5,6)	34
Mild confusion (levels 1,2,3)	46
Intact (level 0)	20
Base	2222

Table 4.9: Transition rates for levels of cognitive functioning

At 6 months	*At admission*		
	Severe %	*Mild* %	*Intact* %
Dead	39	34	35
Severe	35	16	5
Mild	24	37	27
Intact	3	14	34
(Base)	(646)	(843)	(372)
Missing %	15	17	14
(Base)	(751)	(1017)	(447)

At 18 months	*At 6 months*		
	Severe %	*Mild* %	*Intact* %
Dead	44	26	27
Severe	41	23	5
Mild	14	44	28
Intact	1	7	39
(Base)	(358)	(500)	(234)
Missing %	15	16	14
(Base)	(422)	(599)	(272)

At 30 months	*At 18 months*		
	Severe %	*Mild* %	*Intact* %
Dead	38	30	19
Severe	53	25	7
Mild	9	37	29
Intact	0	8	46
(Base)	(297)	(320)	(140)
Missing %	8	16	10
(Base)	(322)	(379)	(156)

Table 4.9 (continued)

At 42 months	*At 30 months*		
	Severe %	*Mild* %	*Intact* %
Dead	41	29	19
Severe	46	17	5
Mild	11	46	29
Intact	2	8	48
(Base)	(253)	(203)	(101)
Missing %	16	8	7
(Base)	(303)	(221)	(108)

Interpretation: At six months, 39 per cent of those whose functioning is 'severe' on admission were dead (based on 646 people). Of those who scored 'severe' on admission, 15 per cent were unrecorded or missing at six months (based on 758 people).

Table 4.10: Healthy life expectancy (physical and mental)

A. Dependency (grouped Barthel scale)

	Dependency on Admission			
	Total	*Severe*	*Moderate*	*Low*
Median life expectancy (months)	7	16	20	28
Mean life expectancy (months)[1]	15	23	26	34
Proportion of remaining life at				
Total dependency	64%	29%	21%	16%
Severe dependency	20%	39%	21%	14%
Moderate dependency	9%	15%	29%	18%
Low dependency	7%	17%	29%	52%
Base	(427)	(556)	(576)	(821)

B. Cognitive functioning (grouped MDS CPS scale)

	Cognitive Functioning on Admission		
	Severe	*Mild*	*Intact*
Median life expectancy (months)	16	21	23
Mean life expectancy (months) [1]	22	27	29
Proportion of remaining life at			
Severe dysfunction	59%	33%	24%
Mild dysfunction	32%	51%	37%
Intact	8%	16%	39%
Base	(758)	(1017)	(447)

Note: 1. As estimated from the model. These estimates are less accurate than those presented in chapter 3.

Interpretation: A person who is totally dependent on admission has a median life expectancy of seven months and a mean life expectancy of 15 months. Their expectation is that 64 per cent of this will be in total dependency, 20 per cent in severe dependency etc.

Chapter 5
Lifetime Costs within a Care Home

5.1 Introduction

This chapter determines the lifetime costs to Social Services (only) for the care of someone aged 65+ admitted for the first time to a residential or nursing home as a supported resident. It is based on the first 42 months of the survey of admissions. It includes an analysis concerning the type of care provided, moves between care settings, unit costs, and uses the evidence about survival that was developed in chapter 3. It develops a model for predicting expected cost from the circumstances at the time of admission.

It is shown that:

- The average gross lifetime cost to social services of a placement is £32,000 for a nursing bed and £38,000 for a residential bed (1996 prices). There is tremendous variation in life-time costs and about 10 per cent will cost more than £100,000. These estimates depend on survival beyond 42 months, but are likely to be within 5 per cent of these figures.
- Net lifetime costs are harder to judge because of problems establishing the client contribution. The cost is much higher in local authority residential homes compared with other types of accommodation. Given the central forecast of survival it likely to be £30,000-£34,000 for a placement in a local authority home, £18,000-£23,000 in other residential homes, and £19,000-£22,000 in a nursing home.
- We recommend that the most appropriate way to estimate the gross lifetime cost of a new client is from the initial weekly cost multiplied by expected survival, given by the prediction model from chapter 3.
- Those factors which raise weekly costs, for example by leading to nursing rather than residential care, are precisely those that lower expected survival. The consequence is that while lifetime cost may be predicted prior to a placement decision, the great variation means such estimates cannot be expected to be very accurate in individual cases.

An example is given of how to calculate expected gross lifetime costs, using the prediction formula.

5.2 Methodology

This chapter is based on the same group of people as those examined in chapters 3 and 4. Costs in this study refer to the cost to social services of the care they have agreed to provide, from the time of first admission up until the client's death. This may include community based care where a person subsequently leaves a care home; but it excludes primary health care and hospital costs, costs to housing and social security. One implication is that where nursing is inclusive, as is usual for nursing homes, it will be included, since is a cost to social services. Where nursing is provided externally, as is the case for some but not all nursing in residential homes, it will be excluded, since it is a cost to health authorities. This of course is expected to change. Both gross and net costs are of interest, the latter being the cost after the client's contribution.

Costs are calculated on the basis of the length of time that a person spent in each type of setting, and the weekly unit cost of the care they received. The reason for this approach was that this study did not determine the actual total costs which local authorities paid during each resident's lifetime. The main source of information about costs is based on the charges that were set shortly after the client had been admitted to the home, and reported to us by the assessment officer. Thereafter the survey was conducted as far as possible in care homes without further reference to social services departments, and it was not practicable to obtain cost information from the SSD. This approach has certain obvious methodological implications relating to the nature and quality of the information about unit costs that was supplied; and to the consequences of not knowing about any change in costs. Section 5.3 deals with these issues concerning unit costs in detail, and also with the imputation of unit costs where data is incomplete.

However, with one quarter of the original entrants still alive after three and a half years, and some of them likely to live for many years, the greatest uncertainty in predicting average lifetime costs are our assumptions about long-term survival.

5.3 Gross Unit Cost Estimates

This section is substantially the same as at the 30 month report (Bebbington et al., 1999), apart from the description of missing cases.

As the study did not determine the total costs that local authorities paid during each resident's lifetime, the total costs are determined by estimating the average weekly cost of the care each

person received. The main source of information about charges was based on information received shortly after the client had been admitted to the home, usually from information obtained during the financial assessment. In this section and the next we will examine the implications of this with regards to:

- Changes in charges arising from reassessment.
- Changes in charges or costs resulting from moves to different establishments.
- The need to impute charges in when people move.
- Comparability of LA homes costs with other institutions' charges.
- Net costs.

In general, where a person remained in the same type of care throughout, the gross average unit cost has been estimated from the fee set at the outset. This is plausible because:

(a) the great majority of people who entered a care home never left again, at least for a different type of care;
(b) it is comparatively unusual for a fee to be renegotiated for an individual once that person is in a home;
(c) few people used local authority homes, for which the true cost (to social services) is harder to determine.

The remainder of this section examines these points.

5.3.1 Moves between types of home

In chapter 2 we found 316 individuals who had moved home, or bed type within home. However, the present chapter is not concerned with moves between homes of the same type, and so the number of moves is smaller. For present purposes we are concerned with eight 'locations' for care:

- local authority residential homes;
- voluntary residential homes;
- private residential homes;
- nursing homes;
- dual registered homes (residential bed);
- dual registered homes (nursing bed);
- long-stay hospitals;
- private households.

Note that we do not record acute hospital episodes, including short terminal stays, where the care home bed was being kept open. These are neither treated as a move nor costed.

Of the 2,386 people in this part of the investigation, only 301 are definitely known to have moved between different types of location as listed above. Nearly half of these made their only known move within a month of admission. Of the remaining 2,085, we do not know the location of 186 people at the end of 42 months. Some of these may be movers, though there is no particular reason to suppose the proportion is exceptionally high. It is also possible that some of the 1,711 people who died had moved shortly prior to death. However, in general, we tracked all moves up to the time of death. Our conclusion is that comparatively few people will change their type of accommodation following first admission, and most of those that do, do so quite quickly. This simplifies the subsequent costing.

5.3.2 Changes in charges

We do not have direct evidence regarding changes in charges from this study. However, the PSSRU 1996 survey of care homes that was undertaken in parallel with the present survey did investigate the pricing process in detail (Netten et al., 1999, chapter 4). The following analysis is based on reports from the heads of 459 private and voluntary homes in that study.

While charging reviews for publicly funded residents are usually carried out annually, in only one home in six did the head of home say that these reviews are conducted on an individual resident basis (table 5.1A). In the great majority of cases the reviews are undertaken collectively for all residents, though in a few cases as well as a collective review, some residents may in addition be reviewed individually. In fact, in most cases not only are the individual circumstances of residents not normally examined during review, but the homes themselves are not directly consulted (table 5.1B). For only 20 per cent of homes was the home or its managers involved in the review.

So the processes of review themselves would appear to militate against price changes on an individual basis, say in response to a gradual change in health. Moreover, it appears unlikely that reviews of the contracted price take place on a per home basis, unless the home has changed function. Indeed, the initial contracted price appears to vary only a little with staffing levels, physical fabric, organisational arrangements, and size (Netten et al., 1999, §4.3.1).

The main factor which affects changes in the contracted weekly price for local authority funded clients through time is very probably inflationary, reflecting perhaps the local authority's desire to manage its demand-supply position for this form of care. On this basis

we would consider it reasonable to assume that prices for most residents remain unchanged throughout the period they are supported in a care home, apart from inflationary changes, unless it is necessary for the resident to change homes.

5.3.3 People who move

What matters for costing purposes is how long a person was resident in a location, and what type of services they were getting. Most people remained in their first placement until they died: see chapter 2 for a description of movers. Where people moved the unit cost is likely to change and the following describes how unit costs were imputed. Because of the relatively small number of people involved, the method is simplified.

The cost will also depend on the timing of the move. Dates are recorded but, as usual there is some missing information: in 77 (25 per cent) of cases the exact date was unknown and has been imputed between the relevant waves of the survey.

(a) *Similar type of home.* Where people move between similar settings (e.g. from one private residential home to another), our assumption is that this is unlikely to affect the weekly unit costs much.

(b) *Different types of home.* The weekly cost of the second or subsequent home was unknown, so it has been imputed by the following method. A prediction formula was devised on the basis of the factors that were found to be most significant in the report by Forder and Netten (1997). The factors included were authority group, the type of placement, and Barthel score. Other factors found by Forder and Netten (1997) to be significant, including behaviour problems, nursing input, source of admission, and reason for admission all have a comparatively small impact compared with the above. Table 5.2 shows the formula, which was derived using regression based on the average weekly costs for all first admissions.

(c) *To private households*. Of these, in 43 (50 per cent) of cases we were able to track their subsequent use of support services, up to 30 months based on care manager records. Costs of domiciliary services are estimated from the volume of care and the unit cost estimates given by Netten and Dennett (1996), and are for social services only, excluding community nursing, hospital care etc. We justify this approximate approach in terms of the fairly small number of people concerned. The average cost is almost exactly £100 per week (outside London) and this figure has been used (with London inflation where appropriate) for all the remaining cases where volume of support services was unknown. However the actual amount was probably extremely varied. Of the 43 known cases, nine had no subsequent input from social services at all. At the other extreme were eight cases receiving care worth between £200 and £300 per week. In several cases this included

very substantial amounts of phased residential care, together with domiciliary support at other times. About one-quarter had returned to a care home by 42 months.

(d) *To hospitals*. Long-stay hospital care has not been costed. For the most part, the period in long-term hospital care was usually under two months. A few returned to a care home: almost all the remainder died.

5.3.4 Local authority homes

The great majority of people go to homes in the private and voluntary sector, and for these a charge is set which represents the total cost to social services for the care provided. Inputs from personnel outside the home such as social work care managers is presumed to be quite small.

For those who were admitted to local authority homes, the cost basis is rather different. Here the social services faces direct costs for providing the labour and capital that is needed for residential care, rather than meeting a pre-set charge. This makes establishing the cost of care rather more difficult, since it becomes a combination of recurrent costs of running the home, amortised capital, and overheads in terms of administration in order to run the home (as distinct from undertaking the care management). Moreover the question of marginal costs may arise. When paying for an extra place in a privately owned institution, the local authority will have a pretty clear idea what that will be. Variations in marginal costs will be a good deal less clear when providing care in their own homes, and potentially could be very variable, dependent on such factors as occupancy level. We have avoided this complication by focussing on average costs throughout. This chapter does not consider such matters as the likely impact of change in demand on costs. In essence, our focus is descriptive.

What we cannot be sure of is whether the reported costs in each case for local authority residential care is truly inclusive of all the costs that the local authority faces in providing it. However, it is pretty certain that, in general, it is not. The average unit cost reported here is £280 per week, fairly close (but a little below) the figure Netten et al. (1998) report for the recurrent costs alone. Effectively capital costs are discounted, though Netten and Dennett (1996) imply that these could add a further 10 per cent to the real cost of care.

We have decided to analyse the data as provided, i.e. effectively to ignore capital costs, for local authority provision. This should be borne in mind through the analysis, particularly where it relates to comparisons between type of home. In general, however, the comparatively small number of people in local authority homes means that this assumption is unlikely to affect other conclusions greatly.

5.4 Net Unit Cost Estimates

5.4.1 Client contribution cost

Remarkably few people being admitted were assessed at the point of admission as possessing significant assets of their own. The great majority are reported as having income levels that would appear to imply they are relying on state benefits. Only 10 per cent are reported as having income above £130 per week (1995/6).

A similar picture is given for assets. Although nearly one half have some capital assets, in a mere one per cent of cases is this reported as being above £8,000: the threshold for claiming income support at the time of the study. The value of property is reported as nil in 82 per cent of cases. Where there was property, in most cases its value was reported as unknown. Where given, property values averaged £40,000.

As a result, the client contribution was rarely likely to be greater than their personal income support and residential allowance entitlement, which varies with age, location, type of home but at the time was unlikely to be more than £123 per week. Only 5 per cent of residents were assessed for contributions of more than this per week, while just 3 per cent were receiving top-up payments from other sources (which rarely amounted to more than £20 per week).

5.4.2 Net weekly cost

The average net weekly assessed cost to social services of the placement is £178, £100 less than the gross cost. It differs slightly according to type of home. This leads to the recommendation for imputing net weekly cost shown in table 5.2.

Based on §5.4.1, we would have expected 16 per cent of applicants to have had sufficient property capital to fund their entire costs. However this was not what was reported. In nearly all these cases the local authority was still expecting to make the main financial contribution. We must assume that the assessed client contribution reported shortly after admission does not, at this stage, include any contribution from their property. The local authority normally underwrites costs until the former home is sold. Normally the proceeds will be used to offset back payments, but authorities differ in their practices on this.

It will be evident from the foregoing that client contribution, and net charges are rooted in the rules that were current at the time of the admissions survey in 1966. These have changed since, and are set to change further.

5.5 Total Costs

5.5.1 Lifetime gross totals

Total costs for social services are estimated by the unit cost of the service (package), as described in section 5.3, multiplied by the length of time for which that service is used. This assumes that the unit cost of services remains constant (at 1996 prices).

To estimate the additional costs for survivors beyond 42 months, we have used the estimated survival time based on the microsimulation approach described in chapter 3, and assumed that the same service will continue to be used until death. This would appear to be a reasonable assumption, for as time has gone by, fewer and fewer people move from the care home in which they are currently placed.

Table 5.3 shows the gross lifetime costs to social services of a placement in a care home. These costs average approximately £32,000 for a placement in a nursing bed and £38,000 for a placement in a residential bed (at 1996 prices). Although the weekly cost of nursing care is higher, the likely length of stay is much lower.

The second part of table 5.3 shows that these means are very variable indeed. Many people, about one quarter of all those admitted, leave very quickly and cost less than £5,000. At the other extreme, around 10 per cent of cases are projected to cost over £100,000: one or two may eventually be as high as £250,000.

5.5.2 Accuracy of estimates

These estimates have of course required a large number of assumptions and approximations, described through the preceding sections, which we can summarise as follows:

1. Prediction of life expectancy for individuals not known to have died within 42 months (727 cases).
2. Imputation of date of move where not known precisely (57 cases).
3. Imputation of gross unit cost for movers (83 cases).
4. Imputation (or partial imputation) of service use for some people who returned to private households (73 cases).
5. Assumption that costs will remain constant (at 1996 prices) while the person remains in the same care home.
6. Ignoring capital costs in local authority homes (176 cases).

Of these, we believe that the first is likely to be by far the most important to the accuracy of the final estimate, because although only a very small proportion of people live a long time after admission, their cost implications can be enormous. In chapter 3, the consequences of a rise or a fall in the monthly death rate was examined, given that that death rate had been fairly level since about a year after admission. The third part of table 5.3 shows the consequences for the average costs if the monthly death rate for these survivors were to be 10 per cent higher or lower than forecast. This table shows how sensitive the estimate of the average cost is to assumptions about future death rates.[1]

It should be noted that in 314 (13 per cent) of cases no initial weekly cost was reported. No attempt has been made to estimate lifetime costs in these cases. This group has been removed from the main analysis of costs shown in table 5.3, bringing the effective sample size to 2,072. Despite what was speculated in the 30 month report, this group were not greatly different in their circumstances, their length of stay, or the type of home to which they were admitted, from the remainder, and the effect of this seems unlikely to be great.

5.5.3 Lifetime net costs

Because we did not have access to local authority financial records, in order to derive estimates of this we must additionally make assumptions about the client's contribution. These assumptions are on a less certain basis than for gross costs, and depend on the client's resources.

The great majority of residents have no significant resources of their own. Their assessed income is based on income support and the residential care allowance (the latter will cease in its present form shortly). In §5.4, we found that only 10 per cent of residents are assessed as having income significantly above these levels. In the absence of information to the contrary, we will assume that this income, most likely from a pension, will continue, so that the assessed client contribution based on income remains unchanged.

In §5.4, we found that 16 per cent of residents have resources in property. We will assume that these must be used to pay for care, until remaining assets are spent down to the threshold of £16,000 (the limit as at 1/4/96), whereon the local authority will take over responsibility. There are however two additional problems in assessing the contribution of this group:

[1] The median gross costs are almost the same with each variant, since by 42 months we are well past the median life expectancy.

(a) The value of property is unknown in 230 cases. This may be as much due to uncertainty about the legal position of the property, as to doubts about its market value. (The average net value of property where known is £40,000.)
(b) It is impossible to judge the likely client contribution that would be made once spend-down has occurred. Income support entitlement will be affected by remaining capital. Note however that complete spend-down will only occur in a minority of cases of people with property capital at the outset.

These uncertainties create difficulties for the calculation of net life-time cost. We have therefore examined two slightly different sets of assumptions regarding capital:

(a) For people without capital, client contribution remains throughout their lifetime as it was assessed initially. This assumes income (if any) remains constant. For people with capital, it is assumed they will pay the total cost up to the limit of their capital (less £16,000) and thereafter client contribution will be as originally assessed. For people with unknown capital, an average value of £40,000 is assumed.
(b) Client contribution remains throughout the lifetime as it was originally assessed.

These should represent the likely extremes with regard to client contribution from capital. With the first assumption, 260 (11 per cent) of the sample will be able to pay for their entire care, and the net cost to the local authority will be nil. With the second assumption, the local authority will contribute to everyone, though that contribution will be under £100 per week in 7 per cent of cases.

Table 5.4 shows the net unit costs under each of these assumptions, by type of care home. Taking account of capital, the mean lifetime net cost (over all types of home) would be £20,000 whereas if capital is not realised, it would be £23,000. This represents the likely range for the true net cost to social services, though once again note the high variability.

5.5.4 Predicting lifetime costs

Our final question concerns the predictability of the total costs of long-term care following first admission as a supported resident. This again concerns the costs to social services.

It follows from the arguments above that the factors at the outset which affect the total cost will be those that influence life expectancy and the unit cost of care.

Because so few people leave the type of care to which they are first admitted, once a person is placed the total costs can be estimated from the weekly placement charge and the forecast

average life expectancy. The models developed in chapter 3 for forecasting life expectancy can be used for this purpose.

The above method assumes the placement is known. Sometimes it might be of interest to estimate likely costs before a placement decision has been made. In this case we have to combine the estimated unit cost with the life expectancy. Slightly simpler is to construct a direct estimate of gross total lifetime cost by standard regression methods. This is shown in table 5.5, where the predictors are all the factors that have proved statistically significant in predicting either unit cost or life expectancy. Note that as is customary, this analysis is based on the logarithm of costs (because of the long-tailed distribution). Table 5.6 shows how this can be used to estimate likely cost in a particular case.

A surprise here is that the predictability of lifetime costs is quite low. This is partly because of the immense variability in costs, which was remarked on earlier. It is also partly because several of the factors that contribute to the need for a relatively high-cost intervention (in particular nursing care), are the very ones that are associated with low life expectancy. Overall, the prediction equation is counter-intuitive in that the factors that might seem to be least associated with need, are the ones which result in highest lifetime costs. Thus low levels of dependency at admission will result in high costs. The final column of table 5.5 shows the magnitudes involved. For example, all else being equal a man will cost only three-quarters (76 per cent) as much as a woman: someone with a Barthel score below five at entry will cost little more than a third of someone with a score above 12. Local authority of origin is not statistically significant, due to the quite small numbers from London. Had it been so, then the model tends to indicate higher costs for inner London residents.

Table 5.1: Reviews of charges for local authority funded residents in independent homes

A. Regularly reviewed for:

	Private Homes %	*Voluntary Homes* %
Individual residents	17	15
All residents	68	72
Both of these	9	10
Not regularly reviewed	6	3
	100 (n=327)	100 (n=143)

B. Reviewed by:

	Private Homes %	*Voluntary Homes* %
The LA without the home	73	50
The LA together with the home	16	17
The LA with the home's managing organisation	9	25
Other	2	8
	100 (n=322)	100 (n=141)

Table 5.2: Formula for imputing weekly charge (where unknown)

Estimated gross weekly charge for a client is given by exp(z), where z is the sum of the applicable terms:

All clients	5.950
Local authority	
Shire	-0.210
Metropolitan	-0.276
Inner London	-0.085
Outer London	0.000
Placement	
Nursing home	0.001
LA Residential home	-0.115
Voluntary residential home	-0.207
Private residential home	-0.285
Dual registered (residential bed)	-0.273
Dual registered (nursing bed)	0.000
Barthel score on first admission	
0-4	0.032
5-8	0.036
9-12	0.023
13+	0.000

This formula is based on a log regression of 2067 cases where initial gross charge was known. Standard errors are not shown, but all factors are statistically significant. $R^2 = 0.68$.

For imputing assessed net weekly charge, £95 should be deducted in the case of residential homes and £105 in the case of nursing and dual registered homes.

Table 5.3: Gross lifetime cost of a local authority placement, by type of home to which originally admitted

A. Mean, median, standard deviation

	Median cost £	*Mean cost £*	*Standard Deviation*	*N*
LA residential home	29,200	43,500	40,200	176
Voluntary residential home	22,700	32,200	30,300	219
Private residential home	24,700	39,307	38,200	693
Dual registered home (residential bed)	22,400	36,500	36,600	84
Dual registered home (nursing bed)	17,700	37,400	46,900	58
Nursing home	15,200	32,400	42,200	839
Overall	20,600	35,900	34,868	2069

B. Frequency

	Residential beds %	*Nursing beds %*
Under £5,000	18	34
£5,000 - £10,000	10	10
£10,000 - £20,000	16	13
£20,000 - £50,000	27	22
£50,000 - £100,000	22	9
Over £100,000	8	12
Total	100 (1339)	100 (897)

C. Means, with different assumptions about death rates beyond 42 months

	Residential beds	*Nursing beds*
High variant	£37,000	£31,600
Central forecast	£38,400	£32,700
Low variant	£40,100	£34,100

Table 5.4: Estimated net lifetime cost of a local authority placement, by type of home to which originally admitted

A. Mean, median, standard deviation (allowing for client's capital)

	Median cost £	*Mean cost £*	*Standard Deviation*	*N*
LA residential home	15,700	30,000	32,200	177
Voluntary residential home	11,100	17,700	18,400	219
Private residential home	12,100	19,900	22,700	94
Dual registered home (residential bed)	12,400	18,600	21,100	84
Dual registered home (nursing bed)	5,800	23,200	31,100	58
Nursing home	5,900	19,200	28,900	840
Overall	9,900	20,300	26,300	2072

B. Mean, median, standard deviation (not allowing for client's capital)

	Median cost £	*Mean cost £*	*Standard Deviation*	*N*
LA residential home	19,500	33,800	32,400	176
Voluntary residential home	12,100	19,300	18,900	219
Private residential home	13,600	22,300	23,100	693
Dual registered home (residential bed)	13,100	20,200	21,000	84
Dual registered home (nursing bed)	11,300	25,100	32,100	58
Nursing home	9,600	21,900	30,000	839
Overall	12,500	22,800	27,000	2069

Table 5.5: Model for predicting lifetime cost given circumstances on admission (prior to a placement decision)

Estimated gross lifetime cost is given by exp(z) where z is the sum of the following model coefficients:

	Model coefficient	*Standard Error*	*F*	*df*	*Sig at 1% level?*	*Exp(z)*
Constant	9.751	0.362	6121.00	1	Yes	
Area of origin			1.10	3	No	
Shire county	-0.243	0.156				0.78
Metropolitan district	-0.228	0.158				0.80
Outer London	-0.007	0.214				0.99
Inner London	0.000	-				1.00
Gender			11.32	1	Yes	
Man	-0.274	0.081				0.76
Woman	0.000	-				1.00
Age at admission			19.31	2	Yes	
65-74	0.645	0.119				1.91
75-84	0.370	0.078				1.45
85+	0.000	-				1.00
Diagnosed illness on entry						
Respiratory	-0.441	0.102	18.67	1	Yes	0.64
Malignancy	-1.148	0.135	72.80	1	Yes	0.32
Barthel Score on entry			25.75	3	Yes	
0-4	-0.990	0.114				0.37
5-8	-0.352	0.099				0.70
9-12	-0.423	0.095				0.64
13+	0.000	-				1.00
MDS Cognitive Scale			0.46	2	No	
Intact	0.099	0.106-				1.10
Mild impairment	0.028	0.085				1.03
Severe impairment	0.000	-				1.00
Source of admission			3.53	3	Yes	
Private household	0.437	0.289				1.55
Care home	0.790	0.322				2.20
Hospital	0.334	0.287				1.40
Other	0.000	-				1.00

$R^2 = 0.13$.

Table 5.6: Illustrative calculation of predicted gross lifetime cost to social services of admitting someone in particular circumstances

	Coefficient from table 5.5
Constant	9.751
Living in shires	-0.243
Woman	0.000
Aged 75-84	0.370
No diagnosed medical conditions	0.000
Barthel score 0 – 4	-0.990
Mild cognitive impairment	0.028
Admitted from hospital	0.334
Total score	9.250

Estimated gross lifetime cost = exp(9.250) = £10,400

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