Economic Evaluation of Palliative Care in Ireland

Final Report

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EXECUTIVE SUMMARY

Introduction

This project examines evidence on the cost and cost effectiveness of alternative models of specialist palliative care (SPC) (e.g., variations in the mix of specialist palliative in-patient, day, and home care) in Ireland.

For three comparator areas the specific objectives are to

1) estimate total formal care costs per patient in receipt of SPC over the last year of life
2) estimate total informal care costs per patient in receipt of SPC over the last year of life
3) measure specified outcomes (accessibility and quality of care, location of death, palliative care outcomes, and quality of life) per patient in receipt of SPC

Based on the above data, the subsequent objective is to

4) jointly assess the pattern of costs and outcomes.

The three comparator areas include the HSE Midlands Area (incorporating Laois, Offaly, Longford, and Westmeath), the HSE Mid West Area (incorporating Clare, Limerick, and North Tipperary), and the HSE South East Area (including South Tipperary, Waterford and Wexford, excluding Carlow/Kilkenny).

Background

International Context

Palliative care is defined as ‘an approach that improves the quality of life of patients and their families facing the problem[s] associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’.

Despite the expansion of palliative care worldwide, application of economic evaluation in palliative care has been slow to develop and the evidence base remains small. In the context of limited resources, evidence on costs and cost effectiveness of healthcare services is increasingly important to facilitate appropriate resource allocation decisions.

A review of the literature on economic evaluation in palliative care finds that despite wide variation in study type, palliative care is often statistically significantly less costly relative to comparator groups, although there may be complex interactions with diagnosis and other factors. It is important to note that the main focus of these studies is on formal care costs with little focus on informal care or out-of-pocket costs.

This study contributes to the evidence base on the costs and outcomes in palliative care by drawing on variations in how services are organised within the Irish health system. Careful examination of formal and informal costs of care across different models of SPC provision is combined with analysis of variations in patient experience (palliative outcomes, death in preferred location, satisfaction with care). Given the challenges in applying standard economic evaluation techniques to palliative care, rather than seeking to construct incremental cost effectiveness ratios, the focus is on identifying patterns in costs and patient experiences across models of care, and to observe systematic variations to inform policy on resource allocation to, and within, palliative care services.

Palliative Care Services in Ireland

There are wide variations in the availability of SPC services in Ireland. While all areas have access to specialist community palliative care/home care teams, not all have access to a SPC in-patient unit or to specialist palliative day care centres or outpatient clinics attached to SPC units.

There are also variations in how services are structured and resourced. For community SPC care, most community SPC teams are consultant-led, multidisciplinary services, but in some areas they are nurse-led. Service availability varies from seven days a week, twenty four hours per day to office hours only. Many community SPC teams do not have the full complement of staff for a multidisciplinary team. Home help and public health nursing capacity is often insufficient to meet the needs of patients and can make it difficult to maintain patient care in the community, resulting in in-patient admission.

SPC teams in acute hospitals support and collaborate with other hospital teams. Patients receiving SPC hospital team services usually remain on their own wards under the care of the referring consultant. Most SPC hospital teams provide services five days a week. Hospital staff, GPs and community services have access to telephone advice from SPC teams linked to in-patient units seven days a week, twenty four hours a day. Large variations exist in the staffing levels of SPC teams in acute hospitals.

The voluntary sector contributes significantly to all aspects of palliative care in Ireland. In-patient, day care, outpatient, and community SPC services are provided on behalf of the HSE by the Donegal Hospice, Galway Hospice, Marymount Hospice, the Milford Care Centre, North West Hospice, Our Lady's Hospice and Care Services, St Brigid’s Hospice, and St. Francis Hospice.

The three study areas have different levels of development of SPC services and, to an extent, different models of care. In the Mid West there is a facility with in-patient and ambulatory palliative care services. In the Midlands and the South East SPC services are mainly provided on an outreach basis in people’s homes.

Methods and Data

Formal and Informal Care Costs

Objectives 1, 2, and 4 require methods to estimate formal and informal care costs for a sample of deceased patients, who had been in receipt of SPC, in the last year of life. This study adopts a societal perspective, including care costs incurred by State institutions (e.g., public health services) and by private bodies/individuals (e.g., out-of-pocket payments).

Formal care costs are those incurred by formal providers (e.g., hospitals). Informal care refers to care provided by family/friends of the decedent and in this study is valued at the formal care replacement cost. Where possible, the study adopts a bottom-up approach to generating cost estimates by multiplying utilisation of specific services by unit costs. Thus, data are required on formal and informal care utilisation for patients over the last year of life, and on unit costs. These data were collected using both primary and secondary data collection methods:

- Primary data collection of service use using 'after-death' interviews with ‘key informants’ (KIs) for a sample of deceased patients who had received SPC. The KI is a person involved in the decedent's care and decision-making in the last year of life. Normally this person was the next of kin or a friend.

- Additional secondary data on service utilisation were collected from administrative sources.
- Unit costs were estimated using data from administrative sources. The approach to estimating unit costs was based on methods applied by the Personal Social Services Research Unit (PSSRU) in the UK.
- To estimate hospital costs a casemix adjusted cost was calculated from the HIPE (Hospital In-Patient Enquiry) record of each patient. For a small number of decedents for whom hospital records were not available, casemix adjusted costs were estimated based on age and diagnosis.
- Out-of-pocket expenditure data on non-prescription drugs and home modifications were collected during the KI interviews.

Patient Outcomes

Objectives 3 and 4 require methods to measure patient outcomes for a sample of deceased patients, who had been in receipt of SPC, over the last year of life. The outcomes or experiences of interest are drawn from literature and include the accessibility and quality of care, preferences about location of death, and health-related quality of life of the patient over the last year of life including patient palliative outcomes (e.g., experience of pain and other symptoms). These outcomes were explored during the KI interviews using validated measurement scales where possible.

Ethical Approval and Gatekeeper Permissions

Approval to undertake the study was granted from the relevant Research Ethics Committees at Trinity College, Dublin, and from those governing each study area. Gatekeeper permission was granted by each of the local palliative care teams and by the relevant providers of hospital-specific HIPE data.

Primary Data Collection

Economic Evaluation of Palliative Care in Ireland (EEPCI) Questionnaire

The KI interviews were conducted by phone (unless a face to face interview was requested) using a structured questionnaire developed for this study. The questionnaire incorporates several tools from previous end-of-life studies. The EEPCI Questionnaire examines demographic and socioeconomic characteristics of the deceased patient and informal carers, health and informal care utilisation, eligibility for publicly funded schemes (e.g., medical card), accessibility and quality of care, and preferences about location of death. The Palliative Outcome Scale (POS) is used to measure patient palliative outcomes in the week prior to death. Part I of EuroQol EQ-5D is incorporated to measure patient health-related quality of life.

Sample Identification & Recruitment

The sampling frame for the study is decedents who received SPC during the last year of life. The sample for each area was stratified by diagnosis in the approximate ratio of 70:30 for cancer and non-cancer cases, and by sex in the ratio of 50:50. Data were collected on decedents whose death occurred between 3–10 months prior to the study. Eligibility for inclusion was selected on the basis of a set of criteria referring to characteristics of the deceased patients and their KIs. 215 participants were recruited, including 80 in the Midlands, 75 in the Mid West and 60 in the South East.

In each study area, the local palliative care team selected the list of eligible participants in line with the criteria and made the initial contact with potential KIs to introduce them to the study. Where the KI agreed to receive further information, an information booklet and consent form were posted to them. If no consent form was received within 7–10 days one reminder letter was posted. If no consent form was received following the reminder letter, no further contact was made. The local palliative care teams returned details of those who agreed to participate to the research team. Participants were then contacted by the interviewer coordinator. During the interview, each participant was offered a local bereavement support number in case of distress.

Variation in recruitment: Recruitment timing varied across study areas. There was a longer average lead time between date of death and date of KI interview in the Mid West compared to the South East and the Midlands. There is a risk that a longer period between date of death and KI interview may lead to increased errors in reporting.

Secondary Data Collection

Community SPC, hospital, and hospice utilisation data collected during the interviews were triangulated with available administrative data. Permission to seek access to these data was requested from the KI.

Decedent Profile

Efforts were made to minimise bias in the study sample. At the selection stage there are no statistically significant differences between participants and eligible non-participants in demographic and diagnostic (cancer/non-cancer) characteristics (for each area). Within the sample of participants, there are no statistically significant variations across the three study areas for key decedent characteristics (e.g., age (p=0.215), marital status (p=0.200), and employment status (p=0.888)).

In the first month of the last year of life, the South East had the highest proportion of decedents living alone (28.3%) and the lowest proportion living in an institution (3.3%) relative to the other areas. In the last months of life, similar proportions of decedents across areas were living in their own homes with spouses and/or others (55–56%), but a lower proportion of decedents were in an institution in the South East (18.3%) compared to other areas (Midlands 30.0%, Mid West 29.3%).

Key Findings & Discussion

Formal and Informal Care Utilisation

- Formal and informal care utilisation over the last year of life are examined for the sample of decedents recruited into the study (based on data collected during the telephone interviews with the KIs and from HIPE records for public hospital day and in-patient utilisation). Utilisation over the last year of the decedent's life is split into two time periods: the first nine months of the last year and the last three months of life. Mean and median level of utilisation is assessed for all decedents and for service users. In most cases the median is less than the mean, suggesting that there are small numbers of intensive users. The discussion below refers to the mean level of utilisation by service users only. Statistical significance of variations in utilisation/costs across study areas and across time periods (i.e., first nine months and last three months within the last year of life) are determined where sample sizes permit. P-values are deemed significant if p<0.1. The use of the term significant implies statistical significance.

Community Care

- Almost all decedents had visits from/with a General Practitioner (GP) in the first nine months of their last year. In the last three months of life the proportion having visits decreased by around 10% in each area. In addition to the move of some decedents from home to institutional care, this may reflect increased use of community SPC nurses and Public Health Nurses (PHNs) in the last three months of life. This suggests that in the end-of-life period there is a tendency for SPC services to replace other healthcare. For those continuing to receive GP visits, the mean number doubled in each area.

- High proportions of decedents received visits from PHNs in the last three months of life. Variation in the mean number of visits across the three areas is significant in the three-month period (p=0.017). Decedents in the Midlands received almost twice the mean number of PHN visits of decedents in the South East.
- Most decedents did not use allied health professional services in community settings (although in the case of the Mid West some patients receive these services as part of SPC day care and in-patient hospice services). Chiropody was the most widely used, and there were fewer users in the last three months compared to the previous nine. For other allied health professions there was increased use amongst service users in the last three months. The overall low use of allied health professional services may reflect shortages of such staff and difficulty in gaining access.
- The difficulty in gaining access suggests there are advantages in making such services available via day care and outpatient/walk-in facilities. Such provision is a feature of the specialist palliative day care and in-patient hospice services in the Mid West, although use of individual services within this provision was not recorded in the KI-reported data. It is acknowledged that the KI-reported use of allied health professional services in the Mid West is lower than actual use. However, since specialist palliative day care and in-patient hospice stays were included in the cost calculations this shortcoming does not apply to the estimated costs.
- The proportion of decedents using complementary therapies was low but those who did avail of them used them relatively intensively.
- The most widely used paid help in the home in the three study areas was home help. The feasibility of remaining at home depends on retaining mobility and other skills, but also on the availability of social care and especially home helps. The proportion of decedents using home help was significantly higher in the Mid West and South East than in the Midlands in both time periods (p=0.015 nine-month period, p=0.085 three-month period). This may reflect higher dependency in these two areas relative to the Midlands. Informal care utilisation patterns further suggest higher dependency amongst decedents living at home in the South East relative to the Mid West and the Midlands.

Specialist Palliative Care

- The timing of referral to SPC reflects the needs of service users, the capacity of SPC services and the extent to which other clinicians recognise the value of such referrals. Where SPC is well developed and its role is well understood it is likely that there will be more referrals and that these will be generally earlier. Given that SPC services in the three study areas differ substantially, it is interesting to see how this affects who are referred and when.

- It is appropriate for many people to use SPC services only in the last few weeks of life, but there is substantial variation in the timing of referral to SPC across the three study areas: 68.4% of decedents in the Midlands were referred to SPC in the last three months of life including 20.3% who were referred in the last week. In the Mid West 60.8% were referred in the last three months including 14.9% referred in the last week. In the South East 57.7% were referred in the last three months (11.5% in the last week). The differences across areas in the proportions of decedents referred within the last three months (p=0.519) and the last week (p=0.388) are not significant.
- Clearly, the SPC services in all areas are providing more than end-of-life care, with some people receiving support for long periods. Where services are more fully developed there are earlier referrals to SPC. Earlier referral may improve patient experiences. It increases the chance of a gradual and orderly transition between services with a more curative intent and those with a more palliative intent. There is evidence from other studies that patients who are referred earlier are more likely to have fewer high cost interventions and may have better quality of life.
- High proportions of decedents in all three areas received community SPC nurse visits in the last three months of life (more than 77% in the Mid West and Midlands). The proportions vary significantly across areas (p=0.003). Fewer decedents in the South East (58.5%) received community SPC nurse visits in the last three months of life compared to the other areas. As there was a higher level of recruitment from in-patient hospital SPC teams in this area, this may explain why fewer decedents received community SPC nurse visits in the South East.
- The patterns of use of community SPC services were similar in the three study areas. In each area the proportion of decedents using the services and intensity of service use was higher in the last three months of life than in the previous nine months.
- More than 40% of decedents in the Mid West had in-patient hospice stays in the last three months of life.

Hospital Care

- The frequency of visits by decedents to the emergency department in the last three months of life was 2.4 times higher in the South East compared to the Midlands and three times higher than in the Mid West. This variation is significant (p=0.079) but may be driven in part by the higher proportion of decedents recruited into the study from hospital-based SPC teams in the South East.

- More than 38% of decedents in each area were admitted as hospital day patients in the first nine months of the last year. There was a small drop in the proportions in the Midlands and South East in the last three months of life but in the Mid West the proportion fell to under 20% and variation across areas is significant (p=0.006).
- Similar proportions of decedents had in-patient hospital stays across the three areas in the first nine months of the last year (60.0–65.3%). In the Midlands and South East the proportions of decedents with a hospital in-patient stay increased in the last three months of life but decreased in the Mid West (and variation across areas is significant, p=0.085).
- It was not possible to determine if the admissions to acute hospitals were appropriate. However, there is extensive evidence that many admissions to acute hospitals are not appropriate and reflect the lack of viable alternatives. This study shows that where in-patient hospice services are available the level of admissions with both malignant and non-malignant diseases to acute hospital beds is significantly lower in the last three months of life. Patients in hospice beds receive many of the same services that are provided in hospitals as well as SPC. While hospice beds and hospital beds are not exact substitutes, when no hospice bed is available there is more chance of a hospital admission. It is reasonable to argue that experiences of patients will be better where hospice services can prevent some hospital admissions.

Informal Care

- Informal carers are people who played an important role in caring for the decedent during the last year of life. They included anyone who helped care for them at home on a regular basis (e.g., washing, dressing and household tasks).
- A high proportion of KIs in the Midlands and Mid West were the spouse or partner of the decedent but in the South East a larger proportion were children of the decedent. The majority of KIs in all areas were women aged 35-64.
- When spouses are providing informal care they tend to provide the majority of this care in all three study areas, with over 70% of spouse/partner informal carers providing more than 60% of the informal care to the decedent. Children and others providing care tend to share the caring duties, with more than 40% of child informal carers providing less than 20% of the informal care.

- The proportion of decedents requiring informal care and the intensity of use is generally higher in the last three months of life than in the previous nine months.
- Personal care and taking medications were the most utilised forms of assistance in the last three months of life. The most time intensive forms of care provided by informal carers in the last three months of life were household tasks, followed by personal care, and eating and drinking.
- Across the three areas the data indicate that decedents (service users) in the South East were most dependent in both time periods, requiring the highest mean number of minutes of care per day in care weeks for most tasks.

Findings on Objectives 1 & 2

Estimate total formal and informal care costs per patient in receipt of SPC over the last year of life in each of three comparator areas.

- Total costs refer to costs of formal and informal care received by each decedent over the last year of life. All costs are in 2011 prices, consistent with the period during which the decedents were using services.
- Mean total formal costs include costs of community services, SPC services, allied health professional services, hospital services, nursing home services, medications and equipment. Mean total formal costs (calculated over the total sample of decedents, n=215) in the last year of life varied from €50,071 in the Midlands, to €50,036 in the Mid West, to €40,137 in the South East (p=0.136).
- Total informal care costs include costs of providing assistance with basic (personal care, eating and drinking, using the toilet, mobility indoors) and instrumental (taking medications, household and administrative tasks) activities of daily living. Mean total informal costs (calculated over the sample of decedents who were not living in an institution for the entire last year of life, n=198) varied from €17,966 in the Mid West, to €16,037 in the South East, to €13,651 in the Midlands (p=0.312).
- Mean total formal and informal costs (calculated over the total sample of decedents, n=215) in the last year of life varied from €66,564 in the Mid West, to €61,845 in the Midlands, to €56,174 in the South East (p=0.233).
- Mean costs per month of SPC services vary significantly across areas in the three-month period (p<0.001). Mean SPC costs per month in the Mid West are significantly higher than in the Midlands (p<0.001) and South East (p<0.001) mainly due to the high utilisation of in-patient hospice services in the Mid West.

- The most costly component of care in the Midlands and South East in each time period was hospital care followed by informal care. This contrasts with the Mid West where the most costly component of care in the three-month period was SPC, followed by hospital care and informal care. Variation in mean hospital costs per month is not significant across areas in the nine-month period (p=0.347) but is significant in the three-month period (p=0.039). This is evident when comparing mean hospital costs per month in the three-month period between the Mid West and the Midlands (p=0.005) and between the Mid West and South East (p=0.035), suggesting that the ability to access in-patient hospice beds leads to savings within hospitals in the last three months of life and reduces inappropriate hospital admissions.

Findings on Objective 3

Measure specified outcomes (accessibility and quality of care, location of death, palliative care outcomes, and quality of life) per patient in receipt of SPC in each of three comparator areas.

Accessibility and Quality of Care

- KIs were asked how easy it was for the decedent to access a bed in hospital, the hospice, and community SPC if it was deemed necessary. Most KIs in all areas reported that getting access to community SPC or hospice (where available) when required was either 'fairly easy' or 'very easy'. Perceived ease of access to a bed in hospital when required was seen as more difficult particularly in the Mid West and Midlands with almost 40% and 35% of KIs respectively reporting that it was 'fairly difficult' or 'very difficult'.
- KIs were asked to rate, on a scale of one to ten, with ten being excellent, the quality of care provided by each of the in-patient hospital, hospice, and community SPC teams, where applicable. For all aspects of care examined (communication with the decedent and family, management of symptoms, emotional support, respect for decedent’s wishes and respect for changes in decedent’s wishes), KIs were most satisfied with the quality of care received from the community SPC team in each study area. Given the diversity of how these services are delivered it is interesting that they are so universally given high ratings.
- The reported quality of in-patient hospital care was lower, particularly emotional support for families, although management of symptoms in hospitals was highly rated. The rating of in-patient hospital care was not restricted to SPC services, and may reflect both underlying problems in the experience of hospital care, and a more general perception of the inappropriateness of the acute hospital setting for many people nearing the end of life.

- The area in which the in-patient hospital team scored lowest on quality measures, the Mid West, was the only area in the study in which there was an in-patient hospice service. The in-patient hospice team scored higher on all six aspects of care examined than the in-patient hospital team. This suggests that when both in-patient hospital and hospice services are available KIs are better able to rate the services as they have a point of comparison.

Location of Death

An important objective in many cases is for the patient to die in an appropriate (and/or their preferred) location. A patient's preferred place of death may change during the course of an illness. Six months prior to death most decedents in all areas wanted to die at home. By the last week of life this proportion had decreased in all areas. Overall, almost 75% of decedents in this study died in the location for which they (or the KI assumed) had stated a preference in the last week of their life.

- The location of death varied significantly across areas ($p<0.001$). Although the proportions dying at home are quite similar, fewer decedents died in hospital in the Mid West. The availability of in-patient hospice services in the Mid West means that more decedents died in this setting. Those with cancer were very unlikely to die in hospital in the Mid West. Those dying of other causes were more likely to die in hospital (but still less likely than in the other study areas).

Palliative Outcomes and Quality of Life

- The Palliative Outcome Scale consists of 10 items which assess physical symptoms, emotional, psychological and spiritual needs, and provision of information and support. The maximum (worst) score for each POS item is four. Summing the individual scores the maximum (worst) global score is 40.
- As reported earlier, satisfaction with SPC services was high in all three areas as rated by the KIs. The reported palliative outcomes for decedents, as measured by POS, were also generally very good with differences in mean POS scores between the study areas being small and for most POS items, not statistically significant.
- The POS scores suggest the need for focus on communication and support to reduce anxiety and worry experienced by families during the last week of their relative's life. In this study there has been the problem that in some cases the timing of data collection relative to the death of the decedent was later than planned. The POS scores are reported with qualification about the validity of POS when applied in this time context.
- There remains the challenge of how best to measure outcomes (e.g., benefits or otherwise) from the receipt of services such as SPC at the end of life. The

difficulties encountered in this study support the need to develop better tools to assess differences in outcomes in palliative care.

- KIs were asked about the quality of the decedent's life in the first nine months of the last year, the last three months and the last week. Questions covered five dimensions: the decedent's ability to walk about, care for themselves and perform usual activities; their experience of pain and discomfort; feelings of anxiety or depression. Responses were graded in three levels: 'no problems', 'some problems' and 'severe problems'. The mean scores on the quality-of-life dimensions do not show any statistically significant differences across the study areas. This is not surprising since there is evidence that such scores are not very sensitive to differences in the context of complex care.

Findings on Objective 4

> *Jointly assess the pattern of costs and outcomes to determine any systematic interactions, e.g. if better outcomes are associated with lower or higher costs.*

- There are challenges in applying standard economic evaluation techniques to palliative care. In particular, assessing outcomes in palliative care using QALY-type measures has limitations and is not persued in this study. It is argued that valuing the ‘outcomes’ of a sample of patients who had received SPC prior to their death in terms of QALYs does not adequately capture their experiences of services during the last months of their life.
- As an alternative approach, a range of outcome measures have been employed to identify systematic interactions with cost patterns. The POS and Quality of Life indicators lend themselves to comparisons with costs.
- Given the absence of significant variation across study areas in the summary POS and quality of life scores, comparisons across study areas would be driven by costs. Thus, a joint assessment of the pattern of costs and these outcomes would not detect anything other than cost differences.
- There are several possible explanations for the failure of this study to find statistically significant differences in the POS and Quality of Life measures. In all cases the reported outcomes are good, so the scope to find differences is small. It may be that the high reported satisfaction with all the models of care in the study reflects good experience in terms of quality of services provided and the manner in which staff do their work. For any given availability of services it may not matter whether the balance is more towards outreach or more towards facility based services. Although this is a large study, it may require larger samples to detect small differences in palliative outcomes on these scales.

- There has been a lively debate in the literature about the usefulness of existing measurement tools for complex interventions. It is plausible that there are measurable (if not necessarily large) differences that are not detected in this study due to insufficiently sensitive measurement tools.
- Most KIs have only had experience of one type of SPC service. They may be unable to rate services received by the decedent in comparison to services available in other areas. The lower rating given to hospital care where in-patient hospice care is available suggests that knowledge and experience of a wider range of services affects the ratings given to what has been experienced.
- It is useful to highlight some patterns in the data that warrant further investigation. Although there is no significant difference in the POS and Quality of Life outcome measures between the three areas, there are differences in process that may be associated with experiences of different qualities. The most notable are in location of death (and the experience in the last days of life) and quality and accessibility of care. Although total cost per patient is higher in the Mid West compared to the other two areas, the number of decedents in the Mid West sample who die in hospital is much lower. Given the clearly stated preference in most cases for a death outside of hospital it is likely that this higher cost is generally associated with a better experience for patients and families. Poorer levels of perceived quality (including acceptability of death) of in-patient hospital services when compared with SPC services are also identified in the data. In all three study areas a high proportion of KIs reported difficulties in gaining access to acute hospital beds. This may be important given emerging evidence from other studies that people are very stressed by process difficulties in accessing care near the end of life.
- Together these outcome measures point to the desirability of facilitating in-patient hospice use as an alternative to in-patient hospital care where appropriate.

Conclusions

- In other areas of healthcare it has been found that many different approaches can work (and can fail). The three sets of palliative care providers in this study provide different services, and to an extent provide services in different ways. This study identified differences in the care used (much of which reflects differences in availability). There is no evidence from this study of advantages of particular delivery models (e.g. allied health professionals working in day care or outreach care), but there may be cost and access advantages of co-ordinated access to a range of services in a day care setting.

- This study did not set out to compare the costs of care in the end-of-life period with or without palliative care, but only to compare different models of palliative care. Studies that have done this generally show better experiences and outcomes at similar or lower cost.
- This study shows that there is a reduction in use of in-patient hospital care where hospice beds are available, but the overall costs of care are slightly higher where there is a fuller SPC service. The effects on informal care burden are not clear, and in all cases the costs and time commitment from informal care is high. It would be interesting to explore whether increased formal care services can reduce the burden on informal carers.
- There is a risk in a study of this sort that there are differences in the needs of decedents recruited in each area. There are some hints in the findings that would be interesting to explore further. Whereas there are no significant differences in the overall cost of informal care, the breakdown of the different elements of informal care suggests there may be some differences in patient needs, as judged by help with daily living tasks. Although the differences in costs of informal care between the three study areas are small, these could be driven by differences in needs.
- Overall this study shows high levels of satisfaction with SPC services in the three study areas. Patterns of service delivery and utilisation vary across the three areas, with slightly higher costs where SPC services are more developed, but more services provided by SPC services reduce use of other health services. There is a need for better measurement tools to compare costs and outcomes or experiences in palliative care, to allow comparison of different models of care.

1

Introduction

1.1 Introduction

This project aims to examine evidence on the cost and cost effectiveness of alternative models of palliative care (e.g., variations in the mix of specialist palliative in-patient, day, and home care) in the Irish healthcare system. In the context of limited resources, evidence on costs and cost effectiveness of healthcare services is increasingly important to facilitate appropriate resource allocation decisions. Care at the end-of-life is known to account for a large proportion of healthcare resources (Hatziandreu *et al.*, 2008).

Palliative care services have been expanding worldwide with the aim of improving symptom control and quality of life for patients with terminal illness, coordinating their care, and improving communication between professionals and the individual patient and family (Higginson *et al.*, 2003; Zimmermann *et al.*, 2008). However, application of economic evaluation in palliative care has been slow to develop and the evidence base remains small. There is a risk that the absence of robust evidence on the cost effectiveness of palliative care is taken to be evidence that such service interventions are poor value for money, and can encourage simplistic analysis based on naive interpretation of the limited data.

This study seeks to contribute to the evidence base on the cost and outcome implications of palliative care, by drawing on variations in how palliative care services are organised within the Irish healthcare system.

The remaining sub-sections of Section 1 introduce the concept of palliative care, describe how services are organised internationally and nationally, and introduce the aims, objectives and administrative structures for this study. Section 2 summarises available international evidence on the costs and cost effectiveness of palliative care. Section 3 introduces the methods and data sources for the analysis. Results are presented in Section 4 and discussion and conclusions are presented in Section 5.

1.2 What is Palliative Care?

Palliative care has been defined by the World Health Organisation as 'an approach that improves the quality of life of patients and their families facing the problem[s] associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. [1] This definition has been adopted by the Health Service Executive (HSE) Palliative Care Programme in Ireland which emphasises the distinction between palliative and end-of-life care. The Programme describes end-of-life care as a continuum of palliative care, referring to the period when death is imminent (HSE Palliative Care Programme Working Group, 2012).

Specifically, palliative care

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.[2]

1.3 Palliative Care Services – International Perspective

Palliative care has experienced rapid growth since the 1960s. The ground-breaking research undertaken by Cicely Saunders drew attention to the needs of patients with advanced cancer and demonstrated the importance of providing emotional, spiritual and psychological support for both the patient and their family. This approach was embodied in the care delivered by a multidisciplinary

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[1] http://www.who.int/cancer/palliative/definition/en/ [last accessed 19/12/12]

[2] http://www.who.int/cancer/palliative/definition/en/ [last accessed 19/12/12]

team at St. Christopher's, the world's first modern hospice, established by Saunders and her colleagues in London in 1967 (Clark, 2007).

Much of the attention that is now drawn to palliative care was influenced by international organisations. In the early 1980s, the World Health Organization (WHO) Cancer Unit launched a global initiative to advocate for improved pain relief and opiate availability (Sepulveda *et al.*, 2002). The publication and implementation of these guidelines had a significant impact on the development of palliative care and raised debate about the link between palliative care and cancer (Clark, 2007). Over time the WHO approach has broadened, moving from a focus on pain relief towards a model of care that centres on other activities such as the physical, emotional and spiritual needs of the patient and the wellbeing of their family and carers. In addition, the principles of palliative care are now recognised as being useful throughout the course of any life-limiting illness and not only for patients who are not responding to curative treatments (Sepulveda *et al.*, 2002).

Due to ageing demographics, changing disease patterns, and increasingly complex needs at the end-of-life, the WHO has identified palliative care as an important global public health issue (Hall *et al.*, 2011). Other key international organisations working to promote and influence the development of palliative care services include The European Association for Palliative Care, the International Observatory on End-of-Life Care, and the International Association for Hospice and Palliative Care. Collaboratively, these groups contribute to a growing evidence base through a variety of activities including research and collection of data on hospice and palliative care. They have also worked to raise public awareness of palliative care and to influence public policy through the publication of material directed towards policy-makers and healthcare professionals (Davies and Higginson, 2004; Hall *et al.*, 2011).

Some countries have developed and implemented national or regional palliative care strategies to help manage the anticipated growth in demand for palliative care services associated with shifting demographics and changing disease patterns (Davies and Higginson, 2004). In response to increasing interest amongst policy makers, the WHO has highlighted that the key elements of a comprehensive palliative care programme include policy development, education and training, provision of good quality care (including home-based care services), and drug availability (Sepulveda *et al.*, 2002). The organisation has also advocated the integration of palliative care into mainstream medicine and the development of educational programmes directed towards professionals and the general public.

Currently, there are more than 8,000 dedicated palliative care services in the world (Gomes *et al.*, 2009). The organisation and delivery of services varies internationally, and are usually influenced by national policy, funding arrangements, and historical practices. In the UK, there has been an emphasis on promoting generalist palliative care and supporting patients in the community, e.g day care hospice (IHF *et al.*, 2011). The Liverpool Care Pathway was a key component in the UK End-of-Life Care Strategy, but the Department of Health recently recommended that this be replaced with an individualised approach to end-of-life care (Neuberger, 2013). National bodies in a number of countries including Canada, Australia and the USA have also worked towards implementing specific policies on palliative care (HSE and IHF, 2008; May *et al.*, 2013).

1.4 Palliative Care Services in Ireland[3]

1.4.1 National Policies on Palliative Care

In 2001, Ireland became one of the first countries in the world to publish a national policy on palliative care (DoHC, 2001). The National Advisory Committee on Palliative Care (NACPC) report provided a comprehensive overview of the investment and requirements for developing palliative care and hospice services over a 5–7 year timeframe, and the recommendations included in the report were subsequently adopted as government policy for the development of palliative care services (Murray, 2005; May *et al.*, 2013).

The NACPC report emphasised that patients should be able to access palliative care services based on their needs, and these should be provided irrespective of diagnosis or location in the country. Under the NACPC framework, it was envisaged that each of the 10 local health boards would have a specialist in-patient unit serving as a local hub for services. This model of care would also facilitate transfer across a variety of settings, which could include hospice, day care or the home (Murray, 2005). A Regional Consultative Committee and a Regional Development Committee were to be established in each region to conduct needs assessments and prepare a development plan in each of the 10 Local Health Offices (LHOs) (Murray, 2005).[4]

The report also made a number of recommendations related to promoting the concepts of palliative care among primary care in the community: bereavement support, education, training and research, communication and standards in palliative care, funding and accountability, and workforce planning. The

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[3] Appendix 1 provides a timeline and description of key policies/reports on palliative care in Ireland.

[4] Following the publication of the NACPC report the Health Service Executive was established (leading to the abolition of health boards) but this did not affect the organisational framework.

recommendations were informed by research and international policy, but the NACPC highlighted the need for additional research and development of methods for incorporating the preferences of patients and their carers into the planning and delivery of services in an Irish context (May *et al.*, 2013). It was also recommended that a Minimum Data Set should be developed in Ireland in order to provide standardised information on all patients accessing specialist palliative care (SPC) services.

Murray (2005) reports that there were a number of positive developments in the period following the adoption of the NACPC recommendations. These included the completion of the required needs assessments, the appointment of additional consultants in palliative medicine, an increase in the number of hospital teams and the resources available to them, and an expansion of home care services. A training programme for Specialist Registrars and the National Council for Specialist Palliative Care were also established. The profile of palliative care continued to grow during a time of unprecedented economic growth in Ireland and the budget for palliative care services rose from €54 million in 2004 to €76 million in 2007, an increase of 40% (Murray, 2009; May *et al.*, 2013).

A report published by the Irish Hospice Foundation (IHF) in 2006, 'A Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland', found that while progress had been made in the implementation of the recommendations, the pace was slower than had been anticipated (IHF, 2006). Consequently, more than five years after the adoption of the NACPC's recommendations, a number of inequities in the provision and funding of services remained unaddressed. There also continued to be a heavy reliance on the voluntary sector for the planning and delivery of services, in particular home care. Further to this, voluntary funding was being used to pay core staff, despite the NACPC recommendation that the State should provide sufficient funds to cover these costs.

Much of the delay in achieving the NACPC goals was attributed to the time required to carry out needs assessments and develop strategies for the implementation of policy across the regions. Another barrier to full implementation of the recommendations was that the necessary resources had not been made available (Murray, 2009; May *et al.*, 2013). The Baseline report estimated that additional funding of €90 million would be required in order to meet the costs for bringing bed and staffing levels in line with NACPC recommendations.

This initiative led by the voluntary sector demonstrated to policy makers that significant obstacles would need to be overcome if the NACPC recommendations were to be fully realised. In December 2006, Taoiseach (Prime Minister) Bertie Ahern said: 'The baseline study has provided the evidence to underpin the investment and could be viewed as a "roadmap" of where we want to be and how we are going to get there' (Murray, 2009, p98). After Ahern's re-election the following year, the 2007 Programme for Government included a commitment to remove regional disparities in the provision and funding of palliative care services in Ireland (May *et al.*, 2013).

In addition to the Baseline study, each of the four administrative areas of the HSE, in conjunction with the Area Development Committees, carried out an audit with the aim of identifying deficiencies in the provision of palliative care services (HSE, 2009). The findings of these exercises, along with the Baseline report, were used by Department of Health and Children in the development of an implementation strategy. The *Palliative Care Services Five Year/Medium Term Development Framework* (Health Service Executive, 2009), outlined 'the required actions and initiatives necessary to address the gaps in palliative care service provision, against the recommendations set out in the NACPC report' (May *et al.*, 2013, p5). In total, 41 national priorities were identified that would address the gaps in service provision. These priorities were grouped under the following categories: capital development (15), home care services (12), acute hospital support (8), and specialist in-patient beds (6).

Given that Ireland entered a severe economic recession in 2008, emphasis was placed on the reconfiguration of existing resources as opposed to further investment. In fact, between 2009 and 2011, funding for palliative care had fallen to 2007 levels (May *et al.*, 2013). Expenditure continues to decline with the HSE allocating €72 million for palliative care services in 2013 (HSE, 2013), a 1.6% decrease from that provided in 2012. While some objectives remain unaddressed, there have been a number of important achievements in the delivery of palliative care services in recent years. Access to in-patient care for patients with non-malignant conditions increased from 7.2% in 2004 to 8.5% in 2011. Additionally, the proportion of patients with non-malignant conditions availing of homecare services increased from 17% to 20% between 2010 and 2011 (May *et al.*, 2013). Also, when Ireland was compared to other European countries using a classification to compare resource allocation and broader conditions that favour future advancements in palliative care services, the service was found to be amongst the best developed in the European Union (Martin-Moreno *et al.*, 2007).

Since 2011, there is national coordination of services by the Palliative Care Programme. This programme was one of a number of national clinical programmes initiated by the HSE to improve quality, facilitate equitable access, and promote efficient use of resources.[5] The aim is to ensure that patients and their carers have access to palliative care services, regardless of their diagnosis, location or care setting. Given the barriers to expanding services, the focus of efforts have now shifted towards strengthening the provision of palliative care services within the existing infrastructure. Over the coming years, the Palliative Care Programme is seeking to strengthen generalist palliative care services (May *et al.*, 2013). Overall, this approach is reflective of the need to recalibrate services to meet the needs of patients and their carers in the care settings they are most likely to access.

1.4.2 Structure of Palliative Care Services

Palliative care has a long history in Ireland and this continues to influence the delivery of services. Services originated in the voluntary sector with the establishment by religious orders of St. Patrick's Hospital in Cork and Our Lady's Hospice in Dublin as centres for the dying in the late 19th century (HSE, 2009). There have been significant advances in the provision of palliative care services in Ireland since 1995 when it became the second country in Europe to recognise palliative medicine as a distinct medical speciality.

The modern hospice movement resulted in the expansion of services into various settings: home care, hospital and hospice, and movement beyond the established urban centres. Palliative care services are structured in three levels of ascending specialisation as recommended by the NACPC report (Table 1.1). These levels refer to the expertise of the multidisciplinary teams providing services. The basic level (level one) emphasises a palliative approach to care in the community. All healthcare professionals should practice these principles, as it is suggested that a significant proportion of dying patients can have their care needs met without SPC intervention. Staff working in level two services, working across all care settings, have some additional training or expertise in palliative care provision. SPC (level three) services are those services where activity is centred on the delivery of palliative care. The SPC unit (SPCU) is regarded as the core element of the SPC service and the unit serves as a centre for co-ordinating the delivery of SPC services in all care settings, including hospitals and the community.

The NACPC report outlined the following workforce planning recommendations for staffing levels in level three SPC services:

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[5] Clinical Programmes website: http://www.hse.ie/eng/about/clinicalprogrammes [last accessed 06/11/14]

SPC unit (Whole Time Equivalent -WTE)

- One nurse and 0.5 care attendants per bed
- One physiotherapist, one occupational therapist, and one social worker per 10 beds
- Two spiritual care chaplains per unit
- One pharmacist per unit

Consultants

- At least one consultant in palliative medicine per 160,000 of the population, with at least two consultants in each health board area
- At least three or more non-consultant doctors per palliative medicine consultant
- A consultant-led multidisciplinary team in each acute hospital with 150 beds or more (to include nursing and social work, as well as non-consultant doctors)

Community

- A minimum of one SPC nurse per 25,000 of the population
- At least one physiotherapist, one occupational therapist, and one social worker per 125,000 of the population.

TABLE 1.1 Organisation of Palliative Care in Ireland

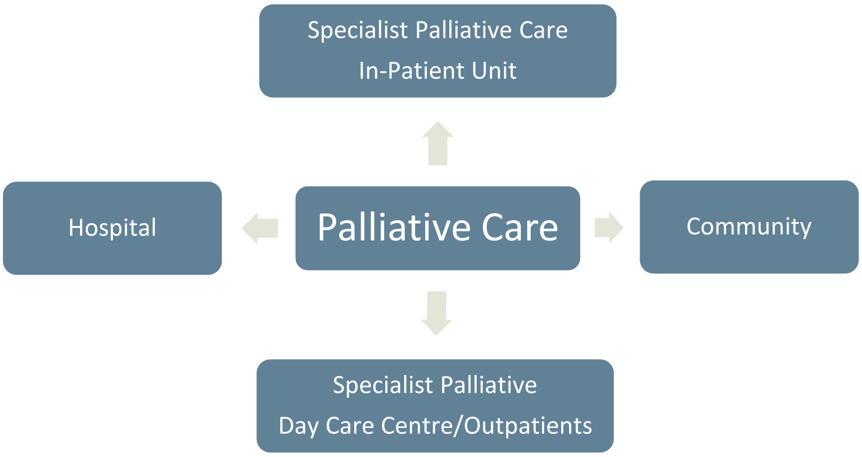
		LEVEL 1	LEVEL 2	LEVEL 3
		Palliative care principles should be practiced by all healthcare professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to SPC units or personnel.	At an intermediate level, a proportion of patients and families will benefit from the expertise of healthcare professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level. Such intermediate level expertise may be available in hospital or community settings.	SPC services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources.
Setting	**In-Patient**	-	Community hospital – palliative care support bed/s	Hospice – SPC team Acute general hospital – SPC team
	Day Care Centre	-	-	Hospice
	Outpatient Clinic	-	-	Hospice Acute general hospital
	Community	GP Public Health Nurse	GP Public Health Nurse	Home care – SPC team

Source: DoHC, 2001

Overview of Palliative Care Service Provision in Ireland

Figure 1.1 outlines the core elements of palliative care service provision in Ireland.

FIGURE 1.1 Principal Settings for Palliative Care Services in Irish Healthcare System



Source: Health Service Executive (HSE), 2009

SPC In-Patient Unit

The NACPC report recommended the SPC in-patient unit should act as the focal point for the delivery of SPC services, supporting and complementing other service providers at hospital and community level. The unit should also provide facilities for research and education (DoHC, 2001).

There are eight dedicated SPC in-patient units in Ireland. The Baseline report (IHF, 2006) highlighted the existence of wide regional and intra-regional variation in the availability of SPC in a specialist in-patient unit. Currently, nine LHO areas have no specialist in-patient units and no access to specialist in-patient beds. These are:

- Cavan/Monaghan LHO
- Meath LHO
- Louth LHO
- Laois/Offaly LHO
- Longford/Westmeath LHO.
- Wexford LHO
- Carlow/Kilkenny LHO
- Waterford LHO
- South Tipperary LHO

Staffing levels vary with some specialist in-patient units having all members of the multi-disciplinary team recommended in the NACPC report while others do not have a full complement of staff. Access to services can also be delayed as waiting lists exist for admission to some units.

Specialist Palliative Day Care Centre/Outpatients

Specialist palliative day care centres and outpatients clinics attached to SPC units provide access to specialist care, change of environment for patients, and respite for families and carers. There are six specialist palliative day care services, the majority of which operate Monday to Friday from 9am to 5pm. Again, there is wide intra-regional variation in availability of SPC in day care centres. The nine LHO areas where there are no in-patient units also have no specialist palliative day care centres.

Community SPC

SPC in the community ('home care team') provides specialist support and advice to patients, families and community-based professionals. The teams may also be involved in care of patients in palliative care support beds. All LHO areas have access to specialist community palliative care/home care teams in the community (2013 data). The vast majority of these services are consultant-led, multidisciplinary services, but in some areas they continue to be nurse-led services.

Service availability varies with some community SPC teams operating seven days a week, twenty four hours a day, others working seven days a week from 9am to 5pm and some teams can only provide services five days a week from 9am to 5pm. Many community SPC teams do not comprise the full complement of staff for a multidisciplinary team. Home help and public health nursing capacity is often insufficient to meet the needs of patients, while additional night nursing support from the ICS/IHF is limited to 70 hours per patient. Thus, in some situations it becomes more difficult to maintain patient care in the community, resulting in admission to in-patient facilities.

Night nursing services are provided free of charge by the ICS to cancer patients and are funded by voluntary contributions. Until 2006, non-cancer patients did not have the same access to night nursing services as those with advanced cancer. However, since 2006 the IHF has been funding the extension of the ICS service to non-cancer patients dying at home. The services delivered by ICS night nurses are for a maximum of 10 nights. In some circumstances the total number of nights funded can be increased to 14.[6]

Overall, GPs and Public Health Nurses are the main providers of general palliative care in the community setting (including local community hospitals and nursing homes). Emphasis has been placed on adopting this approach to providing palliative care to help manage the growing number of patients with chronic conditions (May *et al.*, 2013).

SPC Services in Acute General Hospitals

SPC teams in acute hospitals support and collaborate with other hospital teams. This is the same model of care as that provided in the community. Patients receiving services of the SPC hospital team usually remain on their own wards under the care of their referring consultant.[7] Approximately 38 of the acute general hospitals in Ireland have access to dedicated SPC teams.

The majority of the teams provide services five days a week. All hospitals, GPs and community services have on-call access to telephone advice from SPC teams linked to in-patient units (IPUs) seven days a week, twenty four hours a day. In a small number of hospitals, weekend and out-of-hours services are provided by the clinical nurse specialist in the community, by the home care team. Large variations exist in staffing levels of SPC teams in acute general hospitals.

Public/Voluntary Sector Interface

The voluntary sector makes significant contributions to the provision of palliative care services in Ireland, across all aspects of service provision. In-patient, day care, outpatient, and community SPC services are provided on behalf of the HSE by the Donegal Hospice, Galway Hospice, Marymount Hospice, the Milford Care Centre, North West Hospice, Our Lady's Hospice and Care Services, St Brigid’s Hospice, and St. Francis Hospice.

The voluntary sector has met nearly all capital development costs and contributes significantly to funding the provision of SPC staff in the community. The Irish Cancer Society (ICS) fully funds the night nursing palliative care services in the community while the IHF funds night nursing services (provided by the ICS) for non-malignant patients. In the Five Year/Medium Term Development Framework,

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[6] http://hospicefoundation.ie/what-we-do/palliative-care-for-all/night-care/ [last accessed 06/11/14]

[7] There are some exceptions to this, including, but not exclusive of, St Vincent's University Hospital and Waterford Regional Hospital.

the HSE notes the need for an appropriate funding mechanism to address the level of service provided by the Irish Cancer Society and other voluntary providers (HSE, 2009). This report also recognises the importance of combining the efforts of the voluntary and statutory sectors in order to meet the future challenges of palliative care service provision efficiently and effectively.

1.4.3 Reviews of Palliative Care Services

The Irish Hospice Foundation in partnership with the HSE initiated the Hospice Friendly Hospitals (*HfH*) programme in 2007. The objective of this initiative is to assist acute and community hospitals to integrate the principles of a hospice approach into their end-of-life care. Phase one of the programme (2007–12) included development of the Quality Standards for End-of-Life Care with support from the Health Information and Quality Authority (HIQA), which were published in 2010. This set of standards was developed based on detailed review of international research and practice focused on providing care at the end of life, and was informed by the *National Audit of End-of-Life Care in Ireland, 2008–9* (McKeown *et al.*, 2010a). The second phase of the *Hf*H programme (2012–16) is continuing efforts to support the development of capacity to meet the Quality Standards for End-of-Life Care in Hospitals in acute and residential care settings. Currently, 31 acute hospitals across Ireland and a further 20 care facilities in the Dublin area are directly involved with the work of the programme.[8]

The work undertaken by the H*f*H programme guided the first end-of-life care audit carried out in Ireland (McKeown, 2010). The *National Audit of End-of-Life Care* was the first EU initiative to underpin the development and implementation of standards for end-of-life care in Irish hospitals. The Audit was intended to be used to improve the quality of care delivered at the end of life by allowing hospitals to measure and assess their performance against the Quality Standards for End-of-Life Care in Hospitals. The structure of the audit allows for assessment of the delivery of end-of-life care in hospitals at both the individual and system level.

In total, 24 acute and 19 community hospitals across Ireland were covered by the audit. A series of five reports were released upon completion of the audit, examining a number of aspects of care including resources and facilities for end-of-life care in hospitals, dying in hospital from the perspective of healthcare professionals and families, the culture of end-of-life care in hospitals; and

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[8] http://www.hospicefriendlyhospitals.net/media/k2/attachments/Quick_Guide_to_the_Hospice_Friendly_Hospitals_Programme_1.pdf [date last accessed: 14/01/14]

assessment of the quality of care in the last week of life (McKeown *et al.*, 2010a; McKeown *et al.*, 2010e, d, c, b).

An Evaluation of the Hospice at Home Service Delivered by Milford Care Centre. Evaluation 2009/2011 was undertaken by researchers from the University of Limerick, February 2009 and July 2011 (McKay *et al.*, 2011, p7). The objective of the research was to examine whether or not the service provided 'a viable and effective model for delivering a range of palliative care services to patients and their families in the community' (McKay *et al.*, 2011). The views of a range of stakeholders were considered in the evaluation through the use of questionnaires, focus groups and semi-structured interviews. Participants included users of the Hospice at Home service, members of the home care team, and healthcare professionals in the community who worked with the home care team. This approach provided service users with the opportunity to discuss their experiences and express their needs and concerns. Questions from the 2010 *National Audit of End-of-Life Care in Hospitals* were also incorporated into the so that comparisons could be drawn between the hospital setting and Hospice at Home service with respect to experiences of dying patients, carers and professionals.

When compared to the National Audit, one of the key findings presented in the report was that the quality of care from the Hospice at Home service was rated higher by bereaved caregivers for each of the five quality domains examined. Further to this, the overall scores received by the Hospice at Home service were significantly higher than for care provided in a hospital setting. The evaluation also found that patients and their carers valued the Hospice at Home service with the majority of patients and carers reporting that they were highly satisfied with their contact with the team. In most instances, the Hospice at Home service exceeded carers' expectations. The report concludes that the service provides a high level of care and support, enables patients to be cared for at home in accordance with their wishes.

1.5 Aims and Objectives

The overall aim of this study is to examine evidence on the cost and outcomes of alternative models of palliative care (e.g., variations in the mix of specialist palliative in-patient, day, and home care) in the Irish healthcare system. The focus is on the costs incurred and outcomes experienced during the last year of life.

The specific objectives are to

1) estimate total formal care costs per patient in receipt of SPC over the last year of life in each of three comparator areas

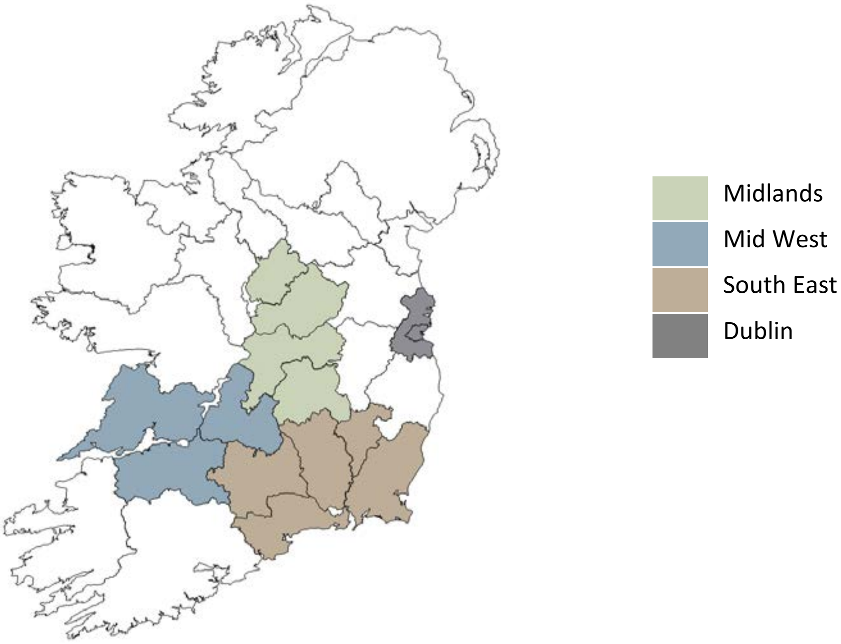
2) estimate total informal care costs per patient in receipt of SPC over the last year of life in each of three comparator areas
3) measure specified outcomes (accessibility and quality of care, location of death, palliative care outcomes, and quality of life) per patient in receipt of SPC in each of three comparator areas.

Based on the above data, the subsequent objective is to

4) jointly assess the pattern of costs and outcomes to determine any systematic interactions, e.g. if better outcomes are associated with lower or higher costs.

The three comparator areas include the HSE Midlands Area (incorporating Laois, Offaly, Longford, and Westmeath), the HSE Mid West Area (incorporating Clare, Limerick, and North Tipperary), and the HSE South East Area (incorporating South Tipperary, Waterford and Wexford[9]). See Figure 1.2.[10]

FIGURE 1.2 Comparator Areas



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[9] South Eastern services also cover Carlow/Kilkenny but due to local staffing shortages primary data collection was not undertaken in this area.

[10] A fourth comparator area, Dublin, will be examined as part of the International Access Rights and Empowerment (IARE) Programme. Data on formal and informal care costs and on outcomes are being collected for Dublin as part of the IARE protocol. The purpose of the IARE programme is to improve the rights of palliative care patients and their carers by generating information regarding access and empowerment of people who need end-of-life and palliative care in the four cities of Dublin, New York, San Francisco, and London. The IARE programme forms part of the project BuildCARE (Building Capacity, Access, Rights and Empowerment). BuildCARE aims to create a 'sea change' in the way palliative and end-of-life care is regarded, implemented and prioritised internationally. Led by Professor Irene Higginson, BuildCARE is a four-year project, supported by Cicely Saunders International (CSI) and The Atlantic Philanthropies. BuildCARE comprises four components: a CSI International PhD studentship programme, a CSI international faculty scholar programme, the IARE programme, and a programme to aid the dissemination, empowerment and engagement (DEE) of palliative care stakeholders.

1.6 Administrative Structures

Table 1.2 outlines the key personnel involved and their primary roles in the study. Primary data collection was coordinated by the research team with input from the Steering Group and local palliative care providers on methodology. Participant recruitment for the primary data collection process was managed in each study area by the local palliative care providers. Secondary data collection was undertaken by the research team, in conjunction with the local palliative care providers where required. Data analysis and reporting were undertaken by the research team, with feedback from all the stakeholders on the project. The study was funded by The Atlantic Philanthropies.

TABLE 1.2 Study Personnel

Name	Organisation/Institution	Roles/Responsibilities
Core Research Team		
Charles Normand	Edward Kennedy Professor of Health Policy and Management, Trinity College, Dublin	Principal Investigator
Aoife Brick	Research Officer, Economic and Social Research Institute	Study design, data collection, analysis, and reporting
Samantha Smith[b]	Research Analyst, Economic and Social Research Institute	Study design, data collection, analysis, and reporting
Sinéad O'Hara[a]	Data Analyst, Economic and Social Research Institute	Data collection, analysis, and reporting
Additional Research Support		
Nathan Cunningham	Data Analyst and Support Officer, Economic and Social Research Institute	Assistance with report preparation (January 2014–November 2014)
Elsa Droog	Research Fellow, Centre of Health Policy and Management, Trinity College Dublin	Interview coordinator, local team liaison, and palliative care services profile (April 2012–May 2013)
Bridget Johnston	Research Assistant, Centre of Health Policy and Management, Trinity College Dublin	Supplementary data collection, palliative care services profile, and literature review (February 2013–February 2014)
Ella Tyrrell	Research Assistant, Centre of Health Policy and Management, Trinity College Dublin	Unit cost collation (February 2013–January 2014)
Steering Group		
Paul McCrone	Professor of Health Economics, King's College London	Advice and feedback
Sonja McIlfatrick	Reader in Nursing Research and Development, University of Ulster and Head of Research at the All Ireland Institute of Hospice and Palliative Care	Advice and feedback
Feargal Twomey	Consultant in Palliative Care Medicine, Milford Care Centre and Midwestern Regional Hospital, Limerick	Advice and feedback
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Paul Marsden	Researcher, Cardiovascular Health Strategy, Department of Public Health	Participant recruitment coordination
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Pauline Carberry	Specialist Social Worker, Community SPC Team	Participant recruitment
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Phyllis Howlin	Community SPC Team	Participant recruitment
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Mary Murray	Clinical Nurse Specialist, Community SPC Team	Participant recruitment
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Elizabeth Crossan	Registered General Nurse	Participant recruitment
Geraldine Fallon	Clinical Nurse Specialist, Community SPC Team	Participant recruitment
Caroline Gettings	Registered General Nurse	Participant recruitment
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Deirdre Mannion	Clinical Nurse Specialist, Community SPC Team	Participant recruitment
Sue McDonagh	Clinical Nurse Specialist, Community SPC Team	Participant recruitment
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Evelyn O'Sullivan	Hospice at Home Service, Nursing Team Lead, Milford Care Centre	Participant recruitment
Shirley Real	Physiotherapy Manager, Milford Care Centre	Participant recruitment
Jim Rhatigan	Head of Therapies and Social Care Services, Milford Care Centre	Participant recruitment and supplementary data provision

Name	Organisation/Institution	Roles/Responsibilities
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Cathy Sheehan	Head of Finance, Milford Care Centre	Supplementary data provision
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Waterford:		
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Interviewing Team		
Phillip Coey		Interviewer
Elsa Droog	Research Fellow, Centre of Health Policy and Management, Trinity College Dublin	Interviewer
Ruth McIntyre		Interviewer
Collaborators/Stakeholders		
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Eugene Murray	Former CEO, Irish Hospice Foundation	Phase 1 collaborator
Pat Quinlan	Milford Care Centre, Limerick	Advice and feedback
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Notes: a At the time of publication Sinéad O'Hara had transferred from the Health Research and Information Division at the ESRI to the Healthcare Pricing Office (HPO).

b At the time of publication Samantha Smith was a Research Associate at the ESRI.

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2

Background

2.1 Introduction

As indicated earlier, application of economic evaluation in palliative care has been slow to develop, and the evidence base remains small. There are a number of challenges in applying standard economic evaluation techniques to palliative care, some of which relate to difficulties in capturing all relevant data on costs and impacts (e.g., informal care costs), while others refer to conceptual issues of valuing benefits. There are concerns that the full impacts of the interventions are not being captured. For example, the appropriateness of applying standard techniques (e.g., the Quality Adjusted Life Year, QALY) to measuring outcomes in palliative care has been questioned (Gomes *et al.*, 2009). The duration of effect is inevitably limited in many palliative interventions but a short good experience may be given a high value and this is not captured in the standard approach of adding up QALYs (Zimmermann *et al.*, 2008).

Thus, there are clear reasons why studies in this area do not undertake formal cost effectiveness analyses but rather assess implications of palliative care interventions on costs separately from outcomes. It is important to keep these challenges in mind when reviewing economic studies in this field. Methodological approaches are varied and often rely on relatively small scale observational studies (Higginson *et al.*, 2003). This section provides an overview of available international evidence on the costs and cost effectiveness of palliative care interventions over the period 2002–2011.[1]

2.2 Review of International Literature 2002–2011

2.2.1 Parameters of the Literature Review

The specific objectives of the review of international literature were to

- identify studies that investigate the cost or resource use implications of a 'palliative care intervention' relative to some type of comparator or control
- identify studies that investigate the cost effectiveness of a palliative care intervention relative to some type of comparator or control.

The terms 'palliative' and 'hospice' have not been consistently used in the literature. In some settings, hospice refers to the physical location where patients are cared for

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[1] For a more detailed presentation of this comprehensive literature review, see Smith *et al.*, 2014.

at the end of life, while palliative care may be used to describe the type of care administered. In other settings, hospice refers to the type of care administered, regardless of the physical location. For example, in the US, care funded by the Medicare hospice benefit is typically delivered at home (Lorenz *et al.*, 2006). Given this confusion in terms, and the aim to capture a comprehensive review of studies in this area, this review avoids making strict delineations between hospice and palliative care. In outlining the key findings for each of the studies we adopt the same terminology as applied in the source literature. The general term 'palliative care intervention' used in this review is intended to cover interventions that specify a palliative care focus and/or hospice-related care.[2]

Drawing on previous systematic reviews in this area, bibliographic and review databases were searched, specifically PubMed (including Medline), EURONHEED, the Applied Social Sciences Index (ASSIA), and the Cochrane library of databases. The search strategy employed an extensive list of terms grouped under three main headings intended to identify all publications relevant to the review question:

1) life stage (e.g., end of life, last year of life, life threatening, etc.) *or*
2) type/location of care (e.g., palliative, hospice, etc.) *and*
3) costs/cost effectiveness (e.g., cost, economic, price, etc.).

A total of 46 papers met the criteria of examining the cost and/or utilisation implications of a palliative care intervention with some form of comparator and were included in the literature review. The majority (34) of these papers report on cohort studies, wherein a defined group of participants were followed over time and comparison was made between those who did and did not receive an intervention. There are five randomised controlled trials (RCTs), two non-randomised controlled trials, two case studies, two before-and-after studies and one 'other' study not easily labelled.

2.2.2 Literature Review Findings

Study Findings on Costs

The studies vary in terms of methodological approach and sophistication of statistical analysis, ranging from formal RCTs to non-RCTs that undertake some degree of multivariate analysis, while others undertake univariate analysis.[3] A small number of papers do not undertake any formal statistical analysis.

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[2] In the other sections in this report which focus is on the Irish context and in particular the three study areas, the term hospice refers to the physical location of care.

[3] Multivariate analysis involves analysing the impact of a particular variable on an outcome of interest, while taking into account the effects of all other variables that may influence the outcome of interest (e.g., regression analysis). Univariate

In two out of six RCTs/non-randomised controlled trials that include cost data the costs of the palliative care intervention were significantly lower than the costs for the control group (Brumley *et al.*, 2007; Gade *et al.*, 2008). In three further studies the costs were lower for the palliative care intervention although not significantly different (Engelhardt *et al.*, 2006; Higginson *et al.*, 2009) or reported no statistical significance (Brumley *et al.*, 2003). In the remaining study, costs were higher, but not significantly different in the intervention group relative to the control (Rabow *et al.*, 2004).[4]

In the cohort studies that undertook multivariate analysis of costs, nine out of eleven studies found evidence of significantly lower costs in the palliative care intervention relative to the control group (Lo, 2002; Enguidanos *et al.*, 2005; Penrod *et al.*, 2006; Ciemins *et al.*, 2007; Shnoor *et al.*, 2007; Taylor *et al.*, 2007; Bendaly *et al.*, 2008; Morrison *et al.*, 2008; Penrod *et al.*, 2010). The remaining two studies, both based in the US, identified a more complex picture when disaggregating by age, cancer and length of nursing home enrolment (Campbell *et al.*, 2004; Gozalo *et al.*, 2008).

In the cohort studies that undertook univariate statistical analysis, five out of thirteen studies found evidence of significantly lower costs in the palliative care intervention group compared with the control group (Miccinesi *et al.*, 2003; Smith *et al.*, 2003; Lewin *et al.*, 2005; Tamir *et al.*, 2007; Morrison *et al.*, 2011) and a sixth found evidence of lower costs without reporting statistical significance (Gomez-Batiste *et al.*, 2006). Five others found some evidence of significantly lower costs in the palliative care intervention group but not consistently so, and variations were observed over a number of different factors, including diagnosis, nursing home length of stay, daily cost versus total admission cost, type of ward on which palliative care was provided, and the time period studied (Cowan, 2004; Miller *et al.*, 2004; Pyenson *et al.*, 2004; Hanson *et al.*, 2008; Simoens *et al.*, 2010). One study found evidence of significantly higher costs in a home care scheme relative to conventional hospital care, although these results require careful interpretation because of an increased number of diagnostic tests intentionally provided under the home care scheme (Tzala *et al.*, 2005). One study focusing on out-of-pocket expenses found no significant differences between the intervention and control groups, while finding informal care costs significantly higher in the intervention group (Taylor, 2009), underlining the importance of paying more attention to the informal care costs in palliative care.

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analysis examines the association between a particular variable and an outcome of interest, without controlling for any other factors that may influence the outcome of interest. The association can be tested for statistical significance using a range of statistical tests (e.g., t tests, chi-square tests) depending on the type of variables involved (continuous, categorical).

[4] Throughout this report, the term 'significant' refers to statistical significance, and the level of statistical significance (i.e., p-value) is indicated where available.

The five cohort studies that did not undertake formal statistical analysis observed patterns of lower expenditures related to palliative care (Emanuel *et al.*, 2002; Fassbender *et al.*, 2005; White *et al.*, 2006; Cassel *et al.*, 2010) or no difference in costs between palliative care and non-palliative care patients (Ward-Smith *et al.*, 2008).

Three cohort studies compared palliative care costs across different types of palliative care (Lo, 2002; Tibi-Levy *et al.*, 2006; Stevenson *et al.*, 2007). A study based in Taiwan observed no significant differences between home-based and hospital-based hospice expenditures per patient in the week before death, controlling for other factors (Lo, 2002). One US study examined utilisation differences in hospice care between the institutional and home setting (Stevenson *et al.*, 2007). Multivariate analysis of utilisation over a 30-day period, adjusting for patient characteristics and length of enrolment, found institutional hospice users were significantly more likely to receive several types of services including physician services (Odds Ratio (OR) 2.55, 95% confidence interval 1.68–3.87), prescription medicines (OR 1.6, 95% confidence interval 1.16–2.2) and others. Average length of enrolment was significantly shorter for institutional hospice users than for home hospice users ($p<0.001$). A study based in France examined variations in hospital-based palliative care costs across different types of hospitals (hospitals providing medical, surgical and obstetric care versus hospitals offering extended care and rehabilitation) (Tibi-Levy *et al.*, 2006). Univariate analysis found that the cost per patient per day was significantly lower in the hospitals focused on extended care and rehabilitation ($p<0.05$), driven by differences in personnel and medications costs.

Of the five remaining studies, including case studies, before-and-after and 'other' studies, four found evidence of significantly lower costs related to the palliative care intervention (O'Mahony *et al.*, 2005; Raphael *et al.*, 2005; Pascuet *et al.*, 2010; Seow *et al.*, 2010). The fifth found evidence of higher charges for palliative care relative to a national average charge (Davis *et al.*, 2005).

Study Findings on Utilisation

In general, the impact of palliative care on resource utilisation is mixed. Of the six RCTs/non-randomised controlled trials with utilisation data, three studies found evidence of lower use of some hospital services (Brumley *et al.*, 2003; Brumley *et al.*, 2007; Gade *et al.*, 2008), while three found no significant differences in other hospital services (Rabow *et al.*, 2004; Gade *et al.*, 2008; Bakitas *et al.*, 2009). Of the cohort studies that report specific results on healthcare utilisation, the same mixed pattern is observed (Costantini *et al.*, 2003; Douglas *et al.*, 2003; Miccinesi *et al.*, 2003; Cowan, 2004; Fassbender *et al.*, 2005; Lewin *et al.*, 2005; Tzala *et al.*, 2005;

Gomez-Batiste *et al.*, 2006; Penrod *et al.*, 2006; Ciemins *et al.*, 2007; Bendaly *et al.*, 2008; Hanson *et al.*, 2008; Ward-Smith *et al.*, 2008; Cassel *et al.*, 2010; Penrod *et al.*, 2010; Morrison *et al.*, 2011), while detailed analysis by two studies (Miccinesi *et al.*, 2003; Back *et al.*, 2005) illustrate the varied impacts of palliative care on utilisation (e.g., depending on time period studied, length of enrolment).

Study Findings on Cost Effectiveness

Only one of the studies (one of the RCTs) met the criteria for a cost-effectiveness study (Higginson *et al.*, 2009). This UK study examined the cost effectiveness of a new palliative care service for people with multiple sclerosis. The study found that total costs of care, including acute in-patient, ambulatory, other social/community care costs, and informal care costs were £1,789 (2005 prices) lower for the palliative care intervention group over a twelve-week follow-up period (bootstrapped 95% confidence interval – £5,224 to £1,902). Excluding acute in-patient and informal care, mean service costs were £1,195 lower for the intervention group (bootstrapped 95% confidence interval – £2,916 to £178) (Higginson *et al.*, 2009).

Patient outcomes were measured on the Palliative Care Outcome Scale (POS-8)[5] and caregivers' burden was measured using the Zarit Carer Burden Inventory (ZBI). There was no significant difference in the POS-8 measure over the trial, while ZBI scores improved for the intervention group and worsened for the control group. The point estimates indicate that the intervention is cost saving with equivalent outcomes on the POS-8 scale and improved outcomes on the ZBI. Sensitivity analysis examined uncertainty around those point estimates. For the POS-8 measure, the cost-effectiveness plane shows the intervention group had lower costs and better outcomes than the control group for 33.8% of the replications, and lower costs and worse outcomes for 54.9% of the replications. When the cost-effectiveness analysis is based on the ZBI measure, the intervention group shows lower costs and better outcomes for 47.3% of the replications, and higher costs and better outcomes for 48% of the replications.

2.3 Literature Review Conclusions

Overall, despite the wide variation in study type, characteristic and study quality, there are consistent patterns in the literature review findings. Palliative care is often found to be statistically significantly less costly relative to comparator groups, although there may be complex interactions with diagnosis (e.g. cancer/non-cancer distinctions), age groups, and other factors. It is also important to note that the main

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[5] The scale includes eight questions on anxiety, patient and carer concerns, and practical needs.

focus of these studies is on formal care costs, from the provider or third-party payer perspective, with little focus on informal care or out-of-pocket costs.

In this study the aim is to collect comprehensive data on both formal and informal costs of care during the last year of life for patients in receipt of SPC, together with assessment of the patients' experiences (i.e., 'outcomes') over the same period. Careful examination of costs of care across different models of palliative care service provision is combined with analysis of variations in patient experience (accessibility and quality of care, location of death, palliative care outcomes, and quality of life). In light of the challenges of applying standard economic evaluation techniques to palliative care, rather than seeking to construct incremental cost effectiveness ratios, the focus is on identifying patterns in costs and patient experiences over different models of care, and to observe systematic variations with a view to informing policy on resource allocation to, and within, palliative care services.

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3

Methods and Data

3.1 Overview of Study Design

3.1.1 Introduction

The following sections outline the methods for collecting and analysing the data required to meet the study objectives. Three types of data are required to meet the study objectives: data on service utilisation by a sample of patients in their last year of life, unit cost data, and data on specific outcomes measures for the same sample of patients.

3.1.2 Methods and Data Requirements for Objectives 1, 2, and 4

Methods

Study Perspective

Objectives 1, 2, and 4 require methods to estimate formal and informal care costs for a sample of deceased patients over the last year of life. The methods for estimating formal and informal care costs follow international standards from the cost of illness literature (Rice, 1966; Tarricone, 2006). This study adopts a societal perspective, including costs associated with the care of the selected samples of patients that are incurred by State institutions (e.g., public health services) and by private bodies/individuals (e.g., out-of-pocket payments), including voluntary providers.

Formal and Informal Care Costs

The study estimates both formal and informal care costs. Formal care costs refer to those directly related to the provision of healthcare by formal providers (e.g., acute hospital costs, GP care, etc.). Informal care refers to care provided by family/friends of the decedent. This care can be valued in a number of different ways. In this study, informal care cost refers to the replacement value of the informal care provided by family/friends.

Bottom-Up Methods

Where possible, the study adopts a bottom-up approach to generating the cost estimates whereby utilisation of specific services (e.g., number of GP visits over the last year of life) is multiplied by relevant unit costs (e.g., cost per visit). Thus, data are required on formal care utilisation and on informal care utilisation for specified samples of patients over the last year of life, and on unit costs.

Data Sources

Data on formal and informal care utilisation, and on unit costs, were collected using both primary and secondary data collection methods:

- Primary data collection of service utilisation using 'after-death' interviews with bereaved relatives (or other where appropriate, e.g., a friend), which from this point on are referred to as the key informant (KI) (see Section 3.3).
- Additional secondary data on service utilisation were collected from available administrative sources (see Section 3.4).
- Unit costs were either sourced or estimated using data from available administrative sources (see Appendix 5). Some information on out-of-pocket payments was collected during the KI interviews.

3.1.3 Methods and Data Requirements for Objectives 3 and 4

Objectives 3 and 4 require methods to measure patient outcomes over the last year of life. The outcomes or experiences of interest are drawn from available literature and include the accessibility and quality of care, preferences about location of death, and health-related quality of life of the patient over the last year of life including patient palliative outcomes (e.g., experience of pain and other symptoms). These outcomes were explored during the KI interviews using validated measurement scales where possible.

3.2 Ethical Approval and Gatekeeper Permissions

Approval to undertake the research study was sought and granted from the relevant Research Ethics Committees including overarching approval from the appropriate committee within Trinity College, Dublin, and from the committees governing each of the three study areas:

- Health Policy and Management/Centre for Global Health, Trinity College, Dublin
- Mid Western Regional Hospital, Limerick, HSE Mid West
- HSE Midland Area
- HSE South Eastern Area

Gatekeeper permission was granted by each of the local palliative care teams and by the relevant providers of hospital-specific administrative data from the Hospital In-Patient Enquiry (HIPE).

3.3 Primary Data Collection

Data on service utilisation over the last year of life were collected by interviewing KIs for a sample of deceased patients. The KI acts as a proxy for the decedent and is the person recognised as being somewhat or very involved in the decedent's care and decision-making over the last year of life. In most cases, this person was the next of kin (spouse, relative) but in some cases a close friend or other carer. While more than one person may meet the definition of KI for a decedent, for the purposes of this study, the KI refers to the individual who signed the consent form to participate in the study.

Such after-death interviews have become an important tool in research on end-of-life care. Available evidence indicates that there is relatively good agreement between patients and relatives/proxies in terms of recording patterns of service use and evaluating services (Addington-Hall and McPherson, 2001). The interviews were conducted using a structured questionnaire developed specifically for this study. It is acknowledged that the study sought to interview participants who were themselves in a vulnerable position, being recently bereaved. This is recognised in all studies of this nature that involve after-death interviews with relatives/carers of recently deceased. In order to maximise the benefits and minimise potential risks for prospective participants, the study design closely followed that of other similar studies, in particular the QUALYCARE study,[1] and has referred to relevant guidelines for conducting ethical bereavement research (Parkes, 1995; Gomes *et al.*, 2010). Notwithstanding the potential for triggering upsetting emotions, available evidence indicates that ’most bereaved relatives welcome the opportunity to make a contribution towards improving care for others by taking part in research’ (Gomes *et al.*, 2010 p2).

Structured telephone interviews were selected in preference to postal questionnaires given recent experience of low response rates to postal questionnaires in other studies in this area.[2] Structured telephone interviews were also selected in preference to face-to-face interviews to allow a large enough sample size to be covered within the time and resources available to the study. Although the majority of the interviews were conducted over the phone, a small number of face-to-face interviews were conducted in the home of the KI when specifically requested.

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[1] The QUALYCARE study has a similar focus to the current study, examining variations in the quality and costs of end-of-life care preferences and palliative outcomes associated with death across different settings. At the time of writing, comparative results were not available from the QUALYCARE study; therefore it is not possible to compare outcomes from that study to those presented in Section 4.

[2] For example, 46% response rate in the National Audit of End-of-life Care in Hospitals in Ireland, 2008/9 (McKeown *et al.*, 2010) and 36% response rate in the recent evaluation of the Milford Home Hospice Service (McKay *et al.*, 2011).

The content of the questionnaire and the details of the primary data collection processes for identifying and recruiting study participants in each of the Midlands, Mid West and South East areas are outlined here.

3.3.1 Economic Evaluation of Palliative Care in Ireland (EEPCI) Questionnaire

The questionnaire for this study follows the approach outlined by the QUALYCARE study (Gomes *et al.*, 2010), integrating a number of measurement tools that have been previously used in end-of-life studies.

As in the QUALYCARE questionnaire, the current study incorporates the Client Service Receipt Inventory (CSRI).[3] The CSRI tool provides structure for the questions on service utilisation. Further questions examine demographic and socioeconomic characteristics of the decedent and informal carers, use of informal care, eligibility for publicly funded schemes (e.g., medical card), accessibility and quality of care, and preferences about location of death. To ensure consistency of measures, many of these questions are drawn from available and well-established surveys, namely the Irish national census (CSO, 2011), The Irish Longitudinal Study on Ageing (TILDA)[4], the Survey of Health, Ageing and Retirement in Europe (SHARE)[5], the QUALYCARE study (Gomes *et al.*, 2010) and the National Audit of End-of-life Care in Hospitals in Ireland, 2008/9 (McKeown *et al.*, 2010). The Palliative Outcome Scale[6] is incorporated to measure patient palliative outcomes in the week prior to death. Part I of the EuroQol EQ-5D[7] is incorporated to measure patient health-related quality of life.

Table 3.1 outlines the different sections covered in the questionnaire together with the main sources for the questions. The full questionnaire is available in Appendix 2.1.

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[3] www.kcl.ac.uk/iop/depts/hspr/research /cemph/tools/csri.aspx [date accessed 22/02/12]

[4] www.tcd.ie/tilda [date accessed 06/02/12]

[5] www.share-project.org [date accessed 06/01/12]

[6] http://pos-pal.org [date accessed 23/02/12]

[7] www.euroqol.org [date accessed 29/02/12]

TABLE 3.1 EEPCI Content

Section		Content Summary	Main Question Sources[a,b]
1	Decedent profile	- Age - Gender - Marital status - Occupation - Nationality - Main diagnosis	- Census - QUALYCARE - TILDA
2	Carer profile	- Age - Gender - Occupation - Frequency of contact with decedent - Impact of any caring role on work	- Census - QUALYCARE - TILDA
3	Decedent living pattern	- Residential status of decedent in each month in last year of life	- TILDA
4	Informal care utilisation	- Amount (hours, weeks, months) of assistance required from family or friends with various basic and instrumental activities of daily living	- QUALYCARE - TILDA

5	Community services utilisation	- Number of visits (and in some cases telephone consultations), during first nine months and last three months of the decedent's last year of life for each of the following areas:
		  - Medical and nursing
		  - Allied health professionals
		  - Other community services
		- Where relevant, details on out-of-pocket payments
			- QUALYCARE
			- TILDA

6	Eligibility	- Medical card, GP Visit card, Long Term Illness, Drugs Payment Scheme, other public scheme status - Private health insurance status	- TILDA

7	Drugs, equipment and modifications	- Expenditure on prescription and non-prescription drugs
		- Acquisition and payment details for a range of equipment options, e.g.
		  - Wheelchair
		  - Special bed
		  - Oxygen equipment
		- Acquisition and payment details on home modifications
			- TILDA

8	Hospital, nursing home and hospice utilisation	- Number of visits and/or length of stay for the following types of care:
		  - Hospital care
		  - Nursing home
		  - Hospice
		- Where relevant, details on public/private distinctions and on out-of-pocket payments
		- Respite and convalescence arrangements
			- TILDA

9	Access and quality	- Ease of access to hospital, hospice, community SPC and palliative day care services - Quality of services received in terms of communication, management of pain, respectful of patient wishes, etc. - Acceptability of death	- National Audit of End-of-life Care in Hospitals - QUALYCARE
10	Decedent death profile	- Expected/unexpected death - Preferences about location of death - Location of death	- QUALYCARE - TILDA
11	Quality of life	- Palliative Care Outcome Scale (POS) - EuroQol EQ-5D Part I	- POS - EQ-5D
12	Bereavement support	- Number of visits/telephone contacts with palliative care services since bereavement	
13	Final comments	- Comment on any major expenses not covered during the questionnaire - Final comments by KI - Additional notes by interviewer	

Notes: a Established scales such as the Palliative Care Outcome Scale and Part I of the EQ-5D were modified only in terms of the time periods covered. Wording of the questions and response options were replicated from the original versions. In all other sections, the questions were based on, but not always replicated from, the questionnaires listed here. Additional questions and modifications to existing questions were required to adapt to the context of the Irish healthcare setting, and to the purposes of the study.

b Questionnaire sources: Gomes *et al.*, 2010; CSO, 2011; TILDA – www.tcd.ie/tilda;, SHARE – www.share-project.org; palliative outcome scale – http://pos-pal.org; EQ 5D – www.euroqol.org

Pilot Process

The questionnaire was piloted in June 2012. Four pilot telephone interviews were conducted with volunteers who had a connection with a Dublin-based SPC service. The interviews were recorded to facilitate analysis of the process. The purpose of the pilot was to examine the likely duration of the interview, the flow of the questionnaire script, the appropriateness of the sequences of the questionnaire sections, and the ease of interpretation of the questions. On the basis of the pilot, some changes were made to the questionnaire and the expected mean duration of 1 hour 40 minutes was included in the study information pack for potential participants.

3.3.2 Sample Identification

Sampling Frames, Sample Sizes, and Stratification

The sampling frame for the study is a set of decedents who received SPC during the last year of life.[8]

Sample size selection follows the approach of the QUALYCARE study which noted that formal sample size calculations are hindered by the absence of data on the magnitude of differences in outcomes and costs in palliative care services (Gomes *et al.*, 2010). As a general rule it is accepted that the measurement of costs requires relatively large sample sizes given that cost data typically have skewed distributions (Gomes *et al.*, 2010). This study adopted the pragmatic approach of identifying a sample size that is large enough to allow stratification by area (Midlands, Mid West, South East), diagnosis (cancer, non-cancer), and sex without generating cell sizes that are too small for statistical analysis. A sample size of 214 was selected to allow for 70 participants in the Midland and the Mid West areas and 74 participants in the South East area (explained in more detail below). Table 3.2 gives the breakdown of the target sample sizes for each area.

The sample for each area was stratified by diagnosis in the approximate ratio of 70:30 for cancer and non-cancer cases. Available data from the national Palliative Care Minimum Dataset indicates that non-cancer cases accounted for 17% of new patients accessing community SPC services in 2010, and 7% of new patients accessing specialist palliative in-patient services in 2010 (HSE, 2010). Thus, this study is purposely over-sampling non-cancer cases to allow for stratification by sex.

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[8] It had been envisaged that a second smaller sampling frame would be recruited. This would have included a set of decedents who did not receive, for whatever reason (e.g., geographical constraint), but who might have benefited from services provided by a SPC team before their death. The recruitment process was necessarily exploratory and it was not feasible to find a way to recruit a representative sample of this population.

The samples of cancer and non-cancer cases in each area were further stratified by sex in the ratio 50:50 for males and females, in line with the general breakdown of males and females accessing palliative care services in Ireland (HSE, 2010). Services in the Midlands are provided by two separate palliative care teams covering the Laois/Offaly and Longford/Westmeath areas. The population in Laois/Offaly is higher than in Longford/Westmeath (see Table 3.2) and thus the total sample of 70 cases was not divided evenly between the two areas (36 in Laois/Offaly; 34 in Longford/Westmeath).

Services in the South East are provided by four community SPC teams that operate independently from one another. Three of these community SPC teams participated in the study (Waterford, Wexford, South Tipperary).[9] For ease of stratifying the sample across these three teams, and then by diagnosis and sex, the overall sample size for the South East was set at 74, bringing the total target sample size to 214. As community SPC services in the Mid West are coordinated by Milford Care Centre it was not necessary to split the sample in that area.

TABLE 3.2 Stratified Samples by Area, Diagnosis, and Sex

	Population 2011[a]		Cancer		Non-Cancer		Total
			Male	Female	Male	Female	
	N	%	N	N	N	N	N
Midlands	**282,410**	**100**	**25**	**25**	**10**	**10**	**70**
Laois/Offaly	157,246	55.7	13	13	5	5	36
Longford/Westmeath	125,164	44.3	12	12	5	5	34
Mid West	**379,327**	**100**	**25**	**25**	**10**	**10**	**70**
South East[b]	**367,263**	**100**	**26**	**26**	**11**	**11**	**74**
Waterford	127,807	34.8	9	9	4	4	26
Wexford	145,320	39.6	9	9	4	4	26
South Tipperary	94,136	25.6	8	8	3	3	22
All Areas	**1,009,000**	**100**	**76**	**76**	**31**	**31**	**214**

Notes: Percentage column subject to rounding.
a Population data are based on Local Health Office (LHO) boundaries using Census 2011 data. LHO boundaries were derived from Electoral Division Boundaries which were available from Small Area Population Statistics.
b Excluding Carlow/Kilkenny LHO
Sources: CSO personal communication, 22 April 2014
http://www.cso.ie/en/census/census2011smallareapopulationstatisticssaps/ [last accessed 22/04/14]

Sampling Reference Period

Data were collected on decedents whose death occurred between 3–10 months prior to the date of initial contact by the local palliative care team to introduce the study. Three months is the minimum period adopted in other studies of end-of-life care in the UK and Ireland (e.g., Keegan *et al.*, 1999; Gomes *et al.*, 2010; McKeown *et al.*, 2010; McKay *et al.*, 2011; University of Southampton, various). The cut-off of three months post-bereavement was selected in order to avoid the most intense

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[9] The team in Carlow/Kilkenny were supportive of the study but due to staffing shortages were unable to participate at the time.

period of grief, allowing sufficient time to pass before approaching the bereaved relative or other KI to request their participation in the study. The end date of the sampling reference period was left open to allow the target sample sizes to be achieved in each area (i.e., as the data collection period extended, additional months could be added to the sampling reference period without breaching the three-month cut-off). As a result, the length of the sampling reference period (i.e., number of months included in the period) varies by area (see Table 3.3).

Data collection did not start at the same time in each area due to variations in the time required to set up recruitment processes. Thus, a balance needed to be struck between ensuring consistency in the sampling reference periods across the study areas in terms of the time since bereavement and ensuring consistency in the months selected. Efforts were made to avoid large seasonal variations in the months selected. Although there has been evidence to suggest that there will be some issues with the validity of using retrospective data from caregivers (Addington-Hall and McPherson, 2001), similar to other studies, KIs were contacted no later than 10 months post-bereavement in any of the areas to minimise potential problems with recall (Gomes *et al.*, 2010; University of Southampton, various).[10]

TABLE 3.3 Sampling Reference Periods and Time Since Bereavement by Area

	Sampling Reference Period 2012[a]								Data Collection Start Date	Time Since Bereavement[b]
	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct		Mean number of months
Midlands	✓	✓	[c]	✓	✓	✓	✓	✓	28/09/12	5
Mid West	✓	✓	[c]	✓	✓	✓	[e]	[e]	18/07/12	7
South East	[d]	[d]	[d]	✓	✓	✓	✓	✓	14/11/12	5

Notes: a Deaths occurring in the months specified
b Time since bereavement is calculated as the mean number of months between the date of death and the date of initial contact by the local palliative care team to introduce the study. Note that sampling reference periods had to be specified in advance while the precise start date for data collection was difficult to pre-specify as this depended on availability of the local palliative care team.
c May was not included in the Midlands and Mid West
d March to May were not included in the South East
e Recruitment in the Mid West had concluded

Sample Selection

The sampling unit refers to the eligible decedent and his/her KI. Eligibility of sampling units for selection into the study was determined on the basis of a set of inclusion and exclusion criteria. These criteria (Table 3.4) refer to characteristics of decedents and of KIs and are similar to those used in previous studies (Tilden *et al.*, 2004; Gelfman *et al.*, 2008; Neergaard *et al.*, 2008; McKay *et al.*, 2011). For a

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[10] Five interviews in the Mid West were carried out 11 months post-bereavement for a variety of reasons including a time lag between posting the reminder letter and return of the consent form by the KI. In some cases it took longer to establish contact and arrange the interview with the KI following consent.

sampling unit to be selected into the study, both the decedent and the KI in that unit had to be in line with the relevant criteria.

In each study area, the local palliative care team was responsible for selecting the list of eligible units (decedent and KI) in line with the criteria. In a small number of cases, additional sampling units were excluded by the local teams for reasons other than those specified in Table 3.4. The main reason for exclusion was that, in the assessment of the local team, the KI was in an acute stage of grief and contact at that time was not appropriate.

The local palliative care teams were responsible for making the initial contact with potential participants to introduce them to the study. The lists of eligible units (decedent and KI) in each area were ordered by date of death.[11] The teams were requested to contact KIs in this order to ensure that no other factors influenced the selection of participants from the list of eligible units. In practice, this was not always possible in the Mid West and the South East, where the task of contacting potential participants was allocated to more than one person. In these areas each person was given a block of names to contact from the master list of eligible units. Given that the numbers of eligible units were lower or only marginally higher than the required sample size it was in any case necessary to contact all eligible units.

As far as possible, while recruitment progressed and the quotas of the different sample strata were filled, no further contacts were made to eligible units falling into those strata (e.g., when the requisite number of eligible units with non-cancer male decedents were recruited no further eligible units with those characteristics were contacted). In some cases where quotas were over-filled, primary data were collected for all (i.e., all those who consented to participate were interviewed).

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[11] Lists included decedents who died in hospital during the sampling reference period and who may have only received SPC in an in-patient hospital setting.

TABLE 3.4 Inclusion and Exclusion Criteria

	Included in this study are:	Excluded from the study are:
Decedent	- had needs requiring, and had been referred to, SPC services.	- Death took place outside of the sampling reference period. - Was, but should not have been, referred to SPC. - under the age of 18 years at the time of death[b] - any legal issues pending (e.g., inquest, litigation, or formal complaints)[c]
KI[a]	- bereaved relative or other individual known to the decedent and identified as being a 'KI' for the decedent	- under the age 18 years - unable respond in English - a significant cognitive impairment or other significant vulnerability that would interfere with respondent being able to participate in an interview[d] - previously involved in palliative care research - any legal issues pending (e.g., inquest, litigation or formal complaints)[c]

Notes: a The KI will in most cases be the next of kin, but in some cases may be someone other than the next of kin who was most connected with the decedent over the last year of life (i.e., the person most involved in the decedent's care and decision-making over the period).

b The focus of this study is on palliative care for adults. Different issues arise in the case of paediatric palliative care and these are not the focus of this study.

c This ensures that the sample is not skewed by unusually complicated cases.

d This ensures that the KI has the physical, cognitive and emotional capacity to undertake the interview.

3.3.3 Sample Recruitment

Participant Initial Contact Process

Eligible study participants were identified and recruited by the local palliative care teams in each of the Midlands, Mid West, and South East. Each team coordinated the recruitment process as follows:

1) Introductory phone call or face-to-face visit: Eligible KIs were contacted by a member of the local palliative care team to introduce the study. In the majority of cases this was done over the phone although in some cases the study was introduced during a scheduled face-to-face bereavement visit, which comprised 38.3% of the total interviews carried out in South East.[12] The aims and objectives of the study were explained, along with a description of the phone interview and an overview of the content of the questionnaire. The KI was asked if they were willing to receive an information pack about the study. If the KI refused to receive this pack, no further contact was made with them. A protocol for how best to introduce the study during this initial contact was developed and disseminated to the local teams.

2) Dispatch of study information booklet and participation consent form: Where the KI agreed to receive further information about the study, an information booklet and consent form were posted to them (Appendix 2.2 and 2.3). In the information booklet, the KI was requested to return the consent form in the enclosed stamped addressed envelope within 7 days.

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[12] The South East is made up of four community SPC teams, three of which participated in this study (Waterford, Wexford, South Tipperary). The team at the South Tipperary Hospice Movement introduced the study to participants during scheduled bereavement visits. They made 23 contacts in this manner, and 16 of these agreed to be interviewed.

3) Reminder letter: If no consent form was received within 7–10 days from the date when the information pack was dispatched, one reminder letter was posted (Appendix 2.4). If no consent form was received following the dispatch of a reminder letter, no further contact was made with the KI.

4) Return list of participants to research team: The local palliative care teams returned details of those who had agreed to participate in the study to the research team. Details included name of decedent, date of death, age, gender, name of KI, and relationship to decedent.

Interview Process

Upon receipt of details of consenting KIs, the interviews were arranged by the interview coordinator as follows:

1) Phone call by interview coordinator: The interview coordinator contacted each participant to arrange a time and date for the interview. Where preference for face-to-face interviews had been specified on the consent form, this was accommodated as far as possible.[13]

2) Interview[14]: The interviews were conducted at the designated time, using a structured questionnaire, with immediate data entry onto encrypted laptops (i.e., computer aided telephone interview (CATI)).

3) Follow-up support: At the end of (or during) the interview, each participant was offered a local bereavement support number (e.g., local bereavement service, local palliative care team) in case of distress. If the interviewer was concerned about the well-being of any participant at the end of an interview, this was followed up by the interview coordinator with the local palliative care team.

4) Thank you card: A signed thank-you card was posted to each study participant.

3.3.4 Sample Coverage

To estimate the coverage of the EEPCI study, Table 3.5 shows a comparison of the final EEPCI sample (215 decedents) to the total deaths reported by the Palliative Care Minimum Dataset (PC MDS)[15] and the total deaths registered by the Vital Statistics section of the Central Statistics Office (CSO).[16] The data are disaggregated by month of death, diagnosis, area, and age group (for CSO data only). It should be noted that the EEPCI was using a quota sample, and recruitment of particular

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[13] In a number of cases, once the participant had spoken with the interview manager they changed their minds and accepted the option of telephone interview.

[14] Interviewers were assigned to interview slots on the basis of availability (e.g., one interviewer was only available for evening interviews). The team of four interviewers (including the interview coordinator) received specific training in the area of bereavement interviews and received regular peer support.

[15] This data set comprises of the total number of deaths reported to the PC MDS by SPC services in each area.

[16] This dataset is comprised of the total number of registered deaths in each area that are reported to the General Registry Office, and subsequently forwarded to the Vital Statistics section of the CSO.

decedents (e.g., non-cancer) ceased once the quota was reached. Also, the EEPCI sample only included decedents deemed eligible for inclusion in the study whereas deaths reported by the PC MDS and CSO relate to total decedents. While coverage fluctuates over the particular months across the different areas, when comparing the EEPCI to the PC MDS, overall, the highest level of coverage was achieved in the South East at 36.1%, followed by the Mid West (26.4%), and Midlands (21.6%). Compared to the CSO, the overall coverage ranged between 7–10% of the total deaths in each area.

TABLE 3.5 Percentage of PC MDS/CSO Reported Deaths Captured by EEPCI by Diagnosis (Cancer/Non-Cancer) and Area

	Sample Reference Period (2012)													
	March		April		June		July		August		September		October	
	C	NC	C	NC	C	NC	C	NC	C	NC	C	NC	C	NC
PC MDS														
Midlands	28.1	25.0	18.9	15.8	21.1	11.8	20.5	26.7	33.3	7.1	28.2	22.7	17.2	8.3
Mid West	16.3	6.7	37.8	36.4	33.3	46.7	32.6	33.3	4.5	36.4	-	-	-	-
South East	-	-	-	-	29.6	33.3	44.2	60.0	25.0	40.0	45.0	25.0		40.0
CSO														
Midlands														
<55 Years	50.0	-	-	-	-	-	20.0	-	12.5	-	14.3	-	33.3	-
55–64 Years	-	-	33.3	-	18.2	11.1	12.5	-	36.4	-	22.2	-	12.5	-
65–74 Years	28.6	-	18.8	8.3	12.5	-	16.7	-	8.3	-	11.1	11.1	-	5.3
75–84 Years	22.2	6.7	8.3	3.4	42.9	-	17.4	3.8	13.3	3.1	25.0	5.6	8.3	-
85 Years +	14.3	9.6	-	2.2	33.3	3.6	11.1	8.6	-	-	20.0	3.8	-	-
Total	**20.9**	**6.4**	**15.6**	**2.8**	**20.0**	**2.5**	**15.8**	**4.4**	**16.0**	**1.1**	**19.6**	**4.5**	**8.2**	**0.7**
Mid West														
<55 Years	50.0	-	33.3	-	20.0	-	25.0	-	14.3	4.3	-	-	-	-
55–64 Years	-	-	-	-	37.5	11.1	25.0	-	-	15.4	-	-	-	-
65–74 Years	11.1	-	38.5	-	22.7	18.2	37.5	5.3	7.1	-	-	-	-	-
75–84 Years	10.5	2.1	45.5	5.3	17.6	2.2	22.7	3.2	-	-	-	-	-	-
85 Years +	40.0	-	14.3	2.7	36.4	2.1	0.0	1.8	-	1.9	-	-	-	-
Total	**14.3**	**0.6**	**33.3**	**2.7**	**25.4**	**4.8**	**22.6**	**2.3**	**2.9**	**2.7**	**-**	**-**	**-**	**-**
South East[a]														
<55 Years	-	-	-	-	-	-	33.3	-	-	-	40.0	-	-	-
55–64 Years	-	-	-	-	33.3	10.0	25.0	-	-	-	22.2	-	-	-
65–74 Years	-	-	-	-	15.4	-	38.5	-	11.8	-	5.9	-	-	11.8
75–84 Years	-	-	-	-	29.4	-	25.0	2.8	16.7	2.8	12.5	2.6	-	-
85 Years +	-	-	-	-	54.5	2.2	41.7	4.2	9.1	2.0	40.0	-	-	-
Total	**-**	**-**	**-**	**-**	**29.6**	**1.6**	**32.2**	**2.3**	**10.7**	**1.6**	**17.3**	**0.9**	**0.0**	**1.4**

Notes: C= Cancer, NC= Non-Cancer

: a Data were not available from the CSO by county and age-group; therefore the South East contains deaths for Wexford from August to October, which were months when no recruitment for the study took place in this area. Percentages, therefore, are underestimated in the South East for these months.

Source: CSO personal communication, 13 December 2013
HSE personal communication, 30 September 2013

3.3.5 Interview Duration

The mean telephone interview duration was 1 hour 52 minutes (median – 1 hour 45 minutes). Interview duration varied across the areas. The area with the shortest mean telephone interview duration was in the Mid West at 1 hour 47 minutes (median – 1 hour 40 minutes), followed by the Midlands with a mean time of 1 hour

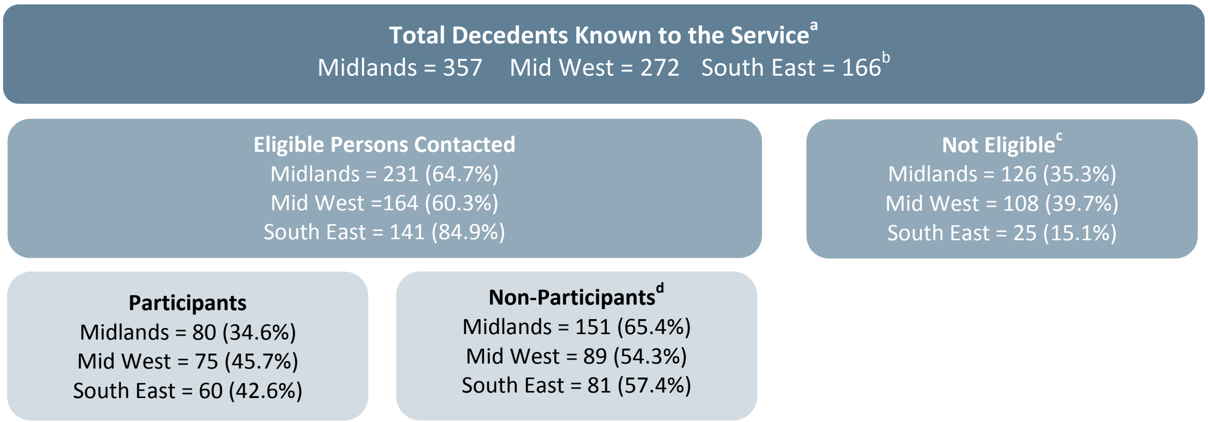
53 minutes (median – 1 hour 40 minutes). The South East recorded a slightly longer average time of 1 hour 56 minutes (median – 2 hours). There were no significant differences in mean telephone interview duration recorded across the areas.

The team facilitated 19 interviews which were conducted in the KIs home. These face-to-face interviews were significantly longer than the telephone interviews with an average duration of 2 hours 25 minutes compared to 1 hour and 50 minutes for interviews conducted over the phone (p<.001).

3.3.6 Sample Profile

Figure 3.1 shows variations across the three study areas in the proportion of cases who were deemed eligible from the total list of decedents.

FIGURE 3.1 Number of Eligible and Ineligible Participants by Area



Notes:
- a This is the total number of decedents known to the service across the months included in the sampling reference period (Table 3.3). Where additional persons were required to meet strata toward the end of the recruitment process, only the total number of KIs contacted for these months are included.
- b For the South East the total decedents known to the service is estimated from the PC MDS as this number was not available from the local Palliative Care teams. This appears to be a consistent estimate when comparing the number of decedents reported by the local teams to the study against those reported by the PC MDS for the other two areas; the PC MDS reported 370 total decedents for the Midlands and 284 total decedents for the Mid West.
- c This includes KIs who could not be contacted by the local palliative care team.
- d This includes KIs who declined to participate, and those who sent back their consent form but subsequently withdrew.

Table 3.6 shows baseline demographics and diagnostic (cancer/non-cancer) characteristics of the participants and eligible non-participants (for each area). Within each of the areas there is no significant difference in the mean age of the decedents included and not included in the study (Midlands p=0.894; Mid West p=0.894; South East p=0.557). Nor are there significant differences in the proportion of decedents who were male (Midlands p=0.802; Mid West p=0.780; South East p=0.351) or in the proportion of deaths that were caused by cancer (Midlands p=0.398; Mid West p=0.698; South East p=0.141).

The mean age of participating KIs is similar across the areas (Midlands = 57, Mid West = 56, South East = 55). The proportion of KIs who were male was lowest in the South East (25.0 per cent), with similar proportions reported in the Midlands (36.3 per cent) and the Mid West (40.0 per cent).

TABLE 3.6 Baseline Characteristics of Participants and Non-Participants by Area (Mean, %)

				Participants	Non-Participants	Test of Significance	
						Test Statistic	p
Midlands	Decedent	Age	mean[a]	74	77	1.319	0.894
		Male	%[b]	50.0	51.7	0.063	0.802
		Cancer	%[b]	71.3	65.7	0.714	0.398
	KI	Age	mean	57	n/a	–	–
		Male	%	36.3	n/a	–	–
Mid West	Decedent	Age	mean[a]	73	72	-0.134	0.894
		Male	%[b]	53.3	51.1	0.078	0.780
		Cancer	%[b]	74.7	77.3	0.151	0.698
	KI	Age	mean	56	n/a	–	–
		Male	%	40.0	n/a	–	–
South East	Decedent	Age	mean[a]	76	75	-0.588	0.557
		Male	%[b]	46.7	54.8	0.871	0.351
		Cancer	%[b]	83.3	72.6	2.171	0.141
	KI	Age	mean	55	n/a	–	–
		Male	%	25.0	n/a	–	–

Notes: n/a=not available

[a] Test statistic = Independent Samples t-test

[b] Test statistic = Chi-Squared Test

Table 3.7 shows the final quota of decedents recruited in the study. The Midlands were recruiting participants over a longer period of time (7 months) and achieved above their quota across all categories, while the other two areas did not recruit as many participants as they were recruiting over a shorter number of months (5 months in both areas). There is some compensation between male and female categories which helped to achieve targets in the total category. For example, the higher number of female decedents with a cancer diagnosis in the South East almost fully compensates for the lower recruitment of male decedents with a cancer diagnosis recruited in that area. The most difficult quotas to achieve were in the non-cancer categories, particularly in the South East where less than half the target for non-cancer decedents was achieved.

TABLE 3.7 Quota of Study Participants, and Quota Achieved by Each Study Area (N, % Difference)

	Cancer			Non-Cancer			Total
	Male	Female	Total	Male	Female	Total	
Midlands							
Quota	25	25	50	10	10	20	70
Quota achieved	28	29	57	12	11	23	80
% Difference	12.0	16.0	14.0	20.0	10.0	15.0	14.3
Mid West							
Quota	25	25	50	10	10	20	70
Quota achieved	31	25	56	8	11	19	75
% Difference	24.0	0.0	12.0	-20.0	10.0	-5.0	7.1
South East							
Quota	26	26	52	11	11	22	74
Quota achieved	21	29	50	8	2	10	60
% Difference	-19.2	11.5	-3.8	-27.3	-81.8	-54.5	-18.9
All Areas							
Quota	76	76	152	31	31	62	214
Quota achieved	80	83	163	28	24	52	215
% Difference	5.3	9.2	7.2	-9.7	-22.6	-16.1	0.5

3.4 Secondary Data Collection

3.4.1 Utilisation

Community SPC, hospital, and hospice utilisation data collected during the interviews were triangulated with available administrative data (see Appendix 4). Permission to access these data was requested from the KI both prior to and during the interview. Of the 215 completed interviews, 207 (96.3%) of the KIs agreed to allow the decedent's administrative records to be accessed.

Decedent Records

- *Hospital records* on day patient and in-patient episodes of care in acute public hospitals during the last year of life were extracted from the Hospital In-Patient Enquiry (HIPE) Scheme.
- *Community SPC administrative records* on the number of visits received by decedents from the community SPC nurses during the last year of life were obtained for decedents in the Midlands, Mid West (complete records for the last 3 months only) and South East areas.

3.4.2 Costs

In order to estimate the cost of care over the last year of life it was necessary to gather both unit costs and hospital episode costs.

Unit Costs

There is no central database of healthcare unit costs in Ireland. Specific methods were required to generate unit costs drawing on available Irish data and these are outlined, together with data sources and the final unit cost estimates, in Appendix 5. Data were collated from a number of different administrative secondary data sources including HSE salary rates for specific community services, financial management records for SPC services, and published reports (e.g., nursing home rates, private GP fees).

Hospital Costs – Day Patient and In-Patient

To give an estimate of the cost per hospital episode, a casemix adjusted cost was calculated from the HIPE record of each patient for whom permission was given by the KI to access.[17] The cost is calculated by multiplying their allocated Casemix Unit (CMU) by the national average cost per CMU for a patient (Base Price 2011: day patient – €637, in-patient – €4,580).[18]

Community SPC Team

Time use diaries were completed by community SPC team nurses in the Midlands, Mid West, and South Tipperary over one typical working week. The activities recorded in the diaries were divided into eight categories:

1) Patient/Family Visit
2) Patient/Family Telephone Contact
3) Contact with Other Healthcare Providers Directly Related to Individual Patient Care – Face-to-Face
4) Contact with Other Healthcare Providers Directly Related to Individual Patient Care – Telephone
5) Other Administration
6) Audit and Research
7) Education
8) Driving

These diaries allowed for the calculation of a ratio of direct patient contact to time spent on other aspects of the role and provide important information for the cost estimation process outlined in Appendix 5.

Other Costs

Some data on costs were also collected during the structured phone interview. These included estimates of monthly expenditure on non-prescription drugs and the cost of any home modifications.

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[17] For a small number of decedents for whom hospital records were not available (e.g., permission not granted), CMUs were estimated based on age and diagnoses (see Appendix 5 for further details).

[18] Each discharge in HIPE is assigned to a Diagnosis Related Group (DRG). DRGs group together cases which share common clinical attributes and similar patterns of resource use. A casemix unit (CMU) measures the complexity (in terms of resource use) of the DRG to which a case has been assigned relative to all other DRGs, and is adjusted to take into account the specific length of stay of the case. The national average cost per CMU for in-patients is calculated by dividing total hospital in-patient costs by the number of CMUs.

3.5 Methodological Issues

- Potential bias in the primary data: As outlined, the aim of the study is to examine variations in costs of care and outcomes for a sample of decedents in receipt of specialist palliative care across three study areas. The main focus is to determine how costs and outcomes vary with respect to alternative ways of delivering specialist palliative care. Given that this is not a randomised controlled trial, efforts were made to minimise potential sources of bias in the study sample. At the selection stage, although there were some variations across study areas in recruitment practices (see Section 3.3.3), Table 3.6 shows that there are no statistically significant differences between participants and eligible non-participants in terms of demographic and diagnostic (cancer/non-cancer) characteristics in the study (for each area). Within the sample of participants, Section 3.6 and Table 3.8 show that there are no statistically significant variations across the three study areas for the majority of key decedent characteristics (e.g., age ($p=0.215$), marital status ($p=0.200$), and employment status ($p=0.888$)). However, it is not possible to eliminate all sources of bias and there are likely to be residual variations in decedent characteristics across the study areas that influence the observed patterns of service utilisation and costs. It is not possible to isolate fully the influence of different models of service delivery on utilisation and costs and potential sources of bias are highlighted where relevant (e.g., patterns of informal care utilisation suggest higher levels of dependency in the sample of decedents in the South East relative to the Mid West and the Midlands).

- Potential reporting errors in the primary data: Local teams were provided with instructions on how to compile the list of decedents, combining decedents from both community SPC teams and hospital teams within each area. Once this list was compiled, teams were instructed to order the list by date of death, and make contact with KIs in this order. For logistical reasons, there may have been variations in how this list was compiled, and the order in which KIs were contacted.[19] Also given the nature of the service, progress was slower in some areas when the team involved did not have the capacity to make calls during busier periods. As shown in Table 3.3, there was a longer average lead time in the Mid West of seven months between date of death and date of initial contact compared to five months in the South East and the Midlands. There is therefore a risk that the longer period may lead to increased errors in reporting.

- Outliers in the primary data: In some cases there were obvious instances of over-estimation by KIs of utilisation of services, that is, a clearly unrealistic number of visits/hours were reported. These outliers were found to have a large

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[19] Overall, in the South East, there appears to be a higher level of recruitment of decedents who died in hospital and who only received SPC from the in-patient hospital team compared to other areas. Without further details on the proportion of decedents who died in hospital in the South East, it is unclear if this is an accurate reflection of service provision in this area.

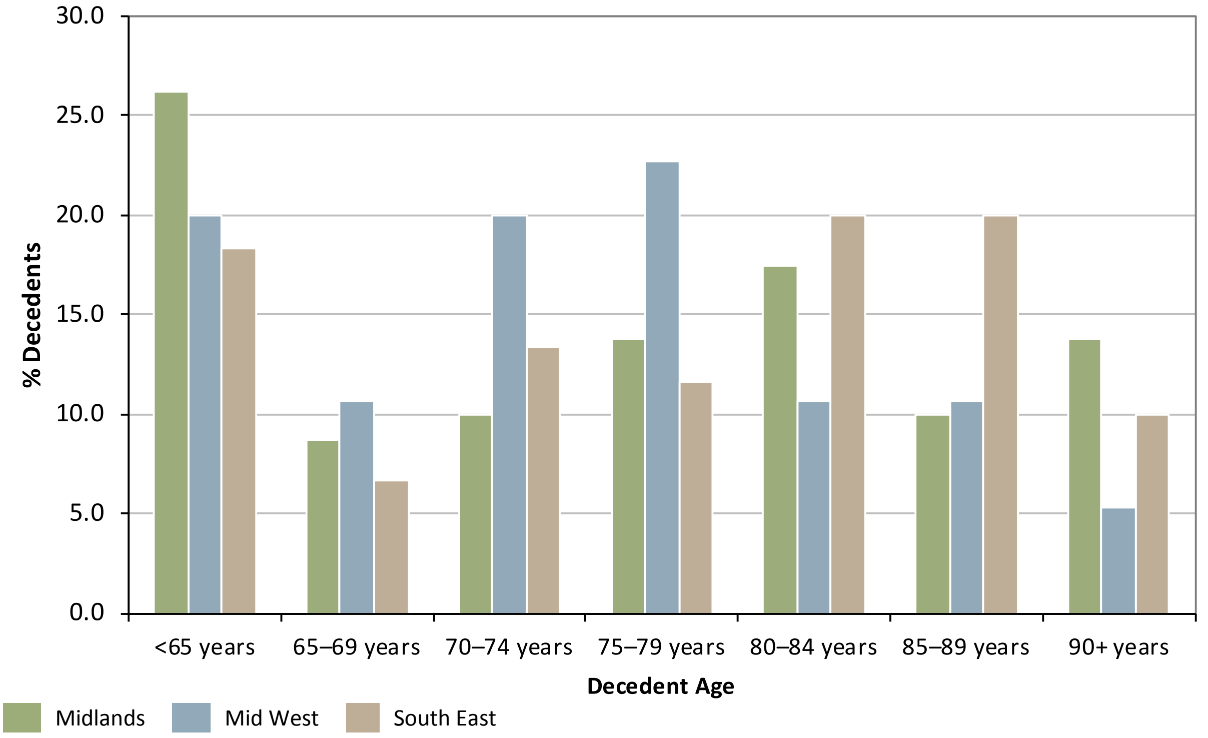
impact on the mean number of visits/hours. To account for this, utilisation data were censored. Observations greater than or equal to the value recorded at the 97th percentile were capped at the next lowest value. The maximum number of cases adjusted was four. The variables affected by the recode were community services and care in the home (see Section 4.2.1).

3.6 Decedent Profile

Demographic and Socioeconomic Characteristics

This section outlines some key demographic and socioeconomic characteristics of the decedents recruited in the study for primary data collection. It is important to identify any systematic differences in decedent characteristics across the three study areas in order not to over-interpret the influence on costs of care and patient experiences of the different methods of delivering specialist palliative care in the three areas. Figure 3.2 presents decedent age by area. The Midlands area had the highest proportion of decedents under the age of 65 years (26.3%) while the South East had the highest proportion over 80 years (50.0%). However, the overall variations in age patterns across the areas were not statistically significant (p=0.215).

FIGURE 3.2 Decedent Age by Area (%)



Note: p = 0.215

Demographic and socioeconomic characteristics are presented in Table 3.8. For example, the proportion of decedents with children under the age of 18 years was highest in the Midlands; this was also the area with the highest proportion of decedents under the age of 65 years.

TABLE 3.8 Demographic and Socioeconomic Characteristics of Decedents by Area

	Midlands		Mid West		South East		Test of Significance	
	N	%	N	%	N	%	Test Statistic[a]	p
Total Number of Interviews Completed	80	100	75	100	60	100		
Nationality, Language, and Religion								
Born in Republic of Ireland	72	90.0	72	96.0	57	95.0	2.602	0.272[b]
English first language	79	98.8	75	100	59	98.3	1.146	0.564[b]
Roman Catholic	76	95.0	72	96.0	57	95.0	0.110	0.946[b]
Children								
Decedent had children <18 years	5	6.3	3	4.0	3	5.0	0.406	0.816[b]
Decedent had children 18 years+	63	78.8	60	80.0	55	91.7	4.644	0.098
Marital Status								
Married	36	45.0	43	57.3	29	48.3	5.994	0.200
Widowed	27	33.8	23	30.7	25	41.7		
Other (including single, separated and divorced)	17	21.3	9	12.0	6	10.0		
Education (Highest Level Attained)								
<= Primary	34	43.0	26	34.7	29	48.3	3.369	0.498
Any secondary	26	32.9	30	40.0	16	26.7		
> Secondary	19	24.1	19	25.3	15	25.0		
Employment Status								
Working for payment or profit	6	7.5	8	10.7	5	8.3	2.317	0.888
Retired from employment	39	48.8	39	52.0	33	55.0		
Looking after home/family	18	22.5	17	22.7	14	23.3		
Other	17	21.3	11	14.7	8	13.3		
Eligibility								
Medical Card	79	98.8	71	94.7	59	98.3	2.767	0.251[b]
Private Health Insurance	23	28.8	34	45.3	23	38.3	4.601	0.100
How well was the decedent managing financially during the last year of their life								
Living comfortably	51	64.6	46	61.3	43	71.7	4.082	0.850[b]
Doing alright	17	21.5	17	22.7	10	16.7		
Just about getting by	9	11.4	7	9.3	4	6.7		
Finding it quite difficult	1	1.3	2	2.7	2	3.3		
Finding it very difficult	1	1.3	3	4.0	1	1.7		

Notes: Missing values are excluded from the calculation of percentages.

a Test statistic= Chi-Squared Test

b >20% of cells have an expected cell count less than 5 making the result unreliable.

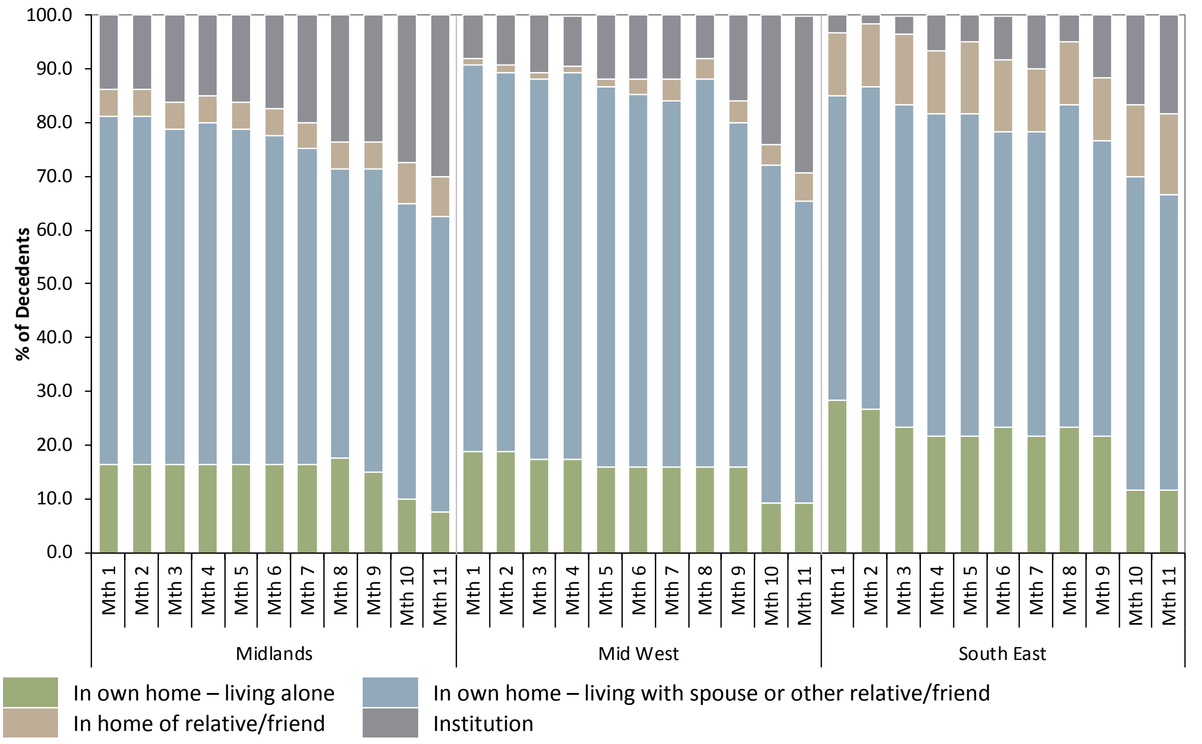
Living Pattern – Month 1 to Month 11

Given the focus in this study on the utilisation and cost patterns of a range of institutional, community and informal care, it is important to take into account the variations in living patterns for the decedents to better inform the results. Figure 3.3 outlines where the decedent was living in each month of the last year of life (excluding episodes in hospital or other institution lasting less than 4 weeks) up until the eleventh month in that year (location of death is addressed in 4.5.2 as a specified outcome measure of the study).

In the first month of the last year of life, the South East had the highest proportion of decedents living alone (28.3%) and the lowest proportion living in an institution (3.3%) relative to the other two areas. In the last months of life, similar proportions of decedents across areas were living in their own homes with their spouses and/or others (55–56%), but a lower proportion of decedents were in an institution in the South East (18.3%) compared to the other areas (Midlands 30.0%, Mid West 29.3%). The proportion of decedents living alone in month 11 was again highest in the South East (11.7%) compared to the other two areas (Midlands 7.5% and Mid West 9.3%).

Between 56.0% (Mid West) and 62.5% (Midlands) of decedents did not move (e.g., from home to an institution, or from living alone to living with a relative) during the first 11 months of the last year of life.

FIGURE 3.3 Decedent Living Pattern in the Last Year of Life (Month 1 to Month 11) by Area

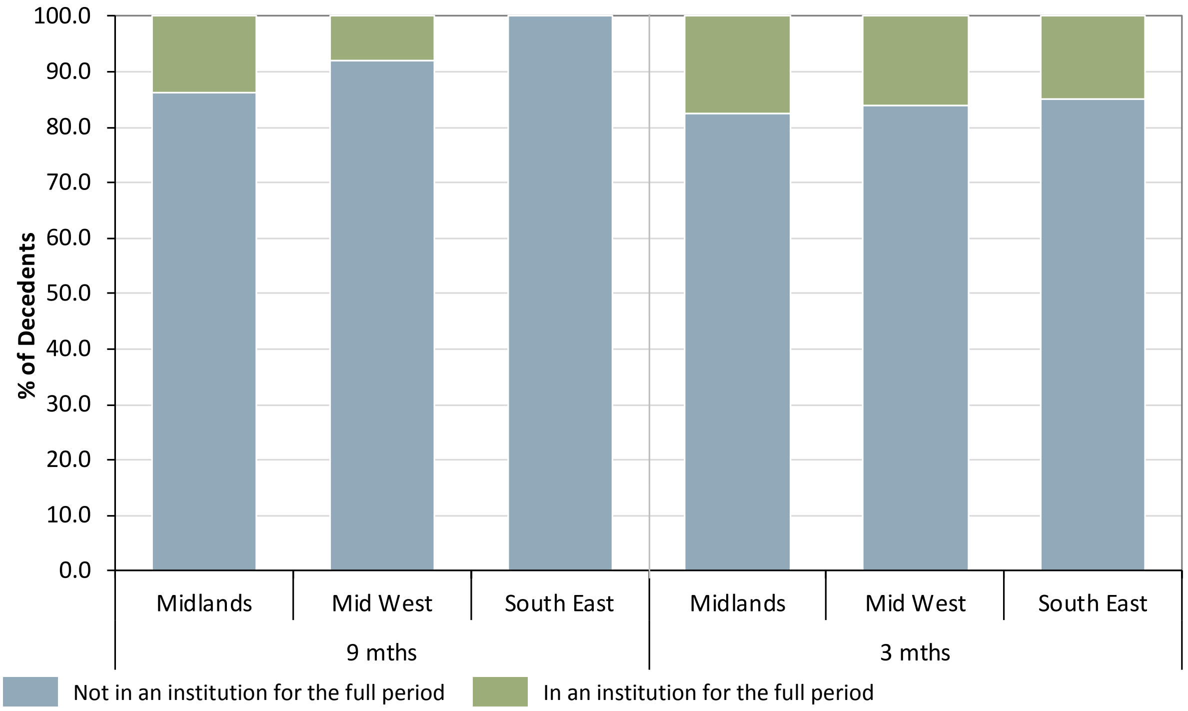


Note: Missing values are excluded from the calculation of percentages.

Living Pattern – Institution[20]

Figure 3.4 shows that the proportion of decedents living in an institution varied significantly across areas in the first nine months of the last year of life (p=0.012). There was a higher proportion of decedents living in an institution in the Midlands (13.8%) over the nine-month period compared to the Mid West (8.0%) and the South East (0.0%). There was an increase in the proportion of decedents living in an institution in the last three months of life (p<0.001 in the Mid West and Midlands) but there was no significant variation across the three areas (0.921).

FIGURE 3.4 Decedent Living Pattern – Living in an Institution



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[20] An institution refers to a hospital, nursing home, hospice or other long term care facility.

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4

Results

4.1 Introduction

This section presents the findings relating to each of the study objectives. Before showing the variations in costs of care and patient experiences across the study areas, Section 4.2 outlines the service utilisation patterns over the last year of life for decedents recruited in the study. Use of informal care by the same sample of decedents is presented in Section 4.3.

Findings on objectives 1 and 2 are presented in Section 4.4, outlining formal and informal care costs per decedent in receipt of SPC over the last year of life in each of the three study areas. Findings on objective 3 are outlined in Section 4.5, describing specified outcomes per patient in receipt of SPC in the last year of life in each of the three study areas. Findings on objective 4 are outlined in Section 4.6. Other issues surrounding death are covered in Section 4.7.

Missing values are excluded from percentage calculations. The p-values[1] for statistical testing (Pearson's Chi-Square test,[2] ANOVA,[3] and paired samples t-tests[4] where appropriate) of utilisation/costs across areas and across time periods are provided in brackets where relevant. The use of the term significant in the text implies statistical significance.

It is important to note that the study is concerned with total healthcare utilisation/costs over the last year of life of decedents and not just utilisation/costs of services provided exclusively by SPC services.

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[1] P-values are deemed significant if $p<0.1$.

[2] Pearson's chi-square test is used to determine if, across the three areas, there is a significant relationship in the proportions of decedents who used a service in each of the time periods. The test is also used to determine if, within each area, there is a relationship between the proportion of decedents who used a service in the nine-month period compared to the three-month period.

[3] ANOVA is used to determine if there are any significant differences in the mean number of visits/admissions across the three areas in the first nine months of the last year of life and the last three months of life.

[4] Paired samples t-test is used to determine if, within each area, there is a significant difference in the mean number of visits/admissions for those using a service in both the nine-month and the three-month periods.

4.2 Formal Care Utilisation

The following section presents the results on formal care utilisation for the sample of decedents recruited into the study as reported by the KIs in the interviews.[5] In each case the KI reported whether or not the decedent received the service. If the decedent received the service in question ('service user') they were asked to recall the number of visits in the first nine months of the last year of life and the number in the last three months of life. **The mean and median level of utilisation is presented for all decedents and for those that used the service. The median is reported in order to highlight the effect of any remaining outliers in the data. In the majority of cases the median is less than the mean, suggesting that in these cases there are small numbers of intensive users.** The discussion in the text refers to the mean level of utilisation by service users only. The mean and median values are calculated on a per month basis for ease of comparison of utilisation across the nine-month and three-month time periods.

4.2.1 Community Care

This section outlines community care utilisation by the decedents as reported by the KI during their last year of life for each study area. As the KIs were unable to differentiate whether the service was provided by the SPC community team and/or other healthcare providers, the service utilisation data reflect provision by all healthcare providers. For example, if an OT was not part of the SPC community team, this does not mean that decedents in the area did not receive occupational therapy. Decedents may have had OT visits privately or through primary care teams.

Community care utilisation is broken down by type of care and time period within the last year of life (first nine months and last three months in the last year of life). The proportion of decedents receiving community care across each area is presented in Figures 4.1, and 4.2. For each type of community care the mean and median number of visits/hours for total decedents and for only those using the services ('service users') in the time period are presented in Figures 4.1 and 4.3.

Types of community care are grouped into general practitioner (GP), public health nurse (PHN), pastoral care, allied health professionals, and other help at home. For a selection of services (GP, PHN, and pastoral care), data on the number of phone consultations made by or on behalf of the decedent were

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[5] For decedents for whom permission was given to access formal medical records, public hospital day patient and in-patient utilisation were retrieved from the HIPE system and are reported on in lieu of the KI reported visits. For the eight KIs who did not grant permission to access records, utilisation reported by the KIs during the interview are included. See Appendix 4.2 for a comparison of KI reported and HIPE reported admissions.

collected in addition to the number of visits. Phone consultations refer to the decedent or someone on their behalf having a consultation over the phone; they exclude calls to make an appointment or to get test results. Questions on community care were asked to all KIs, including cases where the decedent had been living in an institution.

GP

Visits The proportion of decedents using GP services was high in all areas relative to other community services in both the first nine months and last three months of the last year of life. The fall in the proportion using GP services in the last three months of life could be explained by the movement of some decedents from home to institutional care (e.g., hospital, nursing home, hospice, or other long term care facility) as observed in Figure 3.3.

Nine months	Proportion 94.5% of decedents in the South East had GP visits compared to 91.9% in the Midlands, and 91.5% in the Mid West; this variation across areas is not statistically significant (p=0.793). Service User Visits Decedents had a mean of one GP visit per month in all areas; variation across areas is not statistically significant (p=0.764).
Three months	Proportion The proportion having GP visits decreased relative to the nine-month period in all areas to 85.5% of decedents in the South East, 83.8% in the Midlands, and 83.3% in the Mid West; this variation across areas is not statistically significant (p=0.945). Service User Visits Decedents had a higher number of GP visits per month in the three-month period relative to the nine-month period in all areas with a mean of between 2.5 (Mid West and South East) and 2.7 (Midlands) visits per month; variation across areas is not statistically significant (p=0.868).
Difference	Proportion There is a significant relationship between the proportion of decedents having GP visits in the nine-month period and the proportion having GP visits in the three-month period in the Midlands (p=0.001) and Mid West (p=0.001). That is, within both study areas, a GP service user in the nine-month period was significantly more likely than a non-GP service user to have a GP visit in the three-month period. The relationship is not statistically significant in the South East (p=0.452), but >20% of the cells in each area have an expected count of less than 5 making these results unreliable. Service User Visits The difference in the mean number of visits GP visits between the nine-month and the three-month periods is statistically significant in each area (p<0.001 in all areas).

Phone Consultations The proportion of decedents having phone consultations with the GP was lower than the proportion having visits in both the nine-month and three-month periods.

Nine months	Proportion 38% of decedents in the Mid West and South East had phone consultations with the GP compared to 32.9% in the Midlands; variation across areas is not statistically significant (p=0.761). Service User Consultations Decedents had a mean of 1.1 GP phone consultations per month in the Mid West compared to 0.9 consultations per month in the Midlands and 0.8 consultations per month in the South East; variation across areas is not statistically significant (p=0.718).
Three months	Proportion The proportion having phone consultations with the GP decreased relative to the nine-month period in the Mid West (34.7%) and increased in the Midlands (36.5%) and South East (49.1); variation across areas is not statistically significant (p=0.214). Service User Consultations Decedents had a mean of 2.2 GP phone consultations per month in the Mid West, compared to 1.5 in the Midlands and 1.3 in the South East; variation across areas is not statistically significant (p=0.112).
Difference	Proportion The relationship between the proportion of decedents having phone consultations with the GP in the nine-month period and the proportion having GP phone consultations in the three-month period is statistically significant in all areas (p<0.001 in the Midlands and Mid West; p=0.009 in the South East). Service User Consultations The difference in the mean number of GP phone consultations between the nine-month and the three-month periods is statistically significant in all areas (Midlands p=0.001, Mid West p<0.001, South East p=0.025).

PHN

Visits A high proportion of decedents had visits with PHNs. Utilisation of visits was higher in the last three months than in the first nine months of the last year of life.

Nine months	Proportion 55.7% of decedents in the Mid West had PHN visits, followed by 61.6% in the Midlands, and 61.8% in the South East; variation across areas is not statistically significant (p=0.712). Service User Visits Decedents had a mean of 1.6 PHN visits per month in the South East compared to 1.8 in the Mid West and 2.5 in the Midlands; variation across areas is not statistically significant (p=0.350).

Three months	**Proportion** The proportion having PHN visits increased relative to the nine-month period in all areas to 64.8% in the Mid West, 71.7% in the South East, and 72.2% in the Midlands; variation across areas is not statistically significant (p=0.573). **Service User Visits** Decedents had a higher number of PHN visits per month in the three-month period relative to the nine-month period in all areas with a mean of 3.0 visits per month in the South East, 4.0 visits per month in the Mid West, and 5.7 visits per month in the Midlands; variation across areas is statistically significant (p=0.017).
Difference	**Proportion** The relationship between the proportion of decedents having a PHN visit in the nine-month period and the proportion having a PHN visit in the three-month period is statistically significant in the Midlands (p=0.013) and the Mid West (p=0.049) but not in the South East (p=0.141). **Service User Visits** The difference in the mean number of PHN visits between the nine-month and three-month periods is statistically significant in all areas (p<0.001 in all areas).

Phone Consultations The proportion of decedents having phone consultations with the PHN was much lower than the proportion having visits in both the nine-month and three-month periods.

Nine months	**Proportion** 15.5% of decedents in the Midlands reported phone consultations with the PHN compared to 20.0% in the South East, and 20.3% in the Mid West; variation across areas is not statistically significant (p=0.721). **Service User Consultations** Decedents had a mean of 0.3 PHN phone consultations per month in the South East and 0.8 consultations per month in the Midlands and Mid West; variation across areas is not statistically significant (p=0.388).
Three months	**Proportion** The proportion having phone consultations increased relative to the nine-month period in all areas to 31.0% in the Midlands, 32.9% in the Mid West, and 35.7% in the South East; variation across areas is not statistically significant (p=0.853). **Service User Consultations** Decedents had a higher number of PHN phone consultations per month in the three-month period relative to the nine-month period in all areas with a mean of 1.9 in the Mid West and South East, and 3.0 in the Midlands; variation across areas is not statistically significant (p=0.298).
Difference	**Proportion** The relationship between the proportion of decedents utilising PHN phone consultations in the nine-month period and the proportion using this service in the three-month period is statistically significant in the Midlands (p<0.001), Mid West (p<0.001) and in the South East (p=0.005), but >20% of the cells in each area have an expected count of less than 5 making the results unreliable. **Service User Consultations** The difference in the mean number of PHN phone consultations between the nine-month and the three-month periods is significant in all areas (Midlands p=0.004, Mid West p<0.001, South East p=0.005).

Pastoral Care

Visits [6] – Pastoral care visits include visits by priests; pastoral carers are not necessarily part of the SPC team.[7] Utilisation of pastoral care visits was higher in the last three-months than in the first nine-months of the last year of life in all three areas. Similarly the number of visits also increased across the periods.

Nine months	Proportion 50% of decedents in all three areas had pastoral visits; with no variation reported across the areas (p=0.993). Service User Visits Decedents had a mean of 2.0 pastoral care visits per month the Midlands compared to 1.7 visits in the South East, and 1.6 visits in the Mid West; variation across areas is not statistically significant (p=0.727).
Three months	Proportion The proportion having pastoral care visits increased relative to the nine-month period in all areas to 59.3% of decedents in the South East, 68.2% in the Mid West and 71.6% in the Midlands; this variation across areas is not statistically significant (p=0.325). Service User Visits Decedents had a higher number of pastoral care visits per month in the three-month period relative to the nine-month period in all areas with a mean of 3.1 visits per month the Mid West, and 4.0 visits per month in the Mid West and South East; variation across areas is not statistically significant (p=0.654).
Difference	Proportion The relationship between the proportion of decedents having pastoral care visits in the nine-month period and the proportion having pastoral care visits in the three-month period is statistically significant in all areas (Midlands p=0.012; Mid West p<0.001; South East p<0.001). Service User Visits The difference in the mean number of pastoral care visits between the nine-month and the three-month periods in each area is statistically significant in each area (Midlands p=0.005, Mid West p<0.001, South East p=0.001).

Allied Health Professionals and Day Centre

Data on the utilisation by the decedents of various allied health professional services and day centres was collected during the interviews with the KIs.[8] These data include any visits by/to any allied health professional some of which may have been provided by the SPC team in the community. It should be noted that

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[6] Questions were also asked for phone consultations to and from the pastoral carer but as the number of users was so small (maximum 11.9% in the South East) the responses are not reported.

[7] While it is recognised that the nature of the visit from a pastoral carer may differ depending on whether the decedent had a visit from a pastoral carer from the SPC team or from the community, the questionnaire did not differentiate between these. While this is a potentially important issue in terms of providing a coherent package of palliative care, from the point of view of costs (see Section 4.4) the total amount is small and is therefore not material in resource terms.

[8] To avoid over-crowding the graph, utilisation of particular services (psychologist, psychiatrist, day centre, social worker) is not included in Figure 4.1 where the proportion of decedents utilising the service is less than 10% in both the first nine months and the last three months of life. All service utilisation is accounted for in the costs.

any visits by/to allied health professionals while an in-patient in hospital, hospice, or attending a day care service are not included here. This means for example, that in the Mid West where there is a palliative day care centre and in-patient hospice facility in which these AHP services are also provided, these AHP consultations are not captured in the utilisation data presented in this section.[9] The most highly utilised services across the last year of life, as reported by the KI and discussed below, were chiropody, occupational therapy, physiotherapy, and dietician. Although complementary therapies were not used by large proportions of decedents, those who did avail of them used them relatively intensively (2–3 visits per month).

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[9] An analysis of utilisation of allied health professional services while attending Milford Care Centre specialist palliative day care or as an in-patient is available in Appendix 4.4.2.

Chiropody (CHIR)	Occupational Therapy (OT)	Physiotherapy (PHY)	Dietician (DIET)
Nine months			
Proportion 41.6% of decedents in the Midlands had CHIR visits, followed by 35.0% in the South East, and 25.7% in the Mid West; variation across areas is not statistically significant (p=0.129). Service User Visits Decedents had a mean of 0.5 CHIR visits per month in the Mid West compared to approximately 0.4 in the Midlands and South East; variation across areas is not statistically significant (p=0.461).	Proportion 27.1% of decedents in the South East, 26.8% in the Midlands, and 16.7% in the Mid West had OT visits; variation across areas is not statistically significant (p=0.255). Service User Visits Decedents had a mean of approximately 0.5 OT visits per month in the Midlands and South East compared to 0.2 in the Mid West; variation across areas is not statistically significant (p=0.398).	Proportion 25.7% of decedents in the Midlands and approximately 15% in the Mid West and South East had PHY visits; variation across areas is not statistically significant (p=0.181). Service User Visits Decedents had a mean of 1 PHY visit per month in the South East compared to 0.8 in the Midlands and 0.3 in the Mid West; variation across areas is not statistically significant (p=0.383).	Proportion 15.3% of decedents in the Mid West and 11% in the Midlands, and 8.5% in the South East had DIET visits; variation across areas is not statistically significant (p=0.468). Service User Visits Decedents had a mean of 0.5 DIET visits per month in the Midlands and South East compared to 0.2 in the Mid West; variation across areas is not statistically significant (p=0.182).
Three months			
Proportion The proportion having CHIR visits decreased relative to the nine-month period in all areas to 23.4% in the Midlands, 18.6% in the South East, and 18.3% in the Mid West; variation across areas is not statistically significant (p=0.696). Service User Visits Decedents had a higher or equal number of CHIR visits per month in the three-month period relative to the nine-month period in all areas with a mean of 0.6 visits per month in the Midlands and 0.5 visits per month in the Mid West and South East; variation across areas is not statistically significant (p=0.860).	Proportion The proportion having OT visits increased relative to the nine-month period to 32.9% in the Midlands and 22.2% in the Mid West, and decreased to 24.6% in the South East; variation across areas is not statistically significant (p=0.328). Service User Visits Decedents had a higher number of OT visits per month in the three-month period relative to the nine-month period in all areas with a mean of 0.8 visits per month in the Midlands and Mid West and 0.9 visits per month in the South East and Midlands; variation across areas is not statistically significant (p=0.877).	Proportion The proportion having PHY visits decreased relative to the nine-month period in all areas to 21.6% in the Midlands, 13.9% in the Mid West, and 6.9% in the South East; variation across areas is statistically significant (p=0.058).[10] Service User Visits Decedents had a higher number of PHY visits per month in the three-month period relative to the nine-month period in all areas with a mean of 1.5 visits per month in the Midlands, 1.3 visits per month in the South East, and 0.9 visits per month in the Mid West; variation across areas is not statistically significant (p=0.564).	Proportion The proportion having DIET visits decreased or remained the same relative to the nine-month period in all areas to 11% in the Midlands, 4.2% in the Mid West, and 3.4% in the South East; variation across areas is statistically significant (p=0.133). Service User Visits Decedents had a higher number of DIET visits per month in the three-month period relative to the nine-month period in all areas with a mean of approximately 0.8 visits per month in all areas; variation across areas is not statistically significant (p=0.989).

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[10] It is important to reiterate that decedents may have been receiving these services while an in-patient in hospital, hospice, or attending a day care service. Details of palliative care personnel available across the different settings are available in Table 4.2 and in Table A3.3 in Appendix 3. It is also important to reiterate that the activity captured refers any visits by/to allied health professionals and not only those provided by the SPC team.

Chiropody (CHIR)	Occupational Therapy (OT)	Physiotherapy (PHY)	Dietician (DIET)
Difference			
Proportion The relationship between the proportion of decedents utilising CHIR services in the nine-month period and the proportion using CHIR services in the three-month period is statistically significant in the Midlands (p=0.003), Mid West (p<0.001) and South East (p<0.001) but for the latter two areas >20% of the cells have an expected count of less than five making the results unreliable. Service User Visits The difference in the mean number of CHIR visits between the nine-month and the three-month periods is not statistically significant in any of the three areas (Midlands p=0.500, Mid West p=0.991, South East p=0.944).	Proportion The relationship between the proportion of decedents having OT visits in the nine-month period and the proportion having OT visits in the three-month period is statistically significant in the Midlands (p=0.032), and not significant in the Mid West (p=0.178) and South East (p=0.464) but for the latter two areas >20% of the cells have an expected count of less than five making the results unreliable. Service User Visits The difference in the mean number of OT visits between the nine-month and three-month periods is statistically significant in the Mid West (p=0.009) and South East (p=0.058) but not in the Midlands (p=0.397).	Proportion The relationship between the proportion of decedents having PHY visits in the nine-month period and the proportion having PHY visits in the three-month period is not statistically significant in the Mid West (p=0.112) and Midlands (p=0.564) and is statistically significant in the South East (p=0.048) but in each area >20% of the cells have an expected count of less than 5 making the results unreliable. Service User Visits The difference in the mean number of PHY visits between the nine-month and three-month periods is statistically significant in the Mid West (p=0.050) and South East (p=0.090) but not in the Midlands (p=0.183).	Proportion The relationship between the proportions of decedents having DIET visits in the nine-month period and the proportion having DIET visits in the three-month period is not statistically significant in the South East (p=0.662) and is significant in the Midlands (p=0.011) and Mid West (p<0.001) but in each area >20% of the cells have an expected count of less than five making the results unreliable. Service User Visits The difference in the mean number of DIET visits between the nine-month and the three-month periods is statistically significant in the Mid West (p=0.089) but not in the Midlands (p=0.237).[11]

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[11] Paired t-statistic could not be calculated for the South East due to too few paired observations.

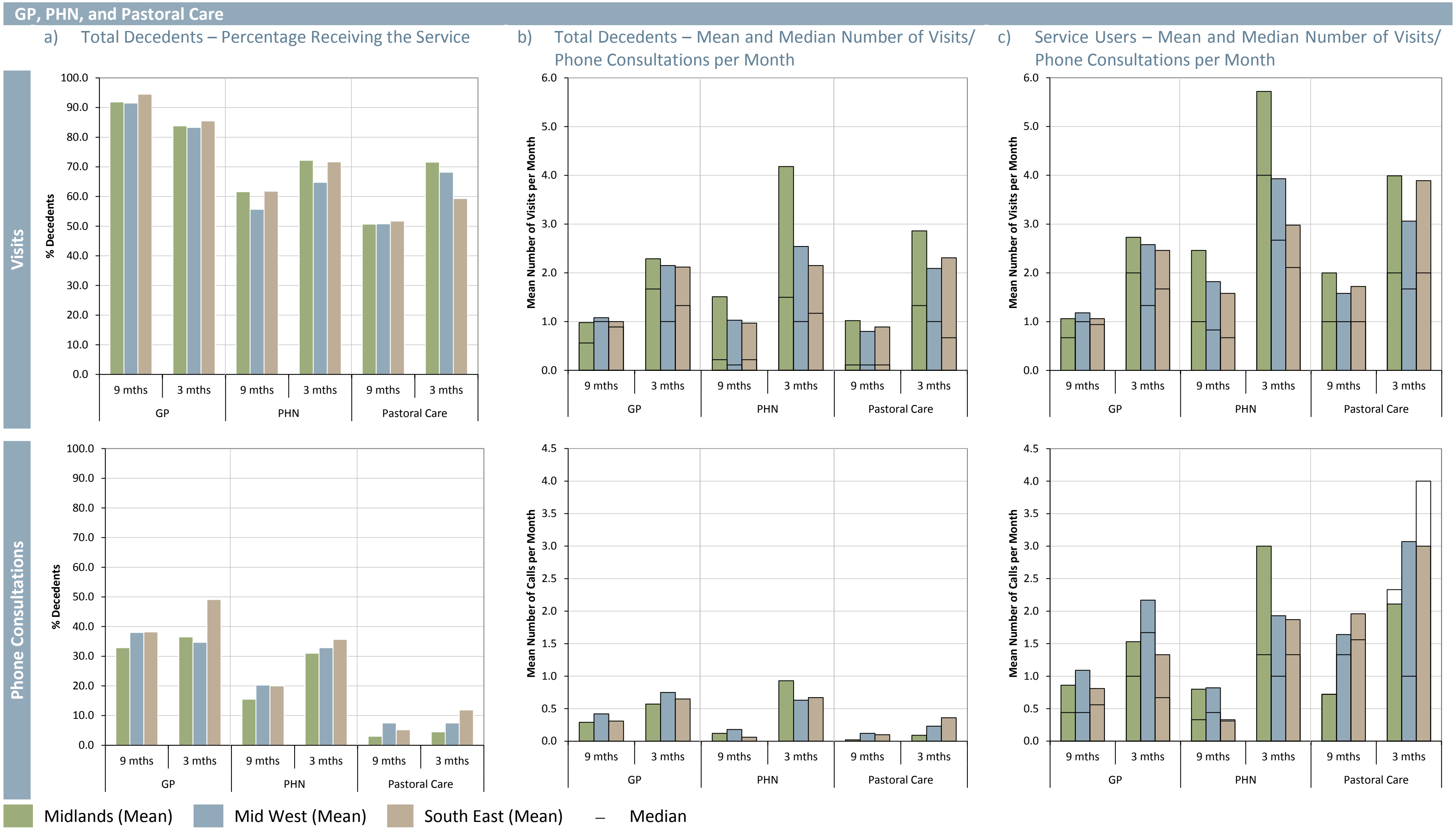


FIGURE 4.1 Utilisation of GP, PHN, Pastoral Care, and Allied Health Professional Services by Type of Care, Time Period, and Area

GP, PHN, and Pastoral Care

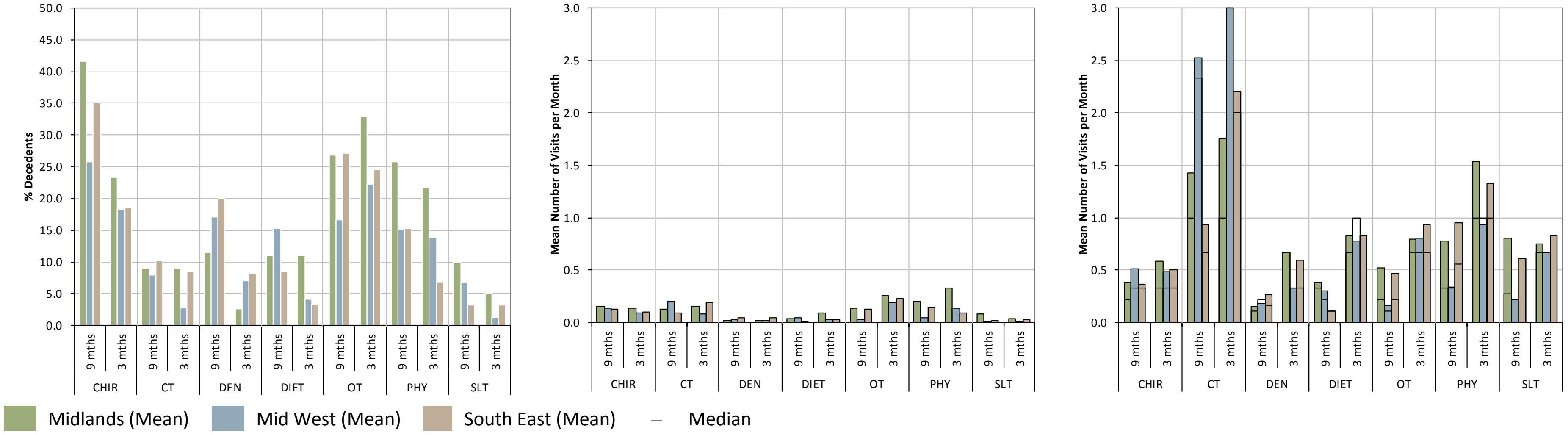
a) Total Decedents – Percentage Receiving the Service

b) Total Decedents – Mean and Median Number of Visits/ Phone Consultations per Month

c) Service Users – Mean and Median Number of Visits/ Phone Consultations per Month

Figure 4.1 Utilisation of GP, PHN, Pastoral Care, and Allied Health Professional Services by Type of Care, Time Period, and Area (contd.)

Allied Health Professionals



a) Total Decedents – Percentage Receiving the Service

b) Total Decedents – Mean and Median Number of Visits per Month

c) Service Users – Mean and Median Number of Visits per Month

Notes: CHIR = chiropody, CT = complementary therapy, DEN = dentist, DIET = dietician, OT = occupational therapy, PHY = physiotherapy, SLT = speech and language therapy
Missing values are excluded from the calculation of percentages.

Home Help, Health Care Assistant, and Formal Paid Helper

In the questionnaire the KIs were asked if the decedent had received any formal paid help in the home during the last year of their life.[12] These questions captured utilisation of home help care, health care assistants, and other formal paid help (e.g., a nurse).[13] Figure 4.2 shows the proportion of decedents who used these services during the last year of life by area. Figure 4.3 presents the mean and median number of hours per week for total decedents and service users across the total weeks in the period and specifically for the weeks in which the service was used, referred to as 'care weeks'. Only the mean number of hours per care week for service users will be discussed in the text.

Home Help The most utilised paid help across all areas was home help.

Nine months	Proportion Approximately 28% of decedents in the Mid West and South East had home help visits, compared to 11.3% in the Midlands; variation across areas is statistically significant (p=0.015). Service User Visits – Mean Hours – Care Weeks Decedents had a mean of 5.9 hours of home help per week in the Midlands compared to 5.4 hours per week in the Mid West and 4.3 in the South East; variation across areas is not statistically significant (p=0.473).
Three months	Proportion The proportion receiving home help visits increased relative to the nine-month period in all areas to 35.0% in the South East, 29.3% in the Mid West, and 18.8% in the Midlands; variation across areas is statistically significant (p=0.085). Service User Visits – Mean Hours – Care Weeks Decedents had a higher number of home help hours per week in the three-month period relative to the nine-month period in all areas with a mean of 6.7 hours per week in the Midlands and 6.1 in the Mid West and South East; variation across areas is not statistically significant (p=0.935).
Difference	Proportion The relationship between the proportion of decedents utilising the home help service in the nine-month period and the proportion utilising the service in the three-month period is significant in the Midlands, Mid West and South East (p<0.001) but in the Midlands >20% of the cells have an expected count of less than five making the result unreliable. Service User Visits – Mean Hours – Care Weeks The difference in the mean number of home help hours between the nine-month and three-month periods is not significant in the Mid West (p=0.117) or South East (p=0.129) but is significant in the Midlands (p=0.091).

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[12] During the course of the interviews it became clear that a small number of families employed a formal paid helper to be with and assist the decedent in a nursing home or other institution. This is not captured in the study.

[13] Questions were also asked about meals-on-wheels, but as the proportion of users was so small (<5% in all areas) the responses are not reported.

Health Care Assistant A lower proportion of decedents used health care assistants over the period when compared to home help.

Nine months	Proportion 10.0% of decedents in the South East had health care assistant visits, compared to 7.5% in the Midlands and 4.0% in the Mid West; variation across areas is not statistically significant (p=0.386). Service User Visits – Mean Hours – Care Weeks Decedents had a mean of 10.5 health care assistant hours per week in the Mid West compared to 7.3 hours per week in the South East, and 5.8 in the Midlands; variation across areas is not statistically significant (p=0.515).
Three months	Proportion The proportion receiving health care assistant visits increased relative to the nine-month period in all areas to 6.7% in the Mid West, 11.3% in the Midlands, and 13.3% in the South East; variation across areas is not statistically significant (p=0.416). Service User Visits – Mean Hours – Care Weeks Decedents had a higher number of health care assistant hours per week in the three-month period relative to the nine-month period in the South East (mean of 8.4 hours per week) and the Midlands (mean of 7.4 hours per week), and a lower number in the Mid West (mean of 6.9 hours per week); variation across areas is not statistically significant (p=0.943).
Difference	Proportion The relationship between the proportion of decedents utilising the health care assistant service in the nine-month period and the proportion using the service in the three-month period is significant in all three areas (p<0.001) but in each area >20% of the cells have an expected count of less than five making the results unreliable. Service User Visits – Mean Hours – Care Weeks The difference in the mean number of health care assistant hours between the nine-month and three-month periods is not statistically significant in either the South East (p=0.391) or the Midlands (p=0.374).[14]

Formal Paid Help

Nine months	Proportion 11.7% of decedents in the South East had formal paid help visits, compared to 8.0% in the Mid West and 6.3% in the Midlands; variation across areas is not statistically significant (p=0.514). Service User Visits – Mean Hours – Care Weeks Decedents had a mean of 28.2 formal paid help hours per week in the South East compared to 18.0 hours per week in the Midlands, and 3.9 in the Mid West; variation across areas is not statistically significant (p=0.569).

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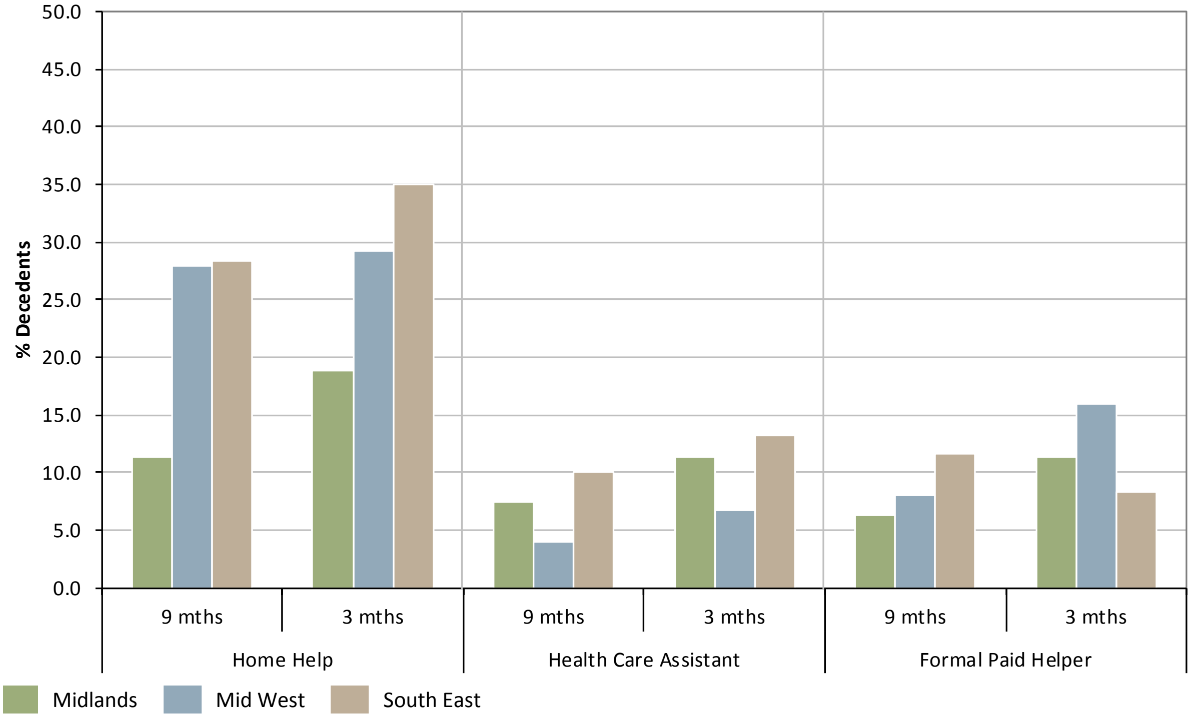
[14] Paired t-statistic could not be calculated for the Mid West due to too few paired observations.

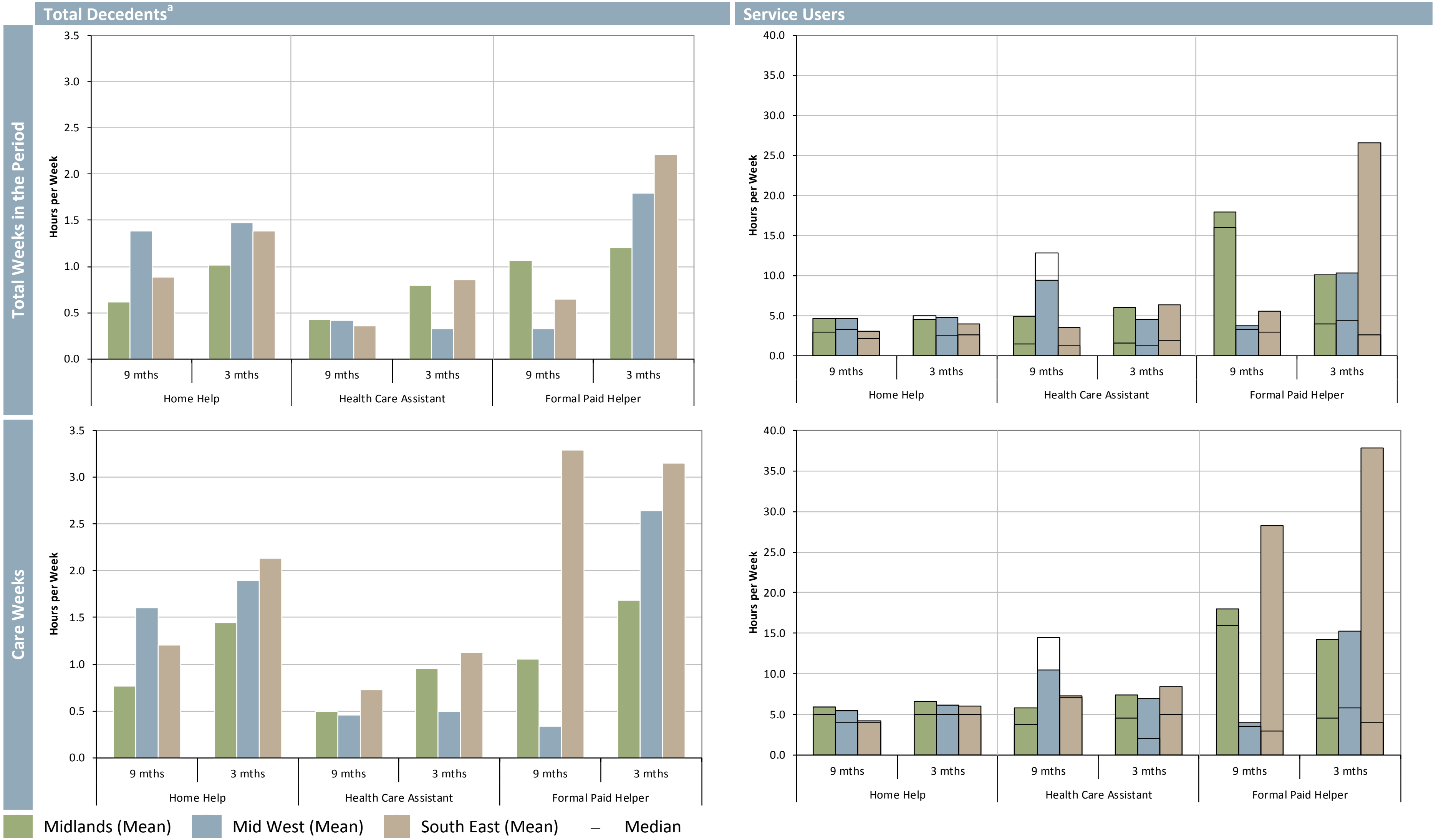
Three months	Proportion The proportion receiving formal paid help visits increased relative to the nine-month period in the Mid West to 16.0% and to 11.3% in the Midlands, and decreased to 8.3% in the South East; variation across areas is statistically significant (p=0.381). Service User Visits – Mean Hours – Care Weeks Decedents had a higher number of formal paid help hours per week in the three-month period relative to the nine-month period in the South East (mean of 37.8 hours per week) and Mid West (mean of 15.2 hours per week), and fewer hours in the Midlands (mean of 14.3 hours per week); variation across areas is not statistically significant (p=0.439).
Difference	Proportion The relationship between the proportion of decedents utilising formal paid help in the nine-month period and the proportion using the service in the three-month period is significant in all three areas (p<0.001) but in each area >20% of the cells have an expected count of less than five making the results unreliable. Service User Visits – Mean Hours – Care Weeks The difference in the mean number of formal paid help hours between the nine-month and three-month periods is not significant in any of the three areas (Midlands p=0.262, Mid West p=0.363, South East p=0.554).

FIGURE 4.2 Utilisation of Home Helps, Health Care Assistants, and Formal Paid Helpers by Type of Care, Time Period, and Area



Note: Missing values are excluded from the calculation of percentages.

FIGURE 4.3 Mean and Median Number of Hours of Home Help, Health Care Assistance, and Formal Paid Help per Week by Type of Care and Duration of Care



Notes: a Median values are not presented for total decedents as they are mostly equal to zero.
Missing values are excluded from the calculation of percentages.
Decedents who lived in an institution for the full 12 months are excluded.
Mean total weeks in the period: The mean number of hours per week calculated across the full year.
Mean Care Weeks: The mean number of hours per week calculated across the number of weeks care was used.

Community Care Summary

- Almost all decedents had visits from/with a GP in the first nine months of the last year of life. In the last three months of life the proportion having visits decreased by approximately 10% in each area. This may be due to the increased use of community SPC nurses and PHNs in the last three months of life, suggesting that in the end-of-life period there is a tendency for SPC services to take the place of other healthcare providers. For those continuing to receive GP visits, the mean number of visits more than doubled in each area.
- High proportions of decedents received visits from PHNs in the last three months of life. Variation in the mean number of visits across the three areas is statistically significant in the three-month period. Decedents in the Midlands received almost twice the mean number of PHN visits of decedents in the South East in the three-month period.
- The utilisation of allied health professionals in the Mid West is underestimated as many visits took place during day centre, palliative day centre, or hospice stays and were not recorded.
- Of the four most widely used of the allied health professionals (chiropody, occupational therapy, physiotherapy, and dietician) occupational therapy is the only case in which there was an increase in the proportion of decedents using the service in the last three months of life (in the Midlands and the Mid West).
- The proportion of decedents using complementary therapies was low but those who did avail of them used them relatively intensively.
- The most widely utilised paid help in the home across all areas was home help. The proportion of decedents reported as having received home help was lower in the Midlands compared to the other areas.

4.2.2 Specialist Palliative Care

Palliative Care Service Composition in the Midlands, Mid West and South East

For each of the three study areas a service profile was compiled to assist with the interpretation of the interview data (see Appendix 3). The service profile was divided into three main sections: infrastructure, personnel, and service description.

(i) Infrastructure – an outline of the palliative care infrastructure available in the area:

- community care
- in-patient care (hospital and hospice)
- day patient care (hospital and hospice)
- outpatient care (hospital and hospice)
- palliative care support beds (level 2 beds)[15]

(ii) Personnel – an outline of the type of personnel available in each aspect of the palliative care service in the area including their availability and the particular role of the consultant.

(iii) Service description – a detailed description of the community SPC service in each area including the referral process; assessment procedure; assessment outcome; availability and coordination of services; record keeping; nursing shifts and out-of-hours service availability; protocol at death; and follow-up and bereavement services.

It is important to refer to the service profiles in Appendix 3 when comparing service utilisation across the three areas. In addition to true differences in the number of visits/phone consultations made, differences may also arise for two reasons:

1) Care Setting – Decedents may have used a particular service, e.g. occupational therapy, within different care settings, some of which were not captured in the data. To illustrate, occupational therapy visits that occurred in the home, in an outpatient setting, or healthcare centre whether provided by the SPC team or not were captured, while visits that occurred while an in-patient in hospital or hospice, or while visiting a day care facility, were not captured.[16]

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[15] 'Palliative care support beds are non-specialist beds, generally located in community hospitals or nursing homes, which provide an alternative to admission to an acute hospital. In some regions, patients availing of these beds have the active support of the community specialist palliative care nursing team; however, their medical care normally falls under the remit of a G.P. or medical officer rather than a consultant in palliative medicine' (Irish Hospice Foundation, 2013 p20).

[16] All areas recorded visits in day care centres, while the Mid West is the only region that has a dedicated specialist palliative day care centre.

TABLE 4.1 SPC Care Settings by Study Area

	Midlands	Mid West	South East
Community SPC	✓	✓	✓
SPC In-Patient Care (Hospital)	✓	✓	✓
Palliative Care Support Beds (Hospital/ Community/Long Stay Unit)[a]	✓		✓
SPC In-Patient Care (Hospice)		✓	[b]
SPC-Day Patient Care (Hospital/Hospice)		✓	
SPC-Out Patient Care (Hospice/Hospital)	✓	✓	✓

Notes: Further details on SPC settings by study area are available in Table A3.1 in Appendix 3.

a Palliative care support beds are non-specialist beds, generally located in community hospitals or nursing homes, which provide an alternative to admission to an acute hospital. In some regions, patients availing of these beds have the active support of the community specialist palliative care nursing team; however, their medical care normally falls under the remit of a G.P. or medical officer rather than a consultant in palliative medicine (Irish Hospice Foundation, 2013 p20)

b There are two dedicated hospice beds in Waterford Regional Hospital.

2) Personnel – As advised in the National Advisory Committee on Palliative Care Report (DoHC, 2001) each area should have a comprehensive SPC service to meet the needs of patients and families in the area. SPC teams are split amongst the various care settings that are available in each area, shown in Table 4.2. The NACPC recommends that all healthcare professionals should be able to access advice and support from SPC service providers when required. There are specific targets set out in relation to the number and type of staff that should be available across the different care settings. For instance, the composition of the SPC teams in the community should, depending on the population size, comprise as a minimum, an SPC nurse (one per 25,000 population), a physiotherapist (one per 125,000 population), an occupational therapist (one per 125,000 population) and a social worker (one per 125,000 population). While Table 4.2 indicates the total number of staff (Whole Time Equivalents, WTEs) on the SPC team across all care settings, Table A3.3 is able to illustrate that the only NACPC target that has been achieved for community SPC is for community SPC nurses in the Midlands and in the Mid West, and deficits remain for all other community personnel across all areas. Disparity still remains with respect to the availability of personnel across the different teams which may give rise to differences in the number of visits. Table A3.4 in Appendix 3 provides details on the role of SPC personnel within each area.

TABLE 4.2 SPC Team Personnel by Study Area[a]

	Midlands	Mid West	South East[b]
Catchment Population (2011)	**282,140**	**379,327**	**367,263**
Medical			
Consultant	1	3	3
Specialist Registrar	–	2	1
Registrar	–	1	1
SHO	–	3	2
Nursing and Nursing Support	–	–	–
Director of Nursing	–	1	–
Deputy Director of Nursing	–	1	–
Nursing Team Manager	2	2	2
Clinical Nurse Specialist	14.56	21.75	8.2
Staff Nurse	1	6.7	1.4
Care Assistant	–	7	–
Allied Health Professionals			
Occupational Therapy	–	5.5	1
Occupational Therapy Assistant	–	0.5	–
Physiotherapist	1.75	6.5	–
Physiotherapy Assistant	–	0.5	–
Social Worker	1	6	–
Pastoral Carer	–	2	–
Dietician	–	1	–
Complementary Therapy			
Music Therapist	–	1.6[c]	–
Art Therapist	–	1.1[c]	–
Art Facilitator	–	1[c]	–
Complementary Therapist	–	1.5[c]	0.6
Other			
Pharmacist	–	1	–
Pharmacy Technician	–	1	–
Administrative Staff (Nursing)	2	3	–

Notes: Further details on SPC personnel by care setting and study area are available in Table A3.3 in Appendix 3.

a The teams were asked to provide data on the number of Whole Time Equivalents (WTEs) available across all care settings in June 2012. Any major changes since this period have been footnoted.

b The WTE data is for the South Tipperary and Waterford regions only

c These WTEs also provide elderly services.

It is important to reiterate that, although, for example, at the time the study was conducted the Midlands community SPC team did not have an occupational therapist as part of the team, this does not mean that decedents in the area did not receive occupational therapy. Decedents may have had OT visits privately or through primary care teams. Also, allied health professional visits received by decedents while attending the Milford Care Centre, specialist palliative day care service or in-patient hospice service are not captured in the utilisation presented in Section 4.2.1. A separate analysis of these visits is presented in Appendix 4.4.2 to illustrate the level of activity taking place.

Referral to SPC Services[17]

When interpreting utilisation of SPC services it is important to note when decedents were referred to the service.[18] Figure 4.4 shows that 68.4% of

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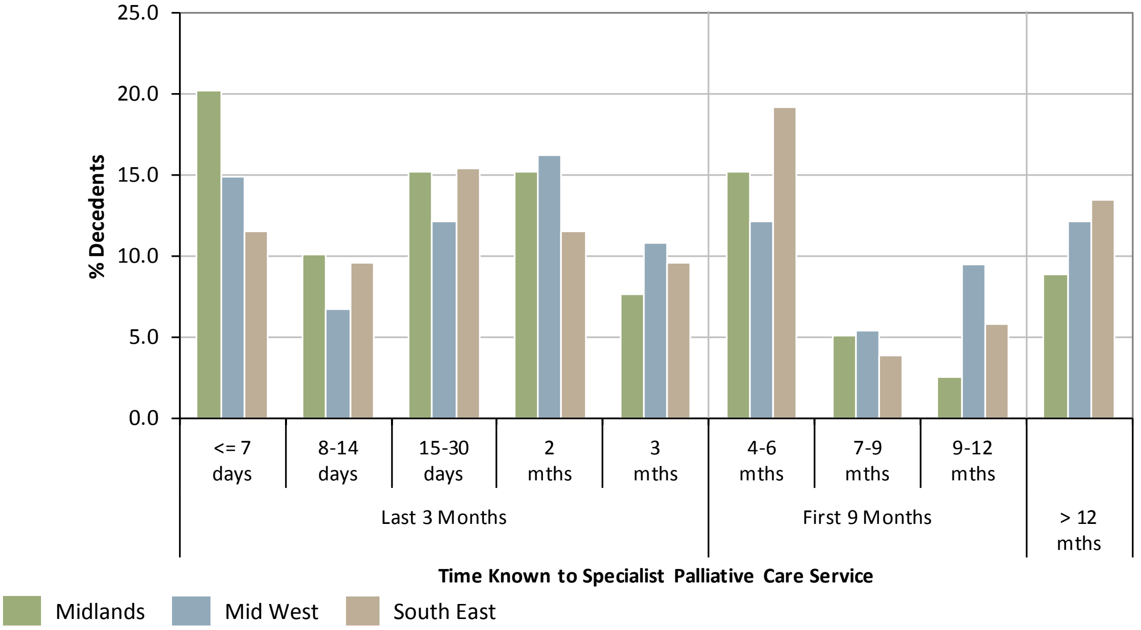
[17] See Table A3.6 in Appendix 3 for details on the referral process and assessment procedures across the study areas.

[18] This includes referrals to both community SPC and hospital-based SPC.

decedents in the Midlands were referred to SPC in the last three months of life including 20.3% who were referred in the last week of life. In the Mid West 60.8% were referred in the last three months including 14.9% who were referred in the last week. In the South East 57.7% were referred in the last three months including 11.5% in the last week. The differences across areas in the proportions of decedents referred within the last three months (p=0.519) and the last week (p=0.388) are not statistically significant.

FIGURE 4.4 Length of time Known to SPC Service Before Death by Area



SPC Consultant Figure 4.5 shows the proportion of decedents who used services provided by the community SPC teams and the mean and median number of visits/phone consultations for total decedents and service users. Home visits by SPC consultants are not a feature of any of the community SPC services, although very occasional visits/phone consultations are made. In general, the SPC consultants provide advice to the SPC nurses when required and attend the multidisciplinary team meetings.[19] The proportion of decedents reported by the KI as receiving visits from SPC consultants at home was small across all areas in both the first nine months (<3% of decedents in each area) and the last three months of life (<11% of decedents in each area). The variation across areas is not significant in either the nine-month period of the last year (p=0.452) or the three-month period (p=0.484).

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[19] See Table A3.5 in Appendix 3 for details of SPC consultant role in each area.

Community SPC Nurse[20]

Visits A high proportion of decedents had visits from community SPC nurses. This is not surprising given the nature of the community SPC services in the three areas.[21] Utilisation of visits was higher in the last three months than in the first nine months of the last year of life.

Nine months	**Proportion** 36.1% of decedents in the Mid West had community SPC nurse visits, compared to 32.8% in the South East, and 27.6% in the Midlands; variation across areas is not statistically significant (p=0.538). **Service User Visits** Decedents had a mean of three community SPC nurse visits per month in the Midlands, and two visits per month in the Mid West and South East; variation across areas is not statistically significant (p=0.191).
Three months	**Proportion** The proportion receiving community SPC nurse visits increased relative to the nine-month period in all areas to 84.7% in the Midlands, 77.5% in the Mid West, and 58.5% in the South East; variation across areas is statistically significant (p=0.003). **Service User Visits** Decedents had a higher number of community SPC nurse visits per month in the three-month period relative to the nine-month period in all areas with a mean of 5.8 visits per month in the South East, 5.0 visits per month in the Midlands, and 4.7 per month visits in the Mid West; variation across areas is not statistically significant (p=0.587).
Difference	**Proportion** The relationship between the proportion of decedents utilising the community SPC nursing service in the nine-month period and the proportion using the service in the three-month period is statistically significant in the Mid West (p=0.097), South East (p=0.001) and Midlands (p=0.021) but in the Midlands >20% of the cells have an expected count of less than 5 making the result unreliable.[22] **Service User Visits** The difference in the mean number of community SPC nurse visits between the nine-month and three-month periods in each area is statistically significant in each area (Midlands p<0.001, Mid West p<0.001, South East p=0.002).

Phone Consultations The proportion of decedents receiving phone consultations from the community SPC nurse[23] was much lower than the proportion receiving visits in both the nine-month and three-month periods.

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[20] For community SPC nurse visits, administrative records of the number of visits made to the decedents included in the study were obtained from the local teams. A comparison of the KI reported and community SPC team reported visits is presented in Appendix 4. The data reported in this section refers to the data provided by the KI.

[21] Not all decedents received a community SPC nurse visit as they only received SPC from the in-patient hospital team and, therefore, did not have the opportunity to avail of community SPC. In a small number of cases, decedents were referred to the community team so late that no visit was possible.

[22] Overall, in the South East, there appears to be a higher level of recruitment of KIs for decedents who died in hospital and who only received SPC from the in-patient hospital team compared to other areas. Data were not readily available on the overall proportion of decedents who died in hospital in the South East, so it is therefore unclear if this is an accurate reflection of service provision in this area.

[23] Phone consultations include those made by carers on behalf of the KI.

Nine months	**Proportion** 9.7% of decedents in the Midlands reported phone consultations from the community SPC nurse compared to 17.1% in the Mid West, and 17.9% in the South East; variation across areas is not statistically significant (p=0.332). **Service User Consultations** Decedents had a mean of 2.0 community SPC nurse consultations per month in the Mid West, 2.2 in the South East, and 3.3 in the Midlands; variation across areas is not statistically significant (p=0.657).
Three months	**Proportion** The proportion receiving phone consultations from the community SPC nurse increased relative to the nine-month period in all areas to 46.5% in the Mid West, 48.6% in the Midlands, and 49.1% in the South East; variation across areas is not statistically significant (p=0.949). **Service User Consultations** Decedents had a higher number of consultations per month from the community SPC nurse in the three-month period relative to the nine-month period in all areas with a mean of 4.7 in the Mid West, 5.0 in the Midlands, and 5.8 in the South East; variation across areas is not statistically significant (p=0.633).
Difference	**Proportion** The relationship between the proportion of decedents receiving phone consultations from the community SPC nurse in the nine-month period and the proportion receiving these phone consultations in the three-month period is only statistically significant in the Mid West (p=0.001). **Service User Consultations** The difference in the mean number of phone consultations from the community SPC nurse between the nine-month and the three-month periods is statistically significant in the Midlands (p=0.045) and the Mid West (p<0.001) but not in the South East (p=0.151).

Specialist Palliative Day and Outpatient Care Specialist palliative day and outpatient care visits were only reported in the Mid West.[24] The palliative day care service was used by 6.7% of patients in the first nine months of the last year and 2.7% in the last three months. The specialist palliative outpatient service was used by 2.7% of decedents in the first nine months of the last year of life and 1.4% in the last three months.[25] These services have been excluded from Figure 4.5 given the relatively small number of users, but are included in the cost calculations.

Night Nurse As outlined earlier the Irish Cancer Society/Irish Hospice Foundation offer a Night Nursing Service to palliative patients in their homes. As the service is generally provided when a patient's illness is at an advanced stage, the KI was only asked about utilisation in the last three months of life. Two out of every five decedents in the Mid West (41.3%) were reported as having received night

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[24] Details are available in Table A3.1 in Appendix 3.

[25] In November 2011, a specialist palliative outpatient service was established at Milford Care Centre. In 2012, a total of 59 patients attended the clinics (HSE and MCC, 2013, p18). As the service was established towards the end of life of many of the decedents in this study this may explain why utilisation of this service was low.

nursing in the last three months of their life (see Figure 4.5). The proportion was smaller in the other two areas at approximately 32% (p=0.498). For service users the level of utilisation was in the Midlands at a mean of 1.9 nights per month compared to 1.7 in the Mid West and 1.6 in the South East (p=0.917). As the service is generally used towards the very end of life, most nights were in the last month (e.g., a mean of 5.7 nights in the last month of life in the Midlands).

Hospice In-Patient[26]

The proportions of decedents, reported by the KI as having had hospice in-patient care, across each area are presented in Figure 4.6. The type of care, mean and median number of visits over total decedents, and only those using the service in the time period are presented, as well as the mean length of stay per admission. The Specialist In-Patient Unit at Milford Care Centre is the only such unit in the three areas included in the study.[27, 28] A very small proportion of KIs in the South East reported in-patient hospice stays in either the nine-month or three-month periods.[29] In the Mid West, a small proportion of decedents were admitted in the first nine months (4.0%) while 42.7% were admitted in the last three months of life. In those last three months the mean number of admissions per month was 0.36 and the mean length of stay per admission was 25 days.

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[26] Questions were also asked about specialist palliative day care but as the number of users was so small (6.7% in the Mid West only) the responses are not reported, but are included in the cost calculations.

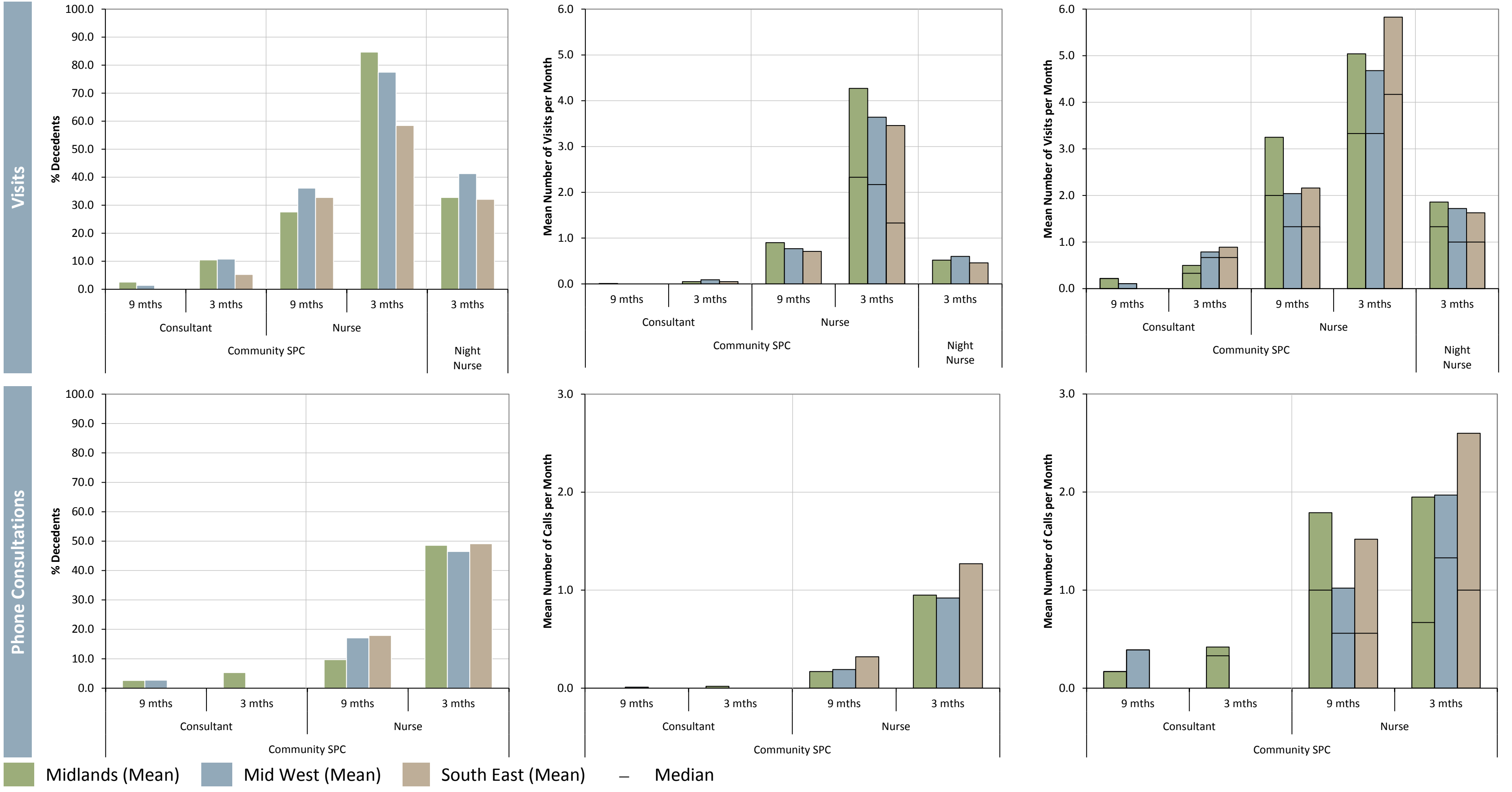
[27] The South East has two dedicated in-patient SPC beds in Waterford Regional Hospital. As KIs could not be expected to know the type of bed occupied by the decedent while in hospital, this specialist in-patient care is likely captured under hospital care rather than hospice care. See Appendix 3 Table A3.1 for more details on SPC services available in each area.

[28] For in-patient admissions to Milford Hospice, administrative records of admission were available. A comparison of the KI reported and Milford reported admissions is presented in Appendix 4.4. The data reported in this section refers to the data provided by the KI.

[29] It is possible that decedents had hospice stays outside the catchment areas in which they resided, or in the case of the South East that KIs were able to distinguish between hospital and hospice beds in Waterford Regional Hospital.

FIGURE 4.5 Utilisation of Community SPC Services by Type of Care, Time Period, and Area

Palliative Care



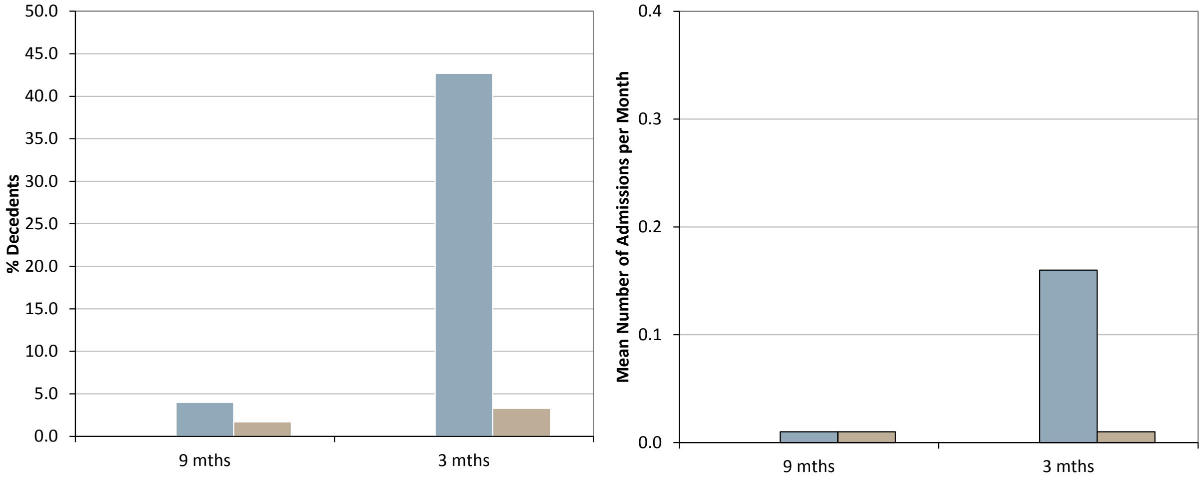
a) Total Decedents – Percentage Receiving the Service

b) Total Decedents – Mean and Median Number of Visits/ Phone Consultations per Month

c) Service Users – Mean and Median Number of Visits/ Phone Consultations per Month

FIGURE 4.6 In-Patient Hospice Admissions by Type of Care, Time Period and Area

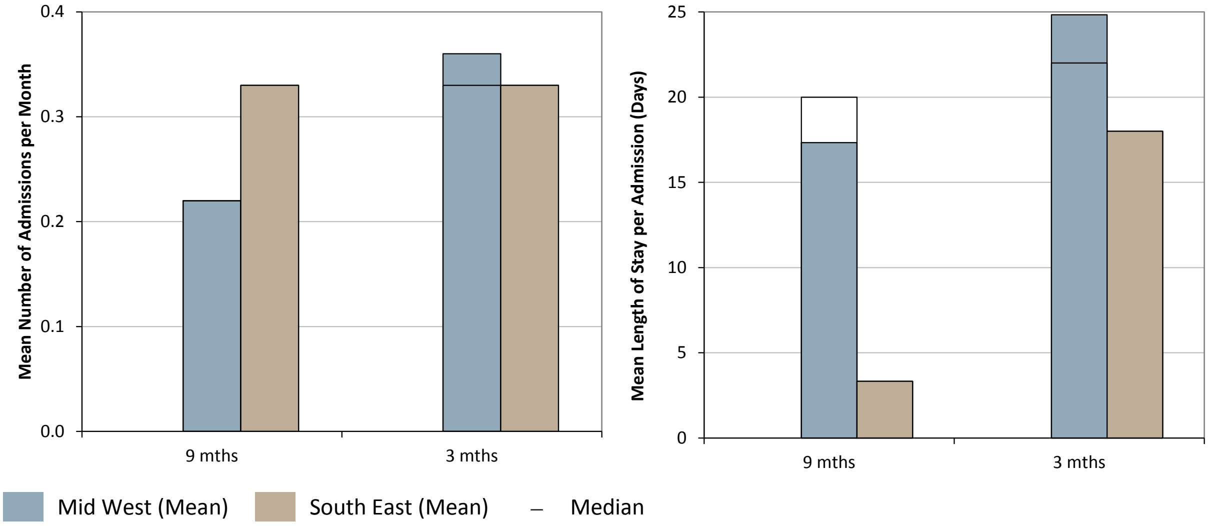
Total Decedents



a) Percentage Admitted

b) Mean and Median Number of Admissions per Month

Service Users



c) Mean and Median Number of Admissions per Month

d) Mean Length of Stay (Days) per Admission

Note: Missing values are excluded from the calculation of percentages.

Specialist Palliative Care Summary

- High proportions of decedents in all three areas received community SPC nurse visits in the last three months of life. The proportions receiving visits vary significantly across areas.
- A smaller proportion of decedents in the South East received community SPC nurse visits in the last three months of life compared to the other two areas. As there was a higher level of recruitment from in-patient hospital SPC teams in this area compared to the other two areas, this may explain why fewer decedents received visits by community SPC nurses in the South East.
- More than 40% of decedents in the Mid West had in-patient hospice stays in the last three months of life.

4.2.3 Hospital Care

This section outlines hospital utilisation by the decedents during their last year of life for each study area. This is broken down by location of care and time period within the last year of life (first nine months of the last year and the last three months of life). Types of hospital care are grouped into emergency department, outpatient, day patient and in-patient. For in-patient hospital care, mean and median length of stay are also presented.

Hospital Emergency and Outpatient Departments

The proportions of decedents, reported by the KI as having had this care, across each area are presented in Figure 4.7. The type of care, mean and median number of visits over total decedents and only those using the services in the time period are presented.

Emergency Department (ED) Visits[30]

Nine months	**Proportion** between 16 and 17% of decedents in the three areas had ED visits; variation across areas is not statistically significant (p=0.994). **Service User Visits** Decedents had a mean of between 0.2 and 0.3 ED visits per month in all areas; variation across areas is not statistically significant (p=0.739).
Three months	**Proportion** The proportion making ED visits decreased relative to the nine-month period in all areas to 11.7% in the Midlands, 8.3% in the South East, and 5.4% in the Mid West; variation across areas is not statistically significant (p=0.384). **Service User Visits** Decedents had a higher number of ED visits per month in the three-month period relative to the nine-month period in all areas with a mean of 1.2 visits per month in the South East, 0.5 visits per month in the Midlands, and 0.4 visits per month in the Mid West; variation across areas is statistically significant (p=0.079).[31]
Difference	**Proportion** The relationship between the proportion of decedents utilising the ED service in the nine-month period and the proportion using the service in the three-month periods is statistically significant in the Mid West (p=0.059) and not significant in the Midlands (p=0.649) and South East (p=0.144) but in each area >20% of the cells have an expected count of less than 5 in each area making the results unreliable. **Service User Visits** The difference in the mean number of ED visits between the nine-month and three-month periods is not statistically significant in the Midlands (p=0.430) or in the South East (p=0.205).[32]

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[30] Visits to the emergency department that resulted in an in-patient admission were not included.

[31] This difference in the South East may be accounted for by the fact that a higher proportion of decedents were recruited into the study from hospital-based SPC teams compared to the other areas.

[32] Paired t-statistic could not be calculated for the Mid West due to too few paired observations.

Outpatient Department (OPD) Visits[33]

Nine months	Proportion 61% of decedents in the Midlands and Mid West had OPD visits compared to 72.2% in the South East; variation across areas is not significant (p=0.332). Service User Visits Decedents had a mean of 0.6 OPD visits per month in the Midlands, 0.5 OPD visits in the Mid West, and 0.4 OPD visits in the South East; variation across areas is not statistically significant (p=0.128).
Three months	Proportion The proportion making OPD visits decreased relative to the nine-month period in all areas to 44.8% in the South East, 35.2% in the Mid West, and 32.0% in the Midlands; variation across areas is not statistically significant (p=0.297). Service User Visits Decedents had a higher number of OPD visits per month in the three-month period relative to the nine-month period in all areas with a mean of 0.9 visits per month in the Midlands and South East, and 0.8 visits per month in the Mid West; variation across areas is not statistically significant (p=0.693).
Difference	Proportion The relationship between the proportion of decedents utilising the OPD service in the nine-month period and the proportion using the service in the three-month period is statistically significant in the Midlands (p=0.001) and the South East (p=0.050) and not statistically significant in the Mid West (p=0.116). Service User Visits The difference in the mean number of OPD visits between the nine-month and the three-month periods in each area is statistically significant in the South East (p=0.021) but not statistically significant in either the Midlands (p=0.761) or Mid West (p=0.190).

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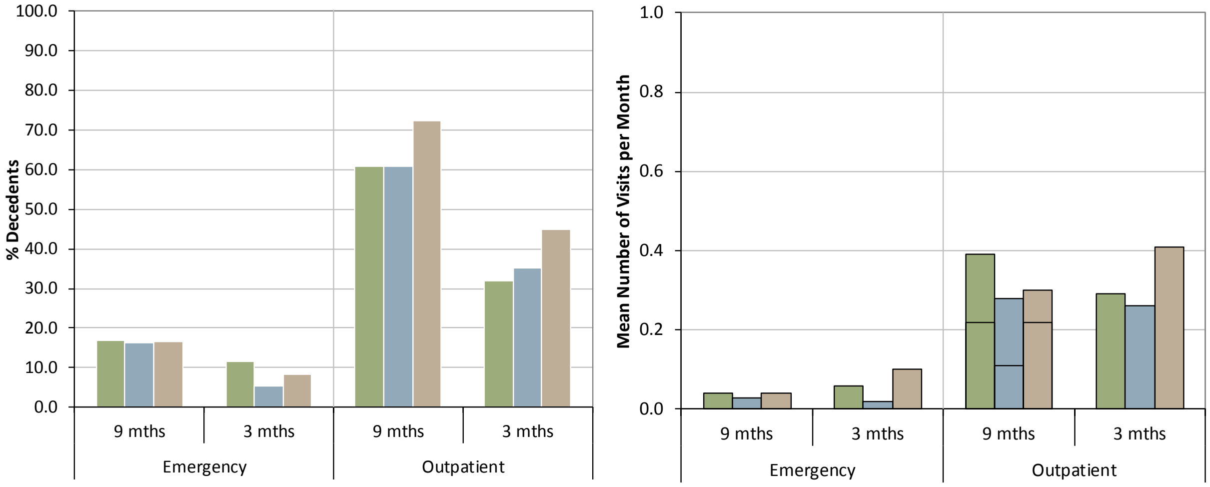
[33] It should be noted that due to the nature of outpatient visits and day patient admissions some KIs may not have been able to distinguish accurately between them.

FIGURE 4.7 Hospital Emergency and Outpatient Department Visits by Type of Care, Time Period and Area

Total Decedents

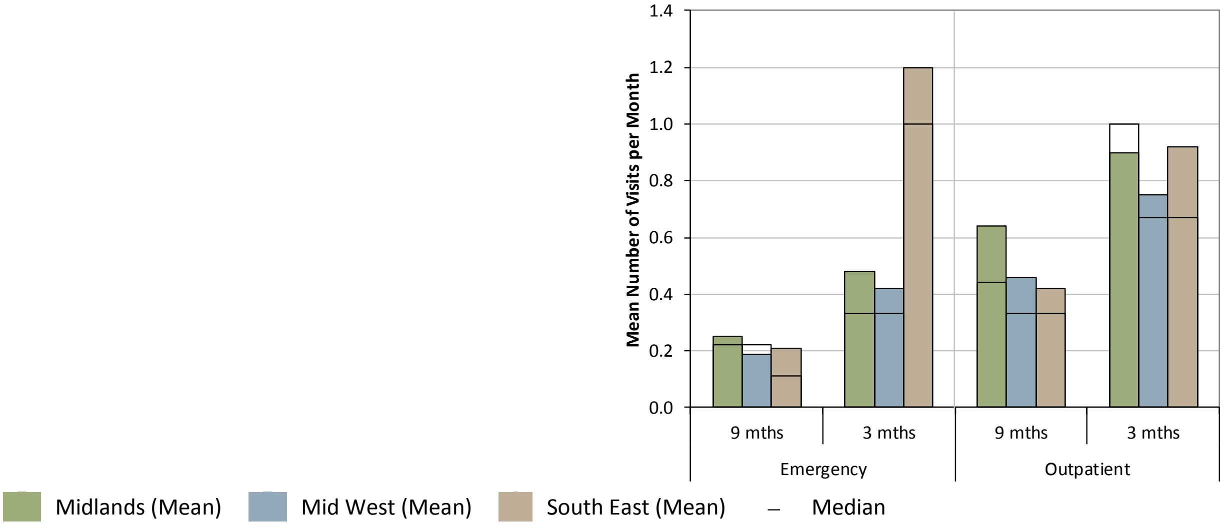
a) Percentage of Decedents Visiting

b) Mean and Median Number of Visits per Month



Service Users

c) Mean and Median Number of Visits per Month



Note: Missing values are excluded from the calculation of percentages.

Hospital Day Patient and In-Patient

Total day patient and in-patient hospital activity refers to both public and private admissions to public hospitals and private admissions to private hospitals.[34] For admissions to public hospitals reporting to HIPE, administrative records of admission for decedents were available and are reported here rather than the KI reported data.[35] A comparison of the KI reported and HIPE reported admissions is presented in Appendix 4.2. Data for private hospitals included in the totals below are as reported by the KI.

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[34] The public/private distinction is used for applying appropriate costs in Section 4.5.

[35] For a small number of decedents for whom hospital records were not available (e.g., permission not granted), KI reported data is presented.

The proportions of decedents reported as having had this day patient and in-patient hospital care, across each area are presented in Figure 4.8. The type of care, mean and median number of visits of total decedents, and only those using the service in the time period are presented, as well as the mean length of stay per admission for in-patients.

Day Patient

Nine months	**Proportion** 45.0% of decedents in the Midlands had day patient admissions compared to 40.0% in the Mid West, and 38.3% in the South East; variation across areas is not statistically significant (p=0.697). **Service User Admissions** Decedents had a mean of approximately 1.2 day patient admissions per month in the Midlands and Mid West, and 0.9 admissions per month in the South East; variation across areas is not statistically significant (p=0.755).
Three months	**Proportion** The proportion having day patient admissions decreased relative to the nine-month period in all areas to 42.5% in the Midlands, 30.0% in the South East, and 18.7% in the Mid West; variation across areas is statistically significant (p=0.006). **Service User Admissions** Decedents had a higher number of day patient admissions per month in the three-month period relative to the nine-month period in all areas with a mean of 2.0 in the Mid West, 1.5 in the South East, and 1.4 admissions per month in the Midlands; variation across areas is not statistically significant (p=0.464).
Difference	**Proportion** The relationship between the proportion of decedents utilising the day patient service in the nine-month period and the proportion using the service in the three-month period is significant in all three areas (Midlands p<0.001, Mid West p=0.001, South East p=0.003). **Service User Admissions** The difference in the mean number of day patient admissions between the nine-month and three-month periods was not statistically significant in any of the three areas (Midlands p=0.336, Mid West p=0.337, South East p=0.906).

Given the cohort of decedents in the study it is likely that much of the day patient activity is related to pharmacotherapy (including chemotherapy), radiotherapy and dialysis.[36]

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[36] Of the 175 decedents for whom HIPE data was available, 905 day patient visits were recorded. In the nine-month period, visits for pharmacotherapy (including chemotherapy), radiotherapy and dialysis for these decedents accounted for 74.4% of day patient visits, this decreased to 55.8% in the three-month period. See Appendix 4.2 for further information on the HIPE data available to the study.

Hospital In-Patient

Nine months	Proportion 65.3% of decedents in the Mid West had hospital in-patient admissions compared to 62.5% in the Midlands and 60.0% in the South East; variation across areas is not statistically significant (p=0.814). Service User Admissions Decedents had a mean of approximately 0.25 hospital in-patient admissions per month in the Mid West compared to 0.22 in the Midlands, and 0.21 admissions in the South East; variation across areas is not statistically significant (p=0.424). Length of Stay Mean length of stay was 10.2 days per hospital in-patient admission in the South East compared to 9.5 days per admission in the Midlands, and 8.4 days per admission in the Mid West; variation across areas is not statistically significant (0.591).
Three months	Proportion The proportion admitted as a hospital in-patient increased relative to the nine-month period in the Midlands to 78.8% and South East to 68.3%, and decreased to 62.7% in the Mid West; variation across areas is statistically significant (p=0.085). Service User Admissions Decedents had a higher number of hospital in-patient admissions per month in the three-month period relative to the nine-month period in all areas with a mean of 0.50 in the Mid West, 0.57 in the South East, and 0.63 admissions per month in the Midlands; variation across areas is statistically significant (p=0.068). Length of Stay Mean length of stay was 19.9 days per hospital in-patient admission in the South East compared to 13.4 days per admission in the Mid West, and 10.9 days per admission in the Midlands; variation across areas is statistically significant (0.056).
Difference	Proportion The relationship between the proportion of decedents with a hospital in-patient admission in the nine-month period and the proportion with a hospital in-patient admission in the three-month period is not significant in any of the three areas (Midlands p=0.832, Mid West p=0.723, South East p=0.734).[37] Service User Admissions The difference in the mean number of hospital in-patient admissions between the nine-month and three-month periods is significant in all areas (Midlands p<0.001, Mid West p<0.001, South East p<0.001). Length of Stay The difference in the mean length of stay per hospital in-patient admission between the nine-month and three-month periods is statistically significant in the Mid West (p=0.007) but not in the Midlands (p=0.421) or in the South East (p=0.222).

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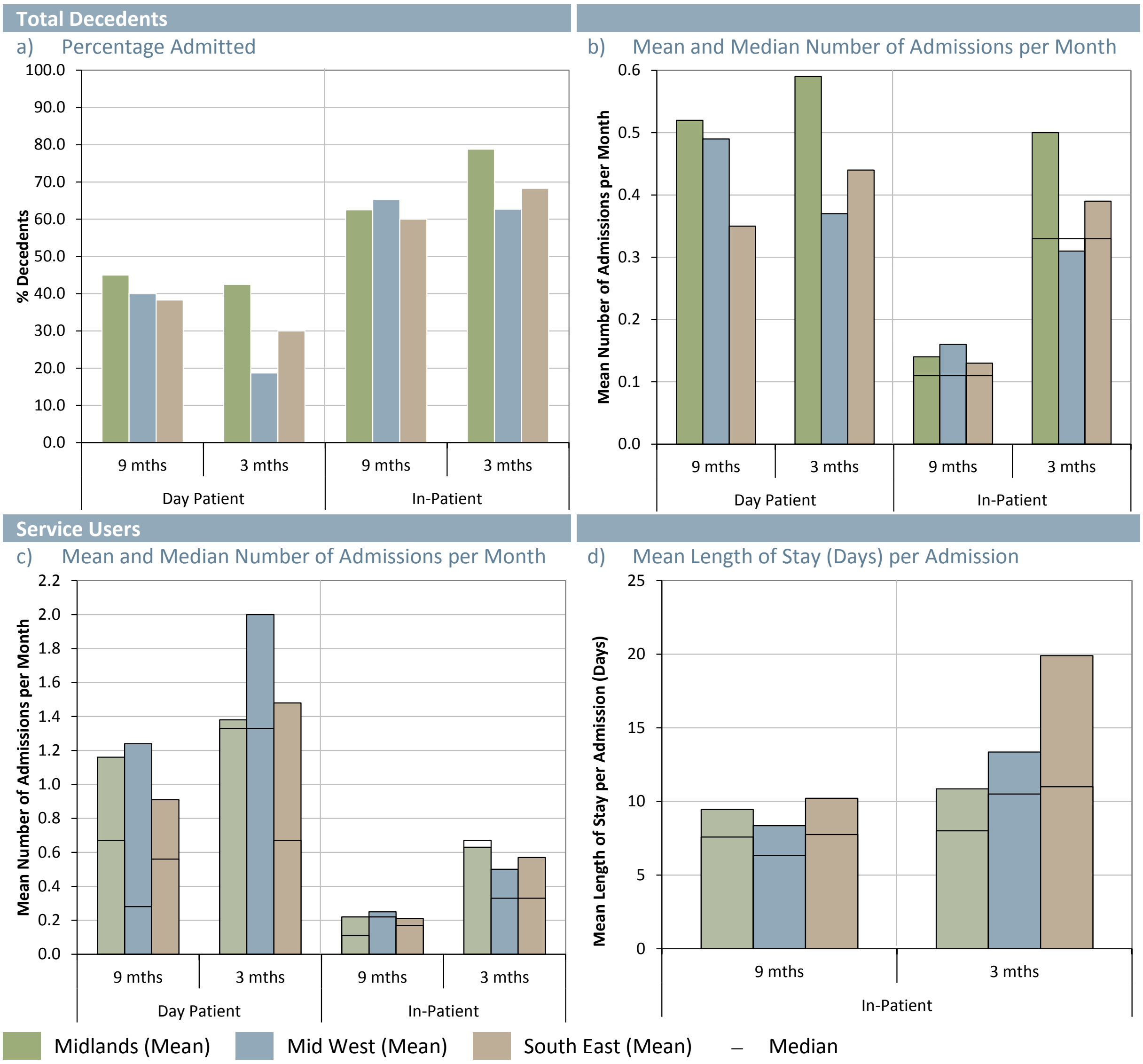
[37] The availability of an in-patient hospice facility in the Mid West may have influenced hospital in-patient admissions in the area.

FIGURE 4.8 Day Patient and In-Patient Hospital Admission by Type of Care, Time Period and Area



Note: Missing values are excluded from the calculation of percentages.

Hospital Care Summary

- The frequency of visits by decedents to the emergency department in the last three months of life was 2.4 times higher in the South East compared to the Midlands and three times higher than in the Mid West.
- Approximately 40% of decedents in each area were admitted to hospital as a day patient in the first nine months of the last year of life. There was a small drop in the proportions in the Midlands and South East in the last three months of life but the proportion in the Mid West halved to less than 20%.
- Similar proportions of decedents had in-patient hospital stays across the three areas in the first nine months of the last year (60.0–65.3%). In the Midlands and South East the proportions of decedents with a hospital in-patient stay increased in the last three months of life but decreased in the Mid West.

4.2.4 Nursing Home Care

The proportion of decedents, reported by the KI as having had received nursing home care across each area is presented in Figure 4.9. The type of care, mean and median number of visits of total decedents and only those using the services in the time period are presented, as well as the mean length of stay per admission. Stays in a nursing home include those for respite and convalescence (see Section 4.2.5).

Nine months	**Proportion** 22.5% of decedents in the Midlands had nursing home admissions compared to 21.3% in the Mid West and 18.3% in the South East; variation across areas is not significant (p=0.831). **Service User Visits** Decedents had a mean of approximately 0.23 nursing home admissions per month in the South East compared to 0.15 in the Mid West, and 0.13 in the Midlands; variation across areas is statistically significant (p=0.096). **Length of Stay** Mean length of stay was 160 days per nursing home admission in the Midlands compared to 101 days per admission in the Mid West, and 26 days per admission in the South East; variation across areas is statistically significant (p=0.007).[38]
Three months	**Proportion** The proportion admitted to a nursing home increased relative to the nine-month period in the Midlands to 31.3% and in the South East to 30.0%, and decreased to 20.0% in the Mid West; variation across areas is not statistically significant (p=0.238). **Service User Visits** Decedents had a higher number of nursing home admissions per month in the three-month period relative to the nine-month period in all areas with a mean of 0.44 admissions per month in the South East, 0.37 in the Midlands, and 0.33 in the Mid West; variation across areas is statistically significant (p=0.092). **Length of Stay** Mean length of stay was 50 days per nursing home admission in the Midlands, compared to 42 days per admission in the Mid West, and 29 days per admission in the South East; variation across areas is not statistically significant (p=0.155).
Difference	**Proportion** The relationship between the proportion of decedents admitted to a nursing home in the nine-month period and the proportion admitted to a nursing home in the three-month period is statistically significant in the Midlands (p<0.001) and in the Mid West (p<0.001) and South East (p=0.007) but in the latter two study area >20% of the cells have an expected count of less than five making the results unreliable. **Service User Visits** The difference in the mean number of nursing home admissions between the nine-month and three-month periods is significant in the Midlands (p<0.001) but not in the South East (p=139).[39] **Length of Stay** The difference in the mean length of stay per nursing home admission between the nine-month and three-month periods is statistically significant in the Midlands and Mid West (Midlands p<0.001, Mid West p=0.009) but not in the South East (p=0.883).

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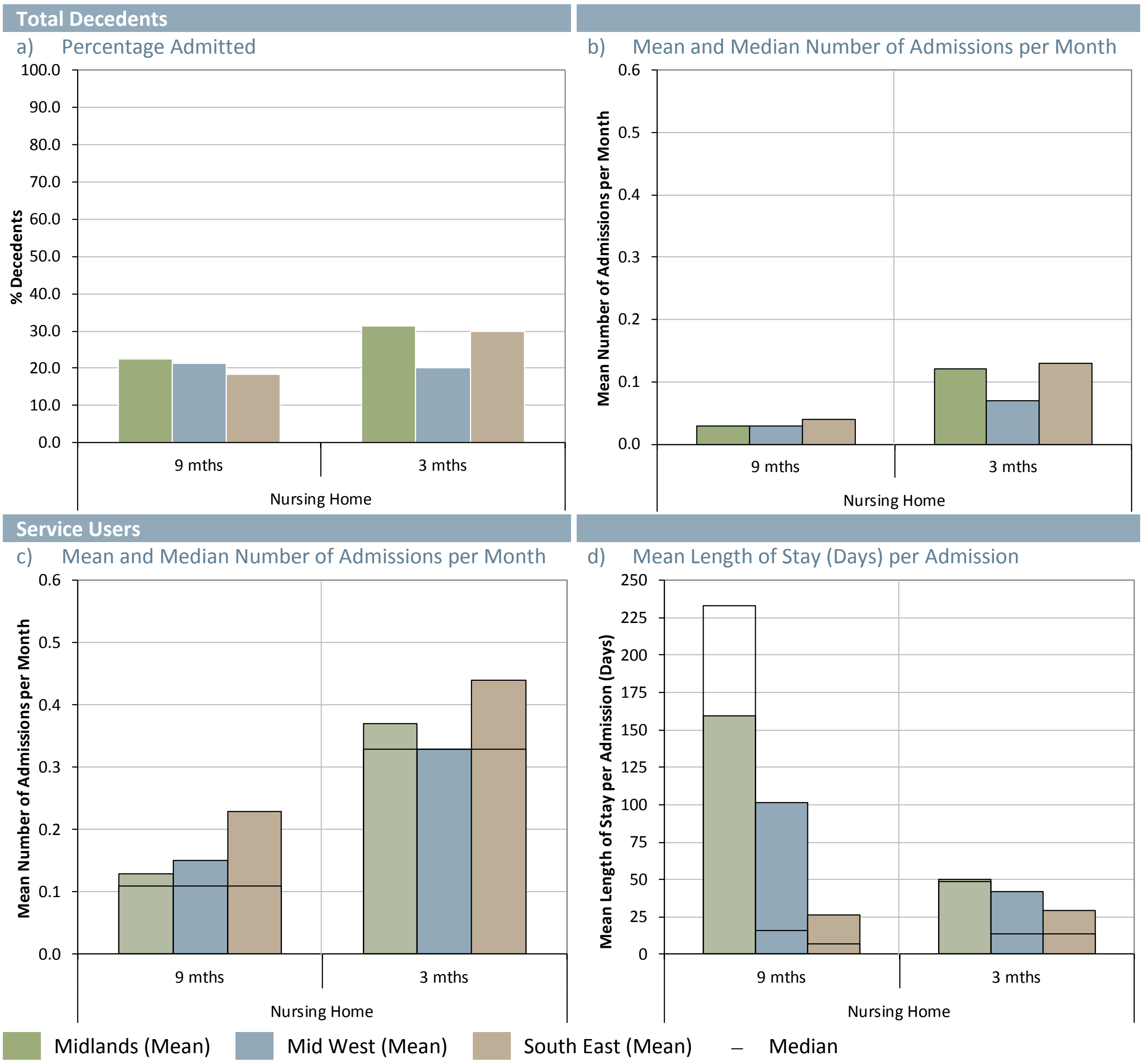
[38] Compared to the other two regions, the South East did not have any decedents who stayed in a nursing home for the full nine-month period. There were also a number of decedents in the South East who had regular respite care. These two factors help to explain the lower length of nursing home stay in the South East relative to the other two areas.

[39] Paired t-statistic could not be calculated for the Midlands due to too few paired observations.

FIGURE 4.9 Nursing Home Admissions by Type of Care, Time Period and Area



Total Decedents

a) Percentage Admitted

b) Mean and Median Number of Admissions per Month

Service Users

c) Mean and Median Number of Admissions per Month

d) Mean Length of Stay (Days) per Admission

Note: Missing values are excluded from the calculation of percentages.

4.2.5 Respite and Convalescence

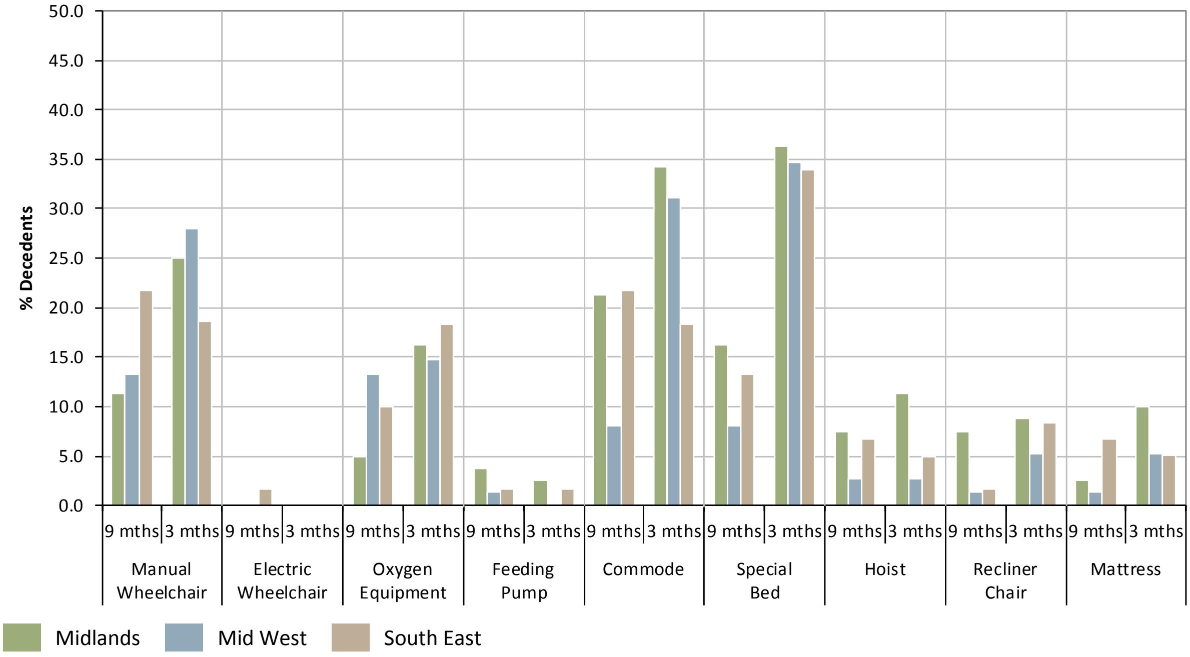
The KIs reported that some of the in-patient stays in hospital, hospice and nursing homes related to respite or convalescence. In the Midlands 10% of decedents availed of respite care in the last year of life and there were no reports of convalescence care. In the Mid West 12% availed of respite care and just 1.3% availed of convalescence care, while in the South East 16.9% availed of respite care and 5% availed of convalescence care. The arrangements described for respite varied across decedents. For some the arrangement was recurring, e.g. admission for one week every six weeks while for others it was a one-off event while home modifications were being carried out. Most KIs reported that there were no out-of-pocket payments for these stays.

4.2.6 Equipment and Home Modifications

Figure 4.10 shows the proportion of decedents who received various categories of equipment during the last year of their life as reported by the KI. The most frequently received items were special beds, commodes, manual wheelchairs, and oxygen equipment. The only significant difference across the study areas is found for commodes in the nine-month period, where approximately 21% of decedents in the Midlands and South East received a commode compared to 8% in the Mid West (p=0.042).

In the South East home modifications are reported for 18.3% of decedents, followed by 15.0% in the Midlands and 10.7% in the Mid West (p=0.444). In eight of the 31 cases for whom home modifications are reported, grants were received to assist with the cost of the modifications but in the majority of cases the full costs were borne by the decedent and/or their family.

FIGURE 4.10 Equipment Received by Time Period and Area



Notes: Missing values are excluded from the calculation of percentages.
Hoist, recliner chair and mattress were not asked specifically in the questionnaire but are reported separately here as they were most frequently listed as 'other' types of equipment that decedents received in the last year of life.

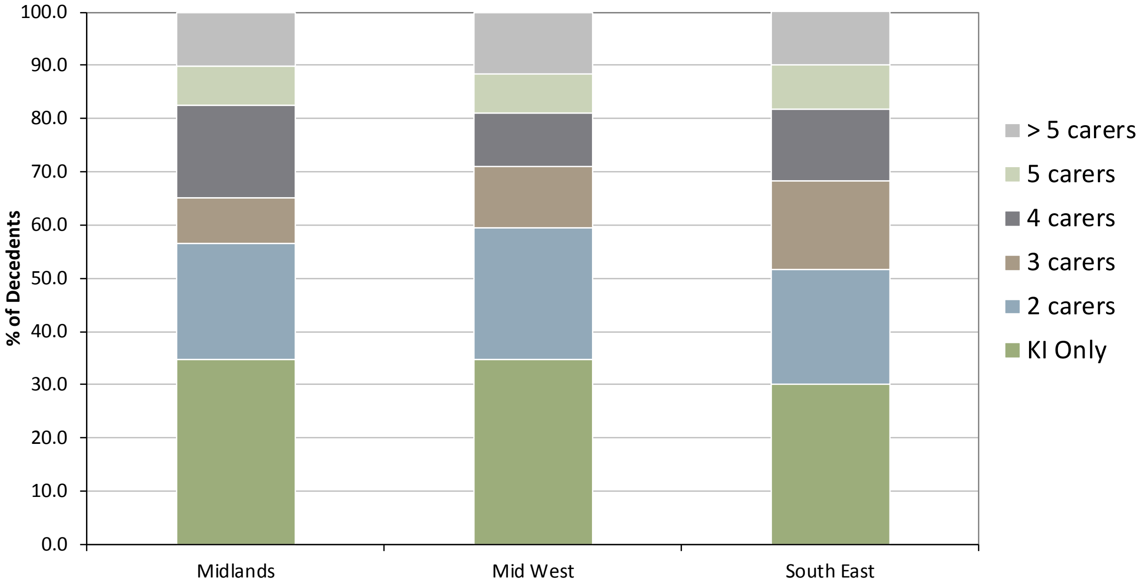
4.3 Informal Care

4.3.1 Informal Carers

The following sections present the results on informal care utilisation as reported by the KIs during the telephone interviews. Informal carers were defined as family and friends who played an important role in caring for the decedent during the last year of life. They did not include those who either visited or spent time with the decedent, but rather included anyone who helped care for them at home (i.e., own home or home of relative/friend) on a regular basis, for example washing, dressing and household tasks. This section examines the characteristics of the informal carers, including the KIs.[40]

There is no significant difference in the mean number of informal carers per decedent across the three areas: 2.8 in the Mid West, 2.9 in the Midlands and South East (p=0.993). Figure 4.11 presents the proportion of decedents with a particular number of informal carers. A slightly higher proportion of decedents in the Mid West had fewer than three informal carers (59.4%) compared with the Midlands (56.5%), and the South East (51.7%),

FIGURE 4.11 Percentage of Decedents by Number of Informal Carers by Area



Notes: Missing values are excluded from the calculation of percentages.
Decedents who lived in an institution for the full 12 months are excluded.

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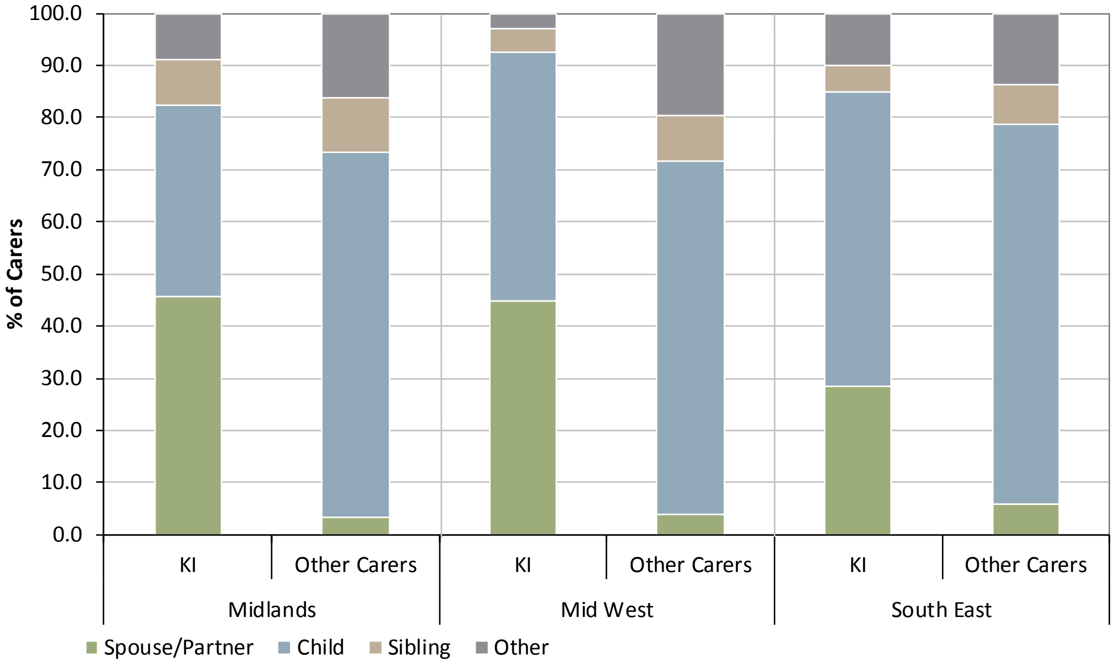
[40] Decedents who lived in an institution for the entire last year of their life are excluded from this section.

Characteristics of Informal Carers Figure 4.12 shows the relationship of the KI and other informal carers to the decedent. The profile of KIs in the Midlands and Mid West is similar, with 45% of KIs being the spouse or partner of the decedent. In the South East a larger proportion of KIs were children of the decedent, and this may be related to the fact that a larger proportion of decedents in the South East were over the age of 80 years compared to the other areas (see Figure 3.2). The composition of other informal carers is very similar across areas, with the majority being children of the decedent.

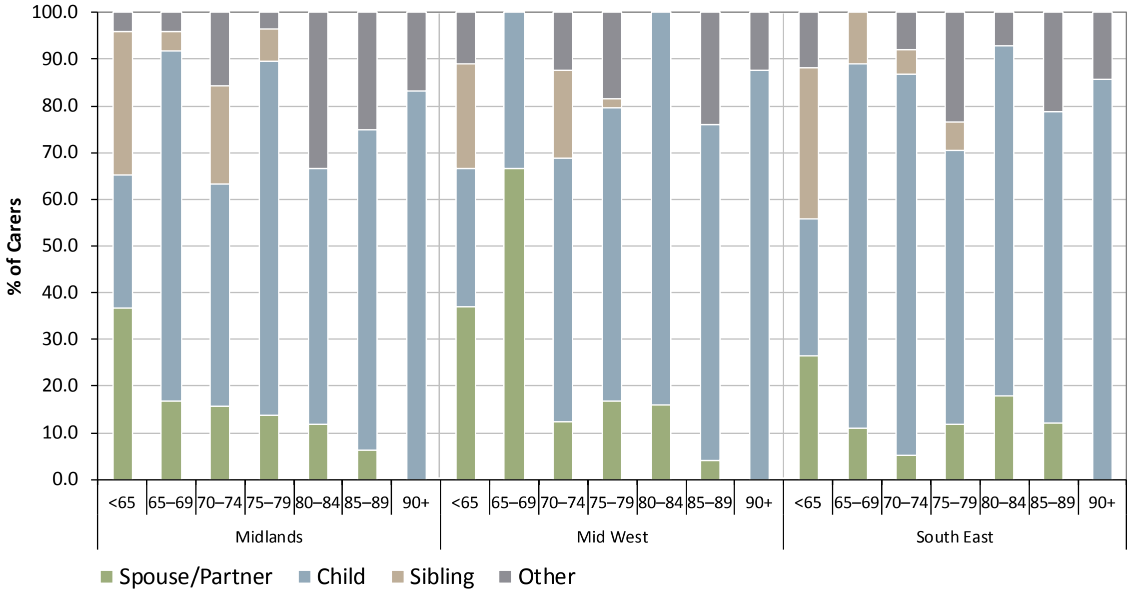
FIGURE 4.12 Informal Carers by Relationship to Decedent and Area



Notes: Missing values are excluded from the calculation of percentages.
Decedents who lived in an institution for the full 12 months are excluded.

Figure 4.13 shows how the composition of carers changes depending on the age of the decedents, with a higher proportion of children caring for the older decedent age groups.

FIGURE 4.13 Informal Carers by Relationship to Decedent, Decedent Age, and Area



Notes: Decedent Age is on the x-Axis.
Missing values are excluded from the calculation of percentages.
Decedents who lived in an institution for the entire last year of their life are excluded.

Figures 4.14a and 4.14b provide a profile of the demographic characteristics of informal carers by age and sex across the study areas. The results show that, across all areas, KIs tend to be older than other carers.[41] For example, in the Midlands 73.9% of KIs are over 50 years old compared to 42.1% of other carers. The majority of informal carers, both KIs and other informal carers, are female in all areas. In the Midlands and South East over 70% of KIs are female, and in the Mid West, 62.3% of KIs are female. In addition, 60% or more of the other informal carers are female in all areas.

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[41] The structure of the data on informal carers precludes testing for statistical significance of variation across area in demographic and other characteristics at this time.

FIGURE 4.14a Informal Carers by Age and Area

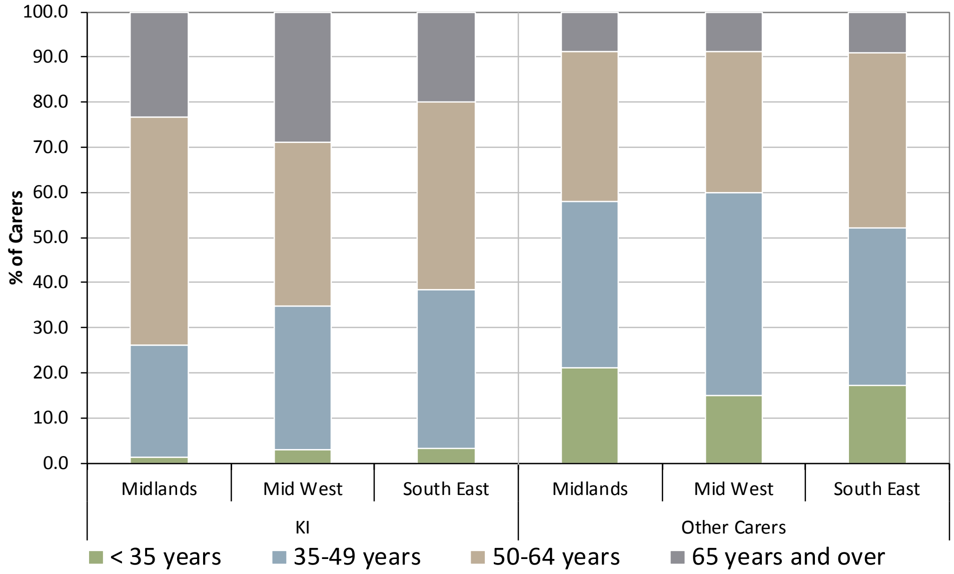
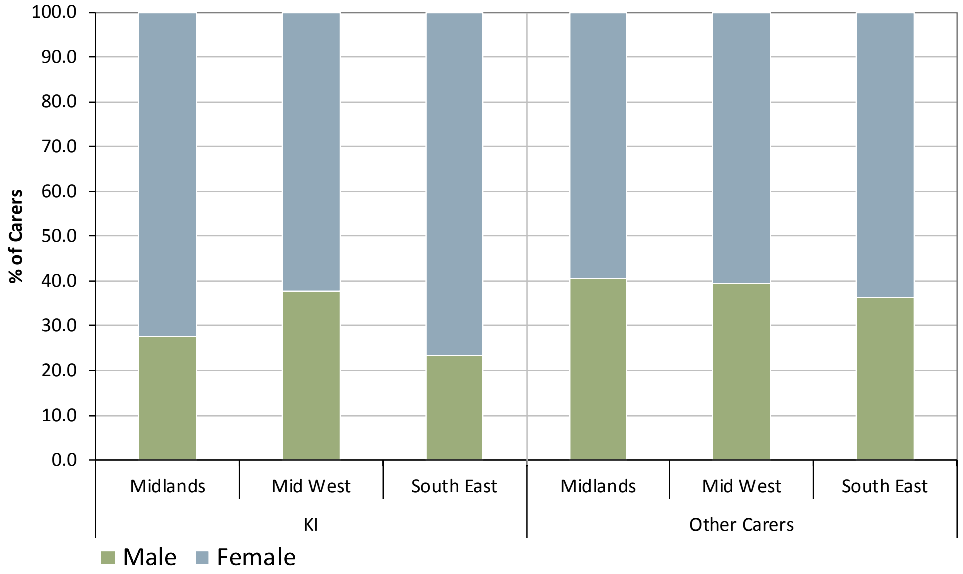


FIGURE 4.14b Informal Carers by Sex and Area

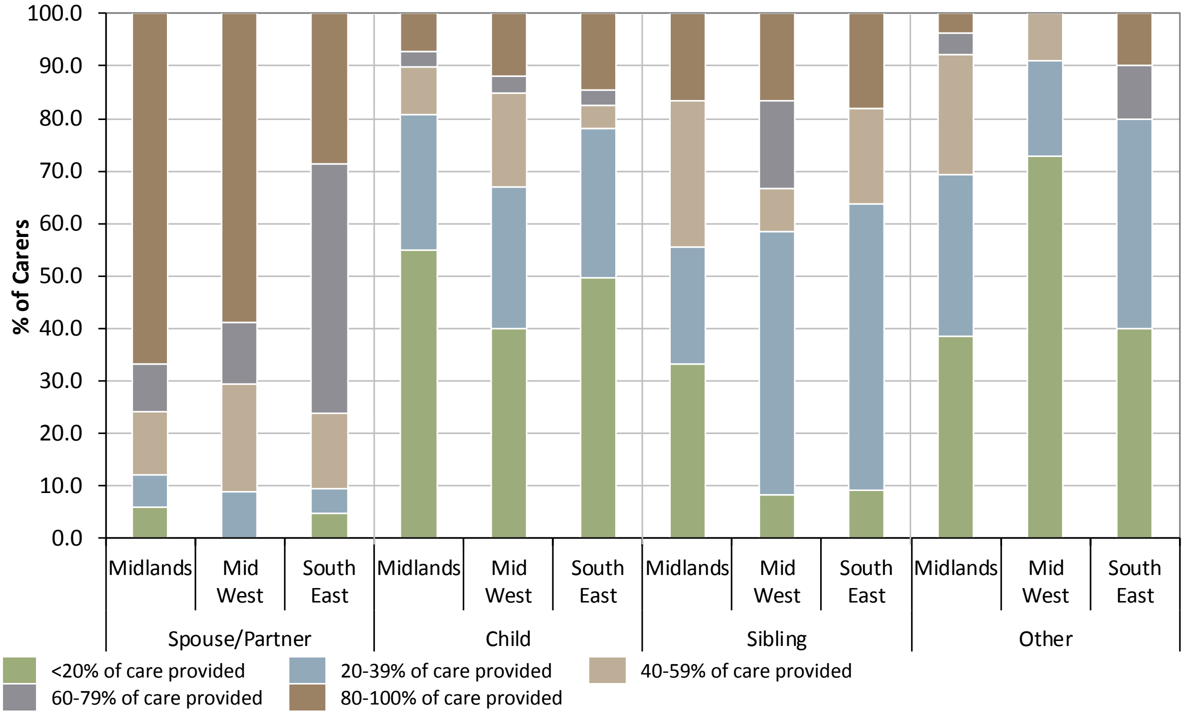


Notes: Missing values are excluded from the calculation of percentages.
Decedents who lived in an institution for the full 12 months are excluded.

Proportion of Informal Care Provided Figures 4.15, 4.16a and 4.16b categorise informal carers (KIs plus other informal carers) by the proportion of care provided to the decedent. KIs were asked to estimate the proportion of total informal care that was provided to the decedent by each of the informal carers for that decedent. This allows examination of how care was divided amongst the different groups of informal carers. For example, although two decedents may have had four informal carers each, for one decedent most of the care may have been provided by one carer, while for the other decedent the care may have been more evenly spread across the four carers. It was found that for 41.7% of decedents in the South East the KI alone provided 80–100% of all informal care required, compared with 45.6% of decedents in the Midlands and 50.7% in the Mid West.

Figure 4.15 shows that when spouses are providing informal care they tend to provide the majority of this care in all areas, with over 70% of spouse/partner informal carers providing more than 60% of the informal care to the decedent. Children and others providing care tend to share the caring duties, with more than 40% of child informal carers providing less than 20% of the informal care.

FIGURE 4.15 Proportion of Informal Care Provided by Informal Carers by Relationship to Decedent and Area



Notes: Missing values are excluded from the calculation of percentages.
Decedents who lived in an institution for the full 12 months are excluded.

Figure 4.16a shows that the highest proportion of care is provided by those carers aged 65 and over in each area. This suggests that those aged less than 65 years combine informal care with other activities, likely paid employment, and generally share caring duties with others, while a large proportion of those over the age of 65 provide over 80% of the care. The results also show that a higher proportion of male carers in the Midlands and South East provide a lower proportion of informal care relative to female carers; while in the Mid West male and female carers provide similar levels of care (Figure 4.16b).

FIGURE 4.16a Proportion of Informal Care Provided by Informal Carers by Age and Area

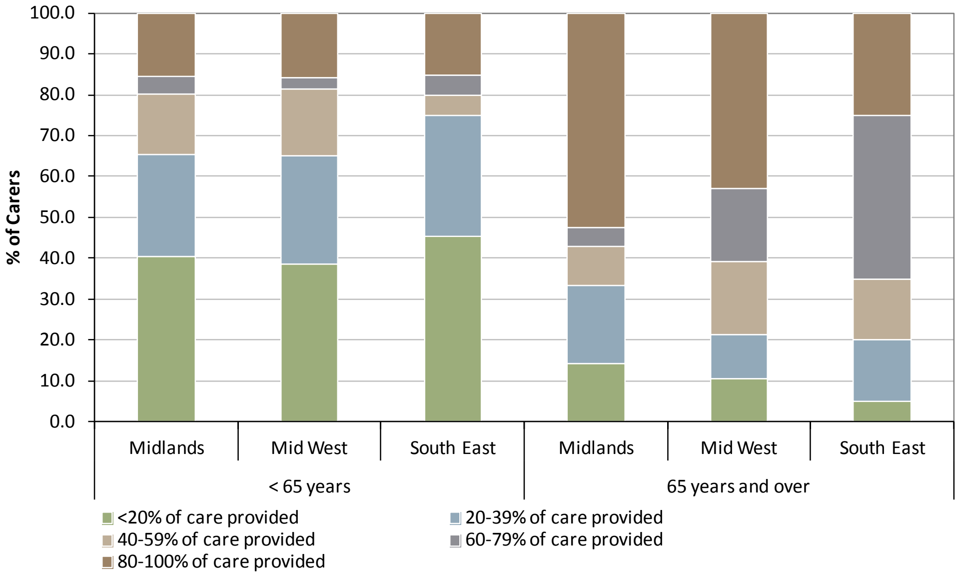
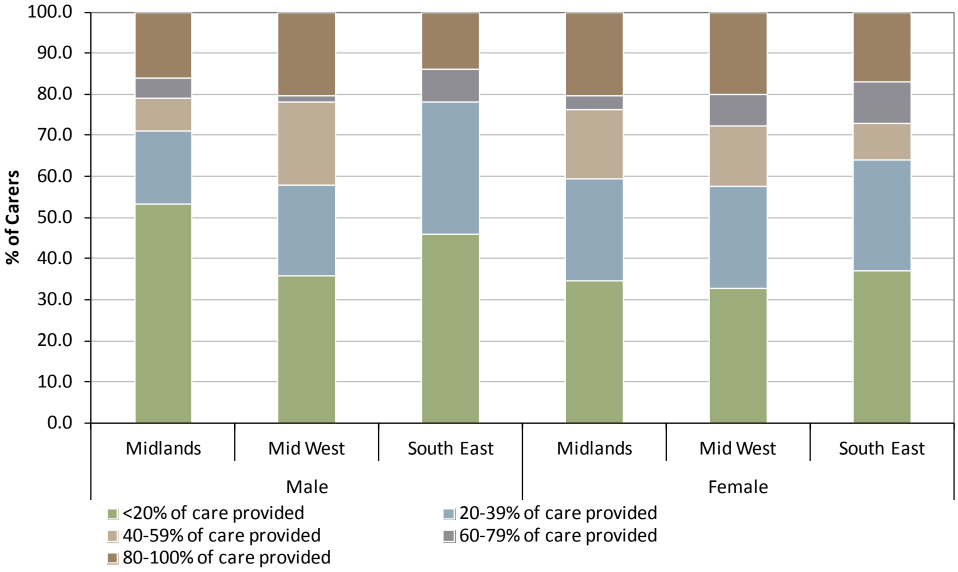


FIGURE 4.16b Proportion of Informal Care Provided by Informal Carers by Sex and Area



Notes: Missing values are excluded from the calculation of percentages.
Decedents who lived in an institution for the full 12 months are excluded.

As well as informal carers who helped care for the decedent, the KIs were asked about the network of informal support available to the decedent over the last year of their life, that is, people who visited and spent time with the decedent on a regular basis. It was reported that approximately 90% of decedents in each area had such a network of support (p=0.706). For the most part these networks consisted of close family members whose visits would range from sporadic visits to regular weekly and in some cases daily visits. Neighbours were also an important part of this network with almost a quarter of KIs noting that they would call in on a regular basis. The visits were usually of about an hour in duration and consisted of sitting chatting with the decedent or in some cases bringing the daily newspaper.

4.3.2 Informal Care Utilisation by Type

This section outlines informal care utilisation by decedents during their last year of life for each study area. KIs were asked detailed questions about the type of tasks the decedent required assistance with in the last year of life. These questions were not asked if the decedent was living in an institution for the entire last year of their life as it is assumed that their care needs were managed by the institution and the KI may not have been best placed to answer these questions.[42]

The questions referred to both basic and instrumental activities of daily living. Basic activities of daily living are related to self-care and include personal care, eating and drinking, using the toilet, and mobility indoors. Instrumental activities include taking medications, household tasks, and administrative tasks, and are those activities which allow a person to live independently. Ability to perform these basic and instrumental activities is often used by healthcare professionals to gauge the functional status of a person.

Figure 4.17 shows the percentage of decedents receiving informal care across the three study areas, disaggregated by type of care and time period within the last year of life. Figure 4.18 shows the mean number of minutes of informal care per day by duration of care (total weeks in the period and care weeks) for total decedents and service users by study area for each type of informal care. Statistically significant patterns of utilisation are discussed in the text below.

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[42] During the course of the interviews it became clear that a small number of families provided assistance to the decedent while they were in a nursing home or other institution. This is not captured in the study.

Basic Activities of Daily Living

Utilisation The proportion of decedents who required informal care for eating and drinking varied significantly across the study areas in the first nine months of the last year, with approximately 10% of decedents in the Midlands and South East requiring this type of care compared with 21.7% in the Mid West (p=0.081). Significant variation across areas was also found for mobility indoors. In the Midlands 24.6% of decedents required assistance with mobility indoors in the first nine-month period compared to 40.6% in the Mid West and 43.3% in the South East (p=0.052). There is no significant variation across areas in the utilisation of informal care for the other basic activities of daily living in the nine-month period. In the last three months of life there is no significant variation in the proportion of decedents requiring assistance with any of these basic activities across areas.

The proportion of decedents requiring informal care for the basic activities of daily living increased in all areas between the nine-month and three-month periods. With the exception of eating and drinking,[43] there is a significant relationship between the proportion of decedents requiring each type of informal care for basic activities in the nine-month period and the proportion requiring the care in the three-month period (all types of care p≤0.017); that is, a service user in the nine-month period is significantly more likely to require assistance in the three-month period than a non-service user.

Quantity of Care Required (Minutes per Day – Service Users – Care Weeks) The mean number of minutes of personal care provided by informal carers to service users varied significantly across the three study areas in the nine-month period. In the Midlands service users received a mean of 54.6 minutes per day of personal care from an informal carer compared to 80.4 minutes in the Mid West and 88.2 minutes in the South East (p=0.012). The mean number of minutes of personal care from an informal carer increased in the three-month period in all areas rising to 90.0 minutes per day in the Midlands, 88.2 in the Mid West, and 106.2 in the South East (p=0.289). The difference in the mean number of minutes of personal care per day between the nine-month and three-month periods is statistically significant in each area (Midlands p=0.025, Mid West p=0.016, South East p<0.001).

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[43] The relationship between the proportion of decedents requiring assistance with eating and drinking in the nine-month period and the proportion requiring this assistance in the three-month period is significant in the Midlands (p=0.002) and South East (p=0.017) but in both cases >20% of the cells have an expected count of less than 5 making the results unreliable.

The other types of informal care for basic activities of daily living followed a similar pattern of increased usage between the nine and three-month periods across all areas with the exception of eating and drinking in the South East (129.0 minutes per day to 100.8 per day minutes; p=0.391) and mobility indoors in the Midlands (115.8 minutes per day to 81.0 minutes per day; p=0.599) and Mid West (72.6 minutes to 63.6 minutes; p=0.616) which all decreased. However, there is no significant variation across areas in the mean usage of the other types of informal care for basic activities of daily living in the three-month period.

Instrumental Activities of Daily Living

Utilisation The proportion of decedents who required informal care for taking medications varies significantly across areas in the first nine months of the last year, with 42.0% of decedents in the Mid West, 52.2% in the Midlands and 66.7% of decedents in the South East requiring this type of care (p=0.020). There is no significant variation across areas in the proportion of decedents requiring informal care for any of the other instrumental activities in either the nine-month or three-month periods.

The proportion of decedents requiring informal care for the instrumental activities of daily living increased in all areas between the nine-month and three-month periods. There was a significant relationship between the proportion of decedents requiring each type of informal care for instrumental activities in the three-month period and the proportion requiring the care in the nine-month period (p<0.001).

Quantity of Care Required (Minutes per Day – Service Users – Care Weeks) Decedents received assistance with taking medications from an informal carer for between 25 and 33 minutes per day in the nine-month period across the three areas (p=0.517) compared to between 32 and 35 minutes per day in the three-month period (p=0.938). The difference in the mean number of minutes between the nine-month and three-month periods in each area is statistically significant (Midlands p=0.046, Mid West p=0.011, South East p=0.050).

Decedents received assistance with household tasks such as cooking, cleaning and laundry from an informal carer for between 94 and 146 minutes per day in the first nine-month period (p=0.215) compared to between 112 and 151 minutes per day in the last three-month period (p=0.338). The difference in the mean number of minutes between the nine-month and three-month period in each area is statistically significant in the Mid West (p=0.006) and the South East (p=0.084) but not in the Midlands (p=0.679).

Relative to the other instrumental activities, a smaller amount of time was spent by informal carers on assisting decedents with administrative tasks, averaging at between 13.2 minutes per day in the Midlands and 29.4 minutes per day in the South East in the first nine-month period. This variation is statistically significant across the three areas (p=0.098). The amount of time spent on administrative tasks generally increased in the three-month period, ranging between 19.2 and 28.2 minutes per day (p=0.456) across the three areas. The difference in the mean number of minutes between the nine-month and three-month periods in each area is not statistically significant in any of the areas (Midlands p=0.822, Mid West p=0.157, South East p=0.148).

Other Activities

KIs were also asked if the decedent required on-going supervision, that is, if the decedent required someone to be with them because they could not be left on their own.[44] The proportion of decedents who required supervision in the nine-months varied across areas. In the Midlands 32.4% of decedents required supervision in the nine-month period compared to 38.3% in the South East and 46.4% in the Mid West (p=0.241). In the three-month period the proportion of decedents requiring assistance increased to 56.1% in the South East, 63.6% in the Mid West, and 67.6% in the Midlands. The variation across areas in the three-month period is not statistically significant (p=0.409). There was a significant relationship between the proportion of decedents requiring supervision in the nine-month and three-month periods in all areas (p<0.001).

The mean number of weeks for which supervision was required in the nine-month period varied across areas at 24 out of 39 weeks in the Mid West, 26 out of 39 weeks in the South East and 30 out of 39 weeks in the Midlands; this variation is not statistically significant (p=0.381). The mean number of weeks for which supervision was required in the three-month period (9 out of 13 weeks) did not vary across areas (p=0.846).

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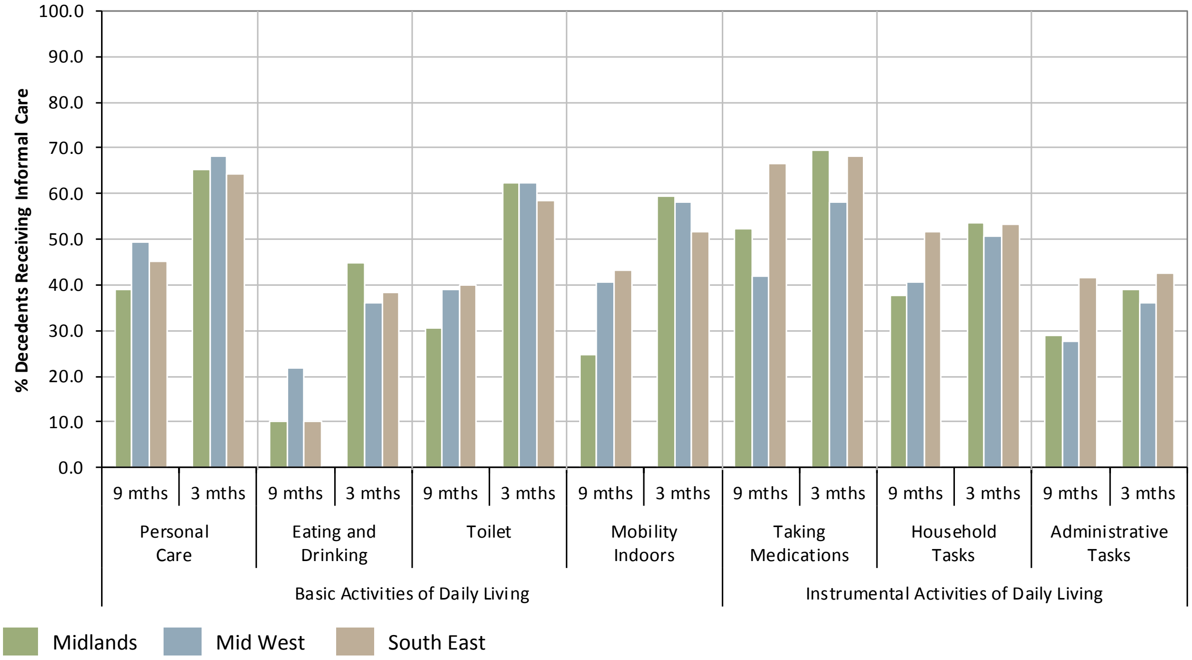
[44] KIs were also asked about driving and childcare required by the decedent but proportions were very small and are not reported here. These activities are not included in the cost calculations.

FIGURE 4.17 Utilisation of Informal Care by Type of Care, Time Period, and Area



Notes: Missing values are excluded from the calculation of percentages.
Decedents who lived in an institution for the full 12 months are excluded.

FIGURE 4.18 Mean and Median Number of Minutes of Informal Care per Day by Type of Care, Duration of Care, and Area

Notes: Missing values are excluded from the calculation of percentages.

A Median values are not presented for total decedents as they are mostly equal to zero.

Decedents who lived in an institution for the full 12 months are excluded.

Mean total weeks in the period: The mean number of minutes per day calculated across the full year.

Mean care weeks: The mean number of minutes per day calculated across the number of weeks care was used.

Informal Care Summary

- The majority of decedents in each area had not more than two informal carers.
- A high proportion of KIs in the Midlands and Mid West were the spouse or partner of the decedent while in the South East a larger proportion of KIs were children of the decedent.
- The majority of KIs in all areas were women aged between 35 and 64 years.
- When spouses are providing informal care they tend to provide the majority of this care, with over 70% of spouse/partner informal carers providing more than 60% of the informal care to the decedent. Children and others providing care tend to share the caring duties with more than 40% of child informal carers providing less than 20% of the informal care.
- The proportion of decedents requiring informal care increased over time in all areas across all categories of care.
- Personal care and taking medications were the most utilised forms of assistance in the last three months of life.
- The most time intensive forms of care provided by informal carers in the last three months of life were household tasks, followed by personal care, and eating and drinking.
- Across the three areas the data indicate that decedents (service users) in the South East were most dependent in both time periods, i.e. they required the highest mean number of minutes of care per day in care weeks for most tasks.

4.4 Findings on Objectives 1 and 2 – Cost of Care During the Last Year of Life

Objectives

1) Estimate total *formal* care costs per patient in receipt of SPC over the last year of life in each of three comparator areas
2) Estimate total *informal* care costs per patient in receipt of SPC over the last year of life in each of three comparator areas

As outlined in Section 3, for the majority of cost components, total costs are calculated for each decedent by multiplying service utilisation by the relevant unit cost for that service. Thus the cost data presented here relate directly to the *total decedent* utilisation data presented earlier in this section. In addition, the costs referred to in this section refer to total costs of care over the last year of life and not only to costs incurred as a result of SPC utilisation. The components of total costs for the last year of life are as follows:

(1–7) Formal Care Costs

1) Community Services
- GP (visits/phone consultations)
- PHN (visits/phone consultations)
- Pastoral care (visits/phone consultations)
- Day care centre
- Home help
- Health care assistant
- Formal paid helper
- Meals-on-wheels

2) SPC
- Community consultant (visits/phone consultations)
- Community nurse (visits/phone consultations)
- Night nurse service
- Day care
- Outpatient care
- In-patient hospice

3) Allied Health Professionals
- Chiropodist
- Complementary therapy
- Dentist
- Dietician
- Occupational therapy
- Physiotherapy
- Psychiatry
- Psychology
- Social work
- Speech and Language Therapy

4) Hospital
- Emergency department
- *Outpatient department*
  - Public
  - Private
- *Day patient*
  - Public – public hospital
  - Private – public hospital
  - Private – private hospital
- *In-patient*
  - Public – public hospital
  - Private – public hospital
  - Private – private hospital

5) Nursing Home

6) Medication
- Non-prescription medication
- Prescription medication

7) Equipment
- Manual wheelchair
- Electric wheelchair
- Oxygen equipment
- Feeding pump
- Commode
- Special bed
- Hoist
- Recliner (chair)
- Other equipment
- Home modifications

8) Informal Care Costs
- Personal care
- Eating and drinking
- Toilet
- Mobility indoors
- Taking medications
- Household tasks
- Administrative tasks

In the following section summary results for each of the eight major cost components are presented while the detailed cost tables with cost per month by individual item are presented in Table A6.1 in Appendix 6. All costs are quoted in

2011 prices, consistent with the time period during which the decedents were using the services.

4.4.1 Mean Total Cost

Table 4.3 presents the mean and median total costs of healthcare utilisation in the last year of life by time period, area and cost component. Both cost per month and total cost per period are presented.

Mean costs per month of *SPC* services vary significantly across areas in the three-month period (p<0.001). In particular, mean SPC costs per month in the Mid West are significantly higher than in the Midlands (p<0.001) and South East (p<0.001) mainly due to the high utilisation of in-patient hospice services in the Mid West. Where in-patient SPC services are available they help to reduce the number of inappropriate admissions to acute hospital beds.[45] There is a significant increase in the mean SPC costs per month between the nine-month and three-month periods in all areas (all areas p<0.001).

The most costly component of care in the Midlands and South East in each time period was hospital care followed by informal care. This contrasts with the Mid West where the most costly component of care in the three-month period was SPC, followed by hospital care and informal care. Variation in mean *hospital costs* per month is not significant across areas in the nine-month period (p=0.347) but is significant in the three-month period (p=0.039). This is evident when comparing mean hospital costs per month in the three-month period between the Mid West and the Midlands (p=0.005) and between the Mid West and South East (p=0.035), suggesting that the ability of patients to access in-patient hospice beds may lead to savings within hospitals in the last three months of life. The variation in mean cost of *informal care* across areas is not significant in either the nine-month (p=0.191) or three-month periods (p=0.792). There is a significant increase in the mean cost per month of both hospital services and informal care between the nine-month and three-month periods in all areas (all areas p<0.008).

Overall, *mean total costs (incl. informal care)* per month did not vary significantly across areas in either the nine-month period (p=0.269) or the three-month period (p=0.498). Costs were highest in the Mid West in each of the time periods, followed by the Midlands and the South East.[46] Mean total costs (incl. informal care) per month increased significantly between the first nine months and last three months of life in all areas (all areas p<0.001), from €3,861.39 to €9,030.72 in the Midlands, from €4,028.86 to €10,101.53 in the Mid West, and from €3,252.95 to €8,965.67 in the South East.

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[45] It has been shown elsewhere that access to SPC services has helped to reduce acute hospital admissions for patients in the terminal phase of illness (Costantini *et al.*, 2003; Gomez-Batiste *et al.*, 2006).

[46] A cost adjustment analysis is presented in Appendix 6.2.

TABLE 4.3 Cost of Healthcare Utilisation by Time Period and Area[a]

	Cost (€)						Statistical Testing						
	Midlands		Mid West		South East		ANOVA[b]	Independent Samples T-Test[c]			Paired Samples T-Test[d]		
							Across Areas	Across Areas			9mth v 3mth		
								ML v MW	ML v SE	MW v SE	ML	MW	SE
	Mean	Median	Mean	Median	Mean	Median	p-value	p-value	p-value	p-value	p-value	p-value	p-value
1 Community Services Costs													
9 months													
Cost per month	401.02	141.22	386.06	150.33	345.34	170.28	0.856	0.883	0.604	0.644	0.000	0.001	0.020
Total cost – 9 months	3,609.18	1,270.95	3,474.56	1,353.00	3,108.09	1,532.55							
3 months													
Cost per month	799.59	431.66	716.87	420.43	777.47	433.53	0.896	0.589	0.916	0.774			
Total cost – 3 months	2,398.77	1,294.98	2,150.61	1,261.30	2,332.42	1,300.58							
12 months													
Cost per month	500.66	216.74	468.76	286.62	453.38	271.43	0.901	0.758	0.683	0.877			
Total cost – 12 months	6,007.96	2,600.84	5,625.17	3,439.40	5,440.51	3,257.14							
2 SPC Costs													
9 months													
Cost per month	92.73	0.00	268.71	0.00	95.37	0.00	0.138	0.123	0.945	0.185	0.000	0.000	0.002
Total cost – 9 months	834.59	0.00	2,418.40	0.00	858.36	0.00							
3 months													
Cost per month	606.14	276.08	4,053.00	1,082.00	702.11	138.15	0.000	0.000	0.630	0.000			
Total cost – 3 months	1,818.41	828.25	12,159.00	3,246.00	2,106.34	414.45							
12 months													
Cost per month	221.08	88.42	1,214.78	384.98	247.06	82.98	0.000	0.000	0.695	0.000			
Total cost – 12 months	2,652.99	1,061.00	14,577.40	4,619.80	2,964.69	995.75							
3 Allied Health Professional Costs[e]													
9 months													
Cost per month	67.31	22.80	39.98	7.33	46.90	19.56	0.296	0.175	0.359	0.580	0.399	0.424	0.508
Total cost – 9 months	605.79	205.20	359.79	66.00	422.06	176.00							
3 months													
Cost per month	81.64	22.80	50.96	0.00	56.34	0.00	0.242	0.134	0.264	0.748			
Total cost – 3 months	244.93	68.40	152.87	0.00	169.03	0.00							
12 months													
Cost per month	70.89	28.95	42.72	17.59	49.26	26.14	0.187	0.113	0.274	0.547			
Total cost – 12 months	850.72	347.43	512.65	211.05	591.08	313.65							
4 Hospital Costs													
9 months													
Cost per month	1,809.46	842.49	1,615.78	878.72	1,243.14	946.72	0.347	0.635	0.157	0.260	0.007	0.000	0.002
Total cost – 9 months	16,285.16	7,582.37	14,542.06	7,908.49	11,188.26	8,520.47							
3 months													
Cost per month	4,794.23	3,308.98	2,622.06	1,747.03	4,747.35	3,122.57	0.039	0.005	0.969	0.035			
Total cost – 3 months	14,382.70	9,926.94	7,866.19	5,241.09	14,242.04	9,367.72							

	Cost (€)						Statistical Testing						
	Midlands		Mid West		South East		ANOVA[b]	Independent Samples T-Test[c]			Paired Samples T-Test[d]		
							Across Areas	Across Areas			9mth v 3mth		
								ML v MW	ML v SE	MW v SE	ML	MW	SE
	Mean	Median	Mean	Median	Mean	Median	p-value	p-value	p-value	p-value	p-value	p-value	p-value
12 months													
Cost per month	2,555.65	1,924.63	1,867.35	1,322.43	2,119.19	1,410.85	0.230	0.103	0.361	0.489			
Total cost – 12 months	30,667.86	23,095.52	22,408.26	15,869.20	25,430.31	16,930.19							
5 Nursing Home Costs													
9 months													
Cost per month	552.85	0.00	342.75	0.00	94.03	0.00	0.033	0.269	0.009	0.082	0.290	0.003	0.004
Total cost – 9 months	4,975.61	0.00	3,084.76	0.00	846.23	0.00							
3 months													
Cost per month	738.46	0.00	383.20	0.00	455.05	0.00	0.145	0.074	0.182	0.696			
Total cost – 3 months	2,215.38	0.00	1,149.60	0.00	1,365.15	0.00							
12 months													
Cost per month	599.25	0.00	352.86	0.00	184.28	0.00	0.057	0.194	0.019	0.246			
Total cost – 12 months	7,190.99	0.00	4,234.36	0.00	2,211.38	0.00							
6 Medication Costs													
9 months													
Cost per month	160.63	169.00	167.26	179.00	163.05	169.00	0.317	0.146	0.573	0.396	0.090	0.489	0.971
Total cost – 9 months	1,445.71	1,521.00	1,505.37	1,611.00	1,467.48	1,521.00							
3 months													
Cost per month	160.13	169.00	168.08	179.00	163.08	169.00	0.201	0.086	0.492	0.325			
Total cost – 3 months	480.39	507.00	504.25	537.00	489.25	507.00							
12 months													
Cost per month	160.51	169.00	167.47	179.00	163.06	169.00	0.282	0.127	0.549	0.376			
Total cost – 12 months	1,926.10	2,028.00	2,009.62	2,148.00	1,956.73	2,028.00							
7 Equipment Costs[f]													
9 months													
Cost per month	38.50	0.00	36.09	0.00	128.23	0.00	0.025	0.884	0.046	0.046	0.002	0.000	0.985
Total cost – 9 months	346.48	0.00	324.84	0.00	1,154.11	0.00							
3 months													
Cost per month	142.68	76.72	114.48	33.63	129.33	0.00	0.667	0.345	0.691	0.674			
Total cost – 3 months	428.04	230.15	343.44	100.90	388.00	0.00							
12 months													
Cost per month	64.54	42.01	55.69	34.70	128.51	47.43	0.028	0.538	0.059	0.039			
Total cost – 12 months	774.52	504.10	668.28	416.40	1,542.11	569.20							
(1–7) Formal Care Costs													
9 months													
Cost per month	3,122.50	2,695.00	2,856.64	2,155.58	2,116.07	1,810.66	0.055	0.546	0.016	0.055	0.000	0.000	0.000
Total cost – 9 months	28,102.52	24,254.98	25,709.79	19,400.23	19,044.60	16,295.92							

	Cost (€)						Statistical Testing						
	Midlands		Mid West		South East		ANOVA[b]	Independent Samples T-Test[c]			Paired Samples T-Test[d]		
							Across Areas	Across Areas			9mth v 3mth		
								ML v MW	ML v SE	MW v SE	ML	MW	SE
	Mean	Median	Mean	Median	Mean	Median	p-value	p-value	p-value	p-value	p-value	p-value	p-value
3 months													
Cost per month	7,322.87	5,873.60	8,108.65	6,343.92	7,030.74	5,267.35	0.601	0.409	0.803	0.365			
Total cost – 3 months	21,968.62	17,620.79	24,325.95	19,031.75	21,092.22	15,802.04							
12 months													
Cost per month	4,172.60	3,701.44	4,169.65	3,644.84	3,344.74	2,887.59	0.136	0.995	0.078	0.059			
Total cost – 12 months	50,071.15	44,417.31	50,035.74	43,738.05	40,136.82	34,651.05							
8 Informal Care Costs[g]													
9 months													
Cost per month	856.69	403.72	1,274.15	504.34	1,136.88	615.93	0.191	0.078	0.193	0.603	0.000	0.000	0.001
Total cost – 9 months	7,710.18	3,633.47	11,467.33	4,539.08	10,231.95	5,543.40							
3 months													
Cost per month	1,980.12	1,284.76	2,166.18	1,374.21	1,934.93	1,435.66	0.792	0.603	0.897	0.536			
Total cost – 3 months	5,940.35	3,854.29	6,498.53	4,122.63	5,804.79	4,306.99							
12 months													
Cost per month	1,137.54	756.98	1,497.15	1,029.69	1,336.40	749.22	0.312	0.135	0.365	0.542			
Total cost – 12 months	13,650.53	9,083.72	17,965.86	12,356.26	16,036.75	8,990.59							
(1–8) Total Costs (Incl. Informal Care)													
9 months													
Cost per month	3,861.39	3,880.42	4,028.86	2,916.37	3,252.95	3,009.90	0.269	0.736	0.120	0.701	0.000	0.000	0.000
Total cost – 9 months	34,752.55	34,923.81	36,259.73	26,247.34	29,276.55	27,089.09							
3 months													
Cost per month	9,030.72	7,617.02	10,101.53	8,415.82	8,965.67	7,403.20	0.498	0.258	0.331	0.909			
Total cost – 3 months	27,092.17	22,851.05	30,304.60	25,247.45	26,897.01	22,209.59							
12 months													
Cost per month	5,153.73	4,680.34	5,547.03	4,705.29	4,681.13	4,296.36	0.233	0.425	0.086	0.408			
Total cost – 12 months	61,844.72	56,164.13	66,564.33	56,463.43	56,173.57	51,556.38							

Notes: See Table A6.1 in Appendix 6 for a detailed list of the costs included in each category.

a Mean and median formal care and total costs (incl. informal care) are calculated for the total sample of decedents, n=215. Mean and median informal care costs are calculated for the sample of decedents who were not living in an institution for the entire last year of life, n=198.

b ANOVA is used to determine if there are any significant differences in the cost per month across the three areas.

c Independent samples t-tests are used to determine if there are any significant differences in the cost per month across the three areas by examining each individual pair.

d Paired samples t-tests are used to determine if within each area there is a significant difference in the cost per month, between the nine-month and the three-month periods.

e Some of the contact with allied health professionals in the Mid West takes place in a palliative day care or in-patient hospice setting and therefore is accounted for in the visit/nightly costs for those services. An analysis of utilisation of allied health professionals while attending Milford Care Centre specialist palliative day care or as an in-patient is available in Appendix 4.4.2.

f Includes home modifications.

g Where decedents lived in an institution for the entire last year of their life these questions were not asked.

4.4.2 Mean Total Cost by Age, Sex, and Living Arrangement

Figure 4.19 shows the mean total formal and informal costs of healthcare utilisation in the last year of life by area, disaggregated by age, sex, and living arrangement.[47, 48]

Formal Care Costs

- Age Mean formal care costs in the last year of life were highest for decedents who were under the age of 65 in the Midlands and the Mid West compared to the other age groups. In the South East the mean formal care costs were similar amongst those who were under the age of 65 and those aged 65–84 years. There was less variation in mean formal care costs across age groups in the three-month period relative to the nine-month period.
- Sex Females had the highest mean formal care costs in all three areas compared to males in the last year of life. There is a significant difference in the mean formal care costs for males compared to females in the Midlands in the nine-month period ($p=0.053$).
- Living arrangement Mean formal care costs are similar in the Midlands and the Mid West for those who were living alone compared to those living with another person/s, while they were slightly lower for those living with another person/s in the South East. The difference in the mean formal care costs for those living alone compared with those living with another person/s is significant in the nine-month period in all areas (Midlands $p<0.001$, Mid West $p=0.054$, South East $p=0.047$).

Informal Care Costs

- Age In the Mid West and the South East, decedents aged 65–84 years had the lowest mean informal care costs in the last year of life relative to the other two age groups (<65 years and 85+ years). In the Midlands, mean informal care costs were lowest in the younger age group (<65 years). There is a significant difference in the mean informal care costs across age groups in the Midlands in the nine-month period ($p=0.007$). There was less variation in mean informal care costs across age groups in the three-month period relative to the nine-month period.
- Sex Mean informal care costs were higher for males in the Mid West and South East and higher for females in the Midlands.
- Living arrangement Decedents who spent most of their last year living with another person/s had higher mean informal care costs in the Mid West and

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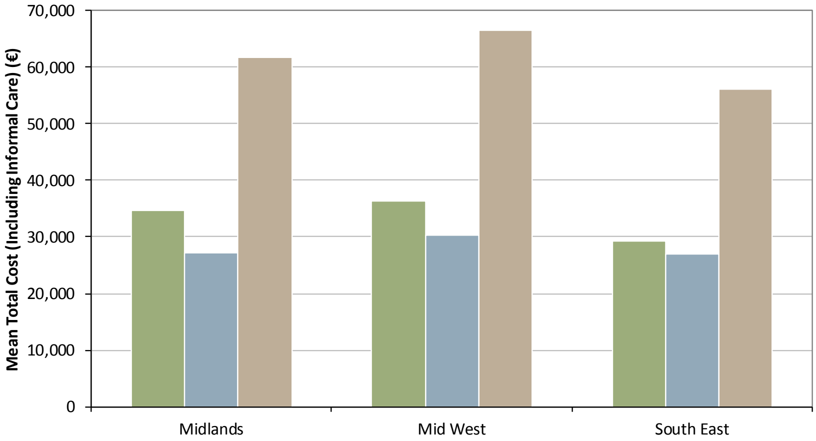
[47] Living arrangement refers to the place the decedent lived for the majority of months of the last year of their life.

[48] Detailed cost tables with cost per month by individual item are presented in Appendix 6 Table 6.1.

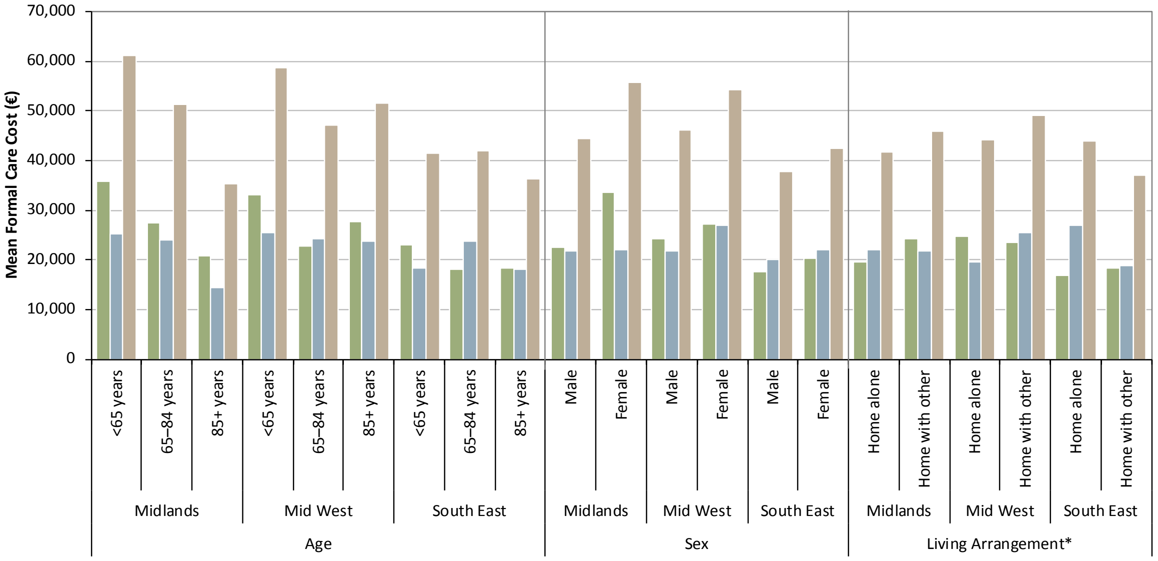
South East in both time periods compared with those living alone, whereas costs were similar across the two living arrangement categories in the Midlands. The difference in the mean informal care costs for those living alone compared with those living with another person/s is significant in the South East in the three-month period (p=0.010).

FIGURE 4.19 Mean Total Cost (Incl. Informal Care), Formal Care Cost, Informal Care Cost by Age, Sex, Living Arrangement, Time Period, and Area (%)

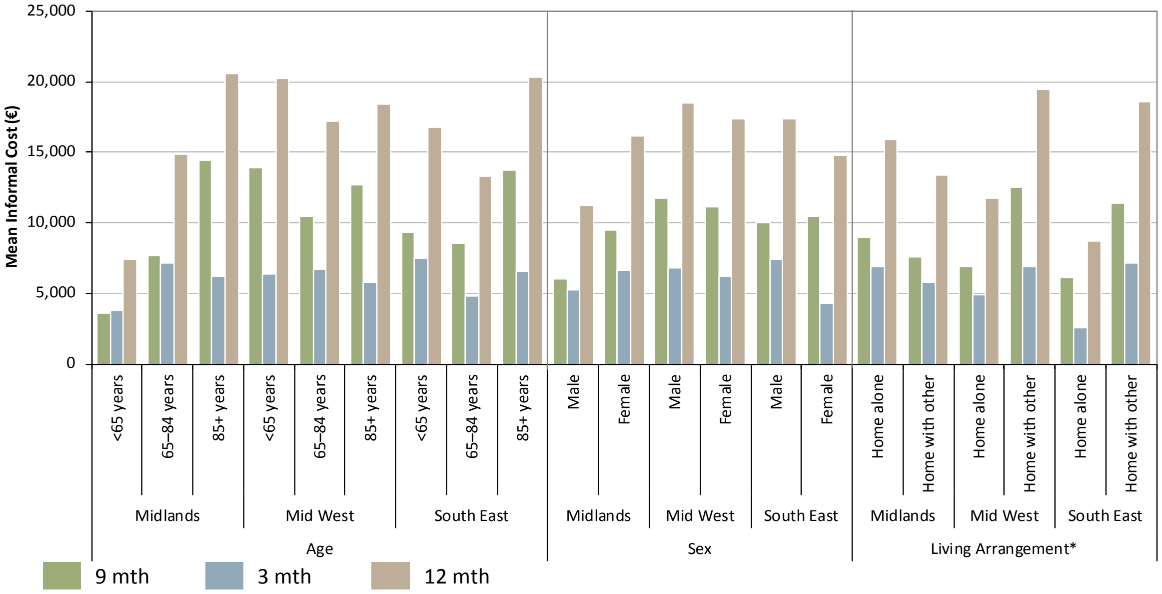
Mean Total Cost (Incl. Informal Care)



Mean Formal Care Cost



Mean Informal Care Cost



Notes: See Table A6.1 in Appendix 6 for a detailed list of the costs included in each category.

* Living Arrangement refers to the place the decedent lived for the majority of months of the last year of their life. The category 'Institution' is excluded as the number of decedents in this category was small.

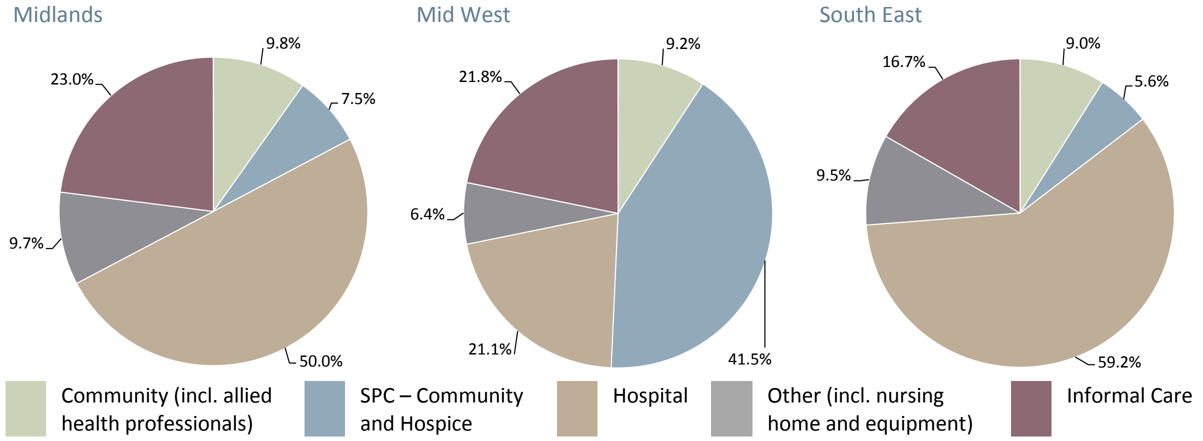
4.4.3 Components of Mean Total Cost (Incl. Informal Care) by Age, Sex, and Living Arrangement

Figures 4.20 and 4.21 present the mean total cost (incl. informal care) of healthcare utilisation in the last year of life across the three study areas disaggregated by cost component, age, sex, and living arrangement. Although mean total costs across areas were similar, the composition of the costs varies across areas, time periods, age, sex, and living arrangement. For example:

Age

- The proportion of mean total cost accounted for by SPC services in the last three months of life for those aged 65–84 years is far higher in the Mid West (41.5%) than in the Midlands (7.5%) and South East (5.6%). Conversely, the proportion of mean total cost accounted for by hospital costs is higher in the South East (59.2%) and Midlands (50.0%) compared with the Mid West (21.1%).

FIGURE 4.20 Components of Mean Total Cost by Age (65–84 Years) and Area in the Last Three Months of Life (%)



- The proportion of mean total cost in the Midlands accounted for by hospital costs in the last three months of life is higher for those under the age of 65 (66.1%) than for those aged 65–84 years (50.0%) or those aged over 85 years (32.8%).
- As age increases there tends to be an increase in the proportion of mean total cost accounted for by informal care in the nine-month period in the Midlands and the South East. This pattern is less consistent in the three-month period for all areas.
- In the Midlands nursing home care accounts for a larger proportion of mean total cost as age increases in both the nine-month and three-month periods.

A similar but less marked pattern in nursing home care costs is observed in the South East but not in the Mid West.

Sex

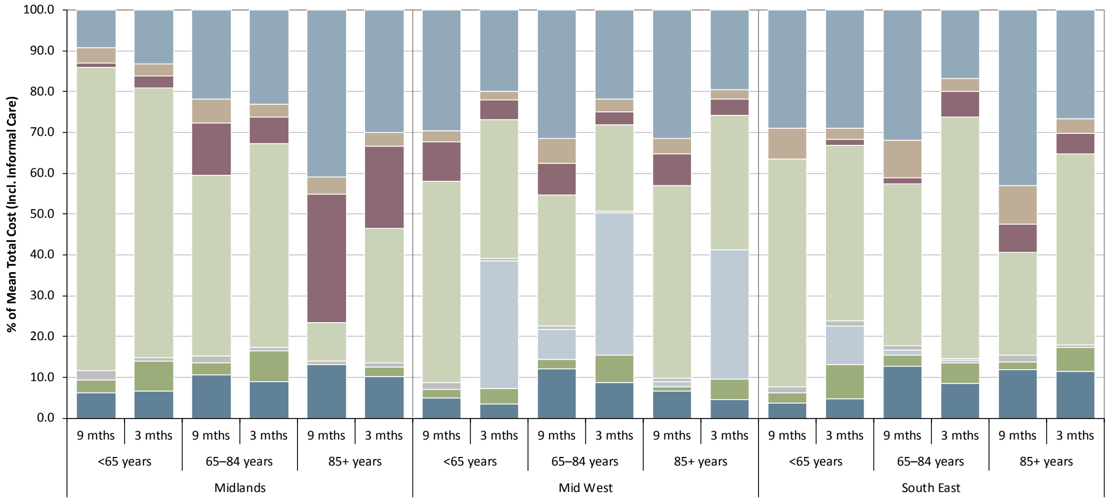
- The proportion of mean total cost accounted for by informal care costs varied by sex although this is most marked in the South East where, in the three-month period, informal care accounted for 26.8% of mean total cost for males and 16.5% for females.
- The proportion of mean total cost accounted for by community care costs was higher for females than males in the Midlands area in both the nine-month and three-month periods.
- In the Mid West SPC costs (hospice and other care settings outside the home) account for a larger proportion of mean total costs for females (nine-month period 8.5%, three-month period 36.8%) than for males (nine-month period 0.5%, three-month period 30.1%) in both time periods.
- In the South East a larger proportion of mean total cost for females (nine-month period 3.9%, three-month period 8.4%) is attributable to nursing home care than is the case for males (nine-month period 1.7%, three-month period 1.7%).

Living Arrangement

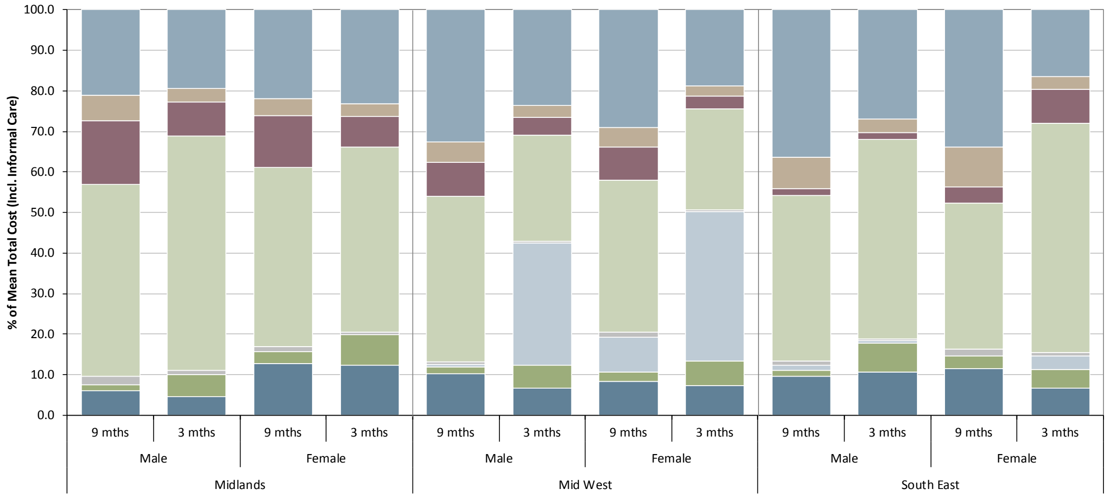
- The proportion mean of total cost accounted for by hospital costs is higher for those living alone in the three-month period in the South East (72.6%) compared with those living with other/s (48.5%).
- In the Mid West the proportion of mean total cost accounted for by SPC in a hospice and other care settings outside the home in the three-month period was higher for those who were living with other/s (38.8%) compared with those living alone (23.3%).
- In the Midlands a lower proportion of mean total cost was accounted for by community care for those living with other/s (nine-month period 8.6%, three-month period 8.3%) compared to those living alone (nine-month period 34.9%, three-month period 16.1%) in both time periods.

FIGURE 4.21 Components of Mean Total Cost (Incl. Informal Care) by Age, Sex, Living Arrangement, Time Period, and Area (%)

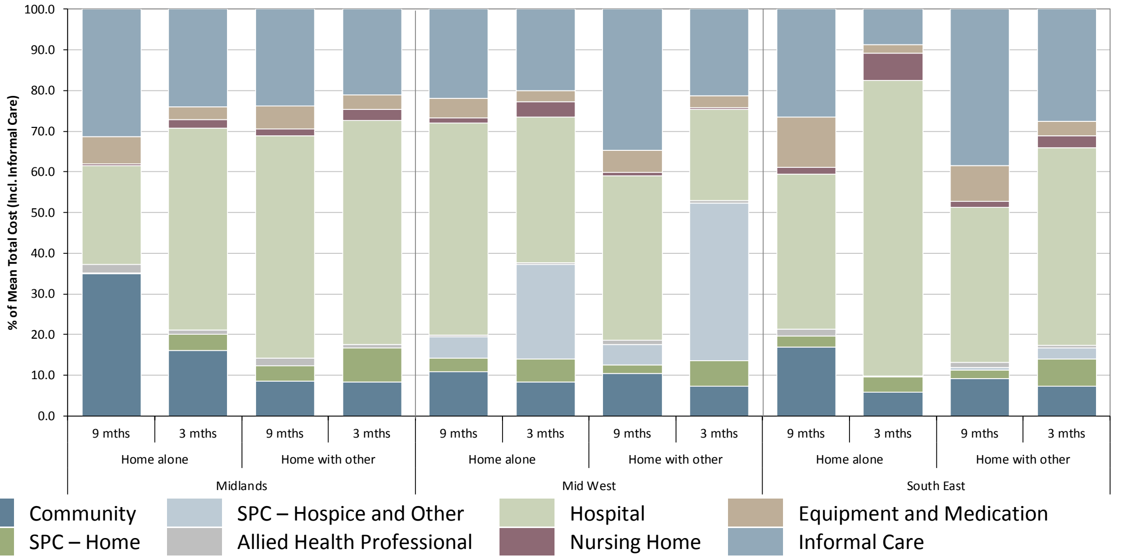
Age



Sex



Living Arrangement*



Notes: See Table A6.1 in Appendix 6 for a detailed list of the costs included in each category.

* Living Arrangement refers to the place the decedent lived for the majority of months of the last year of their life. The category 'Institution' is excluded from the charts due as the number of decedents in this category was small.

4.4.4 Other Costs

KIs were asked if there were any other major expenses in the last year of the decedent's life that were not captured during the interview. Just over one-fifth of all KIs (22.3%) stated that they did incur additional costs during that last year. Over one-third of these KIs reported that the additional costs related mainly to travel costs including petrol costs and parking charges in hospitals. Other additional costs that were referred to were household costs, including the cost of additional heating, laundry costs, and the additional costs of food for the decedent and for visitors.

Costs Summary

- Mean total costs in the last year of life varied from €66,564 in the Mid West, to €61,845 in the Midlands, to €56,174 in the South East (p=0.233).
- With the exception of the Mid West where the most costly component of care was SPC in the form of in-patient hospice care, the most costly component of care across all areas in each time period was hospital care followed by informal care.
- In the Mid West, the potential for patients with SPC needs to access in-patient hospice beds helps to reduce inappropriate admissions to acute hospital beds.

4.5 Findings on Objective 3 – Outcome Measures

Objectives

3) Measure specified outcomes (accessibility and quality of care, location of death, palliative care outcomes, and quality of life) per patient in receipt of SPC in each of three comparator areas

As outlined in Section 3.3, the outcome measures used in this study are drawn from available and well-established surveys, including the QUALYCARE study (Gomes et al., 2010) and the National Audit of End-of-life Care in Hospitals in Ireland, 2008/9 (McKeown *et al.*, 2010a). The Palliative Outcomes Scale (http://pos-pal.org) is incorporated to measure patient palliative outcomes in the week prior to death. Part I of the EuroQol EQ-5D (www.euroqol.org) is incorporated to measure patient health-related quality of life.

At the outset, it was not intended that these outcome measures would be derived from interviews conducted so long after the death of the decedent (see Section 3.5), and they are reported with the proviso that they may not perform as well in this context. It is also recognised that the use of proxy responses from the KI is problematic, particularly with regard to the more subjective measures such as pain, anxiety and depression (McPherson and Addington-Hall, 2004;

McPherson *et al.*, 2008). However, there is acknowledgement that the use of proxies is reasonably valid (Addington-Hall and McPherson, 2001), and they can play a useful role for service evaluation (Hinton, 1996). Some suggestions to improve the design of retrospective surveys including, allowing the respondent to state they did not know the answer, using clearly defined periods and reminding participants of these periods were applied in this study (McPherson and Addington-Hall, 2004).[49] See Section 5 for further discussion around this issue.

4.5.1 Accessibility and Quality of Care

Perceived Ease of Access to Services

KIs were asked how easy it was for the decedent to access a bed in hospital, the hospice, and community SPC if it was deemed necessary.[50,51] Figure 4.22 presents the findings on perceived ease of access to these services from very easy to very difficult (excluding cases where the decedent did not require the service or the service was not available in the area).

The results show that ease of access to a bed in hospital varied significantly across areas (p=0.017). In the South East 75.9% found it 'very easy' or 'fairly easy' to access a bed in hospital when it had been deemed necessary compared to 65.3% in the Midlands and 61.6% in the Mid West. There is no significant variation across areas in terms of access to community SPC services (p=0.734) with over 95% of KIs in each area reporting that it was 'very easy' or 'fairly easy' to access the service. Similarly, 95% of respondents in the Mid West reported that it was 'very easy' or 'fairly easy' to access a hospice in-patient bed when required.

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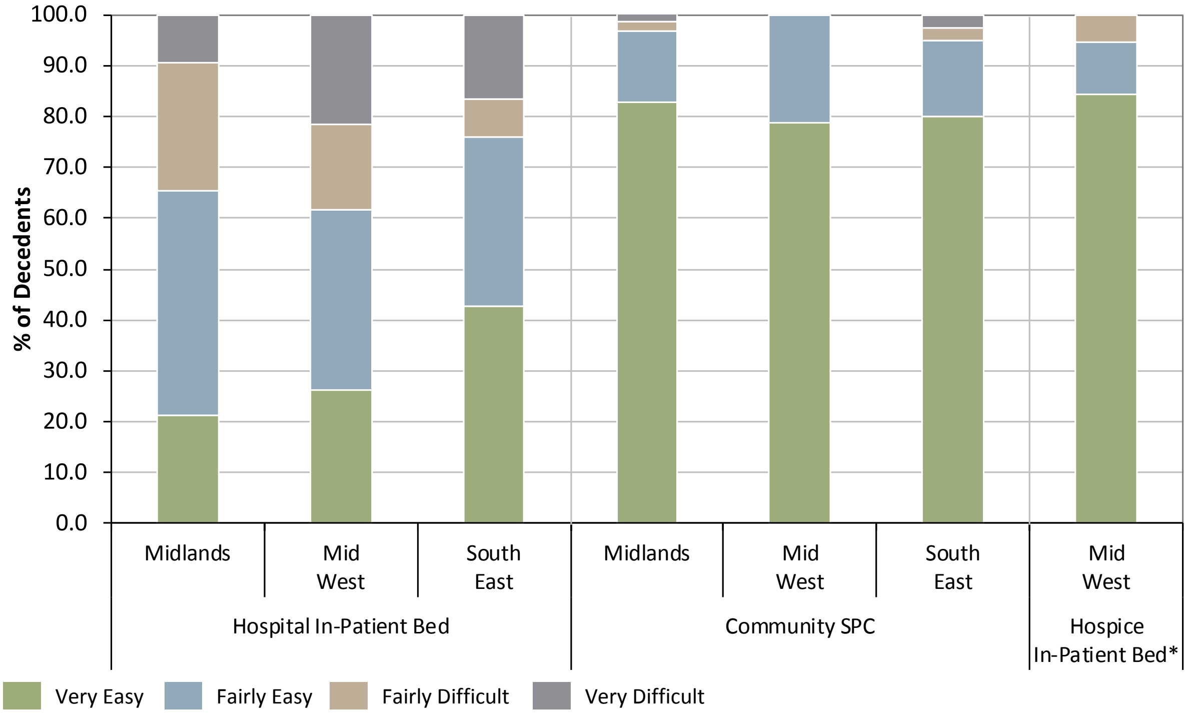
[49] See Appendix 2 for Questionnaire.

[50] Questions were also asked for specialist palliative day care but as the number of users was so small (6.7% in the Mid West only) the responses are not reported.

[51] These questions are similar to those asked in the QUALYCARE study (Gomes *et al.*, 2010). At the time of writing, comparative results were not available from the QUALYCARE study; therefore it is not possible to compare outcomes from that study with those presented here.

FIGURE 4.22 Perceived Ease of Access to Services by Type of Care and Area



Notes: * Sample size in the South East – too small to report.
Not applicable and missing values are excluded from the calculation of percentages.

Perceived Quality of Care

KIs were asked to rate, on a scale of one to ten, with ten being excellent, the quality of care provided by each of the in-patient hospital, community SPC, and hospice teams, where applicable.[52] It should be noted, particularly for quality of care in the hospital, that the questionnaire did not specify SPC team but rather refers to the entire hospital in-patient team. KIs were also asked about the decedents' end-of-life wishes. In particular, KIs were asked if the decedents' wishes had changed in any way during the last three months, and if these changes were respected by each of the respective teams.[53] Table 4.4 presents the mean and median scores across the three teams and areas.

The *in-patient hospital team* received the lowest ratings by KIs on all aspects of care (communication with the decedent and family, management of symptoms, emotional support, respect for decedent's wishes and respect for changes in decedent's wishes) relative to the community SPC and in-patient hospice teams. The South East scored highest on all aspects of care provided by the in-patient hospital team compared to the other two areas, with the exception of the

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[52] Questions were also asked for specialist palliative day care but as the number of users was so small (6.7% in the Mid West) the responses are not reported.

[53] Questions on wishes at the end of life were only asked if care was received by the respective in-patient hospital, community SPC, and hospice teams in the last three months.

question around respect for changes in decedents’ wishes.[54] There are significant differences in the mean rating scores for the in-patient hospital team across areas for communication with the decedent (p=0.021), communication with family (p=0.021), and management of the decedent's symptoms (p=0.002), with the Mid West scoring lower than the other two areas on all aspects of care. In all areas, the lowest mean rating score was assigned for the in-patient hospital team’s provision of emotional support for the family, ranging from a mean of 6 in the Mid West, to 6.8 in the Midlands, and to 7.2 in the South East.

The *community SPC team* was perceived by KIs to have performed well on all aspects of care examined, scoring 9 or more on all measures in each area. The South East scored highest on all aspects of care provided by the community SPC team compared to the other two areas. There is significant variation across areas in terms of the community SPC teams' quality of communication with the family (p=0.070), ranging from a mean of 9.1 in the Midlands, to 9.3 in the Mid West and 9.8 in the South East.

The *in-patient hospice team* in the Mid West received mean scores above 8 for all aspects of care examined. KIs were most satisfied with how the decedent's symptoms were controlled (9.4) and least satisfied with how the decedent's wishes were respected if they had changed (8.3).

TABLE 4.4 Perceived Quality of Care by Aspect of Care, Type of Care, and Area

	Midlands		Mid West		South East		p-value[a]
	Mean	Median	Mean	Median	Mean	Median	
In-Patient Hospital Team							
Communication with decedent	7.9	8	7.1	8	8.4	10	0.021
Communication with family	8.0	8	7.0	8	8.3	10	0.021
Management of symptoms	8.5	10	7.9	8	9.3	10	0.002
Emotional support for family	6.8	7	6.0	7	7.2	9	0.150
End-of-life wishes respected	8.6	10	7.9	9	8.8	10	0.216
Wishes changed respected	9.3	10	7.6	8	8.8	10	0.139
Community SPC Team							
Communication with decedent	9.3	10	9.3	10	9.6	10	0.331
Communication with family	9.1	10	9.3	10	9.8	10	0.070
Management of symptoms	9.3	10	9.4	10	9.7	10	0.177
Emotional support for family	9.0	10	9.3	10	9.5	10	0.269
End-of-life wishes respected	9.4	10	9.4	10	9.7	10	0.423
Wishes changed respected	9.8	10	9.4	10	10.0	10	0.323
In-Patient Hospice Team							
Communication with decedent			9.0	10			-
Communication with family			9.2	10			-
Management of symptoms			9.4	10			-
Emotional support for family			8.9	10			-
End-of-life wishes respected			9.2	10			-
Wishes changed respected			8.3	10			-

Notes: Not applicable and missing values are excluded from the calculation of percentages.
[a] ANOVA is used to determine if there are any significant differences in the mean scores across the three areas.

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[54] The South East is the only area with dedicated in-patient hospice beds in an acute hospital, which may have impacted on the higher scores achieved for these questions.

The rating for the in-patient hospital and community SPC teams are compared with findings from the *National Audit of End-of-Life Care in Hospitals in Ireland* (McKeown *et al.*, 2010b) and *An Evaluation of the Hospice at Home Service Delivered by Milford Care Centre* (McKay *et al.*, 2011) respectively (Table 4.5). The *National Audit* asked the same questions of relatives of a sample of decedents who died in hospitals in Ireland in 2008/9 and the *Milford Evaluation* asked the questions of families and informal carers of patients availing of the Milford Hospice at Home Service between 1 January 2009 and 31 May 2010.[55, 56]

When the results reported for the in-patient hospital team are compared to those in the *National Audit*, the proportions of 'very good' and 'good' responses are generally higher for each aspect of care (with the exception of emotional support for the family) than those reported by the *National Audit* in the Midlands and South East but lower or equal for all aspects in the Mid West.

For the community SPC team the results compare favourably with those reported in the *Milford Evaluation.* With the exception of management of symptoms, the proportions of ‘very good’ and ‘good’ responses are higher in each study area than those reported in the *Milford Evaluation* for each aspect of care.

TABLE 4.5 Perceived Quality of Care Comparisons by Aspect of Care, Type of Care, and Area

	In-Patient Hospital Care (%)					Community SPC (%)				
	VG	G	MG	P	VP	VG	G	MG	P	VP
Communication with decedent										
Midlands	45	31	18	2	5	77	18	5	0	0
Mid West	37	26	21	5	11	88	8	2	0	2
South East	62	18	10	6	4	89	11	0	0	0
National Audit/Milford Evaluation[a]	37	27	16	9	11	77	12	7	2	2
Communication with family										
Midlands	47	37	8	1	7	77	16	3	0	3
Mid West	39	25	20	3	13	88	7	2	2	2
South East	64	18	7	4	7	95	5	0	0	0
National Audit/Milford Evaluation[a]	43	27	14	6	10	69	16	10	4	0
Manage symptoms										
Midlands	57	27	10	4	1	77	18	3	2	0
Mid West	49	30	11	2	8	86	12	0	0	2
South East	80	17	4	0	0	90	10	0	0	0
National Audit/Milford Evaluation[a]	53	25	9	6	7	78	21	0	0	1
End-of-life wishes respected										
Midlands	63	23	8	2	4	80	19	2	0	0
Mid West	54	23	9	6	9	80	20	0	0	0
South East	75	13	8	0	5	91	6	0	3	0
National Audit/Milford Evaluation[a]	50	29	10	4	7	83	13	1	0	3
Emotional support for family										
Midlands	38	22	23	0	17	72	20	4	2	2
Mid West	28	25	14	14	19	82	16	0	2	0
South East	51	17	8	6	19	86	11	0	0	3
National Audit/Milford Evaluation[a]	40	28	15	6	12	65	22	5	3	5

Note: VG – Very Good, G – Good, MG – Moderately Good, P – Poor, VP – Very Poor

Source: a McKay *et al.*, 2011, Table 4.6

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[55] The results presented here from the *Milford Evaluation* of the Hospice-at-Home service relate to bereaved carers only.

[56] To compare the results from this study with the *National Audit* and the *Milford Evaluation* the results from the 10-point scale for each item in this study were converted to a 5-point scale.

Access and Quality Summary

- The majority of KIs across all areas reported that getting access to community SPC or hospice (where available) when required was either 'fairly easy' or 'very easy'.
- Perceived ease of access to a bed in hospital when required was seen as more problematic, particularly in the Mid West and Midlands with almost 40% and 35% of KIs respectively reporting that it was 'fairly difficult' or 'very difficult' to access the service.
- For all aspects of care examined (communication with the decedent and family, management of symptoms, emotional support, respect for decedent’s wishes and respect for changes in decedent’s wishes), KIs were most satisfied with the quality of care received from the community SPC team in each study area.
- The differences in the mean rating scores across areas for the in-patient hospital team were statistically significant for three of the six aspects of care compared with just one of the six aspects of care for the community SPC team.
- In the Mid West where both in-patient hospital and in-patient hospice services are available, the in-patient hospice team scores higher for each of the six aspects of care.

4.5.2 Location of Death and Acceptability of the Quality of Death

The KI was asked a series of questions relating to the location of the decedent's death. As well as ascertaining the location of death, KIs were asked about the decedents’ preferences regarding the location and if these preferences changed over the course of the last year of the decedent's life.

The results show that the proportion of decedents who, to the knowledge of the KI, discussed their location preferences did not vary significantly across areas (p=0.244). In the Midlands 60.8% of decedents discussed their preferences about location of death compared to 52.6% in the South East, and 47.1% in the Mid West.[57]

Where preferences for location of death were discussed, at six months prior to death the majority of decedents in all three areas wanted to die at home (Figure 4.23a). In the Mid West and South East just over 96% of decedents who had stated a preference said that they would like to die at home compared to 86.0% in the Midlands.[58] In the last week of life these percentages had decreased in all

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[57] Similar proportions were reported in the *Milford Evaluation* of the hospice at home service, wherein 48% (57/119) of carers stated that 'place of death' was discussed with the patient (McKay *et al.*, 2011).

[58] The difference in the proportions of decedents stating particular location preferences at six months prior to death is not significant across the three areas (p=0.279) but >20% of the cells have an expected count of less than 5 making the results unreliable.

areas, with 82.8% of decedents in the South East now stating they would like to die at home compared to 76.1% in the Midlands and 69.0% in the Mid West.[59,60,61]

Of those who stated in the last week of life that they wanted to die at home, the proportion that died at home was 83.3% in the South East, 85.7% in the Midlands, and 75.0% in the Mid West.[62] The availability of an in-patient hospice facility in the Mid West would seem to have an influence on decedent preferences, with the proportion of decedents in the Mid West indicating a preference to die in the hospice, nursing home, or other institution increasing to 31% in the last week of life.

Where decedents had not, to the knowledge of the KI, discussed their location of death preference, the KI was asked where they felt the decedent would have wanted to die (Figure 4.29b). In the South East, 76.2% of KIs assumed that decedents wanted to die at home compared to 71.4% in the Mid West and 67.9% in the Midlands.[63] Of those decedents who were presumed to want to die at home, the proportions who died at home were 37.5% in the South East, 52.0% in the Mid West, and 47.4% in the Midlands.[64]

For decedents who had discussed their preference for location of death with the KI, it was found that 82.8% of decedents in the Mid West died in the location for which they had stated a preference, compared to 86.2% of decedents in the South East and 89.1% of decedents in the Midlands. For decedents where preferences were not discussed with the KI, it was found that based on the KI assumed preference 47.6% of decedents in the South East died in their assumed preferred location of death compared to 60.7% of decedents in the Midlands and 65.7% of decedents in the Mid West. Overall, it was found that 74.5% of total

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[59] The difference in the proportions of decedents stating particular location preferences in the last week of life is significant across the three areas (p=0.022) but >20% of the cells have an expected count of less than 5 making the result unreliable.

[60] If the decedent's preference on where they wished to die changed between the last 6 months of life and the last week, KIs were asked if they knew why this preference changed. The reasons for the change in preference included better symptom control, and not wishing to be a burden on the family.

[61] The Hospice Friendly Hospitals report showed that in the last week of life only 14% of patients would have liked to die at home as reported by bereaved carers (McKeown *et al.*, 2010b, p14). This lower proportion may have been affected by the more complex casemix of these decedents who all died in hospitals.

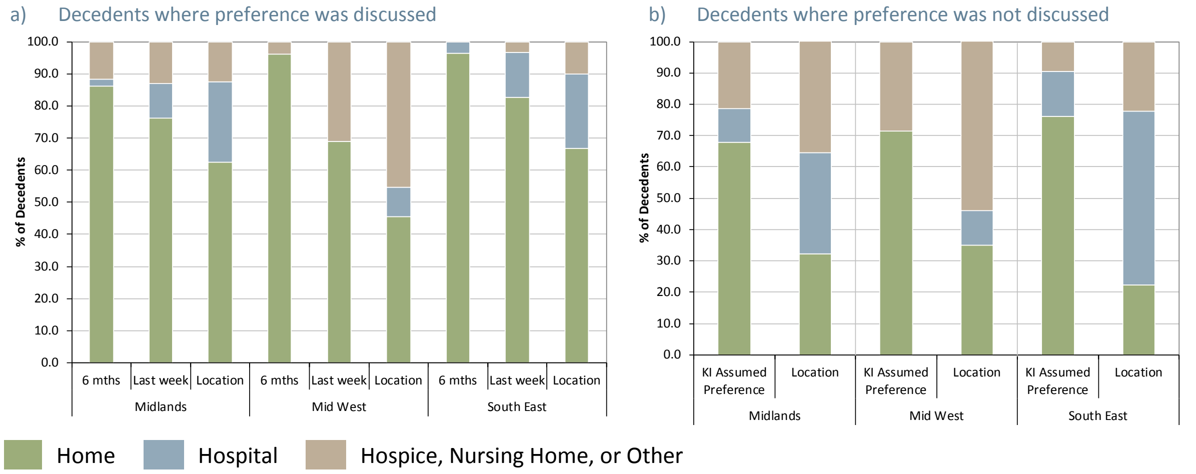
[62] For those decedents who had stated they wanted to die at home in the last week of life there was no significant relationship between their eventual location of death and study area (p=0.193) but >20% of the cells have an expected count of less than 5 making the results unreliable.

[63] The difference in the proportions of KI assumed location of death preferences in the last week of life is not significant across the three areas (p=0.145) but >20% of the cells have an expected count of less than 5 making the result unreliable.

[64] For decedents where the KI had assumed the decedent wanted to die at home there was no significant relationship between their eventual location of death and study area (p=0.145) but >20% of the cells have an expected count of less than 5 making the result unreliable.

decedents died in the location for which they (or the KI assumed) had stated a preference in the last week of their life. This varied from 70.0% in the South East to 73.4% in the Mid West to 78.4% in the Midlands.[65]

FIGURE 4.23 Location of Death Preference by Area



a) Decedents where preference was discussed

b) Decedents where preference was not discussed

Figure 4.24 shows that for total decedents the location of death varied significantly across areas (p<0.001). A higher proportion of decedents in the South East died in hospital (38.3%) compared to 27.5% in the Midlands, and 10.7% in the Mid West. Not surprisingly the highest proportion of decedents dying in hospice, nursing home, or other was in the Mid West (48.0%) compared to 22.5% in the Midlands, and 16.7% in the South East.[66]

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[65] There is a significant association between the preferred (assumed or known) location and actual location of death in all three study areas (p<0.001) but >20% of the cells have an expected count of less than 5 making the results unreliable.

[66] Data reported from the Milford Care Centre in the *Milford Evaluation* of the hospice at home service revealed that 46% of the patients in 2011 died at home, 6% died in hospital, and 48% died in hospice, nursing home, or other (McKay *et al.*, 2011, p156).

FIGURE 4.24 Location of Death by Area

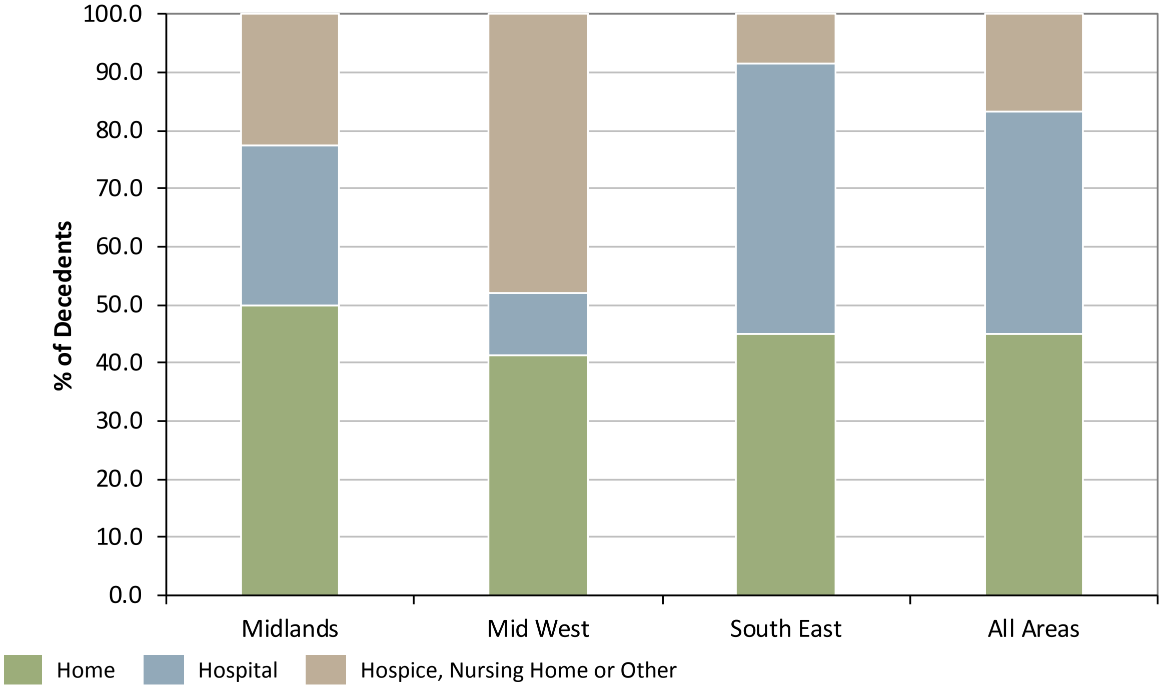

Figure 4.25 shows how the final location of death varied across areas by the characteristics of the decedents. A higher proportion of females died at home in the Midlands (52.5%) and Mid West (47.2%) compared to the South East (38.7%). The variation of death location by sex within areas is not significant in the Midlands (p=0.851) and South East (p=0.141).[67]

Similarly there is no significant variation in death location by age within the Midlands (p=0.498) and South East (p=0.435). In the Midlands a higher proportion of those aged 75 and over died in a hospice, nursing home or other (27.3%) compared to those less than 75 years (16.7%). In the Mid West a higher proportion of those over the age of 75 died in hospital (16.2%) compared to those under the age of 75 (5.3%), and in the South East a higher proportion of those over 75 years died at home (52.9%) compared to those under the age of 75 (36.0%).

In the Mid West there is significant variation in location of death across diagnosis groups (p=0.005) with 26.3% of non-cancer decedents having died in hospital compared to 5.4% of cancer decedents. In the Midlands there is no significant variation in death location across diagnosis (p=0.221). In the South East the majority of non-cancer decedents died in hospital (90.0%).[68]

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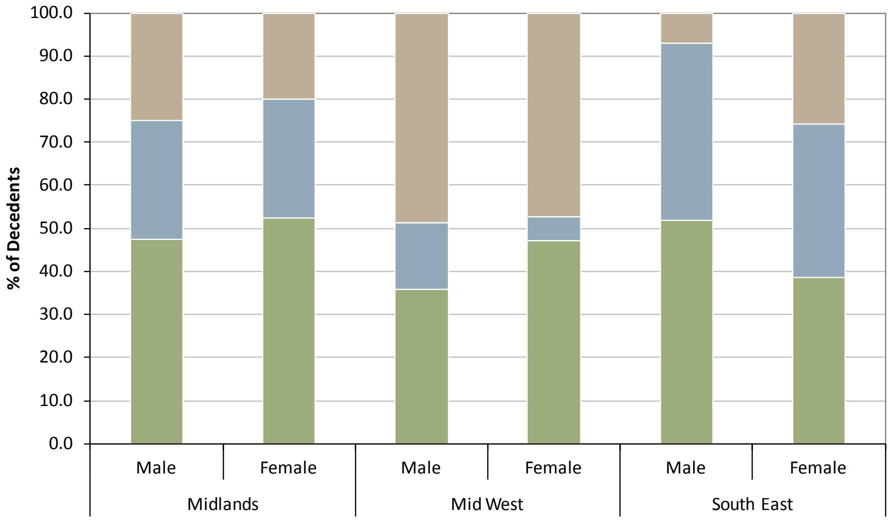
[67] The difference in the proportions of decedents dying in particular locations by sex and age groups is not significant in the Mid West (sex: p=0.319; age: p=0.292) but >20% of the cells have an expected count of less than 5 making the result unreliable.

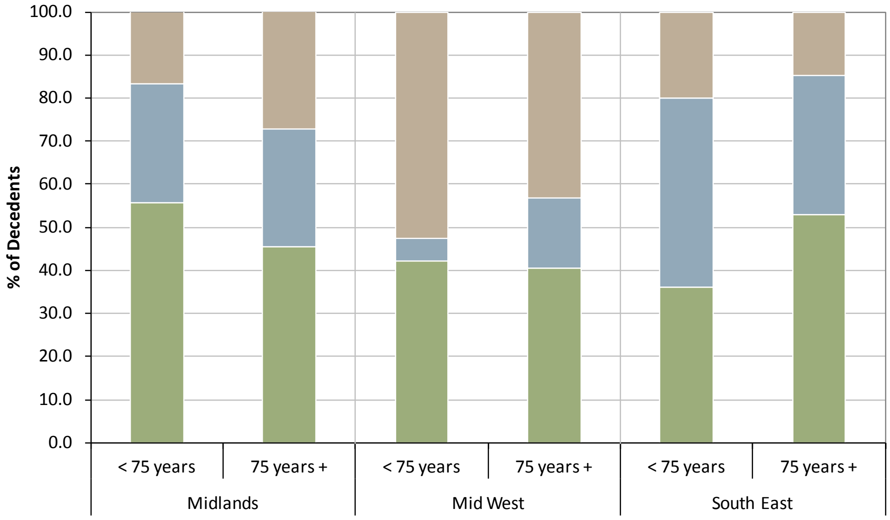
[68] The difference in the proportions of cancer and non-cancer decedents dying in particular locations is significant in the South East (p=0.001) but >20% of the cells have an expected count of less than 5 making the result unreliable.

FIGURE 4.25 Location of Death by Area and Decedent Characteristics

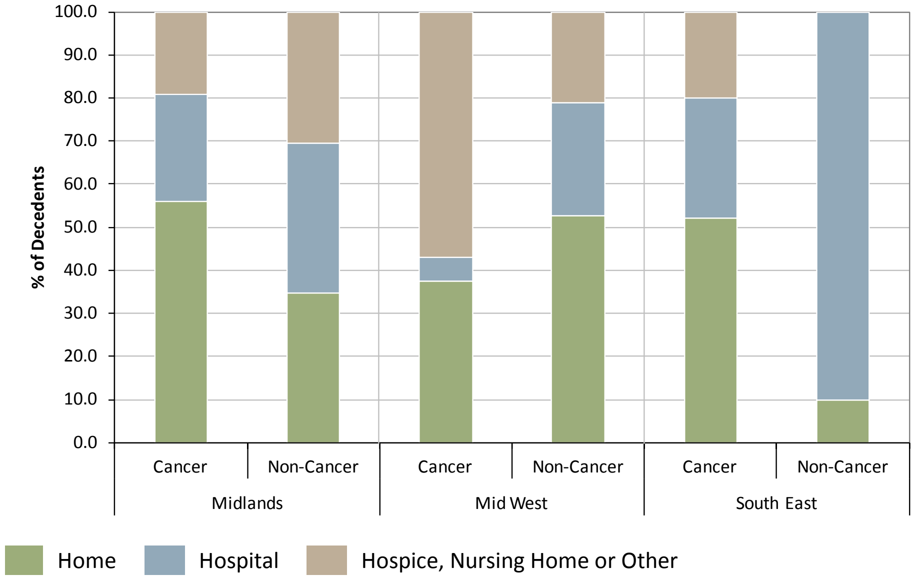
a) Sex



b) Age



c) Diagnosis

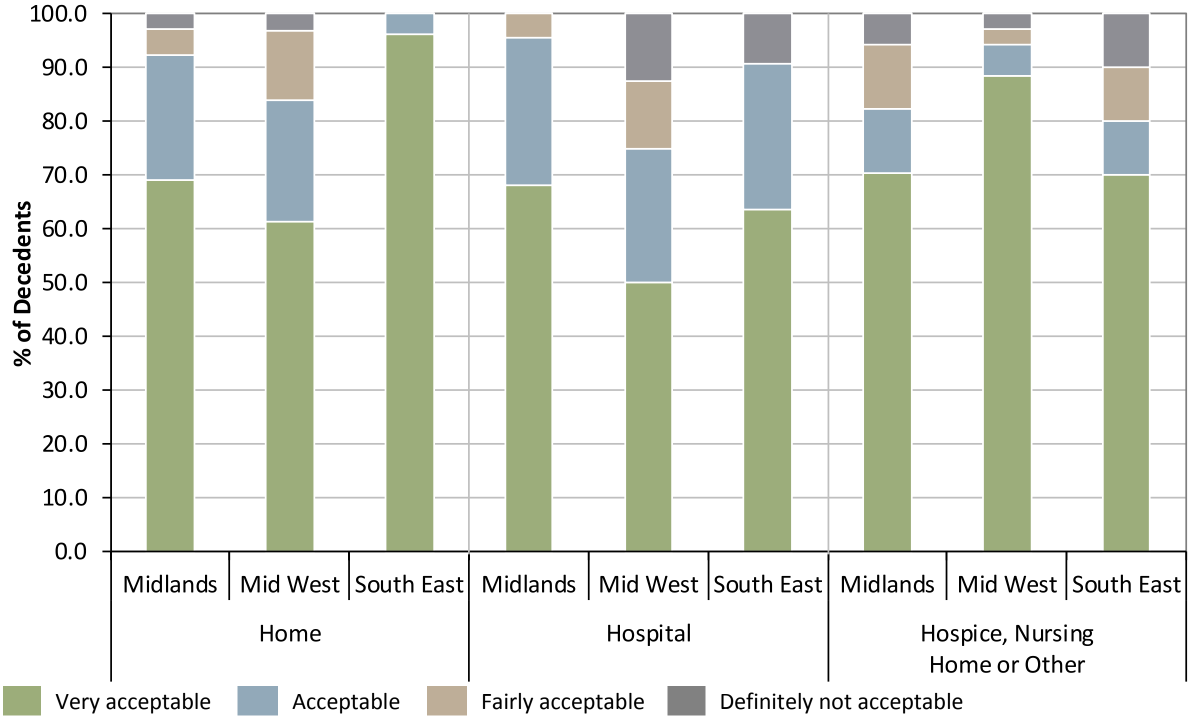


KIs were asked if they felt the decedent's death was acceptable to the decedents and if it was acceptable to the family. Given that there is virtually no difference between acceptability to the decedent and to the family, only acceptability to the family is reported. Figure 4.26 presents the responses disaggregated by location of death. Some of the cells are small so results should be interpreted with care.

Overall, KIs reported that approximately 90% of decedent deaths were 'very acceptable' or 'acceptable' to the family regardless of location of death.[69] Within the different locations, there are differences in the acceptability ratings and KIs reported that 9.6% of decedent deaths in acute hospitals were only 'fairly acceptable' or 'definitely not acceptable'.[70]

The *National Audit of End-of-Life Care in Hospitals in Ireland* reported that 21% of relatives found the decedent's death in an acute hospital to be unacceptable (McKeown *et al.*, 2010b, p30) so the results for deaths in hospital in this sample are more favourable.

FIGURE 4.26 Acceptability of the Quality of the Death to the Decedent and Family



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[69] The difference in the proportions of acceptable deaths at home across areas is significant (p=0.074) but >20% of the cells have an expected count of less than 5 making the results unreliable. The difference in the proportions of acceptable deaths in hospital (p=0.535) and hospice, nursing home and other (p=0.715) across areas is not significant but >20% of the cells have an expected count of less than 5 making the results unreliable.

[70] Statistical tests of differences across areas could not be performed due to the small sample size of these response categories.

Location of Death Summary

- At six months prior to death the majority of decedents in all three areas wanted to die at home. By the last week of life this proportion had decreased in all areas.
- It was found that 74.5% of total decedents died in the location for which they (or the KI assumed) had stated a preference in the last week of their life.
- The location of death varied significantly across areas, and this is likely to have been driven by the presence of an in-patient hospice in the Mid West and the high level of recruitment from the hospital in the South East.
- There is no significant variation in location of death by either age or sex across areas.
- There is significant variation in location of death across diagnosis groups in the Mid West with 26.3% of non-cancer decedents having died in hospital compared to 5.4% of cancer decedents.
- Overall, KIs reported that approximately 90% of decedent deaths were very acceptable or acceptable to the family regardless of location of death but within the different locations the levels of acceptability vary.

4.5.3 Palliative Care Outcomes Scale (POS)

POS was developed for use with patients with advanced disease to improve outcome measurement. It consists of 10 items which assess physical symptoms, emotional, psychological and spiritual needs, and provision of information and support resulting in individual item scores and overall profile (global) scores. An additional question provides patients with the opportunity to list their main problem/s. As in QUALYCARE, in this study POS was asked with reference to the last week of the decedent's life. KIs of 178 decedents, who were not in a coma or unconscious in the last week of their life, were asked to complete the POS carer questions.[71]

This tool has been shown to be reasonably valid and reliable when compared to patients' self-assessments (Higginson and Gao, 2008). The use of this tool was evaluated prior to the QUALYCARE study, and using slight adaptations it concluded that POS can be used retrospectively in bereavement (Gomes *et al.*). As noted earlier, these minor adaptations were applied in this study. It is acknowledged, however, that the use of scales such as POS retrospectively with bereaved KIs is problematic, particularly when evaluating subjective measures such as pain, anxiety, and depression (Addington-Hall and McPherson, 2001; McPherson and Addington-Hall, 2004; McPherson *et al.*, 2008; Jones *et al.*,

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[71] See Appendix 2.1 for the exact wording of the POS questions.

2011).[72] Carer burden has been shown to affect responses to these questions (Higginson and Gao, 2008), and efforts were made in the recruitment process to ensure KIs had the physical, cognitive and emotional capacity to undertake the interview (see Section 3.3). Although POS was originally developed for cancer patients (Hearn and Higginson, 1999), it has also been tested and proven effective for non-cancer patients (Brandt *et al.*, 2005; Bausewein *et al.*, 2010).

Global Score

The maximum (worst) possible score for each individual item on the POS is four. The global POS score is the total score calculated for each decedent for whom there are valid responses for all ten individual item scores for the last week of life, the maximum score being 40 (worst possible outcome).

TABLE 4.6 Palliative Care Outcomes Scale: Global Score for the Last Week of Life by Area

	Total No. of Decedents	No. of Missing Values		Total No. Of Decedents with Full POS Score	Global POS Score		
		Coma or Unconscious	No Answer		Mean	Median	Std. Dev.
Midlands	80	11	14	55	9.6	9	5.94
Mid West	75	18	9	48	7.7	7	5.56
South East	60	7	9	44	8.9	8	5.79
Total	**215**	**36**	**32**	**147**	**8.7**	**8**	**5.78**

Note: Difference in mean scores across the three areas is not significant (p-value=0.266)

The variation in the mean global POS score for the last week of life across the three study areas is not significant (p=0.266), ranging from 7.7 in the Mid West to 9.6 in the Midlands. To put these results in perspective, Higginson and Gao (2008) report a mean global POS score of 10.2 (based on POS carer questions) for a cohort of advanced cancer patients. The higher mean score relative to the findings from the current study may be affected by variations between experiences of cancer and non-cancer patients. Bausewein (2010) compared a cancer and non-cancer cohort using patient-reported data, observing a median total score of 11 amongst cancer patients and 8 for Chronic Obstructive Pulmonary Disease (COPD) patients.

Individual Item Score

Figure 4.27 presents the individual item responses regarding the last week of life for POS 1 to POS 8.[73] The maximum (worst) possible score for each item is four. As well as the individual item responses the mean, median and standard deviation of those item scores are reported as well as the p-value from Pearson's

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[72] See section 3.5.

[73] The results of POS 9 (time wasted – in all areas >97% responded that there was no time wasted on appointments in the last week) and POS 10 (financial and personal matters addressed – in all areas >92% responded that all matters had been addressed) are not presented due to lack of variation across areas.

chi-squared test across areas. The highest proportions of missing values were for POS 7 and POS 8. It seems the KIs were less willing to speculate on the decedent's psychological state in the last week of life.

There is no valid statistically significant variation across the three areas in the responses for any of the POS items. There is some indication that there are differences across the three areas in the responses for POS 1 (Affected by pain) ranging from 0.8 in the Mid West to 0.9 in the Midlands and South East (p=0.057), and POS 3 (Decedent anxious or worried) ranging from 0.7 in the Mid West to 1.2 in the South East (p=0.039), but >20% of the cells have an expected count of less than 5 in each area making these results unreliable. POS 7 (Feeling depressed) also showed some variation across the three areas, ranging from 0.3 in the Mid West to 0.7 in the South East with a lower p-value relative to the remainder of the individual POS scores (p=0.272).

In general, the results show that pain and other symptoms were reasonably well controlled in the last week of life with a mean score of less than one in almost all areas. Mean scores were higher for POS 6 and POS 7 indicating that a larger proportion of decedents were less likely to share their feelings with their families in the last week of life and that in the opinion of the KI the decedent did not feel good about themselves in the last week of life.[74] The highest (worst) mean scores in all areas were reported for POS 4 suggesting that families experience relatively high levels of anxiety and worry throughout the last week of the decedent's life. Similarly, the highest scores were reported for this question in other studies for both patient and staff responses (Brandt *et al.*, 2005; Bausewein *et al.*, 2010) and were also highest in a study that reported both caregiver and patient responses, with patients reporting a mean score of 1.8, compared with caregivers who reported a mean score of 1.6 (Higginson and Gao, 2008).

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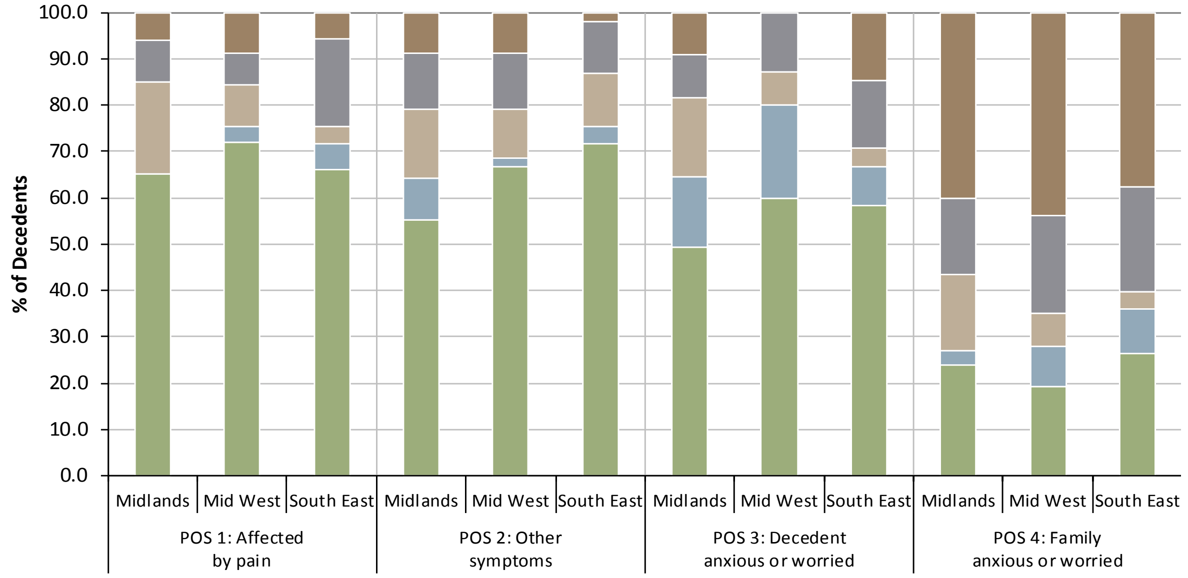
[74] It should be noted that caregiver responses to questions on sharing feelings, whether life felt worthwhile, and whether the patient felt good about themselves as a person, were reported in one particular study as higher than the patient reported responses for these questions (Higginson and Gao, 2008).

FIGURE 4.27 Palliative Outcomes Scale by Area

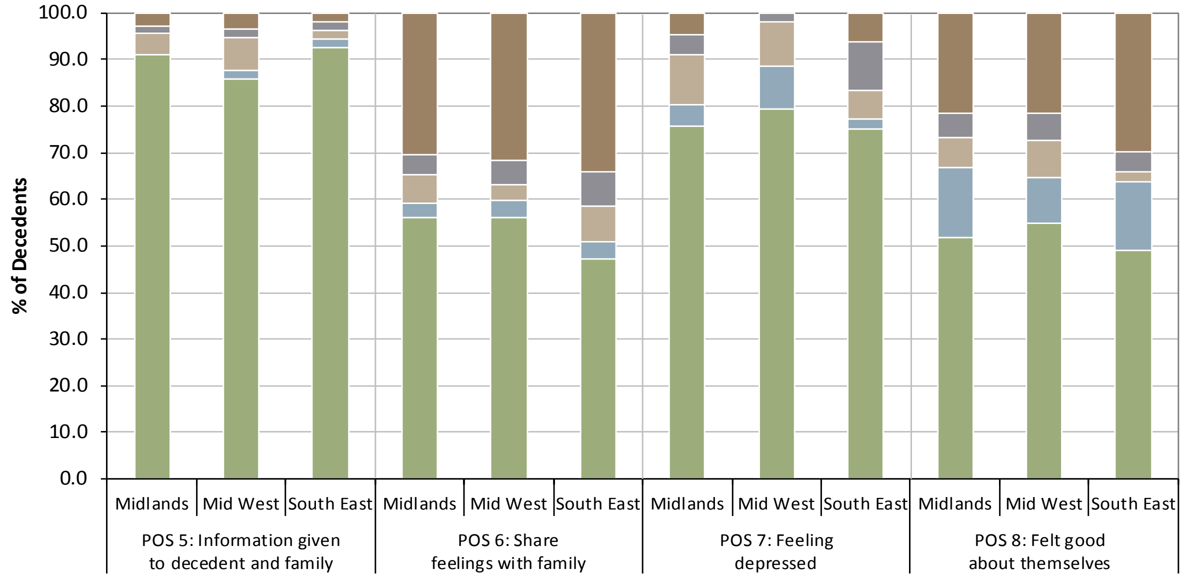
a) POS-1, POS-2, POS-3, and POS-4



Mean	0.9	0.8	0.9	1.1	0.9	0.7	1.1	0.7	1.2	2.5	2.6	2.4
Median	0	0	0	0	0	0	1	0	0	3	3	3
Std. Dev.	1.3	1.4	1.4	1.4	1.4	1.2	1.4	1.1	1.6	1.6	1.6	1.7
p-value[a]	0.057[b]			0.433			0.039[b]			0.314		

🟫	4	Overwhelmingly	Overwhelmingly	Completely preoccupied	Always
⬛	3	Severely	Severely	Most of the time	Most of the time
🟨	2	Moderately	Moderately	Sometimes	Sometimes
🟦	1	Slightly	Slightly	Occasionally	Occasionally
🟩	0	Not at all	Not at all	Not at all	Not at all

b) POS-5, POS-6, POS-7 and POS-8 by Area



Mean	0.3	0.4	0.2	1.5	1.5	1.8	0.6	0.3	0.7	1.3	1.3	1.5
Median	0	0	0	0	0	1	0	0	0	0	0	1
Std. Dev.	0.9	1.0	0.7	1.8	1.9	1.8	1.1	0.7	1.3	1.6	1.7	1.8
p-value[a]	0.910			0.980			0.272			0.902		

🟫	4	None at all	Not at all	Yes, definitely	Not at all
⬛	3	Very little	Occasionally	Most of the time	Occasionally
🟨	2	On request	Sometimes	Sometimes	Sometimes
🟦	1	Hard to understand	Most of the time	Occasionally	Most of the time
🟩	0	Full information	Yes	Not at all	Yes, all the time

Notes: Missing values are excluded from the calculation of percentages.

a Pearson's chi-square test is used to determine if there are significant differences in the POS responses across the areas.

b >20% of the cells in each area have an expected count of less than 5 making the results unreliable.

KIs were also asked an open-ended question about the main problems the decedent had during the last week of their life. In addition to particular problems relating to the diagnosis of the decedent such as swelling, congestion and bleeding, the main problems that were noted included difficulties with eating, breathing, bowel problems, nausea, and swallowing.

When KIs were asked how they would describe the decedent during the last week, approximately two-thirds responded that the decedent was completely disabled; this proportion was similar across all areas ranging from 63.2% in the Mid West to 64.2% in the South East, and 70.1% in the Midlands (p=0.438).

4.5.4 Quality of Life

KIs were asked a series of questions around the quality of the decedent's life in the first nine months of the last year of life, the last three months of life, and the last week.[75] The questions covered five dimensions, namely the decedent's ability to walk about, care for themselves and perform usual activities, their experience of pain and discomfort and any feelings of anxiety or depression. Responses were graded in three levels: 'no problems', 'some problems' and 'severe problems'. Using the responses to these questions a unique health state for each decedent in each time period can be elicited.

Figure 4.28 presents the results for each of the five dimensions across each area and time period under consideration. Also presented are the p-values for Pearson's chi-squared tests which are used to determine if there is significant variation across areas in each time period for each of the five dimensions.

The results show that there is no statistically significant variation across areas for all of the quality of life dimensions and responses follow similar patterns across areas in each time period.

In all three areas, the results show a decreasing ability of the decedent to walk about, care for themselves and perform usual activities as the last year of life progressed. Decedents were reported to have experienced decreasing levels of pain and discomfort as the year progressed and although the reported levels of anxiety and depression increased between the nine-month and three-month periods they also decreased in the last week of life.

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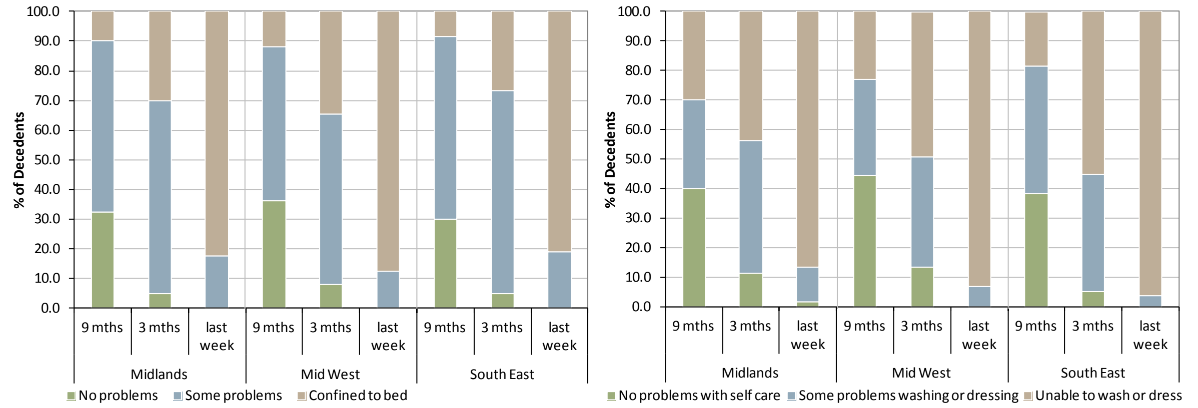
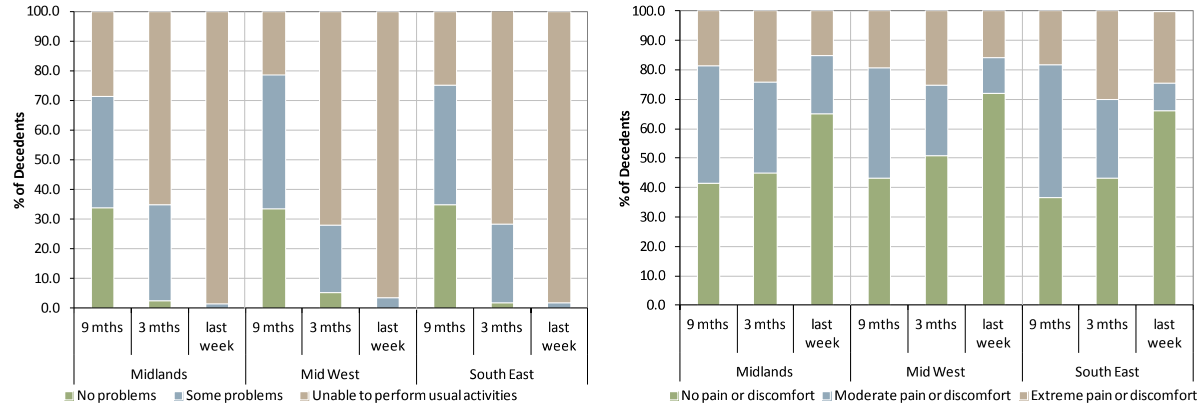
[75] These questions are from the EQ-5D-3L descriptive system. The EQ-VAS (visual analogue scale) was not used.

FIGURE 4.28 Quality of Life Indicators: Five Dimensions by Area



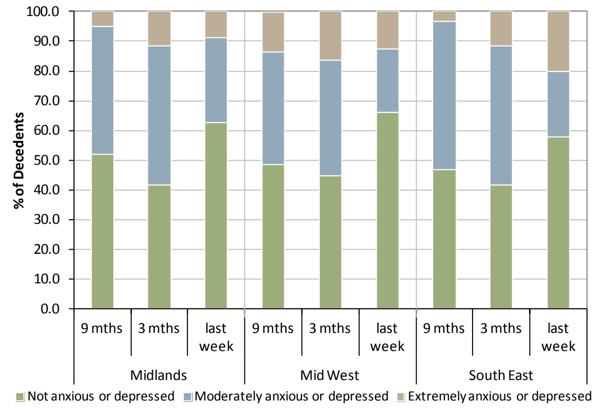
Walking About

Self-Care



Usual Activities

Pain or Discomfort



Anxious or Depressed

Pearson's chi-square across areas p-value

	9 mth	3 mth	Last Week
Walking About	0.848	0.710[a]	0.600[a]
Self-Care	0.371	0.425	0.364[a]
Usual Activities	0.831	0.505[a]	0.729[a]
Pain or Discomfort	0.934	0.816	0.364
Anxious or Depressed	0.141	0.820	0.449

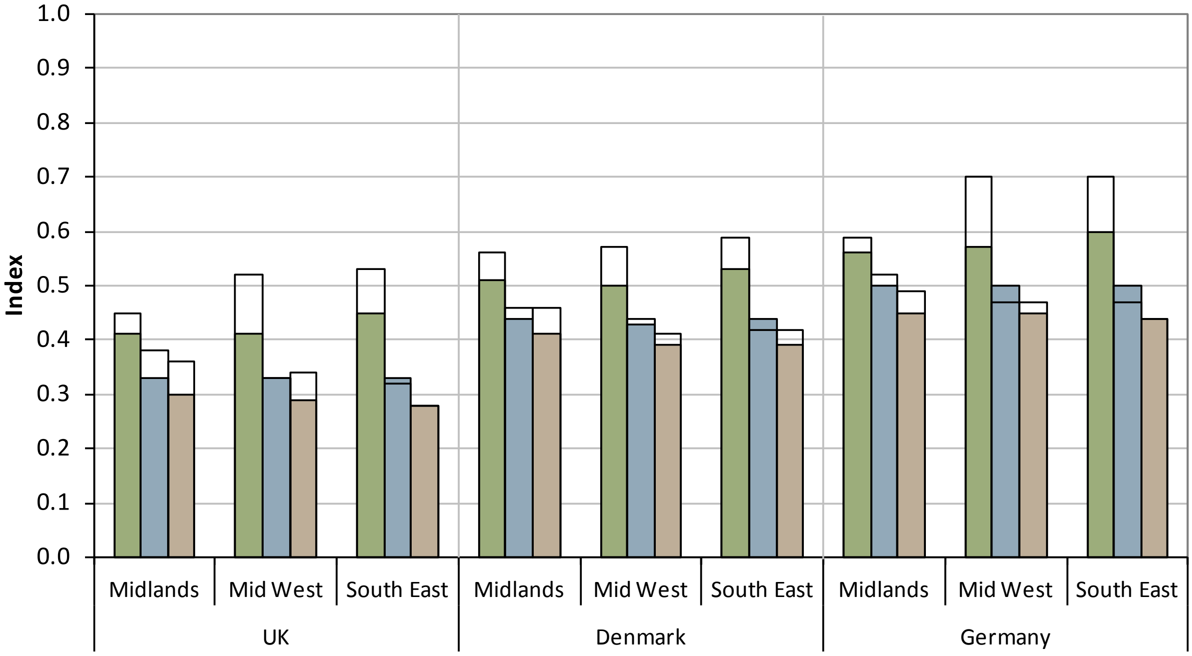
Notes: Missing values are excluded from the calculation of percentages.

a The difference in the proportions of decedents responding in each category across areas in the time period is not significant but >20% of the cells have an expected count of less than 5 making the results unreliable.

Quality of Life Index

The health states are converted into a single summary index by applying a formula that attaches values to each of the levels in each dimension.[76] A value set for Ireland is not yet available so the value sets for the UK, Denmark and Germany are used for comparative purposes. Figure 4.29 shows the mean and median single index values across areas and time periods using the value sets from the three countries. A score of one implies full health. In all cases the mean index score fell over time during the last year of life. The mean index score across areas in each time period did not vary significantly regardless of the value set used. Paired t-tests showed that within each area there was a significant decrease in the mean index score between nine-month and three-month periods and between the last three months and the last week of life in all areas, regardless of the value set used.

FIGURE 4.29 Quality of Life Index by UK, Denmark and German Value Sets, Area and Time Period



p-value[a]	UK	Denmark	Germany
9 mth	0.813	0.788	0.789
3 mth	0.999	0.978	0.993
Last week	0.972	0.899	0.961

🟩 9 months ▨ 3 months ▨ Last week – Median

Notes: Missing values are excluded.

a ANOVA is used to determine if there are any significant differences in the mean values across the three areas in each time period.

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[76] These value sets have been generated by asking members of the general public to consider health states described by the EQ-5D which they may or may not have experienced and to value those states. Value sets have been derived in several countries using the EQ-5D visual analogue scale valuation technique or the time trade-off (TTO) valuation technique. In this case, value sets using the TTO method from the UK, Denmark, and Germany are used to calculate the index.

Palliative Outcomes and Quality of Life Summary

- It was not intended that POS scores would be derived from interviews conducted so long after the death of the decedent (see section 3.5). They are reported with the proviso that POS may not perform well in this context.
- There are no statistically significant differences in POS scores across the three areas.
- There are no statistically significant differences in quality of life scores across the three areas.
- It may be useful to revisit the quality of life index when a value set for Ireland has been established.

4.6 Findings on Objective 4 – Comparison of Costs and Outcomes

Objective

4) Jointly assess the pattern of costs and outcomes to determine any systematic interactions, e.g. if better outcomes are associated with lower or higher costs.

As discussed in Section 2.1, there are challenges in applying standard economic evaluation techniques to palliative care. In particular, assessing outcomes in a palliative care context using standard QALY-type measures has important limitations and is not persued in this study. It is argued that valuing the 'outcomes' of a sample of patients who had received SPC prior to their death in terms of QALYs would not adequately capture their experiences of available services during the last months of their life.

As an alternative approach, a range of outcome measures have been employed in the study to determine any systematic interactions with cost patterns. The POS and Quality of Life indicators lend themselves to systematic comparisons with costs. In particular, there is scope for constructing indices by generating and combining summary POS (or quality of life) scores with cost scores. Appendix 6.3 presents a possible methodology for carrying out this analysis. However, a number of factors mitigate against focusing on these generated cost-outcome indices in this study. Given the absence of significant variation across study areas in the summary POS and quality of life scores, comparisons across study areas would be driven by costs. Thus, a joint assessment of the pattern of costs and these outcomes would not be able to detect anything other than differences in costs which are presented in Section 4.4. This is coupled with uncertainties around the accuracy of the POS and quality of life measures in the context of long time lags between data collection and the events being recalled as discussed earlier. Such cost-outcome indices could however be explored in other studies where POS performs a more discriminatory role across the comparators of interest.

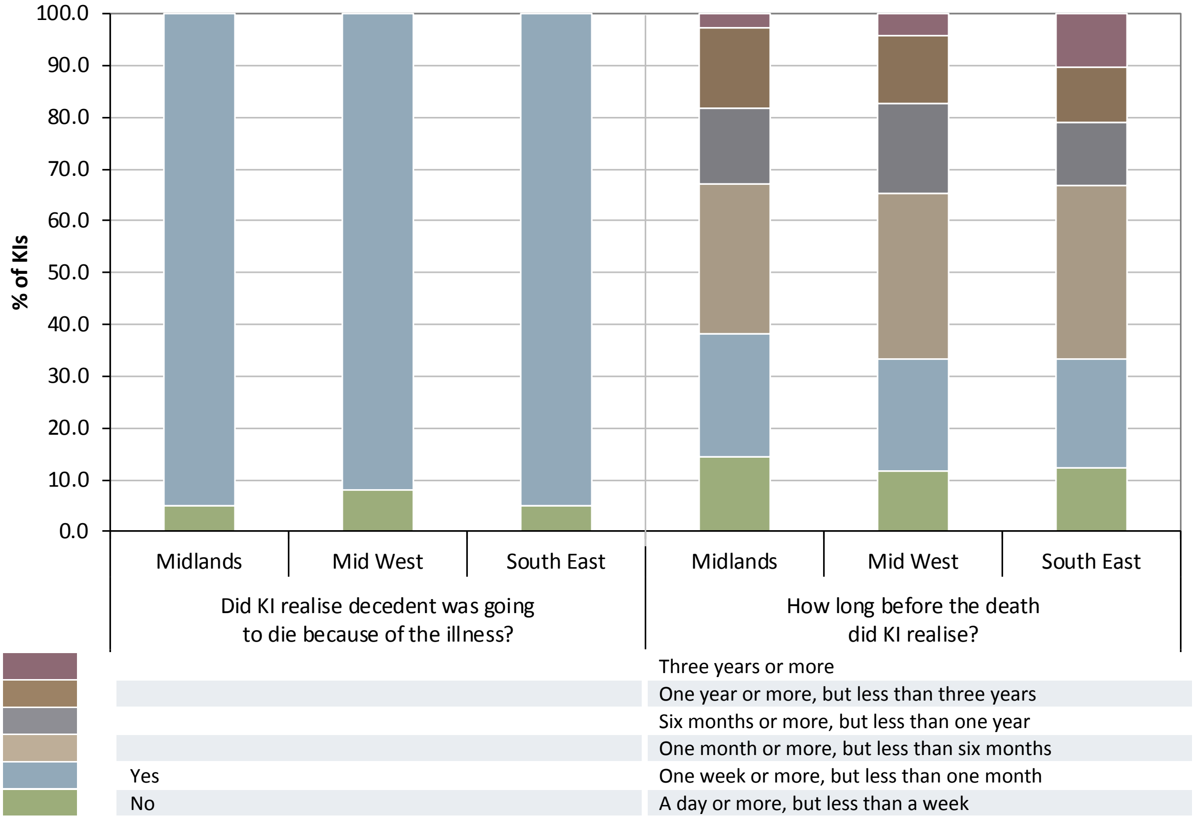
Taking a less index-driven approach, it is possible to highlight some interesting patterns in the data that warrant further investigation and these are discussed in Section 5.6.

4.7 Other Issues Surrounding Death

KIs were asked a series of questions surrounding the death of the decedent. The questions related to the realisation of death and the level of acceptance of death.

Realisation of Death[77] KIs were asked if they realised the decedent was going to die from their illness; the majority knew and there was no significant variation across areas (p=0.679) (Figure 4.30). Those who knew were asked how long before the death they came to this realisation with over one-third in each area responding that they didn't know until the last month of life and there was no statistically significant variation across areas (p=0.833).

FIGURE 4.30 KI: Realisation of Death by Area



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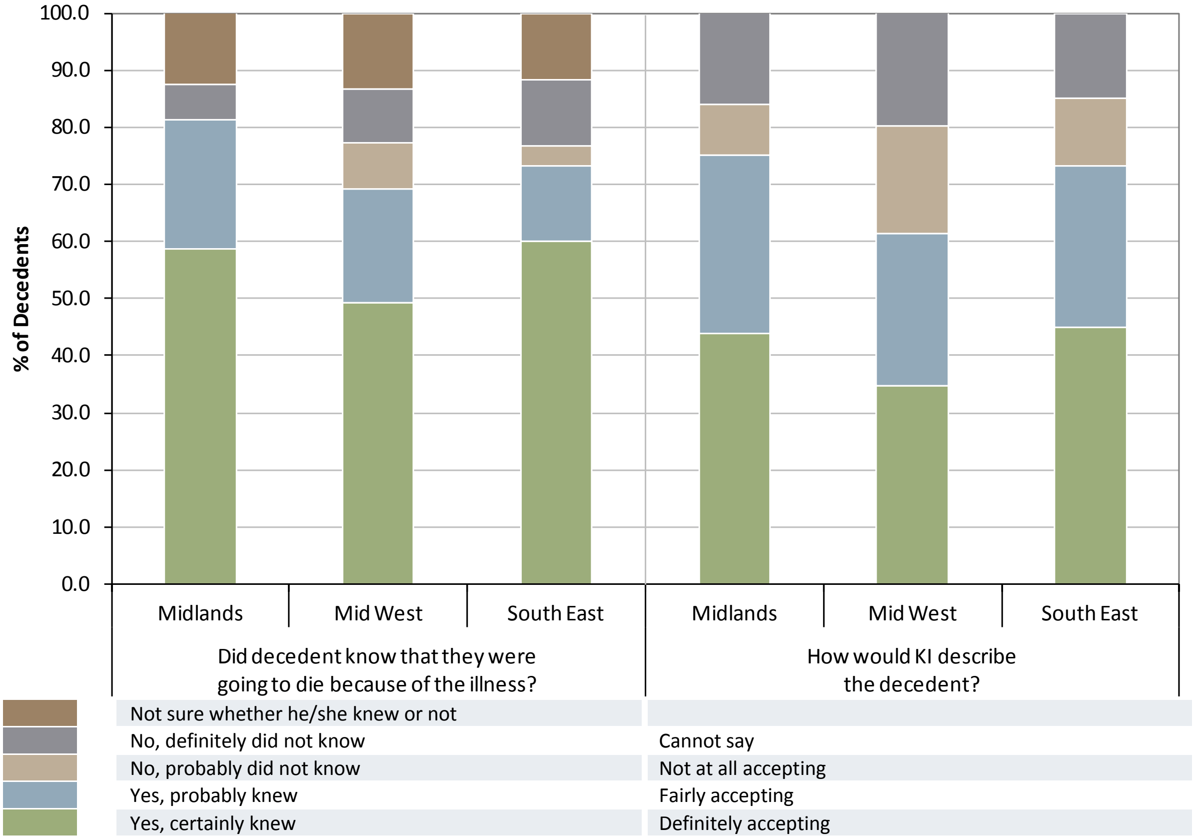
[77] These questions are similar to those asked in the QUALYCARE study (Gomes *et al.*, 2010). At the time of writing, comparative results were not available from the QUALYCARE study; therefore it is not possible to compare outcomes from that study to those presented here.

Acceptance of Death[78] KIs were also asked if the decedent knew they were going to die from their illness and how they would describe the decedent's level of acceptance of the situation (Figure 4.31). The results show that in the majority of cases the decedents certainly knew they were going to die (p=0.240) and were definitely or fairly accepting of this eventual outcome with no variation in responses across areas (p=0.544).

FIGURE 4.31 Decedent: Acceptance of Death by Area



Post-Bereavement Contact

KIs were asked about the contact they or other family members had with the SPC team since the decedent had died. Of those KIs who had received visits from the SPC nurses prior to the death of the decedent, 38.8% in the Midlands, 22.4% in the Mid West, and 48.6% in the South East had made contact with the team since the decedent died (p=0.014).

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[78] *Ibid.*

Issues Surrounding Death Summary

- The majority of KIs and decedents knew that the decedent was going to die and the majority of decedents were accepting of the eventual outcome. There was no statistically significant variation in responses across areas.
- Post-bereavement contact from the SPC team varied significantly across areas: 38.8% in the Midlands, 22.4% in the Mid West, and 48.6% in the South East (p=0.014).

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5

Key Findings and Discussion

5.1 Introduction

The overall aim of the study was to examine evidence on service use, cost of care, and outcomes for decedents who received palliative care in three parts of Ireland. The three specialist palliative care services chosen for comparison represent different levels of development and, to an extent, different models of care. In the Mid West this includes a facility with a range of in-patient and ambulatory palliative care services, while in the other areas the services are mainly provided on an outreach basis in people's homes. This means that there are differences in the patterns of service use and trajectories of care, including the timing of accessing specialist palliative care services. These differences are presented in detail in Section 4 and more detailed information on the differences in specialist palliative care services across the three study areas are presented in Appendix 3.

Data on use of a wide range of healthcare and informal care services were gathered for each of the decedents in the study. This allows for some analysis of how different types of formal health and social care and informal care provided to patients are linked. It also allows for a fuller picture of costs of care at the end of life, and how the burdens fall on the different providers as well as families and friends.

As will be discussed, where specialist palliative care services are more developed it is possible to reduce use of care from other health and social care services, and the evidence suggests it may be possible to improve the options available in terms of preferred places of care and places of death. Higher costs of palliative care may be justified both because there is a reduction in costs to health services and also a more appropriate trajectory of care and improved experience for patients and their families.

Data on service utilisation, costs, and experiences of patients and families who received a specialist palliative care service were collected from a range of sources, including interviews with bereaved relatives (or friends) and, where available, administrative data from service providers. This provides an opportunity to make some comparisons in reported levels of service use, to assess the extent to which estimates based on different sources of data differ, and if any differences are systematic. In the case of in-patient hospice care the reported levels were similar to those in the administrative data, but for outreach services the KI-reported levels of service use were higher (see Appendix 4), suggesting either that there is a tendency to over-report these visits or that visits from other providers were being counted.[1] Since the estimates of the high cost service elements are taken from administrative sources, any overestimation of the costs of outreach services does not materially change the overall cost estimates.

While this study does not allow direct comparison of the costs and experiences of those decedents who received a specialist palliative care service and those who did not, it does allow costs, access to and use of services, and some aspects of the appropriateness of services and patient experiences to be compared across different models of service delivery.[2]

In the following section the key messages emerging from the data are summarised and discussed.

5.2 Palliative Care or End-of-Life Care? – Patterns of Referral

The timing of referral to specialist palliative care can reflect the needs of service users, but can differ depending on the capacity of SPC services and the extent to which other clinicians recognise the potential value of such referrals. Where SPC is well developed and where its role is well understood it is likely that there will be more referrals and that these will in general be earlier. Given that SPC services in the three study areas differ substantially, it is interesting to see how this affects those who are referred and when.

It is appropriate for many people to use SPC services only in the last few weeks of life, but there is substantial variation in the timing of referral to SPC across the three study areas. Over 20% of patients in the Midlands were referred in the last week of life, but this proportion was only 11.5% in the South East and 15% in the Mid West. The proportion referred in the last month of life was 36.5% in the

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[1] Interviewers in this study reported that KIs found it difficult to distinguish between the different types of nursing staff visiting the decedent, for example, visits by the Public Health nurse and the community SPC nurse.

[2] Further comparisons with services provided in Dublin will be carried out in the near future using data from the International Access, Rights and Empowerment study (The IARE study) of London, Dublin, New York, and San Francisco.

South East, 33.8% in the the Mid West, and 45.6% in the Midlands. Although differences are smaller, the same pattern occurs for referral in the last six months of life, with more early referrals in the Mid West and fewer in the Midlands.

Clearly, the SPC services in all areas are providing more than end-of-life care, with some people receiving support for long periods. However, where services are more fully developed this is reflected in earlier referrals to specialist palliative care. There are several reasons why earlier referral may improve patient experiences. It increases the chance that there will be a gradual and orderly transition between healthcare services with a more curative intent and those with a more palliative intent. There is emerging evidence from other studies that those referred earlier are more likely to have fewer high cost interventions and may have better quality of life.

The intensity of use by decedents in this study of most healthcare services, including SPC, increased in the last three months of life when compared to the previous nine months, in line with other evidence that use of healthcare is concentrated near the end of life (Polder *et al.*, 2006; Fassbender *et al.*, 2009). As will be discussed below, while the cost of palliative care in the last three months of life is higher where services are more developed, the use of other health services is lower where patients have more access to palliative care services.

5.3 Service Access, Utilisation, and Perceived Quality

5.3.1 Use of Community Care Services

The patterns of use of community SPC services were similar in the three study areas. In each area the proportion of decedents using the services and intensity of service use was higher in the last three months of life than in the previous nine months. Nurses play the largest role in provision of community SPC services, and visits are augmented with phone support.

Comparing the first nine months and the last three months of the last year of life there is a shift in the patterns and the intensity of use of other community healthcare services. Fewer decedents used GP services in the last three months relative to the nine-month period, but those who did used them more intensively. Conversely, a higher proportion of decedents had PHN visits in the last three months of life than in the previous nine months, with intensity of use also increasing over the period. Comparing means and medians allows some insight into the distribution of service use. In the case of PHN services the care levels vary considerably, with a number of very intensive users bringing up the mean.

The use of services from allied health professionals in community settings shows that most decedents did not use any of the services (although in the case of the Mid West some patients receive these services as part of specialist palliative day care and in-patient hospice services). Chiropody was the most widely used allied health professional service, and there were fewer users in the last three months compared to the previous nine. For the other allied health professions there was increased use amongst service users in the last three months. The overall low use of allied health professional services may reflect shortages of such staff and difficulty in gaining access. This may be of some concern since some of these services can be important in retaining an individual's independence and so reducing admission to institutional care settings.

The difficulty in gaining access may also suggest that there are advantages in making such services available via day care and outpatient/walk-in facilities. Provision of this sort is an important feature of the specialist palliative day care and in-patient hospice services in the Mid West, but use of individual services within this provision was not recorded in the KI-reported data. It is acknowledged that the KI-reported levels of use in the Mid West are lower than actual use of allied health professional services.[3] However, since specialist palliative day care and in-patient hospice stays were included in the cost calculations this shortcoming does not apply to the estimated costs.

This study was not able to determine with certainty differences in the dependency of the decedents cared for in the different settings (see Section 3.5), although there is indicative evidence that in some respects decedents with slightly higher levels of needs were supported in the community in the South East and Mid West. To some extent the feasibility of remaining at home depends on interventions to retain mobility and other skills, but will also depend on the availability of social care and especially home helps. The use of home helps varies between the areas with use being significantly higher in the Mid West and South East than in the Midlands, and this may reflect higher dependency of those who remain outside institutional settings. Informal care utilisation patterns further suggest higher dependency levels amongst decedents living at home in the South East relative to the Mid West and the Midlands.

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[3] The extent of allied health professional utilisation in the specialist palliative day care centre and in-patient hospice service are outlined in Appendix 4.4.2.

5.3.2 Variation in the Use of Acute In-Patient Hospital Care and Nursing Homes

It was not possible in this study to determine if the recorded admissions to acute hospitals or nursing homes were appropriate. However, there is extensive evidence that many admissions to acute hospitals are not appropriate, and reflect the lack of viable alternatives (PA Consulting, 2007). The patterns of service use in this study show that where in-patient hospice services are available (as they are in the Mid West) the level of admissions of decedents with both malignant and non-malignant diseases to acute hospital beds is significantly lower in the last three months of life. Patients in hospice beds can receive many of the same services that are provided in hospitals as well as specialist palliative care. While hospice beds and hospital beds are not substitutes in the sense that they have exactly the same purpose, they are substitutes in the sense that when no hospice bed is available there is more chance of an admission to a hospital bed. It is therefore reasonable to argue that the experiences of patients will generally be better where hospice services can prevent some hospital admissions.

In addition to reducing hospital admissions, the patient experience may be improved in other ways as the presence of fuller palliative care services (embodying characteristics along the lines of those outlined in the NACPC report, see section 1.4.2) can be shown to change the likely trajectory of care in the last year of life. One interesting finding in this study is that KIs in the Mid West reported that it was relatively easy to gain access to hospice beds when needed, while in all areas, and in particular in the Midlands and the Mid West, a relatively high proportion of KIs reported difficulties in gaining access to acute hospital beds. This may be important given the emerging evidence from the other studies that people are very stressed by process difficulties in accessing care near the end of life as reported at the recent Buildcare conference (Kings College London, 2014).

5.3.3 Variation in Perceived Quality of Care in the Different Settings

The quality of SPC services (hospice and community) are rated very highly by the KIs in the study, with the highest mean reported values among all aspects of care and all providers. Given the diversity of how these services are delivered it is interesting that they are so universally given high ratings. This finding deserves further and more intensive study. It may be the case that what determines the perceived quality of SPC is at least in part the attitude and commitment of those providing the services, and the quality of service they are able to deliver.

The reported quality of in-patient hospital care was lower, particularly in terms of emotional support for families, although management of symptoms in hospitals was generally highly rated. The rating of in-patient hospital care was not restricted to specialist palliative care services, and may reflect both underlying problems in the experience of hospital care, and a more general perception amongst patients, their families and healthcare professionals of the inappropriateness of the acute hospital setting for provision of services for the majority of people nearing the end of life (Hospice Friendly Hospitals, 2010).

The area in which the in-patient hospital team scored lowest on quality measures, the Mid West, was the only area in the study in which there was an in-patient hospice service. The in-patient hospice team scored higher on all six aspects of care (i.e., communication with the decedent and family, management of symptoms, emotional support, respect for decedent's wishes and respect for changes in decedent's wishes) than the in-patient hospital team. This suggests that when both in-patient hospital and hospice services are available KIs are better able to rate the services as they have a point of comparison and that KIs may have had difficulty in judging service quality when they had limited knowledge of potential alternatives.

5.4 The Role of Informal Care

A surprising finding was the variation in the levels of informal care provided in the different study areas, suggesting that in the South East the patients who remain at home may be on average more dependent than in other areas. There is some other evidence to support the possibility of differences in dependency of those cared for at home. Although there is no significant difference in the admissions to nursing homes among the three areas in the study, the length of stay of patients admitted to nursing homes is longer in the Midlands, which may reflect less capacity to care for very dependent people in their own homes.

As would be expected, the proportion of decedents requiring informal care and the intensity of use (in terms of minutes of care per day) is generally higher in the last three months of life than in the previous nine months. Informal carers are mainly spouses or children, and mainly female.

5.5 Outcomes in Palliative Care in the Three Study Areas

As reported above, the satisfaction with SPC services was high in all three areas as rated by the KIs in the study.

An important objective in many cases is for the patient to die in an appropriate (and/or their preferred) location. It is recognised that a patient's preferred place of death may change during the course of an illness including as the time of death approaches, and that this preference is affected by the availability of services. Overall, almost 75% of decedents in this study died in the location for which they (or the KI assumed) had stated a preference in the last week of their life.

There is a very marked difference in the place of death between the three study areas. Although the proportions dying at home are quite similar, significantly fewer decedents died in hospital in the Mid West compared to the other areas. The availability of in-patient hospice services means that more decedents in the Mid West sample died in this setting relative to other locations (e.g, home, nursing home). It is, however, interesting to note that those with cancer were very unlikely to die in hospital in the Mid West, but those dying of other causes remained quite likely to die in hospital (but still less likely than in the other areas).

The reported palliative outcomes for decedents, as measured by POS, were also generally very good (i.e., low mean POS scores), with differences in mean POS scores between the study areas being small and for most POS items, not statistically significant. At most, the reported POS scores suggest the need for some focus to be given to communication and support to reduce anxiety and worry experienced by families during the last week of their relative’s life. In this study there has been the additional challenge that in some cases the timing of data collection relative to the death of the decedent was later than planned, and there are problems in the use of POS in this context. The POS scores have been reported in Section 4 with qualification about the validity of POS when applied in this time context. There remains a problem of how best to measure outcomes (e.g., benefits or otherwise) accruing from the receipt of specific services such as specialist palliative care at the end of life. The difficulties encountered in this study support the need to develop more sensitive and context-specific tools to assess differences in outcomes in palliative care.

The mean scores on the quality-of-life dimensions do not show any statistically significant differences across the study areas. This may not be surprising since there is a body of evidence that such scores are not very sensitive to differences in the context of complex care (Douglas *et al.*, 2005).

5.6 Comparing Costs and Outcomes

As outlined in section 4.6, there are no clear systematic patterns emerging in the behaviour of the POS and Quality of Life outcome measures relative to the costs. Since there are no significant differences in the reported POS and Quality of Life outcome measures across study areas, any difference in the ratio of costs and these outcomes must come from differences in costs. There are several possible explanations for the failure of this study to find statistically significant differences in the POS and Quality of Life measures. In all cases the reported outcomes on these scales are good, so the scope to find differences is small. These high ratings may reflect gratitude for the efforts made by the palliative care staff. It may be that the high reported satisfaction with all the models of care in the study reflects good experience in terms of quality of those services that are provided and the manner in which staff do their work. For any given availability of services it may not matter whether the balance is more towards outreach or more towards facility based services. As discussed below, KIs have limited knowledge of different models of care and make judgements based on their experience. Although this is a large study, it may be that it would require larger samples to detect relatively small differences in palliative outcomes as measured on these scales.

There has been a lively debate in the literature about the usefulness of existing measurement tools in the context of complex interventions (Normand, 2009). Several strategies are under review, and it is plausible that there are measurable (if not necessarily large) differences that are not detected in this study due to insufficiently sensitive measurement tools.

It is likely that the KIs responding to the questionnaire have only had experience of one type of SPC service, that available in their own area. Therefore they would be unable to rate the service received by the decedent in the context of the type of services available in other areas. The lower rating given to hospital care where in-patient hospice care is available would support the idea that knowledge and experience of a wider range of services affects the ratings given to what has been experienced.

Although there is no significant difference in the POS and Quality of Life outcome measures between the three areas, there are differences in process that may be associated with experiences of different qualities. The most notable are in location of death (and consequently the experience in the last days of life) and rated quality and accessibility of care. Although cost per patient is higher in the Mid West, the number of decedents in the Mid West sample who die in hospital is much lower. Given the clearly stated preference in most cases for a death outside of hospital it is reasonable to believe that this higher cost is in most cases associated with a better experience for patients and families. Poorer levels of perceived quality of (including acceptability of death), and greater difficulties in accessing, in-patient hospital services when compared with SPC services are also identified in the data. Together these outcome measures point to the desirability of facilitating in-patient hospice use as an alternative to in-patient hospital care where appropriate.

In other areas of healthcare it has sometimes been found that many different approaches can work (and also can fail). The three sets of palliative care providers in this study provide different services, and to an extent provide services in different ways. This study has been able to identify some differences in the care used (much of which reflects differences in availability). There is no evidence from this study of advantages of particular models of delivery (for example allied health professionals working in day care or outreach care), although there may be both cost and access advantages of co-ordinated access to a range of services in a day care setting. It would be useful to look more carefully at both the overall range and scope of services as well as the ways in which they are delivered, but that is beyond the scope of this study.

This study did not set out to compare the costs of care in the end-of-life period with or without palliative care. Studies that have done this generally show better experiences and outcomes at similar or lower cost (see Section 2).

This study does show that there is some reduction in use of in-patient hospital care where hospice beds are available, but the overall costs of care are slightly higher where there is a fuller specialist palliative care service. The effects on informal care burden are not clear, and in all cases the costs and time commitment from informal care is high. It would be interesting to explore whether increased formal care services can reduce the burden on informal carers.

As discussed in Section 3.5, there is always a risk in a study of this sort that there are differences in the needs of the decedents recruited in each area. There are some hints in the findings that would be interesting to explore further. Whereas there are no significant differences in the overall cost of informal care, the breakdown of the different elements of informal care suggests there may be some differences in patient needs, as judged by help with daily living tasks. Although the differences in costs of care between the three study areas are small, this could be driven by differences in needs.

Overall this study shows high levels of satisfaction with SPC services in the three study areas. Patterns of service delivery and utilisation vary substantially across the three areas, with slightly higher mean costs where SPC services are more developed, but to some extent more services provided by SPC services reduce the use of other health services. There is a clear need for better measurement tools to compare costs and outcomes or experiences in palliative care, to allow comparison of different models of care.

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Appendix 1

Timeline of Key Policies/Reports on Palliative Care in Ireland

Year	Title and Source	Key Content/Recommendations
1996	DoHC, 1996 *Cancer Services in Ireland : A National Strategy*	The strategy acknowledges the role played by palliative care in improving quality of life for patients with terminal illness. It underlines the requirement for the expansion of palliative care services in Ireland. It also acknowledges the significant role played by the voluntary sector in palliative care provision and the importance of the primary care sector.
1999	Eastern Health Board, 1999 *Needs Assessment for Specialist Palliative Care Services in the Eastern Health Board Area*	This needs assessment report highlights the need for a comprehensive specialist palliative care service in the Eastern Health Board Area, including home care, day care services, outpatient services, specialist palliative care beds, psychosocial support, and a facility for education, research and collaboration. It acknowledges the importance of service monitoring, evaluation, and research and the need to be cognisant of population trends.
1999	Keegan *et al.*, 1999 *Care for the Dying – Experiences and Challenges*	This is a study of quality of health service care during the last year of life for patients at St James' Hospital, Dublin, from their relatives' perspective. The main recommendations arising from interviews with next of kin highlighted: - Importance of promoting the concept of a good death - Additional training for clinicians in communication - Awareness of death – formally assigning responsibility for informing patients and family members using protocol that outlines roles, and preserves flexibility - Making provisions for privacy at time of death - Importance of the continued development of the palliative care service - Symptom control – the importance of managing expectations and distress - Immediate access to Accident and Emergency and outpatient services for patients with advanced and progressive illness or short prognosis - Bereavement follow-up.
2001	DoHC, 2001a *Primary Care – A New Direction Quality and Fairness: A Health System for You*	The strategy outlines the benefit of the provision of a seamless service by integrating the primary care team with the community-based specialist palliative care team. This would facilitate users by giving them a single point of contact to access specialist palliative care services in the community. This is based on the concept of 'shared care', the success of which relies upon agreed objectives and locally developed written guidelines.
2001	DoHC, 2001b *Report of the National Advisory Committee on Palliative Care(NACP)*	This reports on existing service provision and future requirements of palliative care services in Ireland. The report provides detailed recommendations on all aspects of the palliative care service in Ireland including, specialist palliative care services, specialist palliative care units, specialist palliative care in acute general hospitals, palliative care in the community, bereavement support, and education, training and research. The principal recommendations include the following. - Palliative care services should be structured in three levels of specialisation, all of which should be available in each health

Year	Title and Source	Key Content/Recommendations
		board area: • Level 1: Palliative Care Approach – applied by all health care professionals • Level 2: General Palliative Care– applied by those with some additional training and experience in palliative care • Level 3: Specialist Palliative Care – services whose core activity is limited to the provision of palliative care - Adequate levels of public funding should be provided for provision of palliative care services. - Priorities for development of specialist palliative care services should be based on national policy and decided by Health Boards at regional level, based on need for services as defined by regional needs assessments. - All day-to-day expenditure should be met by Health Boards' specialist palliative care budget (separate and protected budget). - Health Boards should work in partnership with the voluntary service providers in their areas, with service agreements. - There should be at least one specialist palliative care inpatient unit in each health board area. - Minimum staffing levels of specialist palliative care services are identified. - All acute general hospitals should have a consultant-led specialist palliative care service, offering advice and support to health care professionals in the hospital. - The specialist palliative care team in the community should be an inter-disciplinary consultant-led team. - The needs of different population groups, including children, should be addressed by each health board when planning the future delivery of specialist palliative care services. - A Minimum Data Set should be developed in Ireland, in order to provide standardised information on all patients of specialist palliative care services.
2001	Keegan *et al.*, 2001 *Relatives' Views of Health Care in the Last Year of Life*	This reports the views of 155 relatives of patients who died during a 12-month period with varying degrees of palliative care service (hospital-based, hospice-based, home care, and no palliative care). A semi-structured interview schedule was used to collect demographic information, data on activities of daily living, and descriptive and evaluation data on the care provided. The critical incident technique was employed to gather examples of good care and poor care from relatives' perspectives. The range of incidents reported suggest that all aspects of care are considered important, particularly the attitudinal and dignity-preserving aspects of care. The movement to integrate principles of palliative care into all clinical practice is reinforced by the findings from this study.
2002	Smith *et al.*, 2002 *A Needs Assessment for Palliative Care in the Eastern Region*	Based on the recommendations from the National Advisory Committee on Palliative Care this needs assessment highlights shortcomings in the provision of adequate levels of palliative care services taking into account the views of service providers. Population projections together with National Cancer Registry Ireland projections are applied to predict the need for services in the region over the period 2000–2015. Implications and costings of the NACP Recommendations are proposed. Conclusions and recommendations for the delivery of palliative care in the Eastern Region include the following: - A major increase in staffing is required across all sectors of the service - Between 128–160 specialist palliative care beds are required by 2011 to meet the needs of cancer and non–cancer patients - There is a need to be able to cater to the home care needs of 5,000 patients and their families - Different service providers identified common areas of unmet need including palliative care needs of non-cancer patients, the number of beds across all sectors, day care and home services, staffing levels, and communication between hospital, hospice and community palliative care service.

Year	Title and Source	Key Content/Recommendations
2003	Southern Health Board, 2003 *Palliative Care in the Southern Health Board: An Assessment of Service Need*	Using population projections and data from the National Cancer Registry, the level of need for palliative care services in the Cork / Kerry region was determined along with appropriate recommendations for future service development based on the 2001 report by the NACP. It was reported that, over the period 2000–2015, cancer cases were projected to increase by 31% and by 9% in non-malignant cases. Based on projections and views from service providers and service users, 46 recommendations were detailed covering the areas of Specialist Palliative care (In-patient), Staffing, Day Care, Acute General Hospitals, Community, Community Hospitals, Respite, Aids and Appliances, Service Access, Service Integration, Family Support/Bereavement Services, Staff Training, and Information Systems. General recommendations provide for the inclusion of non-cancer patients in palliative care service provision and the separate undertaking of a needs assessment for paediatric palliative care services. The report suggests that specialist palliative care should be available to all patients in need of palliative care in all care settings regardless of age. Recommendations for specialist palliative care include: - Increased numbers of specialist palliative care beds are needed in Cork and Kerry (latter has none as yet) - The planned Regional Specialist Palliative Care Unit at Marymount should be advanced without delay - A satellite Specialist Palliative Care Unit is required for Kerry (based on the grounds of Tralee General Hospital), to provide specialist in-patient palliative care services, outpatient clinics, and day care services for the area. Until established, however, it is imperative that a sufficient number of interim dedicated palliative care beds are identified at Tralee General Hospital to support the work of the appointed Consultant and her team.
2003	Deloitte, 2003 *An Evaluation of 'Cancer Services in Ireland: A National Strategy 1996'*	This report presents the outcome of a comprehensive study that evaluated the extent to which the objectives and actions of the 1996 National Cancer Strategy were achieved. Points relating to palliative care services include the following: - Significant developments in palliative care were identified including a steady increase in funding and a new dedicated budget - Staffing issues remain with a shortage of palliative care staff - Health board needs assessments had been completed - Good relationships with the voluntary sector were observed, although more formalised arrangements sought by the health boards.
2004	East Coast Area Health Board, 2004 *Palliative Care Services in the East Coast Area Health Board 2004*	This publication presents the results of a mapping exercise of Palliative Care Services in the Eastern Regional Health Authority, which was required by the East Coast Regional Consultative Committee on Palliative Care. It describes: - Current services, showing that the level and availability of palliative care services varies considerably throughout the East Coast Area Health Board across the four settings (Community Services/Home Care, Acute Hospitals, In-patient Palliative Care, and Day Patient/Outpatient services) - Each type of service in terms of availability, staffing and bed capacity (where applicable) across the four settings - On-going research and educational resources available for training in Palliative Care - The role of Voluntary Agencies who have a role in contributing to palliative care services in the area.

Year	Title and Source	Key Content/Recommendations
2004	Irish Hospice Foundation and North-Eastern Health Board, prepared by Weafer and Associates Research with TNS MRBI for Care for People Dying in Hospitals Project, 2004 *A Nationwide Survey of Public Attitudes and Experiences Regarding Death and Dying*	A sample of 1,000 adults aged over 15 years were interviewed in various locations throughout the Republic of Ireland. The research focuses on issues surrounding death and dying, from the point of view of recently bereaved people in particular. People were asked where they would like to be cared for if they were dying, and if they felt this care would be available to them in their own locality. It asked about attitudes toward care of people dying in hospitals, the overall rating of care given to family members, what arrangements people had made for how they would like to be treated and what things were most important about the care available to them if they were dying. Main points in report include the following: - The majority of respondents described the provision of care for the terminally ill in Ireland as 'very or extremely' important. - The majority (51%) of Irish adults feel that Irish society does not discuss death and dying enough, with just less than one third (30%) of respondents saying the discussion is 'about the right amount' and approximately one in ten (9%) respondents feeling there is 'too much discussion'. - Over half of Irish people have neither drawn up a will nor have given it serious consideration. However, just over one in ten Irish adults have written up an 'advance directive' or living will. - The majority of Irish people would want to be cared for at home if they were dying - Almost half (47%) of Irish people are not certain that the place in which they would like to be cared for if terminally ill would be available to them - The three most important things for Irish people when they are dying are to be surrounded by people they love, to be free from pain and to be conscious and able to communicate.
2005	DoHC and IHF, 2005 *A Palliative Care Needs Assessment for Children*	This needs assessment aimed to identify the number of children in Ireland living with and dying from life-limiting conditions and to identify their needs. Future developments in paediatric palliative care should be shaped by four key principles: 1) Inclusiveness – All children regardless of diagnosis, geography or age should be able to access care which is appropriate to their individual need. 2) Partnership – The active participation of all stakeholders, including the child, should be promoted. 3) Comprehensiveness – A holistic approach to the planning of care is required, and this should include the child and family and be adaptable to their changing needs. 4) Flexibility – a 'key worker' is needed for each child and family to coordinate and implement a plan of care. Paediatric palliative care services should provide seamless quality care regardless of location or diagnosis with formal links between the different service providers.
2005	Irish Hospice Foundation and North-Eastern Health Board for Care for People Dying in Hospitals Project, 2005 *Death and Dying in an Acute Hospital*	The content of this report was based on focus group discussions, which explore themes including; experiences of staff in handling death, dying and bereavement in a hospital; implications of practice and processes for staff, families and the community; what could be improved, adequacy of staff skill and experience in view of the realities; supports required by staff. The Hospice Friendly Hospitals Programme was informed in part by the learning generated from this report. Concluding comments include: - The physical capacity and resources of the hospital are greatly overstretched and as a result dying and death in the hospital setting do not receive adequate recognition - Staff are uneasy about the fact that the hospital frequently did not deal adequately with the dying and the bereaved. In many instances, things that could and should have been done were not done. This undermined staff morale, both individually and collectively, and sometimes resulted in additional stress in an already pressurised work environment.

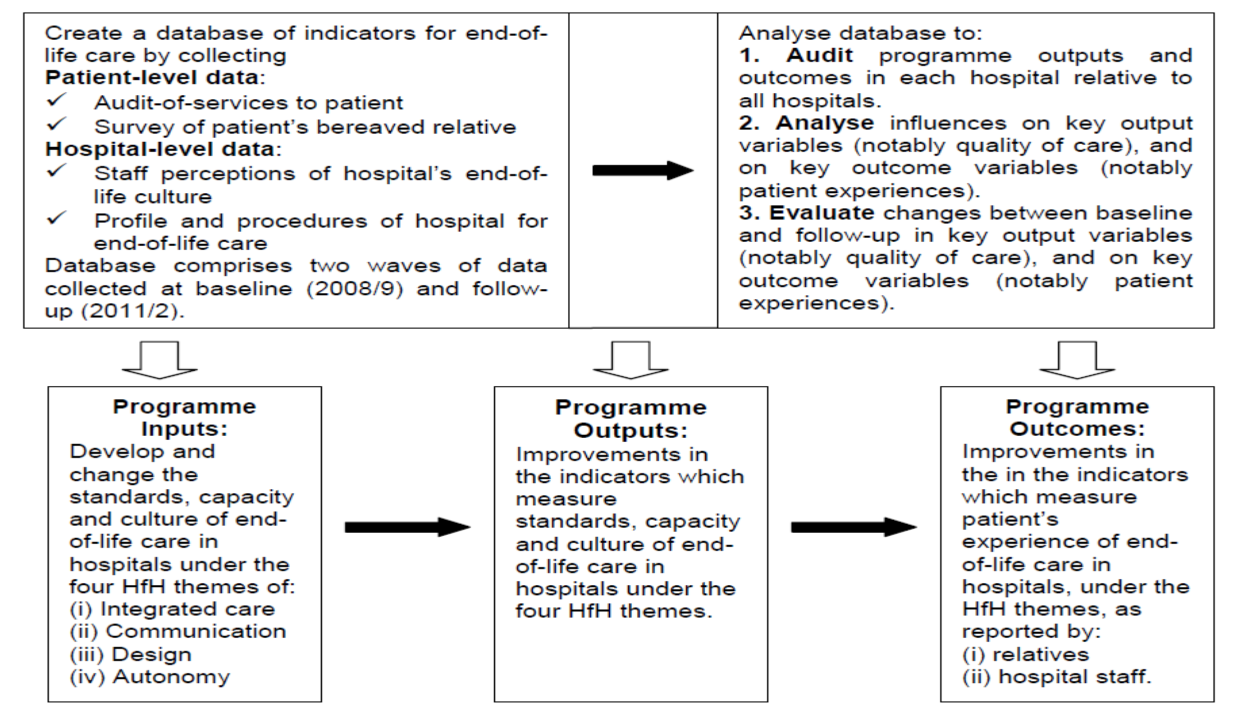
Year	Title and Source	Key Content/Recommendations
		- There is a clear sense of staff feeling disempowered. It is important to break the cycle of disempowerment by selecting a small number of achievable goals that would improve services, for example the reconfiguration of the Accident & Emergency area and the redecoration of the mortuary - The goodwill and skills of staff may be undermined by a hospital system that was regarded as overstretched and, therefore, lacking the capacity to respond adequately and equitably to the day-to-day needs of people dying and their families - There is a pool of talent within the hospital that could be purposefully used for in-service staff training in dealing with dying, death and bereavement in the acute hospital setting.
2005	Murray, 2005 *Quality Hospice Care: A Sign of a Healthy Society*	This paper summarises developments in palliative care since the publication of the NACP in 2001. It reports on developments and gaps remaining in palliative care, highlighting the need for investment and commitment by the government to implement policy in meeting the needs of people with terminal illnesses.
2006	IHF, 2006 *Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland*	This report presented an up-to-date overview of service provision in hospice/specialist palliative care and identified specific gaps in service provision relative to the recommendations of the NACP report. It assessed the future need for palliative care services based on population growth and the projection of growth in the number of cancer and non-cancer deaths, and quantified the gaps in the numbers of staff and beds relative to the recommended levels. It also calculated the cost implications of filling these shortfalls (care staff shortfall was estimated at approx. €51 million and bed shortfall (excl. care staff costs) was estimated at €38.5 million). Conclusions of the report: - There have been a number of positive developments since the publication of the NACPC report (e.g., expansion in the numbers of consultants in palliative medicine appointed, although in many cases, these appointments have not been accompanied by an expansion of hospital-based teams). - There has also been an expansion in the provision of home care services. - The most compelling overall impression from the information gathered is one of inequity in terms of capacity and access to services for people needing specialist palliative care. - Access to specialist palliative care remains far too dependent on where a person lives rather than on medical need. - Manpower planning issues: unreasonable to expect that the numbers of suitably trained staff required to comply with the minimum recommendations of the NACPC report will be available for recruitment in the short term. Short-term responses could include recruitment of suitable staff who may be trained into their new roles and re-training of existing health care staff. 21 implementation challenges are outlined in the report. Many of these challenges relate to resource availability.
2006	Van Doorslaer and McQuillan, 2005 *Home, Hospice or Hospital? A Study of Irish Travellers' Use of Palliative Care Services*	The aim of this study was to gather evidence to inform an understanding of the context within which Travellers in the Eastern Regional Health Authority may use palliative care services, and their views and experiences of service provision. Recommendations of the report include: - Data Collection – collection of ethnicity for existing data sets - Education and training – Training courses on traveller culture should be provided for health care professionals - Communication and liaison – Requirement for culturally appropriate information campaigns and liaison officers in the Travelling community

Year	Title and Source	Key Content/Recommendations
		- Access to services – Health services could explore more acceptable ways of providing care and support to Travellers, such as palliative care in a general hospital setting, rather than a hospice, and hospice homecare to families caring for a relative at home.
2006	Department of the Taoiseach, 2006 *Toward 2016: Ten-Year Framework Social Partnership Agreement, 2006–2015*	The agreement includes a commitment to further develop palliative care in Ireland and refers to the Baseline Study.
2006	National Cancer Forum, 2006 *A Strategy for Cancer Control in Ireland*	Each cancer control network is to include a comprehensive specialist palliative care service to meet the needs of patients and families.
2007	Department of the Taoiseach, 2007 *The National Development Plan 2007–2013*	Includes a commitment to progress palliative care services in the country and in particular to prioritise capital projects.
2007	HSE, 2007 *Transformation Programme 2007–2010*	The Transformation Programme states the HSE's purpose 'to enable people live healthier and more fulfilled lives'. One of the key priorities is to provide access to care in a setting that is close to the client's home. Greater emphasis is placed on delivery of services locally through multi-disciplinary teams and local diagnostic services.
2008	O'Leary and Tiernan, 2008 *Survey of Specialist Palliative Care Services for Non-Cancer Patients in Ireland and Perceived Barriers*	This was a national survey (postal questionnaire) of specialist palliative care services for non-cancer patients. All respondents indicated their service was available for non-cancer patients. However, 19% of services limited care provided to non-cancer patients in some way (e.g., limited access to patients with Motor Neurone Disease, or HIV/AIDS only; provision of once-off medical or nursing visits only; telephone advice to the GP only). The top five most commonly seen non-cancer diagnoses were MND, congestive cardiac failure, COPD, cerebrovascular disease, and pneumonia. Approximately 7% of all patients seen by specialist palliative care services in 2004 were non-cancer cases. The top three barriers to treating non-cancer patients were - unpredictable disease trajectory - resultant difficulties in developing referral criteria - lack of non-cancer disease specific expertise. The proportion of overall specialist palliative care workload directed to non-cancer patients is less than 10%, while it has been estimated that this should be 25%.
2008	HSE and IHF, 2008 *Palliative Care for All. Integrating Palliative Care into Disease Management Frameworks*	Following discussions, the HSE and IHF committed to undertake the Extending Access Study to examine the palliative care needs of adults with diseases other than cancer. The three diseases selected for the initial focus of the study were COPD, dementia, and heart failure. The project team undertook a wide-ranging review of the relevant literature. Views were also sought from service users and/or family members of people with COPD, dementia, and heart failure. The key messages in this report include; the need for palliative care to be embedded within the disease management frameworks, and that SPC must seek to ensure that they accept referrals based on need rather than diagnosis. The report recommendations require action from a large number of stakeholders, including government departments, educational

Year	Title and Source	Key Content/Recommendations
		institutions, frontline staff and clinical personnel. The report makes general recommendations relating to policy including the following: - All policy documents that refer to life-limiting diseases should include plans for access to appropriate non-specialist and specialist palliative care - Governance and monitoring systems should be introduced to ensure that SPC is provided on the basis of need rather than diagnosis to all patients with life-limiting illness - An end-of-life strategy should be introduced to support and guide all health service staff who work with people who are near end of life, in order that all people can maximise quality of life and die with dignity and comfort. General recommendations are also made in relation to education, the service model, and research, while disease specific recommendations were outlined for the three disease groups studied.
2008	IHF, 2008 *Staffing Levels and Bed Numbers in Specialist Palliative Care in Ireland, 2007*	This report was undertaken to update the original Baseline Study information (staffing and beds) as at December 2007, and to establish progress in the intervening three years. A key finding of the baseline study was the level of regional variation in service development. The findings of this report include the following: - There are wide regional disparities in current government spending on palliative care services in all care settings. Spending on care staff and beds in specialist palliative care in-patient units varies from €7.9 per capita in the area of the former South Eastern Health Board to €35 per capita in the former North-Western Health Board area. - Hospice/palliative care staff numbers increased from 570 to 686, an increase of 116 (20%) between 2004 and 2007 - Specialist in-patient bed numbers have risen from 131 to 153, an increase of 22 (17%): 10 in Limerick, 6 in Blackrock and 6 in Kildare - The annual cost of the care staff shortfall comes to approximately €40m, down from €51m in December 2004. The cost of filling the bed shortfall (excluding care staff costs) is approximately €35.5m, down from €39m. This gives a total shortfall in annual expenditure of approximately €75.5m, down from €90m in 2004.
2008	O'Shea *et al.*, 2008 *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland*	The study was undertaken to survey a sample of Irish acute hospitals and long-stay institutions in relation to contextual epidemiology of death and dying, facilities, staffing levels, access and liaison with services, and training and education needs of staff. It explores key stakeholder and direct care managers' perspectives on the current provision of end-of-life care for older people, and also explores the experience of the older person in receipt of end-of-life care. Six key recommendations are made in this report: - Greater consultation with older people in order to establish needs and preferences with respect to end-of-life care - Improvement in the physical environment where people die, particularly with respect to the availability of single rooms and facilities for families and friends - Greater cultural awareness and understanding of dying and death, including consideration of the current disparity of esteem between younger and older deaths within the health and social care system - Policy reform to ensure that end-of-life care is recognised as an important public health issue, separate to palliative care but inclusive of many of its key elements - Measures to develop practice to ensure that end-of-life care for older people is integrated into the everyday life and work

Year	Title and Source	Key Content/Recommendations
		of acute hospitals and long-stay facilities - Testing of new models and approaches that bring about a greater fusion between end-of-life care and gerontological care within all long-stay settings in Ireland.
2009	HSE, 2009 *Palliative Care Services – Five Year/Medium Term Development Framework*	This outlines the required actions and initiatives for addressing the gaps in palliative care service provision, in line with the recommendations set out on the report of the NACP in 2001. Paediatric palliative care is addressed in separate policy. Strong focus is placed on the emphasis outlined in the HSE Transformation Programme to provide services close to the clients' home, which is consistent with international evidence on preferences of patients to receive palliative care services in their own homes. The report outlines priorities for the development of palliative care provision. It focuses on specialist palliative care services including specialist palliative care in-patient units and satellite units, specialist home care teams, acute consultant-led teams, and specialist palliative day care. It excludes level 2 beds/intermediate care beds in community hospitals, generic community care, and children's palliative care. It included priority lists submitted by Area Development Committees, based on regional needs assessments. Criteria for selection of national priorities are: - Does the priority address a major area of need (limited or no service provision)? - Does the priority build capacity or ensure self-sufficiency? - Does the priority address recommendations in the National Advisory Committee on Palliative Care? - Does the priority support wider health care policy (e.g., Primary Care Strategy, HSE Transformation Programme, Cancer Control Programme)? See p23–31 for description of available services and comparison with recommended level of services by HSE area. Forty-one individual priorities were identified for the development framework (see p35–40]) - Priorities relating to home care deficits (12) - Priorities relating to specialist in-patient bed deficits (6) - Priorities relating to capital developments (15) - Priorities relating to acute hospital support (8). The total estimated cost of implementing the 41 priorities includes capital spending of €237.34 million and non-capital expenditure of €71,485 million over the period 2009–2013.
2009	Murray, 2009 *How Advocates Use Health Economic Data and Projections: The Irish Experience*	This paper outlines important Irish policy documents which refer to palliative care, and provides an overview of some international literature on cost savings linked with palliative care.
2009	Department of Health and Children (DoHC), 2009	This report follows the palliative care needs assessment for children in 2005. The aim of policy is to address the issues identified in the needs assessment in order to build a responsive service for children and their families, and to examine and develop policy

Year	Title and Source	Key Content/Recommendations
	Palliative Care for Children with Life Limiting Conditions in Ireland	on: - The principles underlying the development of specialist and non-specialist palliative care services for children nationally and regionally - The organisation and development of an integrated palliative care service for children with life limiting conditions and their families involving both statutory and voluntary providers, and including the delivery of care in all settings - Personnel, education and training. The third section of report provides clear direction for the future development of palliative care for children and final section provides list of recommendations for the future development of children's palliative care service including the following: - Clinical Governance: There should be clear assignment and documentation of responsibility within and between clinical teams involved in the care of the child with a life-limiting condition and their family. - Outreach Nurses: Regionally based Children's Outreach Nurses for children with life-limiting conditions should be appointed to facilitate service delivery and integration between hospital, community services, and specialist palliative care. - A National Committee for Children's Palliative Care should be established by the HSE.
2010	Canavan and O'Neill, 2010 *Palliative Care for Older People in Nursing Homes*	This paper highlights the lack of attention to specialist skills, particularly in gerontological care, which will become increasingly important given the more complex care needs of older people. It reports that the majority of nursing home care staff in Ireland have not received any formal qualifications in palliative care. Current services remain focussed on cancer patients with little emphasis on older people, especially those living in long-stay settings.
2010	McKeown, 2010 *Hospice Friendly Hospitals Programme National Audit of End-of-Life Care in Hospitals in Ireland The Manual*	The Manual describes the system for a national audit of end-of-life care in Ireland. This was devised by, and for, the Hospice Friendly Hospitals Programme to develop comprehensive standards for end-of-life care in the hospital setting, and to underpin these with a comprehensive audit system. The HfH programme is a five year (2007–12) programme and has three aims: 1) to develop comprehensive standards for all hospitals in relation to dying, death and bereavement 2) to develop the capacity of acute and community hospitals to introduce and sustain these standards 3) to change the overall culture in hospitals and institutions in relation to dying, death and bereavement. The figure below illustrates the audit system and how it links to the HfH Programme.

Year	Title and Source	Key Content/Recommendations
		
2010	McKeown *et al.*, 2010e *Hospice Friendly Hospitals Programme National Audit of End-of-Life Care in Hospitals in Ireland Report 1*	Audit Report 1: Resources and Facilities for End-of-Life Care in Hospitals in Ireland This report presents data based on questionnaire 6 in the Audit and is completed by hospital management. The report looked at a number of areas, including staffing, accommodation, standard of facilities, complaints, and policies and procedures on end-of-life care. Other areas, described in more detail here, include: Deaths in Irish Hospitals - Annual death rate (number of deaths divided by number of in-patients) is 2.8% (range 1.3–4.7%) in acute sector; 8.4% (range 0–24%) in community hospitals. - Deaths in acute hospitals: 68% occur in wards, 20% in intensive care, 12% in emergency departments. - Deaths in community hospitals: 85% occurred in the community hospital where patient has lived; 15% took place in acute hospitals. This links with concerns raised about the appropriateness of transferring some patients from community to acute hospitals at the end of life. - Deaths referred to coroner, post-mortems, numbers brought in dead.

Year	Title and Source	Key Content/Recommendations
		Specialist Palliative Care Services - This report gives the number of WTE specialist palliative care staff per 100 deaths in each hospital. Specialist palliative care staff are not distributed in line with number of deaths (e.g. three acute hospitals with the largest number of deaths is below average in terms of WTE per 100 deaths). - Two acute hospitals had no specialist palliative care team, 54% had a partial team (at least a doctor and a nurse), and 38% had a full team. - One community hospital has a specialist palliative care service, 5 others have access to one, but 68% have neither. Data on bereavement services and facilities showed that 42% of acute hospitals and 16% of community hospitals reported having a bereavement service. In relation specifically to community hospitals it was shown that most community hospitals don't have access to specialist palliative care. The fact that a 'substantial minority' (14%) of residents in community hospitals died in acute hospitals could be linked to the lack of access to palliative care.
2010	McKeown *et al.*, 2010d *Hospice Friendly Hospitals Programme National Audit of End-of-Life Care in Hospitals in Ireland Report 2*	Audit Report 2: Dying in Hospital in Ireland: Nurse and Doctor Perspectives This report presents data based on questionnaires 1 and 2 in the audit which were completed by the nurse(s) who gave most care during the last week of the patient's life; and by the doctor(s) who attended the patient prior to death, in order to provide an approximation of how the patient experienced dying and death in hospital. Report looked at a number of areas including; patient characteristics, ward and room characteristics, assessment of the patient while they were dying, communication with the patients and relatives and responding to patients and relatives wishes. Other areas, described in more detail here, include: Palliative Care of Patient - Where patients have been diagnosed as beyond cure and entering the dying phase, hospital staff are expected to reorient care towards comfort and control of symptoms. Questions were asked on the decisions made about the patient during the last week of life and whether those decisions were documented. Responses of nurse and doctors do not always agree on whether a decision was made (67% agreement), or on whether it was documented (62% agreement). - Both nurses and doctors report that even when death is expected, no decisions were taken in the majority of cases to stop antibiotics, stop invasive monitoring, or withhold treatment. - Decisions about end-of-life care were more likely to be taken in oncology wards, involving cancer patients, where death is expected, and for patients in single rooms. - Five to six key symptoms may occur for patients in last hours/days of life: pain, nausea, breathing difficulties, increased secretions, restlessness, anxiety. Nurses and doctors were asked to assess the frequency with which these symptoms were experienced in last week of life. Level of agreement between nurses and doctors on frequency of symptoms was 50%, which indicates ambiguity and uncertainty about the incidence of patient symptoms and needs. - In 58% of cases, there is no agreement between doctors and nurses on whether the patient was kept comfortable. - During the last week of life, 80–90% of patients are kept relatively comfortable (experiencing a symptom some or none of

Year	Title and Source	Key Content/Recommendations
		the time) with respect to pain, nausea, anxiety, restlessness and secretions, but fewer kept comfortable with their breathing. Specialist Palliative Care Services - The majority of patients did not receive specialist palliative care. The proportion of patients who did receive it varies from 22% according to doctors to 32% according to nurses. The results suggest some misunderstanding between nurses and doctors as to what is specialist palliative care. - Specialist palliative care is more likely to be offered in acute hospitals, to cancer patients, where death is expected, to patients less than 65 years, to those who spend a week/more in hospital, and to patients in single rooms. - There is a time-lag between diagnosis of dying and introduction of specialist palliative care in up to half the patients who receive it. Using established instruments, quality of life was measured using the Quality of Dying and Death (QODD) Instrument (self-administered by nurses) and quality of care was measured using a scale taken from the Family Evaluation of Hospice Care (FEHC).
2010	McKeown *et al.*, 2010c *Hospice Friendly Hospitals Programme National Audit of End-of-Life Care in Hospitals in Ireland Report 3*	Audit Report 3 Dying in Hospital in Ireland: Family Perspectives The report presents data based on questionnaire 3 of the audit completed by bereaved relatives of patients who died in hospital, and on whom a corresponding questionnaire had been completed by the nurse/doctor or both. The report covered a wide range of questions asked within the questionnaire, comparing relatives and staff responses including; ward characteristics, preferences of the patient and the quality of staff, quality of life and quality of care (using standard instruments), and acceptability of the way the patient died. Some of these are outlined in greater detail below: Preference to Die at Home - During last week of life, 14% of patients would like to die at home. - Relatives assessed 24% of patients as being able to die at home (similar proportions given by nurses and doctors, but overlap in these assessments small). - In 40% of cases relatives would have liked the patient to die at home (more likely in cases where quality of hospital was given a low rating). Quality of Staff - A majority rated the quality of staff as good/very good. - One-quarter of relatives found there were not enough nursing and medical staff in acute hospitals. Quality of Life (Use of the Quality of Dying and Death Instrument) - In the opinion of relatives, patients experience relationship well-being more frequently than personal well-being. - Relatives are likely to report that patients have more negative experiences compared with nurses, for symptoms including pain, discomfort, anxiety, worry. - QODD score for personal well-being (61.3 SD 24.1) is lower than score for relationship well-being (76.1 SD 18.7). Quality of Care (Use of the Family Evaluation of Hospice Care)

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		- Relatives report a lower overall quality of care (7.4 out of 10) compared with nurses (8.1) and doctors (8.4). Acceptability of the Way a Patient Died - Relatives report a higher proportion of unacceptable deaths (21%) compared with nurses (13%) and doctors (3%). - Patient characteristics that are associated with unacceptable death include anxiety all/most of the time, pain all/most of the time, sudden rather than expected death, death under the age of 45. - Care characteristics that are associated with unacceptable death include poor/very poor staff responsiveness, poor/very poor end-of-life care, a shared room rather than a single room.
2010	McKeown *et al.*, 2010b *Hospice Friendly Hospitals Programme National Audit of End-of-Life Care in Hospitals in Ireland Report 4*	Audit Report 4 The Culture of End-of-Life Care in Hospitals in Ireland The report presents data based on questionnaires 4 and 5 from a survey of nurses and healthcare assistants in each of the wards where a patient died and whose death is included in the audit. Ten staff per ward were randomly selected. It also presents data from a survey of hospital staff outside of wards. A quota sample of 100 staff was drawn in each hospital from different categories (e.g., management, health and social care, general support staff, etc.) The report looked at a number of hospital characteristics including the physical environment, bed occupancy, patient turnover, patient dependency, staff sufficiency and turnover, work satisfaction. In relation to death and dying more detail is provided below: Attitudes to Dying and Death - A minority of staff in the ward (39%) of staff in the hospital (37%) report that they are very or completely comfortable with talking about death and dying. Preferred Place to Die - There is a much higher preference for the patient to die at home among ward staff (81%) and hospital staff (77%) compared to the national population (67%) Quality of end-of-life care in Irish hospitals - A majority of hospital staff (63%) rate the end-of-life care in Irish hospitals as good or excellent, but significantly lower compared to the general population who have had direct experience of end-of-life care in hospital in the past two years (75%) Quality of End-of-Life Care - On a scale from 1–10, ward staff rate the quality of end-of-life care on their ward at 8.1, higher for community hospitals (8.7) than for acute hospitals (8.0). Acceptability of the Way Patients Die - The vast majority of ward staff (90%) and hospital staff (87%) regard deaths in the ward and hospital as acceptable to them. Deaths are perceived to be more acceptable in community hospitals than in acute hospitals.
2010	McKeown *et al.*, 2010a *Hospice Friendly Hospitals Programme National Audit of End-of-Life Care in Hospitals in Ireland Report 5*	Audit Report 5 Dying in Hospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life Outline: This report presents a synthesis of the data collected in all six questionnaires. Combining these gave a matched response of 312 questionnaires across all respondents (doctors, nurses and relatives). The analysis includes multilevel modelling to analyse the influence of each care input on care outcomes. - Five outcomes are measured including acceptability of the way the patient died, quality of patient care, patient's symptom

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		experience, symptom management, support for patient's family (full details are provided in Annex 9, 10 and 11 in the Technical Appendix). - Corresponding to the five core outcomes of interest and the different perspectives of nurses, doctors and relatives, 16 multilevel models were generated. Results are presented in Annex 7 and 8 (statistically significant results are highlighted in bold). Report describes the factors that have a statistically significant influence on quality of care for patients who die in hospitals, including the support offered to relatives. - Eight sets of care inputs have a statistically significant influence on care outcomes: • Disease and cause of death: cancer is a positive predictor of care outcomes, worst care is for patients with dementia/frailty, sudden death is a negative indicator of care outcomes, the only patient characteristic to have a significant influence on care outcome is private health insurance (positive influence). • Route of admission: emergency admissions through the emergency department have a negative impact on care outcomes, transfer from a nursing home has benign influence on care outcomes. • Physical environment: deaths in single rooms are associated with better care outcomes, dignity aspect of room/ward has significant influence on care outcomes. • Multidisciplinary team working: team meetings have a significant positive influence on care outcomes); • Communication: quality of care outcomes is significantly influenced by the quality of discussion with patients and relatives rather than the amount of discussion. • Support for families: relatives being present at the moment of death and staying overnight prior to death both have positive influence on care outcomes. • Staff readiness: nurse characteristics of feeling ready for the death of the patient, number of years of experience, formal training in end-of-life care have significant influence on care outcomes. • Hospital governance: having end-of-life objectives in the hospital service plan has significant positive influence on care outcomes; having insufficient ward staff has significant negative influence on care outcomes. Two sets of inputs known to be important for end-of-life care but not statistically significant in this analysis were: - end-of-life care decisions (including diagnosis of dying, specialist palliative care) and documentation. Performance scores are calculated using a benchmark based on the mean score of the top quartile (25%) of acute hospitals for each care outcome and care input. Having established the benchmark, the performance of each hospital is rated using a 'dashboard' comprising three colour-coded categories (green, amber, red). The results of the audit, including the individual hospital reports, will provide each hospital with guidance on the range of actions that are most likely to have an impact on their quality of care, helping them to orient those actions towards the wider context of quality improvement and standards. These results will supplement the knowledge and expertise that is already available at local level about the changes that are needed.
2010	Hospice Friendly Hospitals, 2010 *Quality Standards for End-of-Life Care in Hospitals: Making End-of-*	The Quality Standards for End-of-Life Care in Hospitals were developed in partnership with healthcare staff and interested parties including bereaved relatives. HIQA were also consulted given their responsibilities under the Health Act 2007, including the responsibility for setting standards in health and social services. They set out a shared vision of the end-of-life care each

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	Life Care Central to Hospital Care	person should have and what each hospital should aim to provide. They identify what hospitals should strive for and how they can ensure that the essential elements of a consistent quality approach to end-of-life care are in place in all parts of the hospital whether death is unexpected or expected. The development of the standards was a stimulus to provide on-going improvement of end-of-life care in hospitals after participating in the National Audit regarding all aspects of end of life, dying, death and bereavement. - To develop standards for end-of-life care in hospitals - To develop the capacity of hospitals to meet these standards - To improve the overall culture of care and organisation in hospitals Standards are listed under four main headings 1) The Hospital 2) The Staff 3) The Patient 4) The Hospital. Under each heading, standards are listed with a guide to monitor how this target is been achieved.
2011	McKay *et al.*, 2011 *Milford Home Hospice Evaluation 2011*	An Evaluation of the Hospice at Home Service Delivered by Milford Care Centre Outline: - description of the Hospice at Home service: staffing levels, activity levels, sources of referral - literature review focused on carers' experience in palliative care (see p26 for discussion of terminology) - carers' Survey • Anonymous postal questionnaire • 81 bereaved and 41 current carers • Questions on expectations of the service, usefulness of the service, access to and communication with the team, etc. • Results on quality of care, quality of death and dying compared with similar questions in the National Audit of End-of-Life Care in Hospitals - Individual Interviews • 15 patients and 15 carers • Questions on information and communication, symptom management, access to the team, psychosocial support, quality of care - Focus Group and Interviews with Milford Care Staff and Public Health Nurses - Primary Care Team Survey • Postal questionnaire • 51 questionnaires returned • Questions on level of contact with professionals at the home hospice service, availability of the service, communication, quality of care, education needs of primary care team members, integration between home hospice

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		and primary care teams - Recommendations • Key recommendations are made with regards to coordination of teams, information, communication, bereavement support, information management, quality assurance. • Overall the Hospice at Home service was found to be delivered for the most part in line with best practice across a number of dimensions of palliative and home-based hospice care.
2011	Irish Hospice Foundation (IHF) *et al.*, 2011 *Primary Palliative Care in Ireland: Identifying improvements in Primary Care to Support the Care of those in their Last Year of Life*	In 2010, the Irish Hospice Foundation, in partnership with the Irish College of General Practitioners and the HSE established the Primary Palliative Care (PPC) programme, in order to identify palliative care initiatives that will support primary care teams' responses to adults living with advancing life-limiting diseases in the community. The PPC programme undertook a series of consultation meetings and conducted a survey across ten HSE Local Health Offices. The themes addressed referred to communication with patients and families; coordination of services and transfer of information; education and training needs; and access to medication and equipment. The majority of health care professionals who engaged with the PPC programme acknowledged their role within the delivery of primary palliative care; however, they had difficulty in relating how this ethos and practice of care existed within their care delivery. Areas identified for improvement were to develop greater awareness amongst professional groups of their role in the area of primary palliative care, a need for enhanced communication systems, and to up-skill in aspects of clinical management of patients with palliative care needs. The particular recommendations of the first phase of the PPC programme were - clarifying access to advice and information from Specialist Palliative Care outside of traditional hours - the development of a resource system that will assist in identifying and supporting patients with palliative care needs in the community - the introduction of a formal mechanism for GPs to communicate to their local out-of-hours service providers with regard to the palliative care needs of their patient. The aim of phase two will be determined by the first phase, and will relate to implementation of the initiatives that have been prioritised. It was due to commence in 2012. Its objectives are to: - Ensure that prioritised initiatives from Phase 1 are established, supported and governed - Develop and establish linkages with other relevant projects from a policy, research, education, and service development perspective to inform future work plan - Develop repository of relevant information - Ensure dissemination and awareness of the work of the programme.
2011	Health Service Executive (HSE) and Milford Care Centre (MCC), 2011 *Strategic Plan for Palliative Care in*	This document reviews the progress made in the implementation of the recommendations of the Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region. In doing this, it interviews key stakeholders involved in health services in the Mid West Region.

Year	Title and Source	Key Content/Recommendations
	the Mid West 2013–2017	- The HSE and MCC have made significant progress in addressing the elements of the Strategic Plan. Of the 34 recommendations, 24 have been achieved, 6 are commenced (and well advanced), with 4 requiring further continuing attention. The report also appraises the implications of policy documents that were published in the interim period. The report discusses issues for the future of Milford Care Centre (MCC), including finances, number of referrals, cancer projections, the implications of reconfiguration of acute hospital services, and the changes in health service reorganisation with HSE Primary Care teams which are seeking to establish closer integration with community-based specialist palliative care. Challenges of extending the service to non-cancer patients, which were highlighted in published reports are also discussed. The report concludes that the running of MCC which is jointly funded by the HSE and voluntary contributions is an ideal system for service delivery. It also concludes that palliative care services in hospital-based teams are of a very high standard. It recognises there is a need to develop an integrated in-patient and community based service, and that access needs to extend to non-cancer cases for people living with acute illnesses.
2011	Health Service Executive (HSE) and Milford Care Centre (MCC), 2011 *Review of Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region 2004–2011*	This report was undertaken to review the recommendations of the seven year plan (2004–2011) in the Mid West region. It also reviews more recent reports on palliative care and assesses their impact on the current and future service provision in the region, also considering the policies determined by the HSE's Clinical Care Programme for Palliative Care. It identifies gaps in service provision across all care settings and makes recommendations for addressing service need areas on a priority basis. It makes a range of recommendations across a number of areas including: - *Sustainability of Current Services:* Service developments made to date must be reviewed and consolidated to ensure current service provision is maintained. - *Access:* Improve access for patients to Specialist Palliative Care services. - *Integration:* Continue to integrate all services involved in the delivery of palliative care. - *Quality and Research:* Specialist palliative care services should promote and participate in the development of quality indicators and outcome measures of services on a national basis. - *Education*: There is a need to continue to develop a flexible range of information and education programmes to meet the needs of a wide and varied audience and support the delivery of palliative care services. Specific objectives with corresponding timeframes are identified within each of these groupings.
2012	National Economic & Social Council, 2012 *Quality and Standards in Human Services in Ireland: End-of-Life Care*	This report is one of a series in a NESC project that examines how quality processes, standards, and regulations contribute to continuous improvement in the delivery of services. This report focuses on the standards in place to improve end-of-life care in hospitals. These standards were developed in consultation with doctors, nurses, and families of the bereaved, and they were also informed by an Audit of End-of-Life care commissioned by the HFH in 2008.

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	in Hospitals	The report identifies key strengths and challenges for hospitals as a result of taking part in the HfH initiative and identifies pointers for future policy development. - The support of the HSE, HIQA, and the Department of Health are important to sustain the work developed by the HfH programme. - The Quality Standards for End-of-Life Care in Hospitals could be integrated by HIQA into other national health and social care standards. - The HSE/Department of Health could link hospital funding allocations to implementation of the standards. The fact that implementing practices in the standards can reduce costs while improving quality provides support for such a move. - A focus on quality end-of-life care could be included in the service plan of the HSE (or its successor body), with related performance indicators, to help sustain implementation of these standards.
2012	Health Service Executive, 2012 *National Service Plan 2012*	The National Service Plan in 2012 reported that the financial allocation for Palliative Care was reduced from €81m in 2011 to €78m in 2012. The Plan supports progressing the recommendations of the Report of the NACPC, 2001, and the Palliative Care Service– Five Year/Medium Term Development Framework (2009–2013). Identified priorities for 2012: - Expand the provision of specialist palliative care services for adults within existing resources - Progress the development of paediatric palliative care services - Work with the clinical programmes to develop national standardised admission, discharge and referral criteria to increase efficiency and uniformity of care - Support the delivery of generalist and specialist palliative care in the community through the development and implementation of evidence-based guidelines, and tailor standardised and optimised clinical pathways for both types of practitioners - Improve collaboration with primary care teams, specifically for out-of-hours services - Improve the quality of palliative care provision in the hospital setting and improve the environment of care for those who are dying, bereaved, or deceased - Strengthen service user and family involvement through a national advance care planning programme to empower patients and their families to express their wishes about treatment choices and care provision towards the end of life - Educate staff and support research programmes in palliative care that promote evaluation and development of services, and improve approaches to care provision - Strengthen the quality, efficiency and effectiveness of existing service provision through the development and collection of evidence-based performance measures that support the quality improvement cycle. The HSE committed to the following access targets: – that 91% of specialist in-patient beds would be provided within 7 days – that 79% of home, non-acute hospital, long term residential care would be delivered by community teams within 7 days

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2013	Health Service Executive, 2013a *National Service Plan 2013*	The financial allocation for the Palliative Care Programme decreased by 1.6% from €73m to €72m The key priorities in 2013: - Support the delivery, and improve the quality of generalist and specialist palliative care services in line with strategic policy direction and improve resource utilisation including systematic assessment of need, access and referral - Progress the development of paediatric palliative care services. The HSE committed to the following access targets: - that 92% of specialist in-patient beds would be provided within 7 days - that 82% of home, non-acute hospital, long term residential care delivered would be by community teams within 7 days
2013	Irish Hospice Foundation, 2013b *The Strategic Importance of Palliative Care within the Irish Health Service, Perspectives on Future Service Delivery*	The report was published with the belief that current reorganisation of the Irish health service provides a real opportunity to ensure better and more cost-effective care of the dying – potentially a powerful measure of success for the reforms proposed. An integrated approach to the planning and delivery of this care across all care settings is essential to ensuring the best possible outcome for those facing death and their families, as well as the most effective use of resources. It recommended better strategic and structural support, strengthening financial support, building capacity through HSE's clinical care programmes, and supporting staff development and training. Key service delivery recommendations include: - Palliative care services should be managed as a single entity in order to avoid fragmentation - To facilitate the effective delivery of service plans for palliative care across all care settings so that there is equitable access to palliative care, a senior official, supported by a professional staff, should be assigned responsibility for the operational delivery of palliative care - Palliative care services should be available in the full range of care settings in which people die. While overall responsibility will be retained within the Social and Continuing Care Directorate, the remit should extend to palliative care services provided in other areas of the healthcare system, such as primary care. - A mechanism should be identified to coordinate and direct all organisational and developmental responsibilities for palliative care across all Directorates. This should include regional service managers with responsibility for the development of palliative care. - Existing levels of service should be maintained and sustained as a matter of utmost priority. Any deterioration in the level of services available to patients who are dying would be unacceptable. - Each hospital group should be required to develop a strategic plan for end-of-life care within each of its hospitals. The Hospice Friendly Hospitals Programme – an Irish Hospice Foundation (IHF) initiative – can assist in the development of these plans. The HSE's Palliative Care Clinical Care Programme will provide leadership as regards clinical care pathways. - Systematic gathering and sharing of information on matters relating to end-of-life and palliative care is needed throughout the health service in order to support the development and adoption of minimum data sets for palliative care in all care settings. This will inform and strengthen service delivery. The report highlights the Department of Health's commitment to introduce Universal Health Insurance and complete a prospective funding model for palliative care in 2013 taking into account the report's recommendations. The report concludes by outlining key challenges for the future including; limited choice of care settings for the dying, retaining focus on dying, death and bereavement across all Directorates of the Health Service, fulfilling national policy and enduring service inequity, and efficiently harnessing the resources of the voluntary sector to achieve common goals.

Year	Title and Source	Key Content/Recommendations
2013	Irish Hospice Foundation, 2013a *Access to Specialist Palliative Care Services and Place of Death in Ireland: What the Data Tells Us*	The aim of this report is to provide data, analysis and commentary to stimulate discussion on emerging trends in relation to the provision of specialist palliative care in Ireland. The report mines existing data from four key sources – the Health Service Executive's (HSE) Minimum Data Set for Palliative Care, the National Cancer Registry, the Hospital In-patient Enquiry, and HSE population records – to compare and contrast administrative regions of the health service against national averages on a number of key indicators (number of hospice beds, waiting times for first assessment of patient, place of death, etc) and to examine the impact of varying levels of investment in palliative care on access to services and service activity. Main Findings - This report estimates that because of regional inequity in resource allocation, approximately 2,470 patients are denied admission to hospice beds in Ireland each year. - While 67% of Irish people express a preference to die at home, in reality only 26% of the circa 28,000 deaths that occur in Ireland each year take place in the home, and 43% occur in hospital. In contrast, 40% of all patients cared for by hospice home care teams die at home. - Regions which are close to compliance with national policy in the provision of hospice beds show a significant reduction in the number of deaths occurring in acute hospitals. - In some regions which provide both hospice in-patient services and home care services (Dublin, Cork and Galway) there appear to be challenges associated with access and waiting times for home care when compared to regions offering home care only. Key Comments - Highlights a range of international research demonstrating that significant savings can be achieved when patients have access to comprehensive hospice in-patient and home care services, with greatly reduced admissions and lengths of stay in expensive acute hospital care. - The failure to implement national policy in relation to specialist palliative care means that many people who are dying are being denied access to fundamental aspects of end-of-life care. These issues can be addressed without major resource implications, by reconfiguring and standardising the allocation of resources across regions. Reconfiguring existing bed provision so that just 1% of all in-patient beds in healthcare settings are hospice beds will resolve this inequity.
2013	Health Service Executive, 2013b *National Service Plan 2014*	Palliative Care services to be delivered under the Acute Services Division. HSE committed toward the implementation of the recommendations contained in the national policy/strategic documents, and to remain engaged with the voluntary sector. Key service delivery recommendations include: - Ensure service provision for adult palliative care by addressing service gaps - Ensure improved capacity and capability for Dublin North East in relation to palliative care ambulatory and inpatient services, specifically the staged opening and usage of St. Francis Hospice, Blanchardstown (24 beds).at the cost of €1m - Develop the quality, efficiency and effectiveness of generalist and specialist palliative care services through process and quality improvements - Develop and integrate community-based paediatric palliative care services. The HSE committed to the following access targets: - that 94% of specialist in-patient beds would be provided within 7 days

Year	Title and Source	Key Content/Recommendations
		- that 82% of home, non-acute hospital, long term residential care would be delivered by community teams within 7 days.
2013	Health Service Executive (HSE) and Milford Care Centre (MCC), 2013 *Strategic Plan for Palliative Care in the Mid West 2013–17.*	The Steering Committee produced this Strategy conscious of the need to 'consolidate and maintain existing services while providing a positive vision and definite framework for the future'. The recommendations concentrate on the need for review and evaluation of existing services and the need to establish their effectiveness and efficiency. A service mapping exercise was carried out to identify current palliative care services available in the Mid West, the strengths and weaknesses of current service provision, and how services might be developed in the future to best meet the palliative care needs of people living in the Mid West region. Areas of development were discussed, and four key themes emerged: 1) Sustainability of Existing Services 2) Access and Integration 3) Quality 4) Education. Key steps to achieve objectives are set out under these headings are listed, alongside actions, timeframe and the groups with lead responsibilities.

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Appendix 2

Questionnaire, Information Booklet, Consent Form, and Reminder Letter

A2.1 QUESTIONNAIRE

Decedent Profile

Hi. My name is [#int_firstname:u]. I'm calling on behalf of the palliative care study. Am I speaking to [#ki_firstname:u]? We had arranged to call at this time today. Does that still suit you? Can you hear me clearly?
You'll remember from your information pack that we are carrying out an evaluation of care received by a sample of patients in Ireland during their last year of life. We hope to make those services more responsive to patients, their families, and carers. We appreciate your participation and I would like to emphasise that this survey is completely confidential and anonymous. We can stop the interview at any time should you prefer not to continue. At the end of the interview, there is also an opportunity for you to comment on any other aspects of [#d_firstname:u]'s care that may not have been covered here. Do you have any questions or concerns before we start? OK. Please stop me at any time if I'm going too fast or if you'd like me to clarify anything.

So, to start can I confirm a few details about [#d_firstname:u] with you...

ki_rel	What was your relationship to [#d_firstname:u]? Were you [#d_his_her]...		
	Spouse/Partner	☐	
	Child/ adopted child	☐	
	Step child	☐	
	Child-in-law (daughter-in-law, son-in-law)	☐	
	Parent	☐	
	Parent-in-law	☐	
	Brother or sister	☐	
	Brother-in-law/Sister-in-law	☐	
	Grandparent	☐	
	Grandparent-in-law	☐	
	Other blood relative	☐	
	Other in-law	☐	
	Grandchild	☐	
	Non-relative (e.g. friend)	☐	
	Other (specify)	☐	
	Don't know	☐	
	Refused	☐	
d_age_confirm	And can I confirm [#d_he_she] was [#d_age] years of age when [#d_he_she] died?		
d_ill	When was [#d_firstname:u] first diagnosed with [#d_his_her] illness (e.g. Oct 2011)? Definition: "Illness" refers to the disease (e.g. cancer) that ultimately led to the decedent's death		
d_diag	What was [#d_firstname:u]'s main diagnosis?		

I will give you a brief introduction to the types of questions I will be asking at the beginning of each section. To start with I'm going to ask some questions about [#d_firstname:u]'s general background that you may be familiar with from the Census.

d_irish	Was [#d_firstname:u] born in the Republic of Ireland?		
	No	☐	(→ d_ctry)
	Yes	☐	(→ d_abroad)

Don't know ☐ (→ d_ethnic)
Refused ☐ (→ d_ethnic)

d_ctry In which country was [#d_he_she] born?

d_ctry_age And at what age did [#d_he_she] first move to the Republic of Ireland?

d_nat So, what was [#d_his_her] nationality?

d_nat_time Since coming to Ireland, did [#d_firstname:u] always live here?
No ☐ (→ d_accul)
Yes ☐ (→ d_ethnic)
Don't know ☐ (→ d_ethnic)
Refused ☐ (→ d_ethnic)

d_accul About how many years did [#d_he_she] live here?
Note: Round up to the nearest year (i.e. minimum value 1)

d_abroad Did [#d_he_she] ever live abroad, in other words, outside of the Republic of Ireland, for more than 6 months?
No ☐ (→ d_ethnic)
Yes ☐ (→ d_abroad_time)
Don't know ☐ (→ d_ethnic)
Refused ☐ (→ d_ethnic)

d_abroad_time In total for how many years did [#d_he_she] live abroad?
Note: If between 6 months and 1 year enter 1.
Note: If there was more than one occasion select the most significant.

d_abroad_age And at what age did [#d_firstname:u] return to Ireland permanently?

d_ethnic Could I ask you what was [#d_firstname:u]'s ethnic or cultural background – I mean for example was [#d_he_she] white or of another origin?
White Irish ☐
Irish Traveller ☐
Any other White background ☐
African ☐
Any other Black background ☐
Chinese ☐
Any other Asian background ☐
Other, including mixed background ☐
Don't know ☐
Refused ☐

d_lang1 Was English [#d_his_her] first language?
No ☐
Yes ☐ (→ d_marstat)
Don't know ☐ (→ d_marstat)
Refused ☐ (→ d_marstat)

d_lang2 So, what was [#d_his_her] first language?

d_lang3 And how well did [#d_he_she] speak English?
Very well ☐

Well ☐
Not well ☐
Not at all ☐
Don't know ☐
Refused ☐

d_marstat At the time [#d_firstname:u] died what was [#d_his_her] marital status?
Married ☐
Single (never married) ☐
Separated ☐
Divorced ☐
Widowed ☐
Don't know ☐
Refused ☐

d_totchld_gt18 At the time [#d_firstname:u] died, how many children did [#d_he_she] have who were 18 years or older?

d_totchld_lt18 And, at the time [#d_firstname:u] died, how many children did [#d_he_she] have who were under the age of 18?

d_totdep_fl At the time [#d_firstname:u] died , did [#d_he_she] have any dependents for whom [#d_he_she] was a primary carer?

Note: This may include dependent children aged 18 years or older or another friend or relative. Do not include [#d_his_her] children who are under the age of 18 years and already accounted for.

No ☐ (→ d_relig)
Yes ☐ (→ d_totdep)
Don't know ☐ (→ d_relig)
Refused ☐ (→ d_relig)

d_totdep Interviewer Only:
Please note the relationship of the dependent to [#d_firstname:u]. E.g. were they [#d_his_her] child?

d_relig And can I ask what was [#d_his_her] religion
Roman Catholic ☐
Church of Ireland ☐
Islam ☐
Presbyterian ☐
Orthodox ☐
Other (specify) ☐
No religion ☐
Don't know ☐
Refused ☐

d_educ OK, so in terms of education, what was the highest level of education or training that [#d_firstname:u] completed – this could be full time or part time?

Note: If the decedent was not educated in the Irish system, note down the education details so that the qualifications can be assigned to the equivalent in the Irish system.

No formal education/training ☐ (→ d_princ)
Primary education ☐ (→ d_princ)
Lower Secondary ☐ (→ d_princ)
Upper Secondary ☐ (→ d_princ)
Technical or Vocational ☐
Advanced Certificate/Completed Apprenticeship ☐
Higher Certificate ☐
Ordinary Bachelor Degree or National Diploma ☐
Honours Bachelor Degree/Professional qualification or both ☐
Postgraduate Diploma or Degree ☐
Doctorate (PhD) or higher ☐
Other (specify) ☐
Don't know ☐

Refused	☐	

d_subj Focusing on [#d_firstname:u]'s highest qualification, what area was it in?

d_prinec How would you describe [#d_firstname:u]'s main employment status in the year before [#d_he_she] died? What I mean is was [#d_he_she]...

Working for payment or profit – full time	☐	(→ d_occ)
Working for payment or profit – part time	☐	(→ d_occ)
Retired from employment	☐	(→ d_occ)
Looking after home/family	☐	(→ d_money)
Unable to work due to permanent sickness or disability	☐	(→ d_money)
Unemployed	☐	(→ d_occ)
Looking for first regular job	☐	(→ d_money)
Student	☐	(→ d_money)
Other (specify)	☐	(→ d_occ)
Don't know	☐	(→ d_money)
Refused	☐	(→ d_money)

d_occ What was [#d_his_her] occupation in [#d_his_her] most recent main job?

d_occ_stop And when did [#d_firstname:u] stop working (e.g. Jun 2011)?

Note: If [#d_firstname:u] stopped working several years ago and [#ki_firstname:u] cannot remember the month enter Jun.

d_money Can I ask you how well would you say [#d_firstname:u] was managing financially during the last year before [#d_he_she] died? Would you say that [#d_he_she] was....

Note: Read out all response options

Living comfortably	☐
Doing alright	☐
Just about getting by	☐
Finding it quite difficult	☐
Finding it very difficult	☐
Don't know	☐
Refused	☐

d_add Can you tell me the name of the townland/village/town/ or suburb in the city that [#d_firstname:u] was living in before [#d_he_she] became ill?

Note: We are asking this question to get an idea of how close the decedent was to services.

Carer Profile

OK. In this next section I will be asking some questions about who played an important role in caring for [#d_firstname:u] in the year before [#d_he_she] died.
In order to see how the care that [#d_firstname:u] required changed in the last year of [#d_his_her] life we have divided the year into two parts.
The questions focus on the first 9 months of that year which would have been from [#month_1] to [#month_9], and the last 3 months of that year which would have been from [#month_10] to [#month_12]. These questions may start to seem repetitive, but it is important to capture any changes in [#d_firstname:u]'s care that may have occurred over the year.
So, let's start with yourself...

Note: The purpose of these questions is to provide us with information on your involvement in [#d_firstname:u]'s care as well as every other family member or friend who played an important role in caring for [#d_him_her] during that last year.

ki_sex KI sex

Male	☐
Female	☐

ki_age What age were you on your last birthday?

ki_lang1	Is English your first language?		
	No	☐	(→ ki_lang)
	Yes	☐	(→ ki_add1_9)
	Refused	☐	(→ ki_add1_9)
ki_lang	How well do you speak English?		
	Very well	☐	
	Well	☐	
	Not well	☐	
	Not at all	☐	
ki_add1_9	So, during the first 9 months of the last year of [#d_firstname:u]'s life, did you usually live with [#d_him_her]?		
	No	☐	
	Yes	☐	(→ ki_add1_3)
	Refused	☐	
ki_freq_9	How often did you see [#d_him_her]?		
	Once a day	☐	
	More than once a day	☐	
	Once a week	☐	
	More than once a week	☐	
	About every two weeks	☐	
	About once a month	☐	
	Less than once a month	☐	
	Refused	☐	
ki_add2_9	And about how far did you have to travel? Was it...		
	Less than 15 minutes	☐	
	Between 15 and 30 minutes	☐	
	Between 30 minutes and one hour	☐	
	Between one and two hours	☐	
	Between two and five hours	☐	
	Between five and 12 hours	☐	
	Over 12 hours	☐	
	Refused	☐	
ki_add1_3	OK, so during the last 3 months of that last year, did you usually live with [#d_him_her]?		
	No	☐	
	Yes	☐	(→ ki_carer)
	Refused	☐	
ki_freq_3	How often did you see [#d_him_her]?		
	Once a day	☐	
	More than once a day	☐	
	Once a week	☐	
	More than once a week	☐	
	About every two weeks	☐	
	About once a month	☐	
	Less than once a month	☐	
	Refused	☐	
ki_add2_3	And about how far did you have to travel? Was it...		
	Less than 15 minutes	☐	
	Between 15 and 30 minutes	☐	
	Between 30 minutes and one hour	☐	
	Between one and two hours	☐	
	Between two and five hours	☐	
	Between five and 12 hours	☐	
	Over 12 hours	☐	
	Refused	☐	

ki_carer Did you receive any financial assistance for looking after [#d_firstname:u]? This could have been from the state through carers benefit or carers allowance, or from a voluntary agency, or from family or friends.

Note: Tick all responses that apply

No ☐
Yes, carers benefit ☐
Yes, carers allowance ☐
Yes, voluntary agency ☐
Yes, family ☐
Yes, friend ☐
Yes, other (please specify) ☐
Don't know ☐
Refused ☐

ki_prinec How would you describe your main employment status in the year before [#d_firstname:u] died? What I mean is were you...

Working for payment or profit – full time ☐ (→ ki_work)
Working for payment or profit – part time ☐ (→ ki_work)
Retired from employment ☐
Looking after home/family ☐
Unable to work due to permanent sickness or disability ☐
Unemployed ☐
Looking for first regular job ☐
Student ☐
Other (specify) ☐
Refused ☐

ki_work During the last year of [#d_firstname:u]'s life, did you have to stop or reduce working due to [#d_his_her] illness?

No ☐
Yes ☐ (→ ki_work_9)
Refused ☐

ki_work_9 During the first 9 months of the last year of [#d_firstname:u]'s life, did you have to stop or reduce working due to [#d_his_her] illness?

No ☐ (→ ki_work_3)
Yes ☐ (→ ki_work_days_9)
Refused ☐ (→ ki_work_3)

ki_work_days_9 Can you tell me about how many days did you have to take off work during that period?

Definition: "To take off work" refers to unpaid leave.

ki_work_3 And during the last 3 months of [#d_firstname:u]'s life, did you have to stop or reduce working due to [#d_firstname:u]'s illness?

No ☐
Yes ☐ (→ ki_work_days_3)
Refused ☐

ki_work_days_3 Can you tell me about how many days did you have to take off work during that period?

Definition: "To take off work" refers to unpaid leave.

ki_occ What was your occupation in your most recent main job?

OK, so, I'm now going to ask you some questions about other family and friends who played an important role in caring for [#d_firstname:u] during the last year of [#d_his_her] life.
This does not include those who either visited or spent time with [#d_firstname:u], but rather includes anyone who helped care for [#d_him_her] on a regular basis, for example washing, dressing and household tasks. Is that OK?

h_num During the last year of [#d_firstname:u]'s life, how many other people played an important role in caring for [#d_him_her]?

Note: Take a note of the names mentioned; and repeat the loops for however many carers are mentioned.

h_name_1 Additional Carer 1: Name

h_name_2 Additional Carer 2: Name

h_name_3 Additional Carer 3: Name

h_name_4 Additional Carer 4: Name

h_name_5 Additional Carer 5: Name

h_name_6 Additional Carer 6: Name

h_name_7 Additional Carer 7: Name

h_name_8 Additional Carer 8: Name

h_name_9 Additional Carer 9: Name

h_name_10 Additional Carer 10: Name

Additional Carer 1 – [#h_name_1:u]

h_sex_1 Is [#h_name_1:u] male or female?

Male ☐
Female ☐

h_rel_1 What was [#h_name_1:u]'s relationship to [#d_firstname:u]?
Was [#h_name_1:u] [#d_firstname:u]'s

Spouse/Partner ☐
Child/ adopted child ☐
Step child ☐
Child-in-law (daughter-in-law, son-in-law) ☐
Parent ☐
Parent-in-law ☐
Brother or sister ☐
Brother-in-law/Sister-in-law ☐
Grandparent ☐
Grandparent-in-law ☐
Other blood relative ☐
Other in-law ☐
Grandchild ☐
Non-relative (e.g. friend) ☐
Other (specify) ☐
Don't know ☐
Refused ☐

h_age_1 What age was [#h_name_1:u] on [#h_his_her_1] last birthday?

h_lang1_1 Is English [#h_name_1:u]'s first language?

No ☐ (→ h_lang_1)
Yes ☐ (→ h_add1_9_1)
Don't know ☐ (→ h_add1_9_1)
Refused ☐ (→ h_add1_9_1)

h_lang_1	How well does [#h_name_1:u] speak English?		
	Very well	☐	
	Well	☐	
	Not well	☐	
	Not at all	☐	
	Don't know	☐	
	Refused	☐	
h_add1_9_1	So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#h_name_1:u] usually live with [#d_him_her]?		
	No	☐	(→ h_freq_9_1)
	Yes	☐	(→ h_add1_3_1)
	Don't know	☐	(→ h_freq_9_1)
	Refused	☐	(→ h_freq_9_1)
h_freq_9_1	How often did [#h_name_1:u] see [#d_him_her]? h_freq_9_1		
	Once a day	☐	
	More than once a day	☐	
	Once a week	☐	
	More than once a week	☐	
	About every two weeks	☐	
	About once a month	☐	
	Less than once a month	☐	
	Don't know	☐	
	Refused	☐	
h_add2_9_1	And about how far did [#h_name_1:u] have to travel? Was it...		
	Less than 15 minutes	☐	
	Between 15 and 30 minutes	☐	
	Between 30 minutes and one hour	☐	
	Between one and two hours	☐	
	Between two and five hours	☐	
	Between five and 12 hours	☐	
	Over 12 hours	☐	
	Don't know	☐	
	Refused	☐	
h_add1_3_1	OK, so during the last 3 months of that last year, did [#h_name_1:u] usually live with [#d_him_her]?		
	No	☐	(→ h_freq_3_1)
	Yes	☐	(→ h_carer_1)
	Don't know	☐	(→ h_freq_3_1)
	Refused	☐	(→ h_freq_3_1)
h_freq_3_1	How often did [#h_name_1:u] see [#d_firstname:u]?		
	Once a day	☐	
	More than once a day	☐	
	Once a week	☐	
	More than once a week	☐	
	About every two weeks	☐	
	About once a month	☐	
	Less than once a month	☐	
	Don't know	☐	
	Refused	☐	
h_add2_3_1	And about how far did [#h_name_1:u] have to travel? Was it...		
	Less than 15 minutes	☐	
	Between 15 and 30 minutes	☐	
	Between 30 minutes and one hour	☐	
	Between one and two hours	☐	
	Between two and five hours	☐	
	Between five and 12 hours	☐	

Over 12 hours ☐
Don't know ☐
Refused ☐

h_carer_1 Did [#h_name_1:u] receive any financial assistance for looking after [#d_firstname:u]? This could have been from the state through carers benefit or carers allowance, or from a voluntary agency, or from family or friends.

Note: Tick all responses that apply

No ☐
Yes, carers benefit ☐
Yes, carers allowance ☐
Yes, voluntary agency ☐
Yes, family ☐
Yes, friend ☐
Yes, other (please specify) ☐
Don't know ☐
Refused ☐

h_prinec_1 How would you describe [#h_name_1:u]'s main employment status in the year before [#d_firstname:u] died? What I mean is was [#h_name_1:u]...

Working for payment or profit – full time ☐ (→ h_work_1)
Working for payment or profit – part time ☐ (→ h_work_1)
Retired from employment ☐
Looking after home/family ☐
Unable to work due to permanent sickness or disability ☐
Unemployed ☐
Looking for first regular job ☐
Student ☐
Other (specify) ☐
Don't know ☐
Refused ☐

h_work_1 During the last year of [#d_firstname:u]'s life, did [#h_name_1:u] have to stop or reduce working due to [#d_firstname:u]'s illness?

No ☐
Yes ☐ (→ h_work_9_1)
Don't know ☐
Refusal ☐

h_work_9_1 During the first 9 months of the last year of [#d_firstname:u]'s life, did [#h_name_1:u] have to stop or reduce working due to [#d_firstname:u]'s illness?

No ☐ (→ h_work_3_1)
Yes ☐ (→ h_work_days_9_1)
Don't know ☐ (→ h_work_3_1)
Refused ☐ (→ h_work_3_1)

h_work_days_9_1 Can you tell me, about how many days did [#h_name_1:u] have to take off work during that period?

Definition: "To take off work" refers to unpaid leave.

h_work_3_1 And during the last 3 months of [#d_firstname:u]'s life, did [#h_name_1:u] have to stop or reduce working due to [#d_firstname:u]'s illness?

No ☐
Yes ☐ (→ h_work_days_3_1)
Don't know ☐
Refused ☐

h_work_days_3_1 Can you tell me, about how many days did [#h_name_1:u] have to take off work during that period?

Definition: "To take off work" refers to unpaid leave.

h_occ_1	What was [#h_name_1:u]'s occupation in [#h_his_her_1] most recent main job?

...repeat for 9 more additional carers

And finally, just so that we have a full picture of the network of support [#d_firstname:u] had during [#d_his_her] last year...

h_visit_fl	Were there other family or friends, who may not have helped to care for [#d_firstname:u], but who visited [#d_him_her] on a regular basis?		
	No	☐	(→ decedent living pattern)
	Yes	☐	
	Don't know	☐	(→ decedent living pattern)
	Refused	☐	(→ decedent living pattern)

h_visit	Can you tell me a little about this?

Decedent Living Pattern

OK, so this next section looks at where [#d_firstname:u] lived during the last year of [#d_his_her] life. For example I would like to record if [#d_firstname:u] moved from home into a nursing home or if a relative moved in or out for any period of time. I will not include short-term stays, in for example hospital, but rather significant changes of one month or more.

Note: Ascertain if there was a change during each month and why. Please record changes in the last month even if less than one month – e.g. if someone moved in for the last week.

d_liv	During the last year of [#d_firstname:u]'s life, where was [#d_he_she] living?

d_liv_m1	[#month_1]	
	In own home – living alone	☐
	In own home – living with spouse/partner	☐
	In own home – living with spouse/partner and other	☐
	In own home – living with other relative	☐
	In own home – living with other	☐
	In home of relative or friend – with spouse/partner	☐
	In home of relative or friend – without spouse/partner	☐
	In a hospice	☐
	In hospital	☐
	In a nursing home	☐
	Community Nursing Unit (HSE long stay unit)	☐
	Other institution (specify)	☐
	Other (specify)	☐
	Don't know	☐
	Refused	☐

d_liv_m2	[#month_2]	
	In own home – living alone	☐
	In own home – living with spouse/partner	☐
	In own home – living with spouse/partner and other	☐
	In own home – living with other relative	☐
	In own home – living with other	☐
	In home of relative or friend – with spouse/partner	☐
	In home of relative or friend – without spouse/partner	☐
	In a hospice	☐
	In hospital	☐
	In a nursing home	☐
	Community Nursing Unit (HSE long stay unit)	☐
	Other institution (specify)	☐
	Other (specify)	☐
	Don't know	☐
	Refused	☐

d_liv_m2r [#month_1] to [#month_2] – If changed, why?

Repeat for all of the last 12 months of life

Informal Care

OK. In this next section I will be asking questions about [#d_firstname:u]'s care needs over the last year of [#d_his_her] life. The purpose of these questions is to provide us with information on the amount of help [#d_firstname:u] may have needed from family or friends with day-to-day tasks in that last year. We would like to know approximately how much time you and other friends and family members spent helping [#d_firstname:u] during the first 9 months and the last 3 months of that last year.

d_badl1_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance at home from family or friends with personal care, for example bathing or showering, dressing or grooming (e.g. brushing teeth, brushing hair, etc)?

No ☐ (→ d_badl4_fl)
Yes ☐
Don't know ☐ (→ d_badl4_fl)
Refused ☐ (→ d_badl4_fl)

d_badl1_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance with personal care?

No ☐
Yes ☐ (→ d_badl1_mth_9)
Don't know ☐
Refused ☐

d_badl1_mth_9 For how many months during that period did [#d_he_she] need this assistance?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
13 weeks ☐
14 weeks ☐
15 weeks ☐
16 weeks (4 months) ☐
17 weeks ☐
18 weeks ☐
19 weeks ☐
20 weeks (5 months) ☐
21 weeks ☐
22 weeks ☐
23 weeks ☐
24 weeks (6 months) ☐
25 weeks ☐
26 weeks ☐
27 weeks ☐
28 weeks (7 months) ☐
29 weeks ☐
30 weeks ☐
31 weeks ☐
32 weeks (8 months) ☐
33 weeks ☐
34 weeks ☐
35 weeks ☐

	36 weeks (9 months)	☐	
	Don't know	☐	
	Refused	☐	
d_badl1_hrs_9	Usually how much time did this involve in a day? I realise it is not easy to break this down, it may help to think about a typical day.		
	15 minutes	☐	
	20 minutes	☐	
	25 minutes	☐	
	30 minutes	☐	
	35 minutes	☐	
	40 minutes	☐	
	45 minutes	☐	
	50 minutes	☐	
	55 minutes	☐	
	1 hour	☐	
	1.5 hours	☐	
	2 hours	☐	
	2.5 hours	☐	
	3 hours	☐	
	3.5 hours	☐	
	4 hours	☐	
	4.5 hours	☐	
	5 hours	☐	
	5.5 hours	☐	
	6 hours	☐	
	6.5 hours	☐	
	7 hours	☐	
	7.5 hours	☐	
	8 hours	☐	
	8.5 hours	☐	
	9 hours	☐	
	9.5 hours	☐	
	10 hours	☐	
	10.5 hours	☐	
	11 hours	☐	
	11.5 hours	☐	
	12 hours	☐	
	24 hours	☐	
	Don't know	☐	
	Refused	☐	
d_badl1_day_9	Usually how many days per week did this involve?		
	1 day per week	☐	
	2 days per week	☐	
	3 days per week	☐	
	4 days per week	☐	
	5 days per week	☐	
	6 days per week	☐	
	7 days per week	☐	
	Don't know	☐	
	Refused	☐	
d_badl1_3	And how about during the last 3 months of that year?		
	No	☐	(→ d_badl4_fl)
	Yes	☐	(→ d_badl1_mth_3)
	Don't know	☐	(→ d_badl4_fl)
	Refusal	☐	(→ d_badl4_fl)
d_badl1_mth_3	For how many months during that period did [#d_he_she] need this assistance? Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)		
	1 week	☐	

2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
Don't know ☐
Refused ☐

d_badl1_hrs_3 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐
4 hours ☐
4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐
7.5 hours ☐
8 hours ☐
8.5 hours ☐
9 hours ☐
9.5 hours ☐
10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_badl1_day_3 Usually how many days per week did this involve?
1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_badl4_fl	During the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance at home from family or friends with eating and drinking?		
	No	☐	(→ d_badl5_fl)
	Yes	☐	
	Don't know	☐	(→ d_badl5_fl)
	Refusal	☐	(→ d_badl5_fl)
d_badl4_9	So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance with eating and drinking?		
	No	☐	
	Yes	☐	(→ d_badl4_mth_9)
	Don't know	☐	
	Refusal	☐	
d_badl4_mth_9	For how many months during that period did [#d_he_she] need this assistance? Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)		
	1 week	☐	
	2 weeks	☐	
	3 weeks	☐	
	4 weeks (1 month)	☐	
	5 weeks	☐	
	6 weeks	☐	
	7 weeks	☐	
	8 weeks (2 months)	☐	
	9 weeks	☐	
	10 weeks	☐	
	11 weeks	☐	
	12 weeks (3 months)	☐	
	13 weeks	☐	
	14 weeks	☐	
	15 weeks	☐	
	16 weeks (4 months)	☐	
	17 weeks	☐	
	18 weeks	☐	
	19 weeks	☐	
	20 weeks (5 months)	☐	
	21 weeks	☐	
	22 weeks	☐	
	23 weeks	☐	
	24 weeks (6 months)	☐	
	25 weeks	☐	
	26 weeks	☐	
	27 weeks	☐	
	28 weeks (7 months)	☐	
	29 weeks	☐	
	30 weeks	☐	
	31 weeks	☐	
	32 weeks (8 months)	☐	
	33 weeks	☐	
	34 weeks	☐	
	35 weeks	☐	
	36 weeks (9 months)	☐	
	Don't know	☐	
	Refused	☐	
d_badl4_hrs_9	Usually how much time did this involve in a day? I realise it is not easy to break this down, it may help to think about a typical day.		
	15 minutes	☐	
	20 minutes	☐	
	25 minutes	☐	
	30 minutes	☐	
	35 minutes	☐	

40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐
4 hours ☐
4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐
7.5 hours ☐
8 hours ☐
8.5 hours ☐
9 hours ☐
9.5 hours ☐
10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_badl4_day_9 Usually how many days per week did this involve?
1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_badl4_3 And how about during the last 3 months of that year?
No ☐ (→ d_badl5_fl)
Yes ☐ (→ d_badl4_mth_3)
Don't know ☐ (→ d_badl5_fl)
Refusal ☐ (→ d_badl5_fl)

d_badl4_mth_3 For how many months during that period did [#d_he_she] need this assistance?
Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐

Don't know ☐
Refused ☐

d_badl4_hrs_3 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐
4 hours ☐
4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐
7.5 hours ☐
8 hours ☐
8.5 hours ☐
9 hours ☐
9.5 hours ☐
10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_badl4_day_3 Usually how many days per week did this involve?
1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_badl5_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance at home from family or friends with using the toilet, including getting up and down?
No ☐ (→ d_badl6_fl)
Yes ☐
Don't know ☐ (→ d_badl6_fl)
Refusal ☐ (→ d_badl6_fl)

d_badl5_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance with using the toilet?
No ☐
Yes ☐ (→ d_badl5_mth_9)

Don't know ☐
Refusal ☐

d_badl5_mth_9 For how many months during that period did [#d_he_she] need this assistance?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
13 weeks ☐
14 weeks ☐
15 weeks ☐
16 weeks (4 months) ☐
17 weeks ☐
18 weeks ☐
19 weeks ☐
20 weeks (5 months) ☐
21 weeks ☐
22 weeks ☐
23 weeks ☐
24 weeks (6 months) ☐
25 weeks ☐
26 weeks ☐
27 weeks ☐
28 weeks (7 months) ☐
29 weeks ☐
30 weeks ☐
31 weeks ☐
32 weeks (8 months) ☐
33 weeks ☐
34 weeks ☐
35 weeks ☐
36 weeks (9 months) ☐
Don't know ☐
Refused ☐

d_badl5_hrs_9 Usually how much time did this involve in a day?

I realise it is not easy to break this down, it may help to think about a typical day.

15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐
4 hours ☐

4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐
7.5 hours ☐
8 hours ☐
8.5 hours ☐
9 hours ☐
9.5 hours ☐
10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_badl5_day_9 Usually how many days per week did this involve?
1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_badl5_3 And how about during the last 3 months of that year?
No ☐ (→ d_badl6_fl)
Yes ☐ (→ d_badl5_mth_3)
Don't know ☐ (→ d_badl6_fl)
Refusal ☐ (→ d_badl6_fl)

d_badl5_mth_3 For how many months during that period did [#d_he_she] need this assistance?
Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
Don't know ☐
Refused ☐

d_badl5_hrs_3 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐

45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐
4 hours ☐
4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐
7.5 hours ☐
8 hours ☐
8.5 hours ☐
9 hours ☐
9.5 hours ☐
10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_badl5_day_3 Usually how many days per week did this involve?
1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_badl6_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance at home from family or friends with mobility indoors, for example getting in and out of bed, going up and down stairs, getting across the room?
No ☐ (→ d_iadl1_fl)
Yes ☐
Don't know ☐ (→ d_iadl1_fl)
Refusal ☐ (→ d_iadl1_fl)

d_badl6_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance with mobility indoors?
No ☐
Yes ☐ (→ d_badl6_mth_9)
Don't know ☐
Refusal ☐

d_badl6_mth_9 For how many months during that period did [#d_he_she] need this assistance?
Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐

5 weeks	☐
6 weeks	☐
7 weeks	☐
8 weeks (2 months)	☐
9 weeks	☐
10 weeks	☐
11 weeks	☐
12 weeks (3 months)	☐
13 weeks	☐
14 weeks	☐
15 weeks	☐
16 weeks (4 months)	☐
17 weeks	☐
18 weeks	☐
19 weeks	☐
20 weeks (5 months)	☐
21 weeks	☐
22 weeks	☐
23 weeks	☐
24 weeks (6 months)	☐
25 weeks	☐
26 weeks	☐
27 weeks	☐
28 weeks (7 months)	☐
29 weeks	☐
30 weeks	☐
31 weeks	☐
32 weeks (8 months)	☐
33 weeks	☐
34 weeks	☐
35 weeks	☐
36 weeks (9 months)	☐
Don't know	☐
Refused	☐

d_badl6_hrs_9 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.

15 minutes	☐
20 minutes	☐
25 minutes	☐
30 minutes	☐
35 minutes	☐
40 minutes	☐
45 minutes	☐
50 minutes	☐
55 minutes	☐
1 hour	☐
1.5 hours	☐
2 hours	☐
2.5 hours	☐
3 hours	☐
3.5 hours	☐
4 hours	☐
4.5 hours	☐
5 hours	☐
5.5 hours	☐
6 hours	☐
6.5 hours	☐
7 hours	☐
7.5 hours	☐
8 hours	☐
8.5 hours	☐
9 hours	☐

9.5 hours ☐
10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_badl6_day_9 Usually how many days per week did this involve?
1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_badl6_3 And how about during the last 3 months of that year?
No ☐ (→ d_iadl1_fl)
Yes ☐ (→ d_badl6_mth_3)
Don't know ☐ (→ d_iadl1_fl)
Refusal ☐ (→ d_iadl1_fl)

d_badl6_mth_3 For how many months during that period did [#d_he_she] need this assistance?
Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
Don't know ☐
Refused ☐

d_badl6_hrs_3 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐
4 hours ☐

	4.5 hours	☐	
	5 hours	☐	
	5.5 hours	☐	
	6 hours	☐	
	6.5 hours	☐	
	7 hours	☐	
	7.5 hours	☐	
	8 hours	☐	
	8.5 hours	☐	
	9 hours	☐	
	9.5 hours	☐	
	10 hours	☐	
	10.5 hours	☐	
	11 hours	☐	
	11.5 hours	☐	
	12 hours	☐	
	24 hours	☐	
	Don't know	☐	
	Refused	☐	
d_badl6_day_3	Usually how many days per week did this involve?		
	1 day per week	☐	
	2 days per week	☐	
	3 days per week	☐	
	4 days per week	☐	
	5 days per week	☐	
	6 days per week	☐	
	7 days per week	☐	
	Don't know	☐	
	Refused	☐	
d_iadl1_fl	During the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance at home from family or friends with taking medications?		
	No	☐	(→ d_super_fl)
	Yes	☐	
	Don't know	☐	(→ d_super_fl)
	Refusal	☐	(→ d_super_fl)
d_iadl1_9	So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance with taking medications?		
	No	☐	
	Yes	☐	(→ d_iadl1_mth_9)
	Don't know	☐	
	Refusal	☐	
d_iadl1_mth_9	For how many months during that period did [#d_he_she] need this assistance? Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)		
	1 week	☐	
	2 weeks	☐	
	3 weeks	☐	
	4 weeks (1 month)	☐	
	5 weeks	☐	
	6 weeks	☐	
	7 weeks	☐	
	8 weeks (2 months)	☐	
	9 weeks	☐	
	10 weeks	☐	
	11 weeks	☐	
	12 weeks (3 months)	☐	
	13 weeks	☐	
	14 weeks	☐	
	15 weeks	☐	

16 weeks (4 months) ☐
17 weeks ☐
18 weeks ☐
19 weeks ☐
20 weeks (5 months) ☐
21 weeks ☐
22 weeks ☐
23 weeks ☐
24 weeks (6 months) ☐
25 weeks ☐
26 weeks ☐
27 weeks ☐
28 weeks (7 months) ☐
29 weeks ☐
30 weeks ☐
31 weeks ☐
32 weeks (8 months) ☐
33 weeks ☐
34 weeks ☐
35 weeks ☐
36 weeks (9 months) ☐
Don't know ☐
Refused ☐

d_iadl1_hrs_9 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐
4 hours ☐
4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐
7.5 hours ☐
8 hours ☐
8.5 hours ☐
9 hours ☐
9.5 hours ☐
10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_iadl1_day_9 Usually how many days per week did this involve?

1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_iadl1_3 And how about during the last 3 months of that year?
No ☐ (→ d_super_fl)
Yes ☐ (→ d_iadl1_mth_3)
Don't know ☐ (→ d_super_fl)
Refusal ☐ (→ d_super_fl)

d_iadl1_mth_3 For how many months during that period did [#d_he_she] need this assistance?
Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
Don't know ☐
Refused ☐

d_iadl1_hrs_3 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐
4 hours ☐
4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐
7.5 hours ☐
8 hours ☐
8.5 hours ☐
9 hours ☐
9.5 hours ☐

10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_iadl1_day_3 Usually how many days per week did this involve?
1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_super_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] require active supervision at home from family or friends?

Definition: "Active supervision" means that the decedent could not be left alone.
No ☐ (→ d_iadl3_fl)
Yes ☐
Don't know ☐ (→ d_iadl3_fl)
Refusal ☐ (→ d_iadl3_fl)

d_super_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] require active supervision?
No ☐
Yes ☐ (→ d_super_mth_9)
Don't know ☐
Refusal ☐

d_super_mth_9 For how many months during that period did [#d_he_she] need this assistance?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
13 weeks ☐
14 weeks ☐
15 weeks ☐
16 weeks (4 months) ☐
17 weeks ☐
18 weeks ☐
19 weeks ☐
20 weeks (5 months) ☐
21 weeks ☐
22 weeks ☐
23 weeks ☐
24 weeks (6 months) ☐
25 weeks ☐

26 weeks ☐
27 weeks ☐
28 weeks (7 months) ☐
29 weeks ☐
30 weeks ☐
31 weeks ☐
32 weeks (8 months) ☐
33 weeks ☐
34 weeks ☐
35 weeks ☐
36 weeks (9 months) ☐
Don't know ☐
Refused ☐

d_super_txt_9 Can you tell me a little about this?

X

d_super_3 And how about during the last 3 months of that year?

No ☐ (→ d_iadl3_fl)
Yes ☐ (→ d_super_mth_3)
Don't know ☐ (→ d_iadl3_fl)
Refusal ☐ (→ d_iadl3_fl)

d_super_mth_3 For how many months during that period did [#d_he_she] need this assistance?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
Don't know ☐
Refused ☐

d_super_txt_3 Can you tell me a little about this?

d_iadl3_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance at home from family or friends with household tasks, for example shopping, cooking, laundry, cleaning – above normal activity?

No ☐ (→ d_iadl2_fl)
Yes ☐
Don't know ☐ (→ d_iadl2_fl)
Refusal ☐ (→ d_iadl2_fl)

d_iadl3_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance with household tasks – above normal activity?

No ☐
Yes ☐ (→ d_iadl3_mth_9)
Don't know ☐
Refusal ☐

d_iadl3_mth_9 For how many months during that period did [#d_he_she] need this assistance?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
13 weeks ☐
14 weeks ☐
15 weeks ☐
16 weeks (4 months) ☐
17 weeks ☐
18 weeks ☐
19 weeks ☐
20 weeks (5 months) ☐
21 weeks ☐
22 weeks ☐
23 weeks ☐
24 weeks (6 months) ☐
25 weeks ☐
26 weeks ☐
27 weeks ☐
28 weeks (7 months) ☐
29 weeks ☐
30 weeks ☐
31 weeks ☐
32 weeks (8 months) ☐
33 weeks ☐
34 weeks ☐
35 weeks ☐
36 weeks (9 months) ☐
Don't know ☐
Refused ☐

d_iadl3_hrs_9 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐
4 hours ☐
4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐

7.5 hours ☐
8 hours ☐
8.5 hours ☐
9 hours ☐
9.5 hours ☐
10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_iadl3_day_9 Usually how many days per week did this involve?
1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_iadl3_3 And how about during the last 3 months of that year?
No ☐
Yes ☐
Don't know ☐
Refusal ☐

d_iadl3_mth_3 For how many months during that period did [#d_he_she] need this assistance?
Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
Don't know ☐
Refused ☐

d_iadl3_hrs_3 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐

	2.5 hours	☐	
	3 hours	☐	
	3.5 hours	☐	
	4 hours	☐	
	4.5 hours	☐	
	5 hours	☐	
	5.5 hours	☐	
	6 hours	☐	
	6.5 hours	☐	
	7 hours	☐	
	7.5 hours	☐	
	8 hours	☐	
	8.5 hours	☐	
	9 hours	☐	
	9.5 hours	☐	
	10 hours	☐	
	10.5 hours	☐	
	11 hours	☐	
	11.5 hours	☐	
	12 hours	☐	
	24 hours	☐	
	Don't know	☐	
	Refused	☐	
d_iadl3_day_3	Usually how many days per week did this involve?		
	1 day per week	☐	
	2 days per week	☐	
	3 days per week	☐	
	4 days per week	☐	
	5 days per week	☐	
	6 days per week	☐	
	7 days per week	☐	
	Don't know	☐	
	Refused	☐	
d_iadl2_fl	During the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance at home from family or friends with travel or driving for appointments or treatments – above normal activity?		
	No	☐	(→ d_iadl4_fl)
	Yes	☐	
	Don't know	☐	(→ d_iadl4_fl)
	Refusal	☐	(→ d_iadl4_fl)
d_iadl2_9	So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance with travel or driving for appointments or treatments – above normal activity?		
	No	☐	
	Yes	☐	(→ d_iadl2_mth_9)
	Don't know	☐	
	Refusal	☐	
d_iadl2_mth_9	For how many months during that period did [#d_he_she] need this assistance? Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)		
	1 week	☐	
	2 weeks	☐	
	3 weeks	☐	
	4 weeks (1 month)	☐	
	5 weeks	☐	
	6 weeks	☐	
	7 weeks	☐	
	8 weeks (2 months)	☐	
	9 weeks	☐	
	10 weeks	☐	
	11 weeks	☐	

12 weeks (3 months) ☐
13 weeks ☐
14 weeks ☐
15 weeks ☐
16 weeks (4 months) ☐
17 weeks ☐
18 weeks ☐
19 weeks ☐
20 weeks (5 months) ☐
21 weeks ☐
22 weeks ☐
23 weeks ☐
24 weeks (6 months) ☐
25 weeks ☐
26 weeks ☐
27 weeks ☐
28 weeks (7 months) ☐
29 weeks ☐
30 weeks ☐
31 weeks ☐
32 weeks (8 months) ☐
33 weeks ☐
34 weeks ☐
35 weeks ☐
36 weeks (9 months) ☐
Don't know ☐
Refused ☐

d_iadl2_3 And how about during the last 3 months of that year?
No ☐ (→ d_iadl4_fl)
Yes ☐ (→ d_iadl2_mth_3)
Don't know ☐ (→ d_iadl4_fl)
Refusal ☐ (→ d_iadl4_fl)

d_iadl2_mth_3 For how many months during that period did [#d_he_she] need this assistance?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
Don't know ☐
Refused ☐

d_iadl4_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance at home from family or friends with administrative tasks, for example making telephone calls, managing money, arranging home adaptations and professional care – above normal activity?
No ☐
Yes ☐
Don't know ☐
Refusal ☐

d_iadl4_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance with administrative tasks – above normal activity?
No ☐

Yes ☐ (→ d_iadl4_mth_9)
Don't know ☐
Refusal ☐

d_iadl4_mth_9 For how many months during that period did [#d_he_she] need this assistance?
Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
13 weeks ☐
14 weeks ☐
15 weeks ☐
16 weeks (4 months) ☐
17 weeks ☐
18 weeks ☐
19 weeks ☐
20 weeks (5 months) ☐
21 weeks ☐
22 weeks ☐
23 weeks ☐
24 weeks (6 months) ☐
25 weeks ☐
26 weeks ☐
27 weeks ☐
28 weeks (7 months) ☐
29 weeks ☐
30 weeks ☐
31 weeks ☐
32 weeks (8 months) ☐
33 weeks ☐
34 weeks ☐
35 weeks ☐
36 weeks (9 months) ☐
Don't know ☐
Refused ☐

d_iadl4_hrs_9 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐

4 hours ☐
4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐
7.5 hours ☐
8 hours ☐
8.5 hours ☐
9 hours ☐
9.5 hours ☐
10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_iadl4_day_9 Usually how many days per week did this involve?
1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_iadl4_3 And how about during the last 3 months of that year?
No ☐
Yes ☐ (→ d_iadl4_mth_3)
Don't know ☐
Refusal ☐

d_iadl4_mth_3 For how many months during that period did [#d_he_she] need this assistance?
Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
Don't know ☐
Refused ☐

d_iadl4_hrs_3 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐

40 minutes	☐
45 minutes	☐
50 minutes	☐
55 minutes	☐
1 hour	☐
1.5 hours	☐
2 hours	☐
2.5 hours	☐
3 hours	☐
3.5 hours	☐
4 hours	☐
4.5 hours	☐
5 hours	☐
5.5 hours	☐
6 hours	☐
6.5 hours	☐
7 hours	☐
7.5 hours	☐
8 hours	☐
8.5 hours	☐
9 hours	☐
9.5 hours	☐
10 hours	☐
10.5 hours	☐
11 hours	☐
11.5 hours	☐
12 hours	☐
24 hours	☐
Don't know	☐
Refused	☐

d_iadl4_day_3 Usually how many days per week did this involve?

1 day per week	☐
2 days per week	☐
3 days per week	☐
4 days per week	☐
5 days per week	☐
6 days per week	☐
7 days per week	☐
Don't know	☐
Refused	☐

d_iadl5_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance at home from family or friends with childcare or care of other dependents – above normal activity?

Note: Answer no if entire period was spent in an institution and the assistance stopped.

No	☐	(→ d_iadl6_fl)
Yes	☐	(→ d_iadl5_9)
Don't know	☐	(→ d_iadl6_fl)
Refusal	☐	(→ d_iadl6_fl)

d_iadl5_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] need assistance at home from family or friends with childcare or care of other dependents?

Note: Answer no if entire period was spent in an institution and the assistance stopped.

No	☐	(→ d_iadl5_3)
Yes	☐	(→ d_iadl5_mth_9)
Don't know	☐	(→ d_iadl5_3)
Refusal	☐	(→ d_iadl5_3)

d_iadl5_mth_9 For how many months during that period did [#d_he_she] need this assistance?

Note: Only deduct time spent in an institution if the assistance stopped during this time.

1 week	☐
2 weeks	☐
3 weeks	☐

4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
13 weeks ☐
14 weeks ☐
15 weeks ☐
16 weeks (4 months) ☐
17 weeks ☐
18 weeks ☐
19 weeks ☐
20 weeks (5 months) ☐
21 weeks ☐
22 weeks ☐
23 weeks ☐
24 weeks (6 months) ☐
25 weeks ☐
26 weeks ☐
27 weeks ☐
28 weeks (7 months) ☐
29 weeks ☐
30 weeks ☐
31 weeks ☐
32 weeks (8 months) ☐
33 weeks ☐
34 weeks ☐
35 weeks ☐
36 weeks (9 months) ☐
Don't know ☐
Refused ☐

d_iadl5_hrs_9 Usually how much time did this involve in a day?
I realise it is not easy to break this down, it may help to think about a typical day.
15 minutes ☐
20 minutes ☐
25 minutes ☐
30 minutes ☐
35 minutes ☐
40 minutes ☐
45 minutes ☐
50 minutes ☐
55 minutes ☐
1 hour ☐
1.5 hours ☐
2 hours ☐
2.5 hours ☐
3 hours ☐
3.5 hours ☐
4 hours ☐
4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐
7.5 hours ☐
8 hours ☐
8.5 hours ☐

	9 hours	☐	
	9.5 hours	☐	
	10 hours	☐	
	10.5 hours	☐	
	11 hours	☐	
	11.5 hours	☐	
	12 hours	☐	
	24 hours	☐	
	Don't know	☐	
	Refused	☐	

d_iadl5_day_9	Usually how many days per week did this involve?		
	1 day per week	☐	
	2 days per week	☐	
	3 days per week	☐	
	4 days per week	☐	
	5 days per week	☐	
	6 days per week	☐	
	7 days per week	☐	
	Don't know	☐	
	Refused	☐	

d_iadl5_3	And how about during the last 3 months of that year? Note: Answer no if entire period was spent in an institution and the assistance stopped.		
	No	☐	(→ d_iadl6_fl)
	Yes	☐	(→ d_iadl5_mth_3)
	Don't know	☐	(→ d_iadl6_fl)
	Refusal	☐	(→ d_iadl6_fl)

d_iadl5_mth_3	For how many months during that period did [#d_he_she] need this assistance? Note: Only deduct time spent in an institution if the assistance stopped during this time.		
	1 week	☐	
	2 weeks	☐	
	3 weeks	☐	
	4 weeks (1 month)	☐	
	5 weeks	☐	
	6 weeks	☐	
	7 weeks	☐	
	8 weeks (2 months)	☐	
	9 weeks	☐	
	10 weeks	☐	
	11 weeks	☐	
	12 weeks (3 months)	☐	
	Don't know	☐	
	Refused	☐	

d_iadl5_hrs_3	Usually how much time did this involve in a day? I realise it is not easy to break this down, it may help to think about a typical day.		
	15 minutes	☐	
	20 minutes	☐	
	25 minutes	☐	
	30 minutes	☐	
	35 minutes	☐	
	40 minutes	☐	
	45 minutes	☐	
	50 minutes	☐	
	55 minutes	☐	
	1 hour	☐	
	1.5 hours	☐	
	2 hours	☐	
	2.5 hours	☐	
	3 hours	☐	
	3.5 hours	☐	

4 hours ☐
4.5 hours ☐
5 hours ☐
5.5 hours ☐
6 hours ☐
6.5 hours ☐
7 hours ☐
7.5 hours ☐
8 hours ☐
8.5 hours ☐
9 hours ☐
9.5 hours ☐
10 hours ☐
10.5 hours ☐
11 hours ☐
11.5 hours ☐
12 hours ☐
24 hours ☐
Don't know ☐
Refused ☐

d_iadl5_day_3 Usually how many days per week did this involve?
1 day per week ☐
2 days per week ☐
3 days per week ☐
4 days per week ☐
5 days per week ☐
6 days per week ☐
7 days per week ☐
Don't know ☐
Refused ☐

d_iadl6_fl Thinking about when [#d_firstname:u] was ill.
At times during the day when [#d_he_she] wasn’t receiving active care, did [#d_he_she] want company from family or friends – above normal activity?

Optional: For example, was [#d_he_she] happy to sit and read the paper, or did [#d_he_she] want someone to sit with [#d_him_her], or if [#d_he_she] was at home and if you were going out did [#d_he_she] want company?
Note: This question is asked whether [#d_firstname:u] was in an institution or not.
No ☐
Yes ☐ (→ d_iadl6_9)
Don't know ☐
Refusal ☐

d_iadl6_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, when [#d_he_she] wasn’t receiving active care, did [#d_he_she] want company from family or friends – above normal activity?
No ☐ (→ d_iadl6_3)
Yes ☐ (→ d_iadl6_mth_9)
Don't know ☐ (→ d_iadl6_3)
Refusal ☐ (→ d_iadl6_3)

d_iadl6_mth_9 For how many months during that period did [#d_he_she] need this assistance?
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐

11 weeks ☐
12 weeks (3 months) ☐
13 weeks ☐
14 weeks ☐
15 weeks ☐
16 weeks (4 months) ☐
17 weeks ☐
18 weeks ☐
19 weeks ☐
20 weeks (5 months) ☐
21 weeks ☐
22 weeks ☐
23 weeks ☐
24 weeks (6 months) ☐
25 weeks ☐
26 weeks ☐
27 weeks ☐
28 weeks (7 months) ☐
29 weeks ☐
30 weeks ☐
31 weeks ☐
32 weeks (8 months) ☐
33 weeks ☐
34 weeks ☐
35 weeks ☐
36 weeks (9 months) ☐
Don't know ☐
Refused ☐

d_iadl6_txt_9 Can you tell me a little about this?

d_iadl6_3 And how about during the last 3 months of that year?
No ☐
Yes ☐
Don't know ☐
Refusal ☐

d_iadl6_mth_3 For how many months during that period did [#d_he_she] need this assistance?
1 week ☐
2 weeks ☐
3 weeks ☐
4 weeks (1 month) ☐
5 weeks ☐
6 weeks ☐
7 weeks ☐
8 weeks (2 months) ☐
9 weeks ☐
10 weeks ☐
11 weeks ☐
12 weeks (3 months) ☐
Don't know ☐
Refused ☐

d_iadl6_txt_3 Can you tell me a little about this?

carer_prop_grid Thinking about all of the care provided for [#d_firstname:u] by family and friends over the last year of [#d_his_her] life, what proportion of this care would you say was provided by each carer? Starting with yourself [#ki_firstname:u].

Note: Enter whole number percentages.
These are rough estimates but please ensure that they sum to 100%.
Names will appear only for those who provided care so the minimum response is 1%.
If the response is 'don't know' or 'refused' enter 0.
0 – 100

	%	
[#ki_firstname:u]		_#ki_firstname_u
[#h_name_1:u]		_#h_name_1_u
[#h_name_2:u]		_#h_name_2_u
[#h_name_3:u]		_#h_name_3_u
[#h_name_4:u]		_#h_name_4_u
[#h_name_5:u]		_#h_name_5_u
[#h_name_6:u]		_#h_name_6_u
[#h_name_7:u]		_#h_name_7_u
[#h_name_8:u]		_#h_name_8_u
[#h_name_9:u]		_#h_name_9_u
[#h_name_10:u]		_#h_name_10_u

Community Services Utilisation

OK. In this next section, I will be asking some questions about the different types of health care services that [#d_firstname:u] may have used in the community in the last year of [#d_his_her] life.

Note: EXCLUDE visits while in-patient in hospital, palliative outpatient department, palliative day care centre, in-patient in hospice. Note: The purpose of these questions is to provide us with information on how often [#d_firstname:u] used these services, for example G.P.s, physiotherapists and home help.

Medical & Nursing

d_serv_gp_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see or have telephone contact with a GP?

Note: "See" refers to surgery, home (including nursing home) and out-of-hours visits (including GP out-of-hours co-ops MIDoc, Care Doc, Shannon Doc etc.).
Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment or to get test results.

No	☐	(→ d_serv_phn_fl)
Yes	☐	(→ d_gp_vis_9)
Don't know	☐	(→ d_serv_phn_fl)
Refused	☐	(→ d_serv_phn_fl)

d_gp_vis_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see a GP?

Note: "See" refers to surgery, home (including nursing home) and out-of-hours visits (including GP out-of-hours co-ops MIDoc, Care Doc, Shannon Doc etc.).

d_gp_vis_3 And how about during the last 3 months of that year?

Note: "See" refers to surgery, home (including nursing home) and out-of-hours visits (including GP out-of-hours co-ops MIDoc, Care Doc, Shannon Doc etc.).

d_gp_ph_9 Also, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] or someone on [#d_his_her] behalf have telephone contact with a GP?

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment or to get test results.

d_gp_ph_3 And how about during the last 3 months of that year?

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment or to get test results.

d_serv_phn_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see or have telephone contact with a public health nurse at home?

Note: "See" refers to home visits (including nursing home) only; it excludes visits while in-patient in hospital, at outpatient department, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment.

Note: A public health nurse is often mixed up with palliative care nurse. Common 'nicknames' for a public health nurse include: 'local health nurse', 'area health nurse', 'nurse out of the health centre', 'nurse that does the dressings & equipment'.

No	☐	(→ d_serv_pcc_fl)
Yes	☐	(→ d_phn_vis_9)
Don't know	☐	(→ d_serv_pcc_fl)
Refused	☐	(→ d_serv_pcc_fl)

d_phn_vis_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times was [#d_he_she] visited by a public health nurse?

Note: "See" refers to home visits (including nursing home) only; it excludes visits while in-patient in hospital, at outpatient department, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

Note: A public health nurse is often mixed up with palliative care nurse. Common 'nicknames' for a public health nurse include: 'local health nurse', 'area health nurse', 'nurse out of the health centre', 'nurse that does the dressings & equipment'.

d_phn_vis_3 And how about during the last 3 months of that year?

Note: "See" refers to home visits (including nursing home) only; it excludes visits while in-patient in hospital, at outpatient department, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

Note: A public health nurse is often mixed up with palliative care nurse. Common 'nicknames' for a public health nurse include: 'local health nurse', 'area health nurse', 'nurse out of the health centre', 'nurse that does the dressings & equipment'.

d_phn_ph_9 Also, during the first 9 months of the last of [#d_firstname:u]'s life, how many times did [#d_he_she] or someone on [#d_his_her] behalf have telephone contact with a public health nurse?

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment.

Note: A public health nurse is often mixed up with palliative care nurse. Common 'nicknames' for a public health nurse include: 'local health nurse', 'area health nurse', 'nurse out of the health centre', 'nurse that does the dressings & equipment'.

d_phn_ph_3 And how about during the last 3 months of that year?

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment.

Note: A public health nurse is often mixed up with palliative care nurse. Common 'nicknames' for a public health nurse include: 'local health nurse', 'area health nurse', 'nurse out of the health centre', 'nurse that does the dressings & equipment'.

d_serv_pcc_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see or have telephone contact with a palliative care consultant at home?

Note: "See" refers to home visits (including nursing home) only; it excludes visits while in-patient in hospital, at outpatient department, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

Note: Include palliative care doctors as well as palliative care consultants.

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment.

No	☐	(→ d_serv_pcn_fl)
Yes	☐	(→ d_pcc_vis_9)
Don't know	☐	(→ d_serv_pcn_fl)
Refused	☐	(→ d_serv_pcn_fl)

d_pcc_vis_9 So, during the first 9 months of the last of [#d_firstname:u]'s life, how many times was [#d_he_she] visited by a palliative care consultant?

Note: "See" refers to home visits (including nursing home) only; it excludes visits while in-patient in hospital, at outpatient department, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

d_pcc_vis_3 And how about during the last 3 months of that year?

Note: "See" refers to home visits (including nursing home) only; it excludes visits while in-patient in hospital, at outpatient department, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

d_pcc_ph_9 Also, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] or someone on [#d_his_her] behalf have telephone contact with a palliative care consultant?

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment.

d_pcc_ph_3 And how about during the last 3 months of that year?

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment.

d_serv_pcn_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see or have telephone contact with a palliative care nurse at home?

Note: "See" refers to home visits (including nursing home) only; it excludes visits while in-patient in hospital, at outpatient department, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment.

Note: Common 'nicknames' for a palliative care nurse include: 'pain and symptom control nurse', 'nurse attached to the hospice'.

No	☐	(→ d_serv_nns_fl)
Yes	☐	(→ d_pcn_vis_9)
Don't know	☐	(→ d_serv_nns_fl)
Refused	☐	(→ d_serv_nns_fl)

d_pcn_vis_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times was [#d_he_she] visited by a palliative care nurse?

Note: "See" refers to home visits (including nursing home) only; it excludes visits while in-patient in hospital, at outpatient department, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

Note: Common 'nicknames' for a palliative care nurse include: 'pain and symptom control nurse', 'nurse attached to the hospice'.

d_pcn_vis_3 And how about during the last 3 months of that year?

Note: "See" refers to home visits (including nursing home) only; it excludes visits while in-patient in hospital, at outpatient department, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

Note: Common 'nicknames' for a palliative care nurse include: 'pain and symptom control nurse', 'nurse attached to the hospice'.

d_pcn_ph_9 Also, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] or someone on [#d_his_her] behalf have telephone contact with a palliative care nurse?

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment.

Note: Common 'nicknames' for a palliative care nurse include: 'pain and symptom control nurse', 'nurse attached to the hospice'.

d_pcn_ph_3 And how about during the last 3 months of that year?

Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment.

Note: Common 'nicknames' for a palliative care nurse include: 'pain and symptom control nurse', 'nurse attached to the hospice'.

d_serv_nns_fl During the last 3 months of [#d_firstname:u]'s life, was [#d_he_she] visited by a night nurse at home?

Note: This includes home visits only.

Note: Common 'nicknames' for a night nurse include: 'daffodil nurse', 'Irish Cancer Society nurse'.

No	☐	(→ allied health professionals)
Yes	☐	(→ d_nns_day_3)
Don't know	☐	(→allied health professionals)

Refused	☐	(→allied health professionals)

d_nns_day_3 How many nights in total over the period?

Note: This includes home visits only.

Note: Common 'nicknames' for a night nurse include: 'daffodil nurse', 'Irish Cancer Society nurse'.

Allied Health Professionals

Now, I'm going to ask you some questions about other professionals, such as physiotherapists and dieticians, that [#d_firstname:u] may have seen during the last year of [#d_his_her] life. I will also be asking here about any fees paid for using those services. This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

Note: EXCLUDE visits while in-patient in hospital, palliative outpatient department, palliative day care centre, in-patient in hospice. Note: "Insurance policy excess" refers to the first part of any insurance claim that you have to pay yourself.

d_serv_ot_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see an occupational therapist?

Note: "See" refers to outpatient appointments in a hospital or a health-care centre, or home visits (including nursing home). It excludes visits while in-patient in hospital, palliative outpatient department, palliative day care centre, in-patient in hospice.

Note: The OT carries out an assessment of ability to function in relation to the normal requirements of living – dressing, eating, bathing, etc. Home arrangements are assessed (e.g. a wheelchair, chair lift, downstairs bathroom, etc.). The OT may then arrange for the provision of some appropriate aids and appliances or may certify eligibility for the housing adaptation grant for people with a disability. They may also provide advice and assistance in relation to changes or adaptations that need to be made to the house.

No	☐	(→ d_serv_phy_fl)
Yes	☐	(→ d_ot_vis_9)
Don't know	☐	(→ d_serv_phy_fl)
Refused	☐	(→ d_serv_phy_fl)

d_ot_vis_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see an occupational therapist?

d_ot_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_ot_vis_3)
Yes	☐	(→ d_ot_oopn_9)
Don't know	☐	(→ d_ot_vis_3)
Refused	☐	(→ d_ot_vis_3)

d_ot_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_ot_cost_9 And what was the average cost per visit?

d_ot_vis_3 If this was during the last 3 months of that year, how many times did [#d_he_she] see an occupational therapist?

d_ot_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_serv_phy_fl)
Yes	☐	(→ d_ot_oopn_3)
Don't know	☐	(→ d_serv_phy_fl)
Refused	☐	(→ d_serv_phy_fl)

d_ot_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_ot_cost_3	And what was the average cost per visit?		
d_serv_phy_fl	During the last year of [#d_firstname:u]'s life, did [#d_he_she] see a physiotherapist? Note: "See" refers to outpatient appointments in a hospital or a health-care centre, or home visits (including nursing home); it excludes visits while in-patient in hospital, at palliative outpatient department, at palliative day care centre and in-patient in hospice.		
	No	☐	(→ d_serv_diet_fl)
	Yes	☐	(→ d_phy_vis_9)
	Don't know	☐	(→ d_serv_diet_fl)
	Refused	☐	(→ d_serv_diet_fl)
d_phy_vis_9	If this was during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see a physiotherapist?		
d_phy_oop_9	Did [#d_he_she] have to pay out-of-pocket for any of these visits? Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.		
	No	☐	(→ d_phy_vis_3)
	Yes	☐	(→ d_phy_oopn_9)
	Don't know	☐	(→ d_phy_vis_3)
	Refused	☐	(→ d_phy_vis_3)
d_phy_oopn_9	So how many of these did [#d_he_she] have to pay for?		
d_phy_cost_9	And what was the average cost per visit?		
d_phy_vis_3	If this was during the last 3 months of that year, how many times did [#d_he_she] see a physiotherapist?		
d_phy_oop_3	Did [#d_he_she] have to pay out-of-pocket for any of these visits? Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.		
	No	☐	(→ d_serv_diet_fl)
	Yes	☐	(→ d_phy_oopn_3)
	Don't know	☐	(→ d_serv_diet_fl)
	Refusal	☐	(→ d_serv_diet_fl)
d_phy_oopn_3	So how many of these did [#d_he_she] have to pay for?		
d_phy_cost_3	And what was the average cost per visit?		
d_serv_diet_fl	During the last year of [#d_firstname:u]'s life, did [#d_he_she] see a dietician? Note: "See" refers to outpatient appointments in a hospital or a health-care centre, or home visits (including nursing home); it excludes visits while in-patient in hospital, at palliative outpatient department, at palliative day care centre and in-patient in hospice.		
	No	☐	(→ d_serv_sw_fl)
	Yes	☐	(→ d_diet_vis_9)
	Don't know	☐	(→ d_serv_sw_fl)
	Refused	☐	(→ d_serv_sw_fl)
d_diet_vis_9	If this was during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see a dietician? X		

d_diet_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_diet_vis_3)
Yes	☐	(→ d_diet_oopn_9)
Don't know	☐	(→ d_diet_vis_3)
Refused	☐	(→ d_diet_vis_3)

d_diet_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_diet_cost_9 And what was the average cost per visit?

d_diet_vis_3 If this was during the last 3 months of that year, how many times did [#d_he_she] see a dietician?

d_diet_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_serv_sw_fl)
Yes	☐	(→ d_diet_oopn_3)
Don't know	☐	(→ d_serv_sw_fl)
Refused	☐	(→ d_serv_sw_fl)

d_diet_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_diet_cost_3 And what was the average cost per visit?

d_serv_sw_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see a social worker?

Note: "See" refers to outpatient appointments in a hospital or a health-care centre, or home visits (including nursing home); it excludes visits while in-patient in hospital, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

No	☐	(→ d_serv_psy_fl)
Yes	☐	(→ d_sw_vis_9)
Don't know	☐	(→ d_serv_psy_fl)
Refused	☐	(→ d_serv_psy_fl)

d_sw_vis_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see a social worker?

d_sw_vis_3 And how about during the last 3 months of that year?

d_serv_psy_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see a psychologist or counsellor?

Note: "See" refers to outpatient appointments in a hospital or a health-care centre, or home visits (including nursing home); it excludes visits while in-patient in hospital, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

No	☐	(→ d_serv_psyt_fl)
Yes	☐	(→ d_psy_vis_9)
Don't know	☐	(→ d_serv_psyt_fl)
Refused	☐	(→ d_serv_psyt_fl)

d_psy_vis_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see a psychologist or counsellor?

d_psy_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_psy_vis_3)
Yes	☐	(→ d_psy_oopn_9)
Don't know	☐	(→ d_psy_vis_3)
Refused	☐	(→ d_psy_vis_3)

d_psy_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_psy_cost_9 And what was the average cost per visit?

d_psy_vis_3 If this was during the last 3 months of that year, how many times did [#d_he_she] see a psychologist or counsellor?

d_psy_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_serv_psyt_fl)
Yes	☐	(→ d_psy_oopn_3)
Don't know	☐	(→ d_serv_psyt_fl)
Refused	☐	(→ d_serv_psyt_fl)

d_psy_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_psy_cost_3 And what was the average cost per visit?

d_serv_psyt_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see a psychiatrist?

Note: "See" refers to outpatient appointments in a hospital or a health-care centre, or home visits (including nursing home); it excludes visits while in-patient in hospital, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

No	☐	(→ d_serv_den_fl)
Yes	☐	(→ d_psyt_vis_9)
Don't know	☐	(→ d_serv_den_fl)
Refused	☐	(→ d_serv_den_fl)

d_psyt_vis_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see a psychiatrist?

d_psyt_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_psyt_vis_3)
Yes	☐	(→ d_psyt_oopn_9)
Don't know	☐	(→ d_psyt_vis_3)
Refused	☐	(→ d_psyt_vis_3)

d_psyt_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_psyt_cost_9 And what was the average cost per visit?

d_psyt_vis_3 If this was during the last 3 months of that year, how many times did [#d_he_she] see a psychiatrist?

d_psyt_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these visits?
Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.
No ☐ (→ d_serv_den_fl)
Yes ☐ (→ d_psyt_oopn_3)
Don't know ☐ (→ d_serv_den_fl)
Refused ☐ (→ d_serv_den_fl)

d_psyt_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_psyt_cost_3 And what was the average cost per visit?

d_serv_den_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see a dentist?
Note: "See" refers to dental surgery visits and dental hospital visits.
No ☐ (→ d_serv_slt_fl)
Yes ☐ (→ d_den_vis_9)
Don't know ☐ (→ d_serv_slt_fl)
Refused ☐ (→ d_serv_slt_fl)

d_den_vis_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see a dentist?

d_den_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these visits?
Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.
No ☐ (→ d_den_vis_3)
Yes ☐ (→ d_den_oopn_9)
Don't know ☐ (→ d_den_vis_3)
Refused ☐ (→ d_den_vis_3)

d_den_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_den_cost_9 And what was the average cost per visit?

d_den_vis_3 If this was during the last 3 months of that year, how many times did [#d_he_she] see a dentist?

d_den_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these visits?
Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.
No ☐ (→ d_serv_slt_fl)
Yes ☐ (→ d_den_oopn_3)
Don't know ☐ (→ d_serv_slt_fl)
Refused ☐ (→ d_serv_slt_fl)

d_den_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_den_cost_3 And what was the average cost per visit?

d_serv_slt_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see a speech and language therapist?
Note: "See" refers to outpatient appointments in a hospital or a health-care centre, or home visits (including nursing home); it excludes visits while in-patient in hospital, at palliative outpatient department, at palliative day care centre and in-patient in hospice.
No ☐ (→ d_serv_ct_fl)
Yes ☐ (→ d_slt_vis_9)

	Don't know	☐	(→ d_serv_ct_fl)
	Refused	☐	(→ d_serv_ct_fl)

d_slt_vis_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see a speech and language therapist?

X

d_slt_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_slt_vis_3)
Yes	☐	(→ d_slt_oopn_9)
Don't know	☐	(→ d_slt_vis_3)
Refused	☐	(→ d_slt_vis_3)

d_slt_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_slt_cost_9 And what was the average cost per visit?

d_slt_vis_3 If this was during the last 3 months of that year, how many times did [#d_he_she] see a speech and language therapist?

d_slt_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_serv_ct_fl)
Yes	☐	(→ d_slt_oopn_3)
Don't know	☐	(→ d_serv_ct_fl)
Refused	☐	(→ d_serv_ct_fl)

d_slt_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_slt_cost_3 And what was the average cost per visit?

d_serv_ct_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see a complementary therapist?

Note: "See" refers to outpatient appointments in a hospital or a health-care centre, or home visits (including nursing home); it excludes visits while in-patient in hospital, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

Definition: Complementary therapy includes art therapy, music therapy, aromatherapy, reiki etc.

No	☐	(→ d_serv_chir_fl)
Yes	☐	(→ d_ct_vis_9)
Don't know	☐	(→ d_serv_chir_fl)
Refused	☐	(→ d_serv_chir_fl)

d_ct_vis_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see a complementary therapist?

d_ct_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐ 1	(→ d_ct_vis_3)
Yes	☐ 1	(→ d_ct_oopn_9)
Don't know	☐ 1	(→ d_ct_vis_3)
Refused	☐ 1	(→ d_ct_vis_3)

d_ct_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_ct_cost_9 And what was the average cost per visit?

d_ct_vis_3 If this was during the last 3 months of that year, how many times did [#d_he_she] see a complementary therapist?

d_ct_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_serv_chir_fl)
Yes	☐	(→ d_ct_oopn_3)
Don't know	☐	(→ d_serv_chir_fl)
Refused	☐	(→ d_serv_chir_fl)

d_ct_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_ct_cost_3 And what was the average cost per visit?

d_serv_chir_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] see a chiropodist?

Note: "See" refers to chiropody surgery visits, health-care centre visits and home visits (including nursing home); it excludes visits while in-patient in hospital, at palliative outpatient department, at palliative day care centre and in-patient in hospice.

Note: Chiropody is often also referred to as podiatry

No	☐	
Yes	☐	(→ d_chir_vis_9)
Don't know	☐	
Refused	☐	

d_chir_vis_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] see a chiropodist?

d_chir_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_chir_vis_3)
Yes	☐	(→ d_chir_oopn_9)
Don't know	☐	(→ d_chir_vis_3)
Refused	☐	(→ d_chir_vis_3)

d_chir_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_chir_cost_9 And what was the average cost per visit?

d_chir_vis_3 If this was during the last 3 months of that year, how many times did [#d_he_she] see a chiropodist?

d_chir_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	
Yes	☐	(→ d_chir_oopn_3)
Don't know	☐	
Refused	☐	

d_chir_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_chir_cost_3 And what was the average cost per visit?

Other Community Services

I'm now going to ask you some questions about other community services, such as home help and day care services, that [#d_firstname:u] may have used during the last year of [#d_his_her] life.

d_serv_hcp_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] receive a home care package?

Definition: A "home care package" is provided by the HSE, and may include services such as home help, health care assistants and various therapy services such as physiotherapy.

No ☐ (→ d_serv_hh_fl)
Yes ☐ (→ d_serv_hcp)
Don't know ☐ (→ d_serv_hh_fl)
Refused ☐ (→ d_serv_hh_fl)

d_serv_hcp And what did this home care package include?

Note: The question on home help may have already been answered in the previous question on home care package.

d_serv_hh_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] use a home help?

No ☐ (→ d_serv_hca_fl)
Yes ☐
Don't know ☐ (→ d_serv_hca_fl)
Refused ☐ (→ d_serv_hca_fl)

d_hh_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] use a home help?

No ☐
Yes ☐ (→ d_hh_mth_9)
Don't know ☐
Refused ☐

d_hh_mth_9 And for how many months over that period did [#d_he_she] use a home help?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

d_hh_hr_9 Usually how many hours per week did this involve?

d_hh_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these hours?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No ☐
Yes ☐ (→ d_hh_oopn_9)
Don't know ☐
Refused ☐

d_hh_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_hh_cost_9 And what was the average cost per hour?

d_hh_3 Focusing now on the last 3 months of that year, did [#d_he_she] use a home help?

No ☐ (→ d_serv_hca_fl)
Yes ☐ (→ d_hh_mth_3)
Don't know ☐ (→ d_serv_hca_fl)
Refused ☐ (→ d_serv_hca_fl)

d_hh_mth_3 And for how many months over that period did [#d_he_she] use a home help?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

d_hh_hr_3 Usually how many hours per week did this involve?

d_hh_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these hours?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_serv_hca_fl)
Yes	☐	(→ d_hh_oopn_3)
Don't know	☐	(→ d_serv_hca_fl)
Refused	☐	(→ d_serv_hca_fl)

d_hh_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_hh_cost_3 And what was the average cost per hour?

d_serv_hca_fl During the last year of [#d_firstname:u]'s life, was [#d_he_she] visited by a health care assistant to assist with tasks such as bathing, dressing and feeding?

No	☐	(→ d_serv_fph_fl)
Yes	☐	
Don't know	☐	(→ d_serv_fph_fl)
Refused	☐	(→ d_serv_fph_fl)

d_hca_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, was [#d_he_she] visited by a health care assistant?

No	☐	
Yes	☐	(→ d_hca_mth_9)
Don't know	☐	
Refused	☐	

d_hca_mth_9 And for how many months over that period was [#d_he_she] visited by a health care assistant?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

d_hca_hr_9 Usually how many hours per week did this involve?

d_hca_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these hours?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	
Yes	☐	(→ d_hca_oopn_9)
Don't know	☐	
Refused	☐	

d_hca_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_hca_cost_9 And what was the average cost per hour?

d_hca_3 Focusing now on the last 3 months of that year, was [#d_he_she] visited by a health care assistant?

No	☐	(→ d_serv_fph_fl)
Yes	☐	(→ d_hca_mth_3)

Don't know ☐ (→ d_serv_fph_fl)
Refused ☐ (→ d_serv_fph_fl)

d_hca_mth_3 And for how many months over that period was [#d_he_she] visited by a health care assistant?
Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

d_hca_hr_3 Usually how many hours per week did this involve?

d_hca_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these hours?
Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.
No ☐ (→ d_serv_fph_fl)
Yes ☐ (→ d_hca_oopn_3)
Don't know ☐ (→ d_serv_fph_fl)
Refused ☐ (→ d_serv_fph_fl)

d_hca_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_hca_cost_3 And what was the average cost per hour?

d_serv_fph_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] use any other paid helper?
No ☐ (→ d_serv_mow_fl)
Yes ☐
Don't know ☐ (→ d_serv_mow_fl)
Refused ☐ (→ d_serv_mow_fl)

d_fph_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] use any other paid helper?
No ☐
Yes ☐ (→ d_fph_mth_9)
Don't know ☐
Refused ☐

d_fph_mth_9 And for how many months over that period did [#d_he_she] use any other paid helper?
Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

d_fph_hr_9 Usually how many hours per week did this involve?

d_fph_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these hours?
Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.
No ☐
Yes ☐ (→ d_fph_oopn_9)
Don't know ☐
Refused ☐

d_fph_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_fph_cost_9 And what was the average cost per hour?

d_fph_3 Focusing now on the last 3 months of that year, did [#d_he_she] use any other paid helper?
No ☐ (→ d_serv_mow_fl)

Yes	☐	(→ d_fph_mth_3)
Don't know	☐	(→ d_serv_mow_fl)
Refused	☐	(→ d_serv_mow_fl)

d_fph_mth_3 And for how many months over that period did [#d_he_she] use any other paid helper?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

d_fph_hr_3 Usually how many hours per week did this involve?

d_fph_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these hours?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_serv_mow_fl)
Yes	☐	(→ d_fph_oopn_3)
Don't know	☐	(→ d_serv_mow_fl)
Refusal	☐	(→ d_serv_mow_fl)

d_fph_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_fph_cost_3 And what was the average cost per hour?

d_serv_mow_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] use a meals-on-wheels service?

No	☐	(→ d_pascare_fl)
Yes	☐	
Don't know	☐	(→ d_pascare_fl)
Refusal	☐	(→ d_pascare_fl)

d_mow_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] use a meals-on-wheels service?

No	☐	
Yes	☐	(→ d_mow_mth_9)
Don't know	☐	
Refused	☐	

d_mow_mth_9 And for how many months over that period did [#d_he_she] use a meals-on-wheels service?

Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)

d_mow_hr_9 Usually how many times per week did this involve?

d_mow_oop_9 Did [#d_he_she] have to pay out-of-pocket for this service?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	
Yes	☐	(→ d_mow_cost_9)
Don't know	☐	
Refusal	☐	

d_mow_cost_9 And what was the average cost per meal?

d_mow_3 Focusing now on the last 3 months of that year, did [#d_he_she] use a meals-on-wheels service?

No	☐	(→ d_pascare_fl)
Yes	☐	(→ d_mow_mth_3)
Don't know	☐	(→ d_pascare_fl)

	Refused	☐	(→ d_pascare_fl)
d_mow_mth_3	And for how many months over that period did [#d_he_she] use a meals-on-wheels service? Note: Deduct full months spent in an institution (e.g., hospice, hospital, nursing home, community nursing unit, other institution)		
d_mow_hr_3	Usually how many times per week did this involve?		
d_mow_oop_3	Did [#d_he_she] have to pay out-of-pocket for this service? Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.		
	No	☐	(→ d_pascare_fl)
	Yes	☐	(→ d_mow_cost_3)
	Don't know	☐	(→ d_pascare_fl)
	Refusal	☐	(→ d_pascare_fl)
d_mow_cost_3	And what was the average cost per meal?		
d_pascare_fl	During the last year of [#d_firstname:u]'s life, did [#d_he_she] see or have telephone contact with a priest or other pastoral carer at home? Note: "See" refers to home visits only. Note: "Telephone contact" refers to decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment.		
	No	☐	(→ d_serv_dc_fl)
	Yes	☐	
	Don't know	☐	(→ d_serv_dc_fl)
	Refusal	☐	(→ d_serv_dc_fl)
d_pascare_vis_9	So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times was [#d_he_she] visited by a pastoral carer at home? Note: Include home visits only.		
d_pascare_ph_9	Also, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] or someone on [#d_his_her] behalf have telephone contact with a pastoral carer? Note: Include calls when at home only.		
d_pascare_vis_3	Focusing now on the last 3 months of that year, how many times was [#d_he_she] visited by a pastoral carer at home? Note: Include home visits only.		
d_pascare_ph_3	Also, during the last 3 months of that year, how many times did [#d_he_she] or someone on [#d_his_her] behalf have telephone contact with a pastoral carer? Note: Include calls when at home only.		
d_serv_dc_fl	During the last year of [#d_firstname:u]'s life, did [#d_he_she] visit a day care centre? Note: This includes visits to community day care centres and day centres attached to hospitals; it excludes palliative day care centres (e.g., Milford runs a day care service for older people as well as a specific day care service for palliative care patients, exclude the latter here).		
	No	☐	
	Yes	☐	(→ d_dc_9)
	Don't know	☐	
	Refusal	☐	
d_dc_9	So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] visit a day centre?		

d_dc_oop_9 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_dc_3)
Yes	☐	(→ d_dc_oopn_9)
Don't know	☐	(→ d_dc_3)
Refusal	☐	(→ d_dc_3)

d_dc_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_dc_cost_9 And what was the average cost per visit?

d_dc_3 Focusing now on the last 3 months of that year, how many times did [#d_he_she] visit a day centre?

d_dc_oop_3 Did [#d_he_she] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	
Yes	☐	(→ d_dc_oopn_3)
Don't know	☐	
Refusal	☐	

d_dc_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_dc_cost_3 And what was the average cost per visit?

d_serv_pallday_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] visit a palliative day care centre?

Definition: A "palliative day care centre" is attached to a palliative care unit, whether in a hospital or in a hospice.
Note: Services received while at a palliative day care centre may include complementary therapy, occupational therapy, physiotherapy, speech & language therapy and other allied health services.
Note: A common 'nickname' for palliative day care is 'day hospice'.

No	☐	(→ eligibility)
Yes	☐	(→ d_pallday_9)
Don't know	☐	(→ eligibility)
Refusal	☐	(→ eligibility)

d_pallday_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] visit a palliative day care centre?

d_pallday_3 And how about during the last 3 months of that year?

Eligibility

OK [#ki_firstname:u]. In this next section, I will be asking some questions about any medical cover that [#d_firstname:u] may have had during the last year of [#d_his_her] life. Note: The purpose of these questions is to provide us with information on how [#d_firstname:u]'s care was paid for, either through public schemes such as the medical card or through private health insurance.

d_med During the last year of [#d_firstname:u]'s life, was [#d_he_she] covered by a medical card?

No	☐	(→ d_gpvis)
Yes	☐	(→ d_med_cng)
Don't know	☐	(→ d_gpvis)
Refusal	☐	(→ d_gpvis)

d_med_cng Was [#d_he_she] covered for all months of that year?

No	☐	
Yes	☐	(→ d_ins_fl)
Don't know	☐	(→ d_gpvis)
Refusal	☐	(→ d_gpvis)

d_med_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, for how many months was [#d_he_she] covered?

d_med_3 And how about during the last 3 months of that year?

d_gpvis During the last year of [#d_firstname:u]'s life, was [#d_he_she] covered by a GP Visit Card?

No	☐	(→ d_lti)
Yes	☐	(→ d_gpvis_cng)
Don't know	☐	(→ d_lti)
Refusal	☐	(→ d_lti)

d_gpvis_cng Was [#d_he_she] covered for all months of that year?

No	☐	(→ d_gpvis_9)
Yes	☐	(→ d_lti)
Don't know	☐	(→ d_lti)
Refusal	☐	(→ d_lti)

d_gpvis_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, for how many months was [#d_he_she] covered?

d_gpvis_3 And how about during the last 3 months of that year?

d_lti During the last year of [#d_firstname:u]'s life, was [#d_he_she] covered by the Long Term Illness Scheme?

No	☐	(→ d_dps)
Yes	☐	(→ d_lti_cng)
Don't know	☐	(→ d_dps)
Refusal	☐	(→ d_dps)

d_lti_cng Was [#d_he_she] covered for all months of that year?

No	☐	
Yes	☐	(→ d_dps)
Don't know	☐	(→ d_dps)
Refusal	☐	(→ d_dps)

d_lti_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, for how many months was [#d_he_she] covered?

d_lti_3 And how about during the last 3 months of that year?

d_dps During the last year of [#d_firstname:u]'s life, was [#d_he_she] covered by the Drugs Payment Scheme?

No	☐	
Yes	☐	(→ d_dps_cng)
Don't know	☐	
Refusal	☐	

d_dps_cng Was [#d_he_she] covered for all months of that year?

No	☐	
Yes	☐	
Don't know	☐	
Refusal	☐	

d_dps_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, for how many months was [#d_he_she] covered?

d_dps_3 And how about during the last 3 months of that year?

d_oth_elig During the last year of [#d_firstname:u]'s life, was [#d_he_she] covered by any other public scheme(s)?

No	☐	(→ d_ins_fl)
Yes	☐	(→ d_oth_elig_spec)
Don't know	☐	(→ d_ins_fl)
Refusal	☐	(→ d_ins_fl)

d_oth_elig_spec Can you tell me the name of the scheme(s)?

d_oth_elig_cng Was [#d_he_she] covered for all months of that year?

No	☐	(→ d_oth_elig_9)
Yes	☐	(→ d_ins_fl)
Don't know	☐	(→ d_ins_fl)
Refusal	☐	(→ d_ins_fl)

d_oth_elig_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, for how many months was [#d_he_she] covered?

d_oth_elig_3 And how about during the last 3 months of that year?

d_ins_fl Did [#d_firstname:u] have private health insurance, for example VHI? This could be either in [#d_his_her] own name or through another family member.

No	☐	(→Drugs, Equipment and Modifications)
Yes	☐	(→ d_ins_comp)
Don't know	☐	(→Drugs, Equipment and Modifications)
Refusal	☐	(→Drugs, Equipment and Modifications)

d_ins_comp Which company was [#d_firstname:u] insured with?

Laya/Quinn Healthcare/BUPA	☐	
VHI Healthcare	☐	
AVIVA/Hibernian Healthcare	☐	
ESB Staff Medical Provident Fund	☐	
Irish Life Assurance Plc Outdoor Staff Benevolent Fund	☐	
Irish Life Medical Aid Society	☐	
New Ireland/Irish National Staff Benevolent Fund	☐	
Prison Officers Medical Aid Society	☐	
St Pauls Garda Medical Aid Society	☐	
The Goulding Voluntary Medical Scheme	☐	
Other (specify)	☐	
Don't know	☐	(→Drugs, Equipment and Modifications)
Refusal	☐	(→Drugs, Equipment and Modifications)

d_ins_plan And can you tell me what health insurance plan was [#d_he_she] on?

X

Drugs, Equipment and Modifications

OK. In this next section, I will be asking some questions about any drugs that [#d_firstname:u] had to pay for, as well as any equipment and home modifications [#d_he_she] required and how these were paid for.

d_pres_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] pay out-of-pocket for prescribed drugs?
Note: For medical card holders there is a charge of 50c for each prescription item up to a maximum of €10 per month per family. If this information is offered please record it but it is not essential.
No ☐ (→ d_non_pres_fl)
Yes ☐ (→ d_pres_9)
Don't know ☐ (→ d_non_pres_fl)
Refusal ☐ (→ d_non_pres_fl)

d_pres_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, on average how much did [#d_he_she] pay out-of-pocket for prescribed drugs per month?
Note: For medical card holders there is a charge of 50c for each prescription item up to a maximum of €10 per month per family. If this information is offered please record it but it is not essential.

d_pres_3 And how about during the last 3 months of that year?
Note: For medical card holders there is a charge of 50c for each prescription item up to a maximum of €10 per month per family. If this information is offered please record it but it is not essential.

d_non_pres_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] pay out-of-pocket for non-prescribed drugs?
No ☐ (→ d_equip2_fl)
Yes ☐ (→ d_non_pres_9)
Don't know ☐ (→ d_equip2_fl)
Refusal ☐ (→ d_equip2_fl)

d_non_pres_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, on average how much did [#d_he_she] pay out-of-pocket for [#d_his_her] non-prescribed drugs per month?

d_non_pres_3 And how about during the last 3 months of that year?

d_equip2_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] get a new wheelchair (manual)?
No ☐ (→ d_equip3_fl)
Yes ☐ (→ d_equip2_9)
Don't know ☐ (→ d_equip3_fl)
Refusal ☐ (→ d_equip3_fl)

d_equip2_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, who paid?
Not applicable ☐
HSE ☐
Voluntary Agency ☐
Out-of-Pocket ☐
Don't know ☐
Refusal ☐

d_equip2_3 If this was during the last 3 months of that year, who paid?
Not applicable ☐
HSE ☐
Voluntary Agency ☐
Out-of-Pocket ☐
Don't know ☐
Refusal ☐

d_equip3_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] get a new wheelchair (electric)?
No ☐ (→ d_equip4_fl)
Yes ☐ (→ d_equip3_9)

Don't know ☐ (→ d_equip4_fl)
Refusal ☐ (→ d_equip4_fl)

d_equip3_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, who paid?
Not applicable ☐
HSE ☐
Voluntary Agency ☐
Out-of-Pocket ☐
Don't know ☐
Refusal ☐

d_equip3_3 If this was during the last 3 months of that year, who paid?
Not applicable ☐
HSE ☐
Voluntary Agency ☐
Out-of-Pocket ☐
Don't know ☐
Refusal ☐

d_equip4_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] get new oxygen equipment?
No ☐ (→ d_equip5_fl)
Yes ☐ (→ d_equip4_9)
Don't know ☐ (→ d_equip5_fl)
Refusal ☐ (→ d_equip5_fl)

d_equip4_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, who paid?
Not applicable ☐
HSE ☐
Voluntary Agency ☐
Out-of-Pocket ☐
Don't know ☐
Refusal ☐

d_equip4_3 If this was during the last 3 months of that year, who paid?
Not applicable ☐
HSE ☐
Voluntary Agency ☐
Out-of-Pocket ☐
Don't know ☐
Refusal ☐

d_equip5_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] get a new feeding pump (gastrostomy)?
Definition: Gastrostomy refers to a surgical opening into the stomach for nutritional support.
No ☐ (→ d_equip6_fl)
Yes ☐ (→ d_equip5_9)
Don't know ☐ (→ d_equip6_fl)
Refusal ☐ (→ d_equip6_fl)

d_equip5_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, who paid?
Not applicable ☐
HSE ☐
Voluntary Agency ☐
Out-of-Pocket ☐
Don't know ☐
Refusal ☐

d_equip5_3 If this was during the last 3 months of that year, who paid?
Not applicable ☐
HSE ☐
Voluntary Agency ☐
Out-of-Pocket ☐
Don't know ☐
Refusal ☐

d_equip6_fl	During the last year of [#d_firstname:u]'s life, did [#d_he_she] get a new commode?		
	No	☐	(→ d_equip7_fl)
	Yes	☐	(→ d_equip6_9)
	Don't know	☐	(→ d_equip7_fl)
	Refusal	☐	(→ d_equip7_fl)
d_equip6_9	If this was during the first 9 months of the last year of [#d_firstname:u]'s life, who paid?		
	Not applicable	☐	
	HSE	☐	
	Voluntary Agency	☐	
	Out-of-Pocket	☐	
	Don't know	☐	
	Refusal	☐	
d_equip6_3	If this was during the last 3 months of that year, who paid?		
	Not applicable	☐	
	HSE	☐	
	Voluntary Agency	☐	
	Out-of-Pocket	☐	
	Don't know	☐	
	Refusal	☐	
d_equip7_fl	During the last year of [#d_firstname:u]'s life, did [#d_he_she] get a new special bed?		
	No	☐	(→ d_equip8_fl)
	Yes	☐	(→ d_equip7_9)
	Don't know	☐	(→ d_equip8_fl)
	Refusal	☐	(→ d_equip8_fl)
d_equip7_9	If this was during the first 9 months of the last year of [#d_firstname:u]'s life, who paid?		
	Not applicable	☐	
	HSE	☐	
	Voluntary Agency	☐	
	Out-of-Pocket	☐	
	Don't know	☐	
	Refusal	☐	
d_equip7_3	If this was during the last 3 months of that year, who paid?		
	Not applicable	☐	
	HSE	☐	
	Voluntary Agency	☐	
	Out-of-Pocket	☐	
	Don't know	☐	
	Refusal	☐	
d_equip8_fl	During the last year of [#d_firstname:u]'s life, did [#d_he_she] get other new equipment?		
	No	☐	(→ d_hmod_fl)
	Yes	☐	(→ d_equip8_spec_9)
	Don't know	☐	(→ d_hmod_fl)
	Refusal	☐	(→ d_hmod_fl)
d_equip8_spec_9	If this was during the first 9 months of the last year of [#d_firstname:u]'s life, please specify Note: If not during the first 9 months of the last year of [#d_firstname:u]'s life – leave blank		
	X		
d_equip8_9	And who paid?		
	Not applicable	☐	
	HSE	☐	
	Voluntary Agency	☐	
	Out-of-Pocket	☐	
	Don't know	☐	
	Refusal	☐	

d_equip8_spec_3 If this was during the last 3 months of that year, please specify
Note: If not during the last 3 months of that year – leave blank

d_equip8_3 And who paid?
Not applicable ☐
HSE ☐
Voluntary Agency ☐
Out-of-Pocket ☐
Don't know ☐
Refusal ☐

d_hmod_fl During the last year of [#d_firstname:u]'s life, were modifications made to [#d_his_her] place of residence to make it easier or safer for [#d_him_her] to live there?

No	☐	(→Hospital, Nursing Home, and Hospice Utilisation)
Yes	☐	(→ d_hmod_euro_9)
Don't know	☐	(→Hospital, Nursing Home, and Hospice Utilisation)
Refusal	☐	(→Hospital, Nursing Home, and Hospice Utilisation)

d_hmod_euro_9 If this was during the first 9 months of the last year of [#d_firstname:u]'s life, approximately what was the total cost of the modifications?
Note: Enter 0 if not applicable.

d_hmod_grt_9 And, how much, if any, of the cost of the modifications was covered by a grant?

d_hmod_euro_3 If this was during the last 3 months of that year, approximately what was the total cost of the modifications?
Note: Enter 0 if not applicable.

d_hmod_grt_3 And, how much, if any, of the cost of the modifications was covered by a grant?

Hospital, Nursing Home, and Hospice Utilisation

This next section moves away from community care and asks questions about hospital care, nursing home care as well as any hospice care that [#d_firstname:u] may have had during the last year of [#d_his_her] life.

Hospital Care

OK. Firstly, I'm going to ask you questions about hospital care. This covers A&E visits, outpatient appointments, day patient and in-patient stays.
For some of these visits and stays, I will be asking you if [#d_firstname:u]'s care was public or private and whether [#d_he_she] had to pay out-of-pocket for using those services.
Note: Be sure that the key informant includes respite & convalescence visits when questioned about in-patient hospital stays.

d_ed During the last year of [#d_firstname:u]'s life, did [#d_he_she] visit A&E?
Note: Do not include if the visit resulted in an in-patient admission.

No	☐	(→ d_op)
Yes	☐	(→ d_ed_9)
Don't know	☐	(→ d_op)
Refusal	☐	(→ d_op)

d_ed_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] visit A&E?
Note: Do not include if the visit resulted in an in-patient admission.

d_ed_oop_9 Did [#d_firstname:u] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_ed_3)
Yes	☐	(→ d_ed_oopn_9)
Don't know	☐	(→ d_ed_3)
Refusal	☐	(→ d_ed_3)

d_ed_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_ed_3 Focusing now on the last 3 months of that year, how many times did [#d_he_she] visit A&E?

Note: Do not include if the visit resulted in an in-patient admission.

d_ed_oop_3 Did [#d_firstname:u] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_op)
Yes	☐	(→ d_ed_oopn_3)
Don't know	☐	(→ d_op)
Refusal	☐	(→ d_op)

d_ed_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_op During the last year of [#d_firstname:u]'s life, did [#d_he_she] have an outpatient appointment?

Definition: An outpatient is a person who attends an outpatient clinic supervised by a medical or surgical specialist/consultant for the purposes of consultation, investigation and/or minor treatment. Outpatient attendances are almost always based on referral by GP.

Note: This includes medical and surgical visits only. It also includes scheduled A&E follow-up appointments. It excludes visits to clinics for psychiatry, physiotherapy, occupational therapy and other allied health professional services. It also excludes visits to a palliative outpatient department (Milford Care Centre only).

No	☐	(→ d_dp)
Yes	☐	(→ d_fund_op)
Don't know	☐	(→ d_dp)
Refusal	☐	(→ d_dp)

d_fund_op Were these appointments...?

Note: Call out responses.

All public	☐	(→ d_pubop_9)
All private	☐	(→ d_priop_9)
Both	☐	(→ d_pubop_9)
Don't know	☐	(→ d_pubop_9)
Refusal	☐	(→ d_pubop_9)

d_pubop_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] have an outpatient appointment as a public patient?

Definition: An outpatient is a person who attends an outpatient clinic supervised by a medical or surgical specialist/consultant for the purposes of consultation, investigation and/or minor treatment. Outpatient attendances are almost always based on referral by GP.

Note: This includes medical and surgical visits only. It also includes scheduled A&E follow-up appointments. It excludes visits to clinics for psychiatry, physiotherapy, occupational therapy and other allied health professional services. It also excludes visits to a palliative outpatient department (Milford only).

d_pubop_fac_9 Can you please name all of the hospitals [#d_he_she] attended?

d_pubop_3

Focusing now on the last 3 months of that year, how many times did [#d_he_she] have an outpatient appointment as a public patient?

Definition: An outpatient is a person who attends an outpatient clinic supervised by a medical or surgical specialist/consultant for the purposes of consultation, investigation and/or minor treatment. Outpatient attendances are almost always based on referral by GP.

Note: This includes medical and surgical visits only. It also includes scheduled A&E follow-up appointments. It excludes visits to clinics for psychiatry, physiotherapy, occupational therapy and other allied health professional services. It also excludes visits to a palliative outpatient department (Milford only).

d_pubop_fac_3

Can you please name all of the hospitals [#d_he_she] attended?

d_priop_9

So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] have an outpatient appointment as a private patient?

Definition: An outpatient is a person who attends an outpatient clinic supervised by a medical or surgical specialist/consultant for the purposes of consultation, investigation and/or minor treatment. Outpatient attendances are almost always based on referral by GP.

Note: This includes medical and surgical visits only. It also includes scheduled A&E follow-up appointments. It excludes visits to clinics for psychiatry, physiotherapy, occupational therapy and other allied health professional services. It also excludes visits to a palliative outpatient department (Milford only).

d_priop_fac_9

Can you please name all of the hospitals or rooms [#d_he_she] attended.

Definition: The word "rooms" refers to an outpatient appointment which takes place off the hospital site.

d_priop_oop_9

Did [#d_firstname:u] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_priop_3)
Yes	☐	(→ d_priop_oopn_9)
Don't know	☐	(→ d_priop_3)
Refusal	☐	(→ d_priop_3)

d_priop_oopn_9

So how many of these did [#d_he_she] have to pay for?

d_priop_3

Focusing now on the last 3 months of that year, how many times did [#d_he_she] have an outpatient appointment as a private patient?

Definition: An outpatient is a person who attends an outpatient clinic supervised by a medical or surgical specialist/consultant for the purposes of consultation, investigation and/or minor treatment. Outpatient attendances are almost always based on referral by GP.

Note: This includes medical and surgical visits only. It also includes scheduled A&E follow-up appointments. It excludes visits to clinics for psychiatry, physiotherapy, occupational therapy and other allied health professional services. It also excludes visits to a palliative outpatient department (Milford only).

d_priop_fac_3

Can you please name all of the hospitals or rooms [#d_he_she] attended?

d_priop_oop_3

Did [#d_firstname:u] have to pay out-of-pocket for any of these visits?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	
Yes	☐	(→ d_priop_oopn_3)
Don't know	☐	
Refusal	☐	

d_priop_oopn_3

So how many of these did [#d_he_she] have to pay for?

d_sp_op_9 During the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] attend the specialist palliative care outpatient department at the Milford Care Centre?

Definition: An outpatient is a person who attends an outpatient clinic supervised by a medical or surgical specialist/consultant for the purposes of consultation, investigation and/or minor treatment. Outpatient attendances are almost always based on referral by GP.

Note: This includes medical and surgical visits only. It also includes scheduled A&E follow-up appointments. It excludes visits to clinics for psychiatry, physiotherapy, occupational therapy and other allied health professional services.

d_sp_op_3 And how about during the last 3 months of that year?

Definition: An outpatient is a person who attends an outpatient clinic supervised by a medical or surgical specialist/consultant for the purposes of consultation, investigation and/or minor treatment. Outpatient attendances are almost always based on referral by GP.

Note: This includes medical and surgical visits only. It also includes scheduled A&E follow-up appointments. It excludes visits to clinics for psychiatry, physiotherapy, occupational therapy and other allied health professional services.

d_dp During the last year of [#d_firstname:u]'s life, was [#d_he_she] admitted to hospital as a day patient – please include any day patient admissions for chemotherapy or dialysis?

Definition: "Day-patient" refers to a patient who is admitted to hospital on an elective basis for care and/or treatment which does not require use of a hospital bed overnight and who is discharged as scheduled.

No ☐ (→ d_ip)
Yes ☐ (→ d_fund_dp)
Don't know ☐ (→ d_ip)
Refusal ☐ (→ d_ip)

d_fund_dp Were these admissions...?

Note: Call out responses

All public ☐ (→ d_dial_fl)
All private ☐ (→ d_fund_dp_hosp)
Both ☐ (→ d_fund_dp_hosp)
Don't know ☐ (→ d_dial_fl)
Refusal ☐ (→ d_dial_fl)

d_fund_dp_hosp And for any of these admissions was [#d_he_she] admitted to any private hospital?

No ☐
Yes ☐
Don't know ☐
Refusal ☐

d_dial_fl Were any of these admissions for dialysis?

No ☐
Yes ☐
Don't know ☐
Refusal ☐

d_dow_fl And, were any in a day oncology ward – please include any day patient admissions for chemotherapy or radiotherapy?

No ☐
Yes ☐
Don't know ☐
Refusal ☐

d_pubdp_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times was [#d_he_she] admitted for a day patient stay as a public patient to a public hospital?

d_pubdp_fac_9 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_pubdp_dial_9 How many of these admissions were for dialysis?

d_pubdp_dow_9 How many of these were in a day oncology ward?

d_dp_oop_9 Did [#d_firstname:u] have to pay out-of-pocket for any of these visits?

Note: Include all day patient stays as a public patient to a public hospital including stays for dialysis and oncology

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_pubdp_3)
Yes	☐	(→ d_dp_oopn_9)
Don't know	☐	(→ d_pubdp_3)
Refusal	☐	(→ d_pubdp_3)

d_dp_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_pubdp_3 Focusing now on the last 3 months of that year, how many times was [#d_he_she] admitted for a day patient stay as a public patient to a public hospital?

d_pubdp_fac_3 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_pubdp_dial_3 How many of these admissions were for dialysis?

d_pubdp_dow_3 How many of these admissions were in a day oncology ward?

d_dp_oop_3 Did [#d_firstname:u] have to pay out-of-pocket for any of these visits?

Note: Include all day patient stays as a public patient to a public hospital including stays for dialysis and oncology

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	
Yes	☐	(→ d_dp_oopn_3)
Don't know	☐	
Refusal	☐	

d_dp_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_pridp_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times was [#d_he_she] admitted for a day patient stay as a private patient to a public hospital?

d_pridp_fac_9 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_pridp_dial_9 How many of these admissions were for dialysis?

d_pridp_dow_9 How many of these admissions were in a day oncology ward?

d_pridp_3 Focusing now on the last 3 months of that year, how many times was [#d_he_she] admitted for a day patient stay as a private patient to a public hospital?

d_pridp_fac_3 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_pridp_dial_3 How many of these admissions were for dialysis?

d_pridp_dow_3 How many of these admissions were in a day oncology ward?

d_phdp_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times was [#d_he_she] admitted to a private hospital as a day patient?

d_phdp_fac_9 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_phdp_dial_9 How many of these admissions were for dialysis?

d_phdp_dow_9 How many of these admissions were in a day oncology ward?

d_phdp_3 Focusing now on the last 3 months of that year, how many times was [#d_he_she] admitted to a private hospital as a day patient?

d_phdp_fac_3 Can you please name all of the hospitals [#d_he_she] was admitted to?

X

d_phdp_dial_3 How many of these admissions were for dialysis?

d_phdp_dow_3 How many of these admissions were in a day oncology ward?

d_ip During the last year of [#d_firstname:u]'s life, was [#d_he_she] admitted to hospital as an in-patient?

Note: This includes stays in acute hospitals, local community hospitals and palliative care support beds; it excludes stays in hospice beds in Waterford Regional Hospital.

Note: Be sure that the key informant includes respite & convalescence visits when questioned about in-patient hospital stays.

No	☐	(→Nursing Home)
Yes	☐	(→ d_fund_ip)
Don't know	☐	(→Nursing Home)
Refused	☐	(→Nursing Home)

d_fund_ip Were these admissions...?

Note: Call out responses

All public	☐	(→ d_pubip_9)
All private	☐	(→ d_fund_ip_hosp)
Both	☐	(→ d_fund_ip_hosp)
Don't know	☐	(→ d_pubip_9)
Refused	☐	(→ d_pubip_9)

d_fund_ip_hosp And for any of these admissions was [#d_he_she] admitted to a private hospital?

No	☐
Yes	☐
Don't know	☐
Refused	☐

d_pubip_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times was [#d_he_she] admitted for an in-patient stay as a public patient to a public hospital?

d_pubip_fac_9 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_pubip_los_9 In total for these admissions, how many nights was [#d_he_she] in hospital?

d_pubip_oop_9 Did [#d_firstname:u] have to pay out-of-pocket for any of these nights?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	(→ d_pubip_3)
Yes	☐	(→ d_pubip_oopn_9)
Don't know	☐	(→ d_pubip_3)
Refusal	☐	(→ d_pubip_3)

d_pubip_oopn_9 So how many of these did [#d_he_she] have to pay for?

d_pubip_3 Focusing now on the last 3 months of that year, how many times was [#d_he_she] admitted for an in-patient stay as a public patient to a public hospital?

d_pubip_fac_3 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_pubip_los_3 In total for these admissions, how many nights was [#d_he_she] in hospital?

d_pubip_oop_3 Did [#d_firstname:u] have to pay out-of-pocket for any of these nights?

Note: This includes any fees paid out of [#d_his_her] own pocket or on [#d_his_her] behalf, including insurance policy excess.

No	☐	
Yes	☐	(→ d_pubip_oopn_3)
Don't know	☐	
Refusal	☐	

d_pubip_oopn_3 So how many of these did [#d_he_she] have to pay for?

d_priip_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times was [#d_he_she] admitted for an in-patient stay as a private patient to a public hospital?

d_priip_fac_9 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_priip_los_9 In total for these admissions, how many nights was [#d_he_she] in hospital?

d_priip_3 Focusing now on the last 3 months of that year, how many times was [#d_he_she] admitted for an in-patient stay as a private patient to a public hospital?

d_priip_fac_3 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_priip_los_3 In total for these admissions, how many nights was [#d_he_she] in hospital?

d_phip_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times was [#d_he_she] admitted for an in-patient stay to a private hospital?

d_phip_fac_9 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_phip_los_9 In total for these admissions, how many nights was [#d_he_she] in hospital?

d_phip_3 Focusing now on the last 3 months of that year, how many times was [#d_he_she] admitted for an in-patient stay to a private hospital?

d_phip_fac_3 Can you please name all of the hospitals [#d_he_she] was admitted to?

d_phip_los_3 In total for these admissions, how many nights was [#d_he_she] in hospital?

Nursing Home

Now [#ki_firstname:u] I'm going to ask you some questions about any stays that [#d_firstname:u] had in a nursing home.

Note: Be sure that the bereaved relative includes respite & convalescent visits when questioned about these stays.

d_nh_fl During the last year of [#d_firstname:u]'s life, was [#d_he_she] admitted to a nursing home?

Note: Be sure that the key informant includes respite & convalescence visits when questioned about nursing home stays.

No	☐	(→ hospice)
Yes	☐	(→ d_fund_nh)
Don't know	☐	(→ hospice)
Refused	☐	(→ hospice)

d_fund_nh Were these admissions...?

Note: Call out responses

All public	☐
All private	☐
Both	☐
Don't know	☐
Refused	☐

d_nh_fac Can you please name all nursing homes [#d_he_she] stayed in?

d_pubnh_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] stay in a public nursing home?

d_pubnh_los_9 During those 9 months, how many weeks did [#d_he_she] stay in a public nursing home?

d_pubnh_oop_9 Can you tell me how much was paid out-of-pocket per week?

d_pubnh_3 Focusing now on the last 3 months of that year, how many times did [#d_he_she] stay in a public nursing home?

d_pubnh_los_3 During those 3 months, how many weeks did [#d_he_she] stay in a public nursing home?

d_pubnh_oop_3 Can you tell me how much was paid out-of-pocket per week?

d_prinh_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times did [#d_he_she] stay in a private nursing home?

d_prinh_los_9 During those 9 months, how many weeks did [#d_he_she] stay in a private nursing home?

d_prinh_oop_9 Can you tell me how much was paid out-of-pocket per week?

d_prinh_3 Focusing now on the last 3 months of that year, how many times did [#d_he_she] stay in a private nursing home?

d_prinh_los_3 During those 3 months, how many weeks did [#d_he_she] stay in a private nursing home?

d_prinh_oop_3 Can you tell me how much was paid out-of-pocket per week?

Hospice

I just have a few questions to ask you about any in-patient hospice care that [#d_firstname:u] may have received during the last year of [#d_his_her] life. Note: Be sure that the bereaved relative includes respite & convalescent visits when questioned about these stays.

d_hospice_fl During the last year of [#d_firstname:u]'s life, was [#d_he_she] admitted to a hospice bed?

Note: This refers to in-patient beds in a hospice and hospice beds in Waterford Regional Hospital. It excludes palliative care support beds (e.g., in a community hospital).

Note: Be sure that the key informant includes respite & convalescence visits when questioned about in-patient hospice stays.

No	☐	(→ d_serv_rs_fl)
Yes	☐	(→ d_hospice_9)
Don't know	☐	(→ d_serv_rs_fl)
Refused	☐	(→ d_serv_rs_fl)

d_hospice_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, how many times was [#d_he_she] admitted to a hospice bed?

d_hospice_los_9 In total for these admissions, how many nights did [#d_he_she] stay in a hospice bed?

d_hospice_3 Focusing now on the last 3 months of that year, how many times was [#d_he_she] admitted to a hospice bed?

d_hospice_los_3 In total for these admissions, how many nights did [#d_he_she] stay in a hospice bed?

Respite and Convalescence

So, before we finish this section, I'd like to ask a few questions about any respite or convalescence arrangements in the last year of [#d_firstname:u]'s life.

d_serv_rs_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] avail of respite care?

Optional: We may have covered this already in previous questions, we would just like to know a little bit more about the arrangements.

Definition: "Respite care" refers to the provision of alternative care for a patient so that the carer can take a short break, a holiday or a rest. It can be for a single evening or it may cover the duration of a substantial holiday.

Note: This includes stays in a hospital, a hospice, a nursing home or other arrangements.

No	☐	(→ d_serv_con_fl)
Yes	☐	(→ d_rs_9)
Don't know	☐	(→ d_serv_con_fl)
Refused	☐	(→ d_serv_con_fl)

d_rs_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] avail of respite care?

No	☐	(→ d_rs_3)
Yes	☐	(→ d_rs_arr_9)
Don't know	☐	(→ d_rs_3)
Refused	☐	(→ d_rs_3)

d_rs_arr_9 Can you describe these respite arrangements

Note: Try to capture the time involved e.g. 2 hours twice per week

d_rs_3 Focusing now on the last 3 months of that year, did [#d_he_she] avail of respite care?

No	☐	(→ d_serv_con_fl)
Yes	☐	(→ d_rs_arr_3)
Don't know	☐	(→ d_serv_con_fl)
Refused	☐	(→ d_serv_con_fl)

d_rs_arr_3 Can you describe these respite arrangements

Note: Try to capture the time involved e.g. 2 hours twice per week

d_serv_con_fl During the last year of [#d_firstname:u]'s life, did [#d_he_she] avail of convalescence care?

Definition: "Convalescence" refers to a period of rest and recuperation for example following treatment in hospital.

No	☐	(→ access and quality)
Yes	☐	(→ d_con_9)
Don't know	☐	(→ access and quality)
Refused	☐	(→ access and quality)

d_con_9 So, during the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] avail of convalescence care?

No	☐	(→ d_con_3)
Yes	☐	(→ d_con_arr_9)
Don't know	☐	(→ d_con_3)
Refused	☐	(→ d_con_3)

d_con_arr_9 Can you describe these convalescence arrangements?

Note: Try to capture the time involved e.g. 2 hours twice per week

d_con_3 Focusing now on the last 3 months of that year, did [#d_he_she] avail of convalescence care?

No	☐	(→ access and quality)
Yes	☐	(→ d_con_arr_3)
Don't know	☐	(→ access and quality)
Refused	☐	(→ access and quality)

d_con_arr_3	Can you describe these convalescence arrangements? Note: Try to capture the time involved e.g. 2 hours twice per week	

Access and Quality

OK. In this next section, I will be asking you some questions about access to services and the quality of services.

d_access1	If hospital admission was deemed necessary how easy was it to get a bed?	
	Not applicable	☐
	Very easy	☐
	Fairly easy	☐
	Fairly difficult	☐
	Very difficult	☐
	Don't know	☐
	Refused	☐

d_access2	If hospice admission was deemed appropriate how easy was it to get a bed?	
	Not applicable	☐
	Very easy	☐
	Fairly easy	☐
	Fairly difficult	☐
	Very difficult	☐
	Don't know	☐
	Refused	☐

d_access3	If palliative home care was deemed appropriate how easy was it to get access?	
	Not applicable	☐
	Very easy	☐
	Fairly easy	☐
	Fairly difficult	☐
	Very difficult	☐
	Don't know	☐
	Refused	☐

d_access4	And if palliative day care was deemed appropriate how easy was it to get access?	
	Not applicable	☐
	Very easy	☐
	Fairly easy	☐
	Fairly difficult	☐
	Very difficult	☐
	Don't know	☐
	Refused	☐

d_qual1_h	On a scale of 1 to 10, with 1 being poor and 10 being excellent, how well did the in-patient hospital team communicate with [#d_firstname:u] about [#d_his_her] illness and how it would develop?	
	1 – Poor	☐
	2	☐
	3	☐
	4	☐
	5	☐
	6	☐
	7	☐
	8	☐
	9	☐
	10 – Excellent	☐
	Don't know	☐
	Refused	☐

d_qual2_h	How well did the team communicate with the family about [#d_firstname:u]'s illness and how it would develop? (In-patient hospital team)

1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual5_h How well did the team manage [#d_firstname:u]'s symptoms such as pain that was acceptable to [#d_him_her]? (In-patient hospital team)
1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual6_h And how well do you think the team provided emotional support for you and the family? (In-patient hospital team)
1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

(In-patient hospital team)
Ask if in-patient hospital days ≥ 1
In-patient hospital days = [#d_pubip_3] + [#d_priip_3] + [#d_phip_3]

d_qual3_h During the last 3 months of [#d_firstname:u]'s life, how well did the team provide end-of-life care that respected [#d_his_her] wishes?
Not applicable ☐
1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐ 1

d_qual4_h And if those wishes changed, was the team responsive to those changes? (In-patient hospital team)

Not applicable ☐
1 – Not responsive ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Very Responsive ☐
Don't know ☐
Refused ☐ 1

d_qual1_ht On a scale of 1 to 10, with 1 being poor and 10 being excellent, how well did the in-patient hospice team communicate with [#d_firstname:u] about [#d_his_her] illness and how it would develop?

1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual2_ht How well did the team communicate with the family about [#d_firstname:u]'s illness and how it would develop? (In-patient hospice team)

1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual5_ht How well did the team manage [#d_firstname:u]'s symptoms such as pain that was acceptable to [#d_him_her]? (In-patient hospice team)

1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual6_ht And how well do you think the team provided emotional support for you and the family? (In-patient hospice team)

1 – Poor ☐

2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

(In-patient hospice team)
Ask if in-patient hospice days ≥ 1
In-patient hospice days = [#d_hospice_3]

d_qual3_ht During the last 3 months of [#d_firstname:u]'s life, how well did the team provide end-of-life care that respected [#d_his_her] wishes?
Not applicable ☐
1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual4_ht And if those wishes changed, was the team responsive to those changes? (In-patient hospice team)
Not applicable ☐
1 – Not responsive ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Very Responsive ☐
Don't know ☐
Refused ☐

d_qual1_hct On a scale of 1 to 10, with 1 being poor and 10 being excellent, how well did the palliative home care team communicate with [#d_firstname:u] about [#d_his_her] illness and how it would develop?
1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual2_hct How well did the team communicate with the family about [#d_firstname:u]'s illness and how it would develop? (Palliative home care team)

1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual5_hct How well did the team manage [#d_firstname:u]'s symptoms such as pain that was acceptable to [#d_him_her]? (Palliative home care team)

1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual6_hct And how well do you think the team provided emotional support for you and the family? (Palliative home care team)

1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

(Palliative home care team)
Ask if palliative home care ≥ 1
Palliative home care = [#d_pcn_vis_3] + [#d_pcn_ph_3]

d_qual3_hct During the last 3 months of [#d_firstname:u]'s life, how well did the team provide end-of-life care that respected [#d_his_her] wishes?

Not applicable ☐
1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐

Refused ☐ 1

d_qual4_hct And if those wishes changed, was the team responsive to those changes? (Palliative home care team)

Not applicable ☐
1 – Not responsive ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Very Responsive ☐
Don't know ☐
Refused ☐ 1

d_qual1_pdc On a scale of 1 to 10, with 1 being poor and 10 being excellent, how well did the palliative day care team communicate with [#d_firstname:u] about [#d_his_her] illness and how it would develop?

1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual2_pdc How well did the team communicate with the family about [#d_firstname:u]'s illness and how it would develop? (Palliative day care team)

1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual5_pdc How well did the team manage [#d_firstname:u]'s symptoms such as pain that was acceptable to [#d_him_her]? (Palliative day care team)

1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

d_qual6_pdc And how well do you think the team provided emotional support for you and the family?
(Palliative day care team)
1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐

(Palliative day care team)
Ask if palliative day care visits ≥ 1
Palliative day care visits = [#d_pallday_3]

d_qual3_pdc During the last 3 months of [#d_firstname:u]'s life, how well did the team provide end-of-life care that respected [#d_his_her] wishes?
Not applicable ☐ (→ d_qual7)
1 – Poor ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Excellent ☐
Don't know ☐
Refused ☐ 1

d_qual4_pdc And if those wishes changed, was the team responsive to those changes?
(Palliative day care team)
Not applicable ☐
1 – Not responsive ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐
9 ☐
10 – Very Responsive ☐
Don't know ☐
Refused ☐

These next questions are a little bit more sensitive.
Overall, in thinking about the care that [#d_firstname:u] received before [#d_he_she] died, we are interested in hearing your views on the experience. There will be time at the end to go into more detail on this, but in particular...

d_qual7 Do you feel the way [#d_firstname:u] died would be acceptable to you?
Definitely not acceptable ☐
Fairly acceptable ☐
Acceptable ☐
Very acceptable ☐
Don't know ☐
Refused ☐

d_qual8	And do you feel the way [#d_firstname:u] died would be acceptable to your family and friends?		
	Definitely not acceptable	☐	
	Fairly acceptable	☐	
	Acceptable	☐	
	Very acceptable	☐	
	Don't know	☐	
	Refused	☐	
	Decedent Death Profile		

Decedent Death Profile

Now we are moving on to the next section which will also be a bit more sensitive. In this section I will be asking about how expected or unexpected [#d_firstname:u]'s death was, and if [#d_firstname:u] had talked about where [#d_he_she] wanted to die.

d_dth_rel	Did you realise that [#d_firstname:u] was going to die because of [#d_his_her] illness?		
	No	☐	(→ d_dth)
	Yes	☐	(→ d_dth_rel_t)
	Don't know	☐	(→ d_dth)
	Refused	☐	(→ d_dth)
d_dth_rel_t	How long before [#d_firstname:u]'s death did you realise [#d_he_she] was going to die? Note: [#d_firstname:u] was diagnosed in [#d_ill].		
	A day or more, but less than a week	☐	
	One week or more, but less than one month	☐	
	One month or more, but less than six months	☐	
	Six months or more, but less than one year	☐	
	One year or more, but less than three years	☐	
	Three years or more	☐	
	Don't know	☐	
	Refused	☐	
d_dth	Did [#d_firstname:u] know that [#d_he_she] was going to die because of the illness?		
	Yes, [#d_he_she] certainly knew	☐	
	Yes, [#d_he_she] probably knew	☐	
	No, [#d_he_she] probably did not know	☐	
	No, [#d_he_she] definitely did not know	☐	
	Not sure whether [#d_he_she] knew or not	☐	
	Refused	☐	
d_dth_acpt	How would you describe [#d_him_her]?		
	Definitely accepting	☐	
	Fairly accepting	☐	
	Not at all accepting	☐	
	Cannot say	☐	
	Refused	☐	
d_dth_exp	Was [#d_firstname:u]'s death expected at about the time it occurred, or was it unexpected?		
	Expected	☐	
	Unexpected	☐	
	Don't know	☐	
	Refused	☐	
d_dth_pref_fl	Did [#d_firstname:u] ever talk to someone about where [#d_he_she] wanted to die?		
	Yes	☐	(→ d_dth_pref6)
	Don't know	☐	
	Not applicable – [#d_firstname] could not communicate	☐	(→ d_dth_loc)
	Refused	☐	(→ d_dth_loc)
d_dth_pref6	So, about 6 months before [#d_firstname:u] died, where did [#d_he_she] want to die?		
	At home	☐	
	At the home of a relative	☐	

At the home of a non-relative (e.g. a friend) ☐
In hospital ☐
In a hospice ☐
In a nursing home ☐
In a Community Nursing Unit (HSE long stay unit) ☐
Other (specify) ☐
Don't know ☐
Refused ☐

d_dth_prefw And what about one week before [#d_he_she] died?
At home ☐
At the home of a relative ☐
At the home of a non-relative (e.g. a friend) ☐
In hospital ☐
In a hospice ☐
In a nursing home ☐
In a Community Nursing Unit (HSE long stay unit) ☐
Other (specify) ☐
Don't know ☐ (→ d_dth_loc)
Refused ☐ (→ d_dth_loc)

d_dth_chg And why do you think that changed?

d_dth_pref_no As far as you know, where would [#d_he_she] have preferred to die?
At home ☐
At the home of a relative ☐
At the home of a non-relative (e.g. a friend) ☐
In hospital ☐
In a hospice ☐
In a nursing home ☐
In a Community Nursing Unit (HSE long stay unit) ☐
Other (specify) ☐
Don't know ☐
Refused ☐

d_dth_loc And can you tell me where did [#d_he_she] die?
At home ☐
At the home of a relative ☐
At the home of a non-relative (e.g. a friend) ☐
In hospital ☐
In a hospice ☐
In a nursing home ☐
In a Community Nursing Unit (HSE long stay unit) ☐
In an ambulance or en route to hospital or en route to hospice etc ☐
Other (specify) ☐
Don't know ☐
Refused ☐

Quality of Life

OK [#ki_firstname:u]. We have come to the final section of this interview. Thank you for your patience so far. These questions ask about [#d_firstname:u]'s quality of life across the different periods of that last year before [#d_he_she] died.
Like before, we are focusing on the first 9 months ([#month_1] to [#month_9]) and the last 3 months ([#month_10] to [#month_12]) of that year. I will also be asking in particular about the last week before [#d_firstname:u] died. These questions have response options which I will read out and you can choose from those options.

d_cons During the last week before [#d_firstname:u] died, was [#d_he_she] unconscious or in a coma?
Note: Answer 'yes' if unconscious or in a coma for 4 days or more. Answer 'no' if unconscious or in a coma for 3 days or less.
No ☐
Yes ☐

Don't know ☐
Refused ☐

d_pos_9_9 During the first 9 months of the last year of [#d_firstname:u]'s life, how much time do you feel was wasted on appointments relating to [#d_firstname:u]'s healthcare, for example waiting around for transport or repeating tests? The response options are:
None at all ☐
Up to half a day wasted ☐
More than half a day wasted ☐
No Answer ☐

d_pos_9_3 How about during the last 3 months of that year? The response options are:
None at all ☐
Up to half a day wasted ☐
More than half a day wasted ☐
No Answer ☐

d_pos_9_7 And how about during the last week of [#d_his_her] life? The response options are:
(Last week of life)
None at all ☐
Up to half a day wasted ☐
More than half a day wasted ☐
No Answer ☐

The next few questions ask about specific problems [#d_firstname:u] may have experienced.
d_eq5d_mob9 During the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] have problems in walking about? The response options are:
No problems ☐
Some problems ☐
Confined to bed ☐
No Answer ☐

d_eq5d_mob3 How about during the last 3 months of that year? The response options are:
No problems ☐
Some problems ☐
Confined to bed ☐
No Answer ☐

d_eq5d_mob7 And how about during the last week of [#d_his_her] life? The response options are:
(Last week of life)
No problems ☐
Some problems ☐
Confined to bed ☐
No Answer ☐

d_eq5d_self9 During the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] have problems with self care? The response options are:
No problems with self care ☐
Some problems washing or dressing [#d_him_her]self ☐
Unable to wash or dress [#d_him_her]self ☐
No Answer ☐

d_eq5d_self3 How about during the last 3 months of that year? The response options are:
No problems with self care ☐
Some problems washing or dressing [#d_him_her]self ☐
Unable to wash or dress [#d_him_her]self ☐
No Answer ☐

d_eq5d_self7 And how about during the last week of [#d_his_her] life? The response options are:
(Last week of life)
No problems with self care ☐
Some problems washing or dressing [#d_him_her]self ☐
Unable to wash or dress [#d_him_her]self ☐

No Answer ☐

d_eq5d_act9 During the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] have problems performing usual activities (such as work, study, housework, family or leisure activities)? The response options are:
No problems ☐
Some problems ☐
Unable to perform usual activities ☐
No Answer ☐

d_eq5d_act3 How about during the last 3 months of that year? The response options are:
No problems ☐
Some problems ☐
Unable to perform usual activities ☐
No Answer ☐

d_eq5d_act7 And how about during the last week of [#d_his_her] life? The response options are:
(Last week of life)
No problems ☐
Some problems ☐
Unable to perform usual activities ☐
No Answer ☐

d_pos_12 During the last week, which of the following would have best described [#d_firstname:u]? The response options are:
(Last week of life)
Fully active ☐
Restricted ☐
Ambulatory ☐
Limited self care ☐
Completely disabled ☐
No Answer ☐

d_eq5d_pain9 During the first 9 months of the last year of [#d_firstname:u]'s life, did [#d_he_she] have pain or discomfort? The response options are:
Not at all, no effect – pain was completely controlled ☐
Slightly – but not bothered to get rid of it ☐
Moderately – pain limited some of [#d_his_her] ability ☐
Severely – activities or concentration markedly affected ☐
Overwhelmingly – [#d_he_she] was unable to think of anything else ☐
No Answer ☐

d_eq5d_pain3 How about during the last 3 months of that year? The response options are:
Not at all, no effect – pain was completely controlled ☐
Slightly – but not bothered to get rid of it ☐
Moderately – pain limited some of [#d_his_her] ability ☐
Severely – activities or concentration markedly affected ☐
Overwhelmingly – [#d_he_she] was unable to think of anything else ☐
No Answer ☐

d_eq5d_pain7 And how about during the last week of [#d_his_her] life? The response options are:
(Last week of life)
Not at all, no effect – pain was completely controlled ☐
Slightly – but not bothered to get rid of it ☐
Moderately – pain limited some of [#d_his_her] ability ☐
Severely – activities or concentration markedly affected ☐
Overwhelmingly – [#d_he_she] was unable to think of anything else ☐
No Answer ☐

d_pos_2 During the last week of [#d_firstname:u]'s life, did any other symptoms seem to affect [#d_him_her] despite medication? The response options are:
(Last week of life)
No, not at all, no effect – all other symptoms were completely controlled ☐

Slightly ☐
Moderately ☐
Severely ☐
Overwhelmingly ☐
No Answer ☐

d_pos_11 If any, what were [#d_firstname:u]'s main problems in the last week before [#d_he_she] died?
(Last week of life)
Note: Problems could include nausea, difficulty communicating, diarrhoea etc.
X

The next few questions ask about [#d_firstname:u]'s feelings.

d_pos_6 During the last week, was [#d_firstname:u] able to share how [#d_he_she] was feeling with you, [#d_his_her] family or friends? The response options are:
(Last week of life)
Yes, as much as [#d_he_she] wanted to ☐
Most of the time ☐
Sometimes ☐
Occasionally ☐
No, not at all with anyone ☐
No Answer ☐

d_pos_8 During the last week, do you think [#d_he_she] felt good about [#d_him_her]self as a person? The response options are:
(Last week of life)
Yes, all the time ☐
Most of the time ☐
Sometimes ☐
Occasionally ☐
No, not at all ☐
No Answer ☐

So, the next questions ask how often, if at all, [#d_firstname:u] or [#d_his_her] family or friends may have felt anxious, worried or depressed.

d_pos_3 During the last week, did [#d_he_she] seem to be feeling anxious or worried? The response options are:
(Last week of life)
No, not at all ☐
Occasionally ☐
Sometimes – affected [#d_his_her] concentration now and then ☐
Most of the time – often affected [#d_his_her] concentration ☐
Did not seem to think of anything else – completely preoccupied by worry and anxiety ☐
No Answer ☐

d_pos_4 During the last week of [#d_firstname:u]'s life, were you or any of [#d_firstname:u]'s family or friends anxious or worried about [#d_him_her]? The response options are:
(Last week of life)
No, not at all ☐
Occasionally ☐
Sometimes – affected our concentration ☐
Most of the time ☐
Always – we were always preoccupied with worry ☐
No Answer ☐

d_pos_7 During the last week, did [#d_he_she] seem to be feeling depressed? The response options are:
(Last week of life)
No, not at all ☐
Occasionally ☐
Sometimes ☐
Most of the time ☐
Yes, all of the time ☐
No Answer ☐

The next questions ask about the intensity of these feelings.

d_eq5d_anx9 Overall, during the first 9 months of the last year of [#d_firstname:u]'s life, was [#d_he_she] anxious or depressed? The response options are:

Not anxious or depressed ☐
Moderately anxious or depressed ☐
Extremely anxious or depressed ☐
No Answer ☐

d_eq5d_anx3 How about during the last 3 months of that year? The response options are:

Not anxious or depressed ☐
Moderately anxious or depressed ☐
Extremely anxious or depressed ☐
No Answer ☐

d_eq5d_anx7 And how about during the last week of [#d_his_her] life? The response options are:
(Last week of life)

Not anxious or depressed ☐
Moderately anxious or depressed ☐
Extremely anxious or depressed ☐
No Answer ☐

d_pos_5 During the last week, how much information was given to [#d_him_her], you and [#d_firstname:u]'s family or friends? The response options are:
(Last week of life)

Full information – always felt free to ask what we wanted ☐
Information given but hard to understand ☐
Information given on request but would have liked more ☐
Very little given and some questions were avoided ☐
None at all ☐
No Answer ☐

d_pos_10 During the last week, were any practical matters resulting from [#d_firstname:u]'s illness, either financial or personal, addressed? The response options are:
(Last week of life)

Practical problems were addressed and [#d_his_her] affairs were as up to date as [#d_he_she] wished ☐
Practical problems were in the process of being addressed ☐
Practical problems existed which were not addressed ☐
Had no practical problems ☐
No Answer ☐

And finally, I would just like to ask you a few questions about contact you may have had with the palliative care team since [#d_firstname:u] died.

d_pbereave_fl Since [#d_firstname:u] died, have you or any member of the family had any contact with anybody from the palliative care team?

No ☐ (→ oth_expenses)
Yes ☐ (→ d_pbereave1)
Don't know ☐ (→ oth_expenses)
Refused ☐ (→ oth_expenses)

d_pbereave1 Can you tell me how many times have you or any member of the family had telephone contact with a palliative care consultant since [#d_firstname:u] died?
Definition: "Telephone contact" does not include calling to make an appointment.

d_pbereave2 And how many times have you or any member of the family had face-to-face contact with a palliative care consultant since [#d_firstname:u] died?

d_pbereave3 Can you tell me how many times have you or any member of the family had telephone contact with a palliative care nurse since [#d_firstname:u] died?
Definition: "Telephone contact" does not include calling to make an appointment.

d_pbereave4 And how many times have you or any member of the family had face-to-face contact with a palliative care nurse since [#d_firstname:u] died?

oth_expenses Were there any other major expenses in the last year of [#d_firstname:u]'s life that have not already been discussed?

h_final_comment So, before we finish up, are there any final comments you would like to make?

Note: If the key informant did not consent in form to allow access to medical records, ask at this stage

So, I had also noted that you hadn't ticked the consent box to allow us access [#d_firstname:u]'s formal patient records. We are just looking at these records to follow-up on the information you have given us today and to fill any gaps. The information collected from these records will be treated in the same confidential manner as this interview.

h_consent Would you feel more comfortable giving consent at this stage now that you have more of an idea of the type of information we are looking for? Can we send a consent form for you to sign?

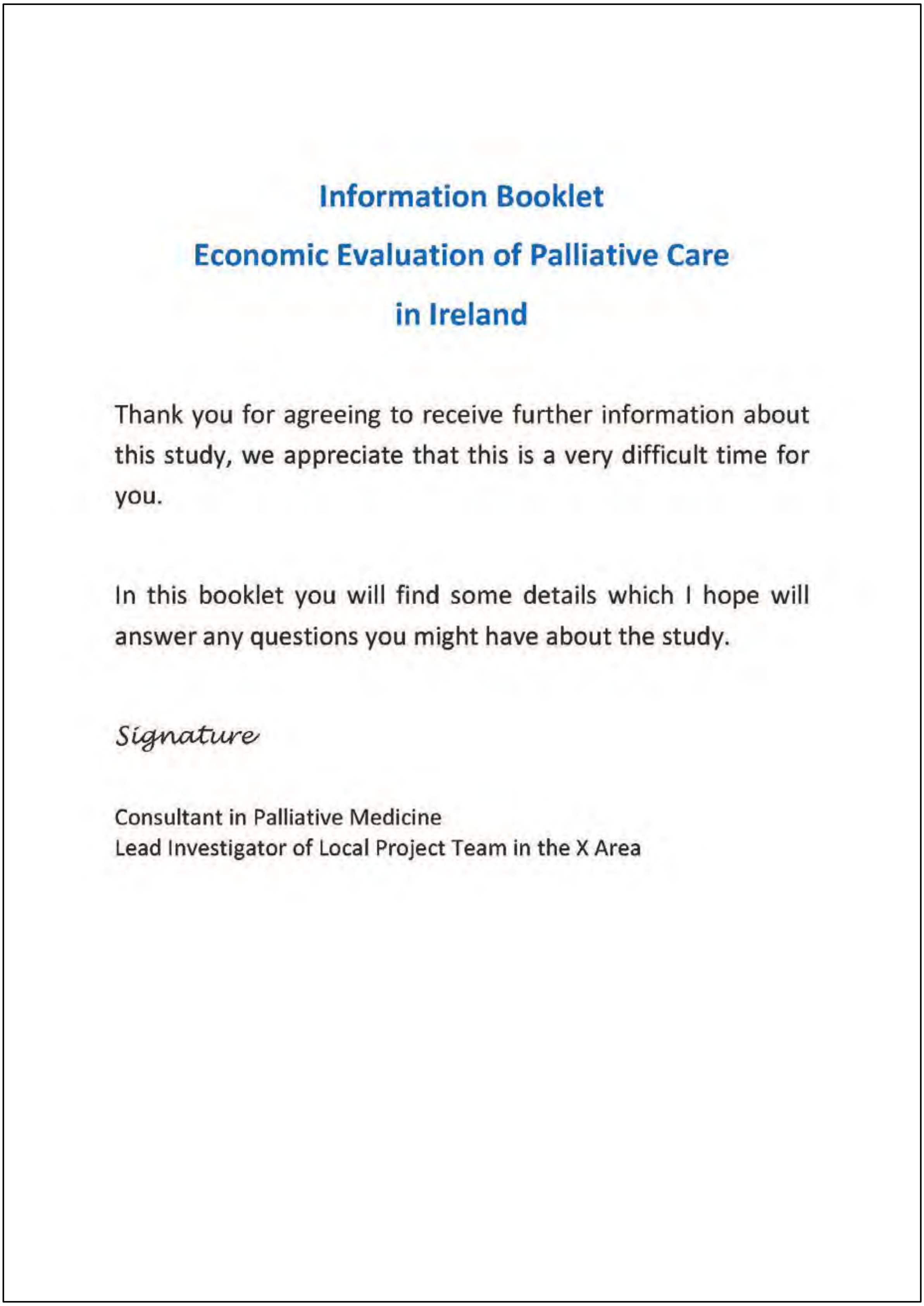
No	☐	(→ consent form)
Yes	☐	(→ no consent form)

That's great [#ki_firstname:u]. I'll need to get your signature on the consent form again. I'll post the form out to you today.

OK. That's no problem.

Thank you very much [#ki_firstname:u] for taking part in this interview. I really appreciate you taking the time and trouble to help us today.
If you feel that you would like to talk to someone after this interview, I have a follow-up support number that I can give you and please do not hesitate to contact this support service if you have anything you want to discuss further, or any questions you may have. Would you like me to give you the number?

A2.2 INFORMATION BOOKLET



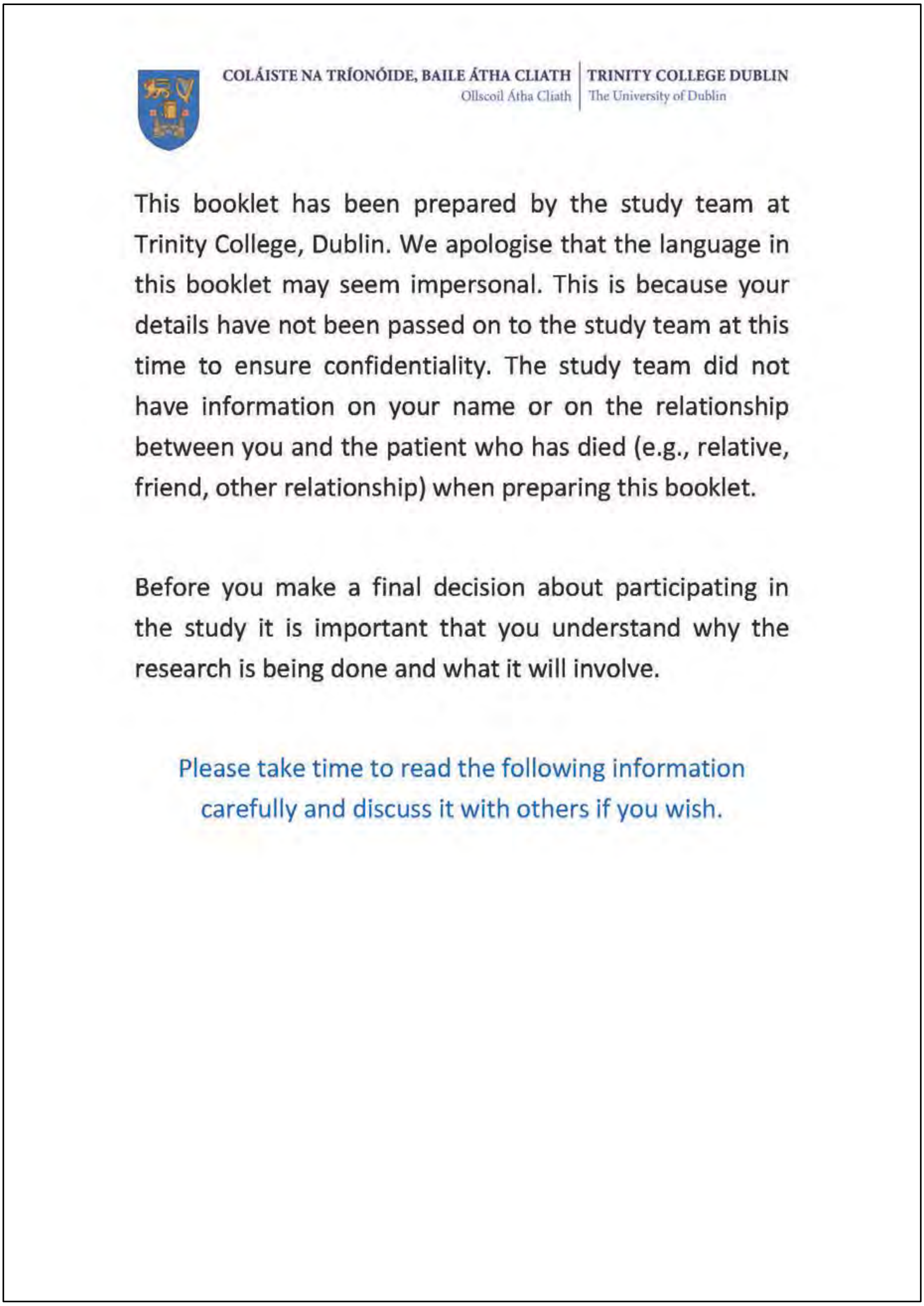
Information Booklet
Economic Evaluation of Palliative Care in Ireland

Thank you for agreeing to receive further information about this study, we appreciate that this is a very difficult time for you.

In this booklet you will find some details which I hope will answer any questions you might have about the study.

Signature

Consultant in Palliative Medicine
Lead Investigator of Local Project Team in the X Area



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Ollscoil Átha Cliath | The University of Dublin

This booklet has been prepared by the study team at Trinity College, Dublin. We apologise that the language in this booklet may seem impersonal. This is because your details have not been passed on to the study team at this time to ensure confidentiality. The study team did not have information on your name or on the relationship between you and the patient who has died (e.g., relative, friend, other relationship) when preparing this booklet.

Before you make a final decision about participating in the study it is important that you understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish.

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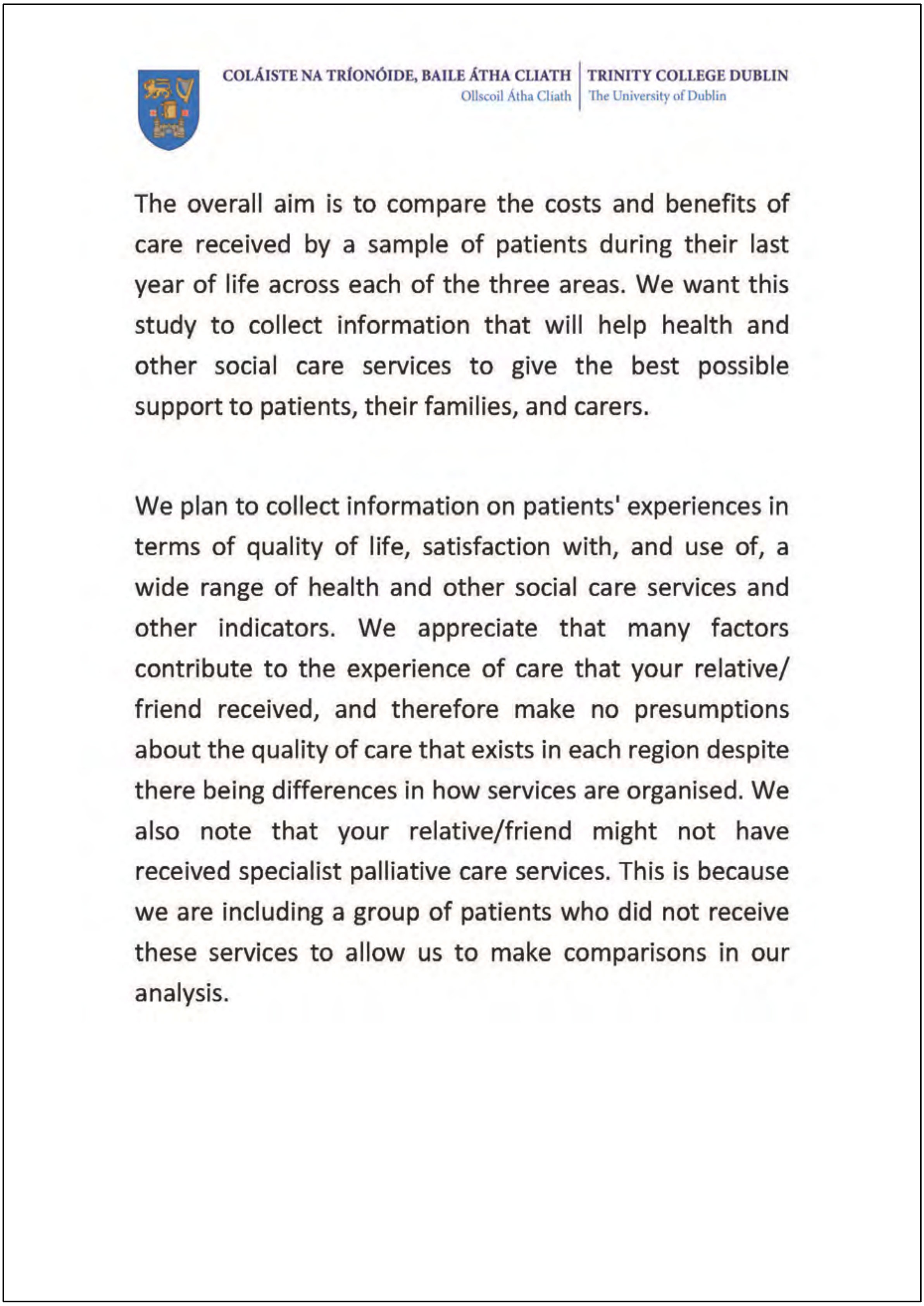
WHY HAVE I BEEN CHOSEN?

You have been chosen at random from within your area to participate in this study. In total, we are contacting up to 100 bereaved people in each area. If you decide to participate in the study, your responses will be used to help improve health and other care services for patients, their families, and carers.

WHY ARE WE DOING THIS RESEARCH?

Palliative care services are organised in different ways throughout Ireland. There may be strengths and weaknesses to these differences. For example, services in one area may offer better value for money than in other areas. In this study we plan to compare the palliative care services that are provided in the Midlands (Laois, Longford, Offaly, Westmeath), the Mid West (Clare, Limerick, North Tipperary) and the South East (Carlow, Kilkenny, South Tipperary, Waterford, Wexford). A separate project is examining services in Dublin so that the final report for this study can also make some comparisons with Dublin.



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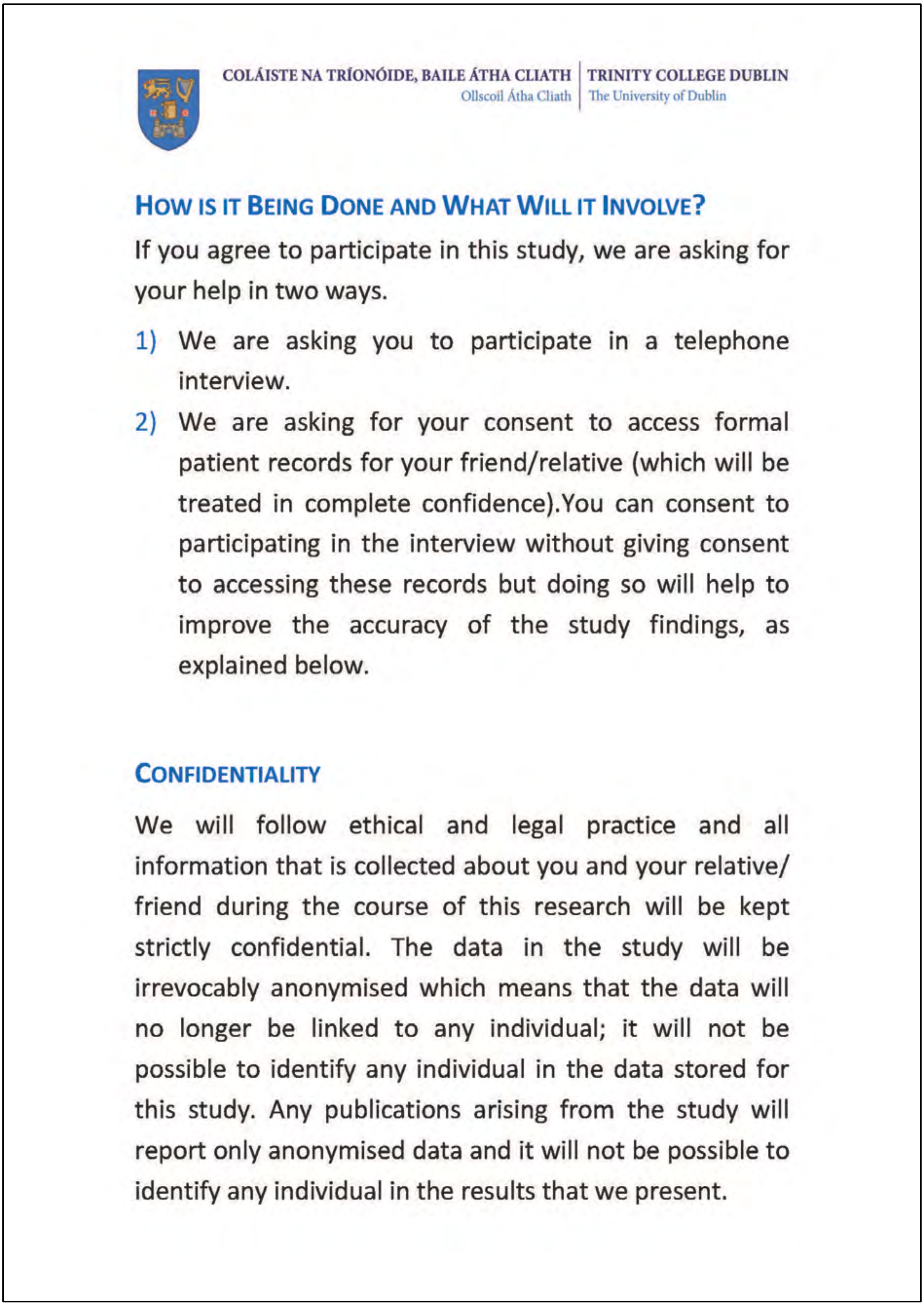
The overall aim is to compare the costs and benefits of care received by a sample of patients during their last year of life across each of the three areas. We want this study to collect information that will help health and other social care services to give the best possible support to patients, their families, and carers.

We plan to collect information on patients' experiences in terms of quality of life, satisfaction with, and use of, a wide range of health and other social care services and other indicators. We appreciate that many factors contribute to the experience of care that your relative/ friend received, and therefore make no presumptions about the quality of care that exists in each region despite there being differences in how services are organised. We also note that your relative/friend might not have received specialist palliative care services. This is because we are including a group of patients who did not receive these services to allow us to make comparisons in our analysis.



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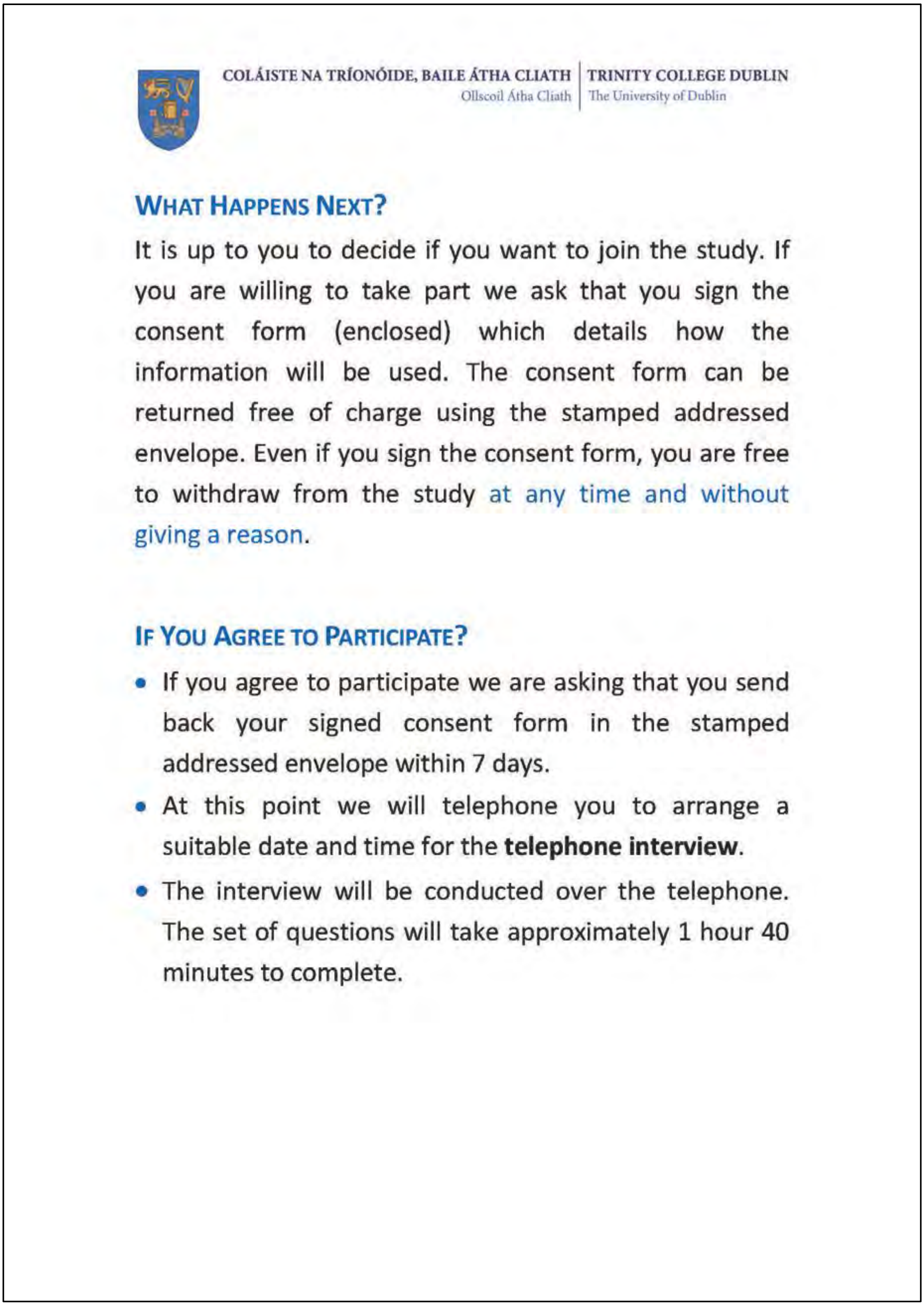
How is it Being Done and What Will it Involve?

If you agree to participate in this study, we are asking for your help in two ways.

1) We are asking you to participate in a telephone interview.
2) We are asking for your consent to access formal patient records for your friend/relative (which will be treated in complete confidence).You can consent to participating in the interview without giving consent to accessing these records but doing so will help to improve the accuracy of the study findings, as explained below.

Confidentiality

We will follow ethical and legal practice and all information that is collected about you and your relative/ friend during the course of this research will be kept strictly confidential. The data in the study will be irrevocably anonymised which means that the data will no longer be linked to any individual; it will not be possible to identify any individual in the data stored for this study. Any publications arising from the study will report only anonymised data and it will not be possible to identify any individual in the results that we present.



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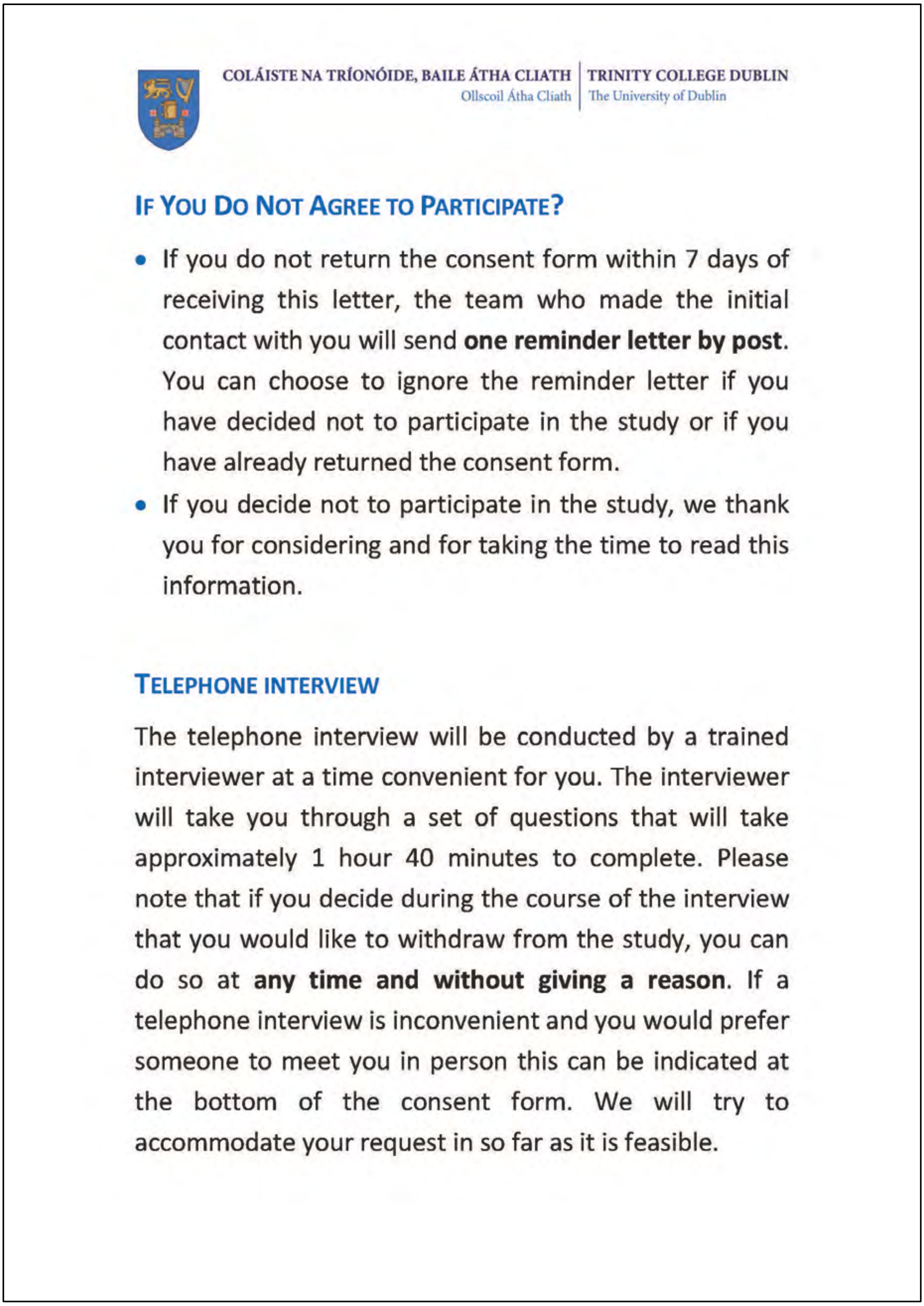
WHAT HAPPENS NEXT?

It is up to you to decide if you want to join the study. If you are willing to take part we ask that you sign the consent form (enclosed) which details how the information will be used. The consent form can be returned free of charge using the stamped addressed envelope. Even if you sign the consent form, you are free to withdraw from the study at any time and without giving a reason.

IF YOU AGREE TO PARTICIPATE?

- If you agree to participate we are asking that you send back your signed consent form in the stamped addressed envelope within 7 days.
- At this point we will telephone you to arrange a suitable date and time for the **telephone interview**.
- The interview will be conducted over the telephone. The set of questions will take approximately 1 hour 40 minutes to complete.



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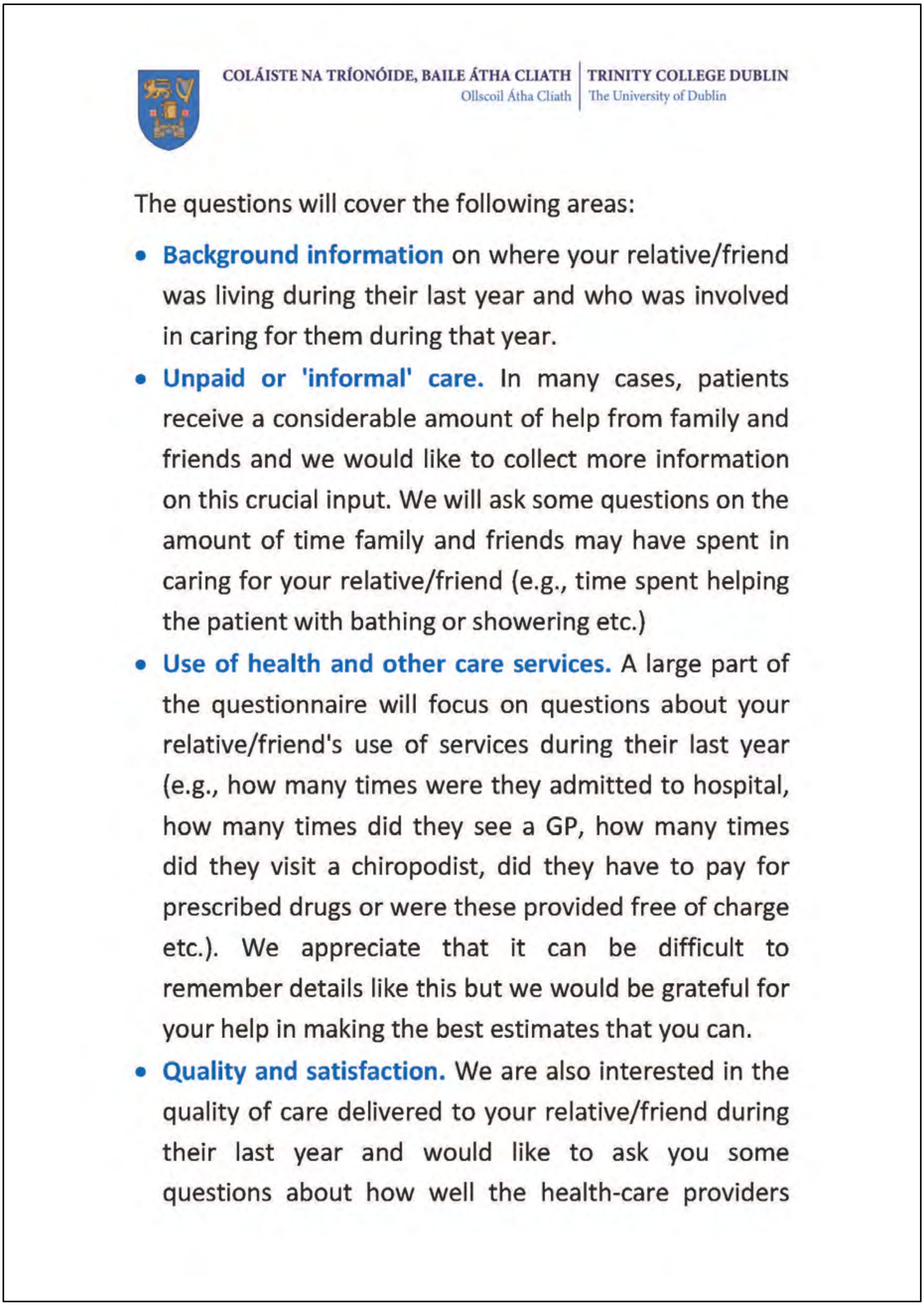
IF YOU DO NOT AGREE TO PARTICIPATE?

- If you do not return the consent form within 7 days of receiving this letter, the team who made the initial contact with you will send **one reminder letter by post**. You can choose to ignore the reminder letter if you have decided not to participate in the study or if you have already returned the consent form.
- If you decide not to participate in the study, we thank you for considering and for taking the time to read this information.

TELEPHONE INTERVIEW

The telephone interview will be conducted by a trained interviewer at a time convenient for you. The interviewer will take you through a set of questions that will take approximately 1 hour 40 minutes to complete. Please note that if you decide during the course of the interview that you would like to withdraw from the study, you can do so at **any time and without giving a reason**. If a telephone interview is inconvenient and you would prefer someone to meet you in person this can be indicated at the bottom of the consent form. We will try to accommodate your request in so far as it is feasible.



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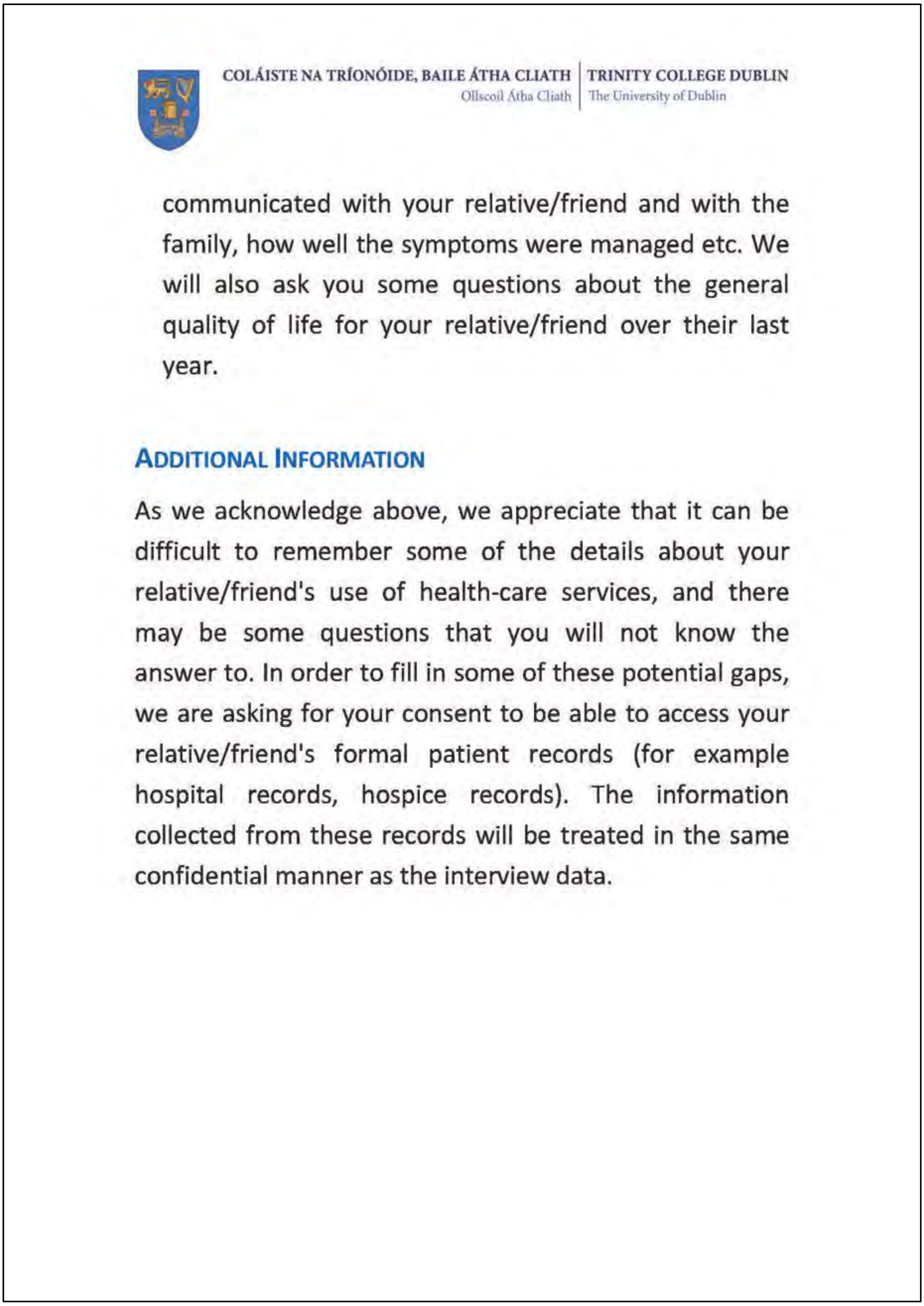
The questions will cover the following areas:

- **Background information** on where your relative/friend was living during their last year and who was involved in caring for them during that year.
- **Unpaid or 'informal' care.** In many cases, patients receive a considerable amount of help from family and friends and we would like to collect more information on this crucial input. We will ask some questions on the amount of time family and friends may have spent in caring for your relative/friend (e.g., time spent helping the patient with bathing or showering etc.)
- **Use of health and other care services.** A large part of the questionnaire will focus on questions about your relative/friend's use of services during their last year (e.g., how many times were they admitted to hospital, how many times did they see a GP, how many times did they visit a chiropodist, did they have to pay for prescribed drugs or were these provided free of charge etc.). We appreciate that it can be difficult to remember details like this but we would be grateful for your help in making the best estimates that you can.
- **Quality and satisfaction.** We are also interested in the quality of care delivered to your relative/friend during their last year and would like to ask you some questions about how well the health-care providers



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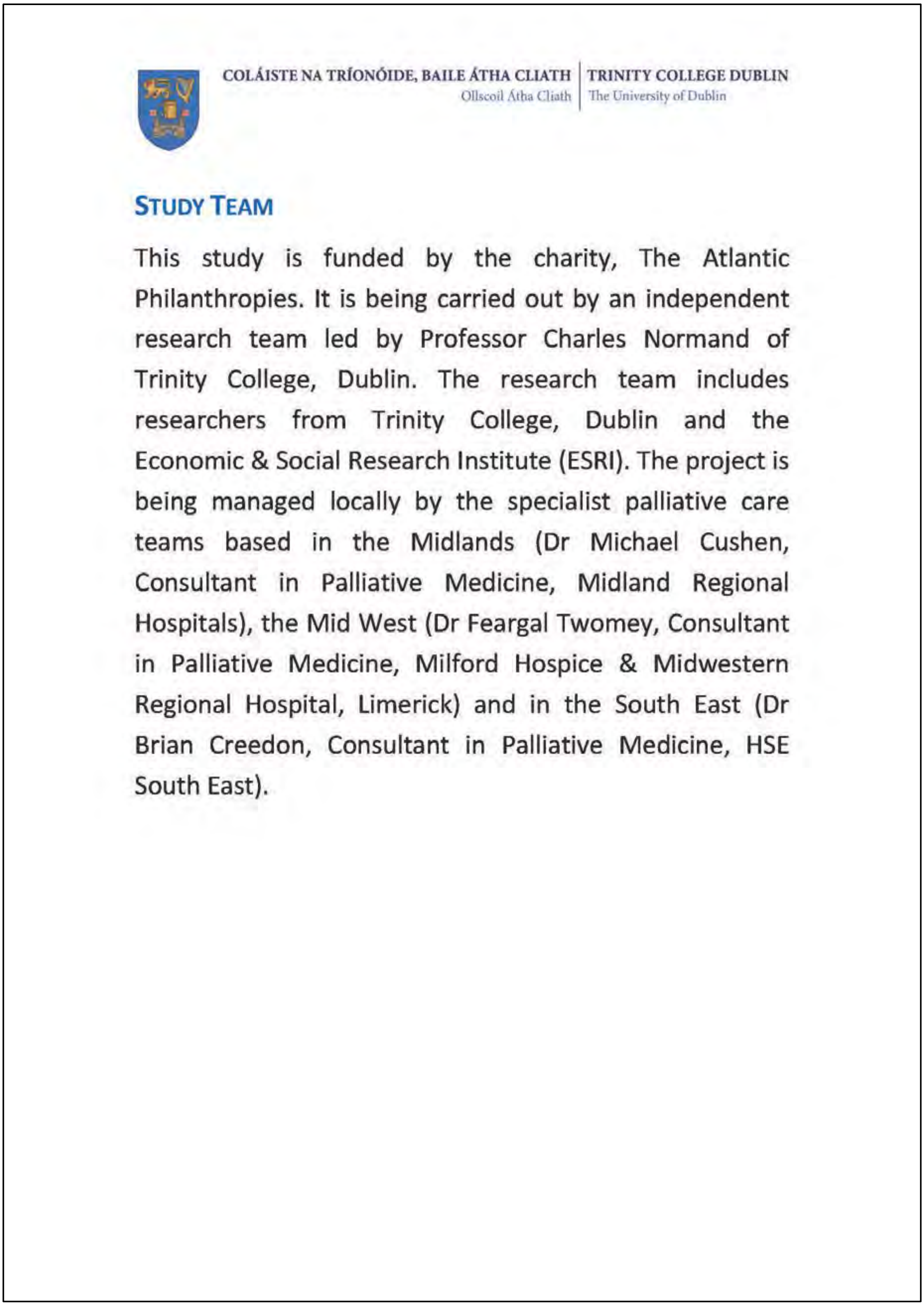
communicated with your relative/friend and with the family, how well the symptoms were managed etc. We will also ask you some questions about the general quality of life for your relative/friend over their last year.

ADDITIONAL INFORMATION

As we acknowledge above, we appreciate that it can be difficult to remember some of the details about your relative/friend's use of health-care services, and there may be some questions that you will not know the answer to. In order to fill in some of these potential gaps, we are asking for your consent to be able to access your relative/friend's formal patient records (for example hospital records, hospice records). The information collected from these records will be treated in the same confidential manner as the interview data.



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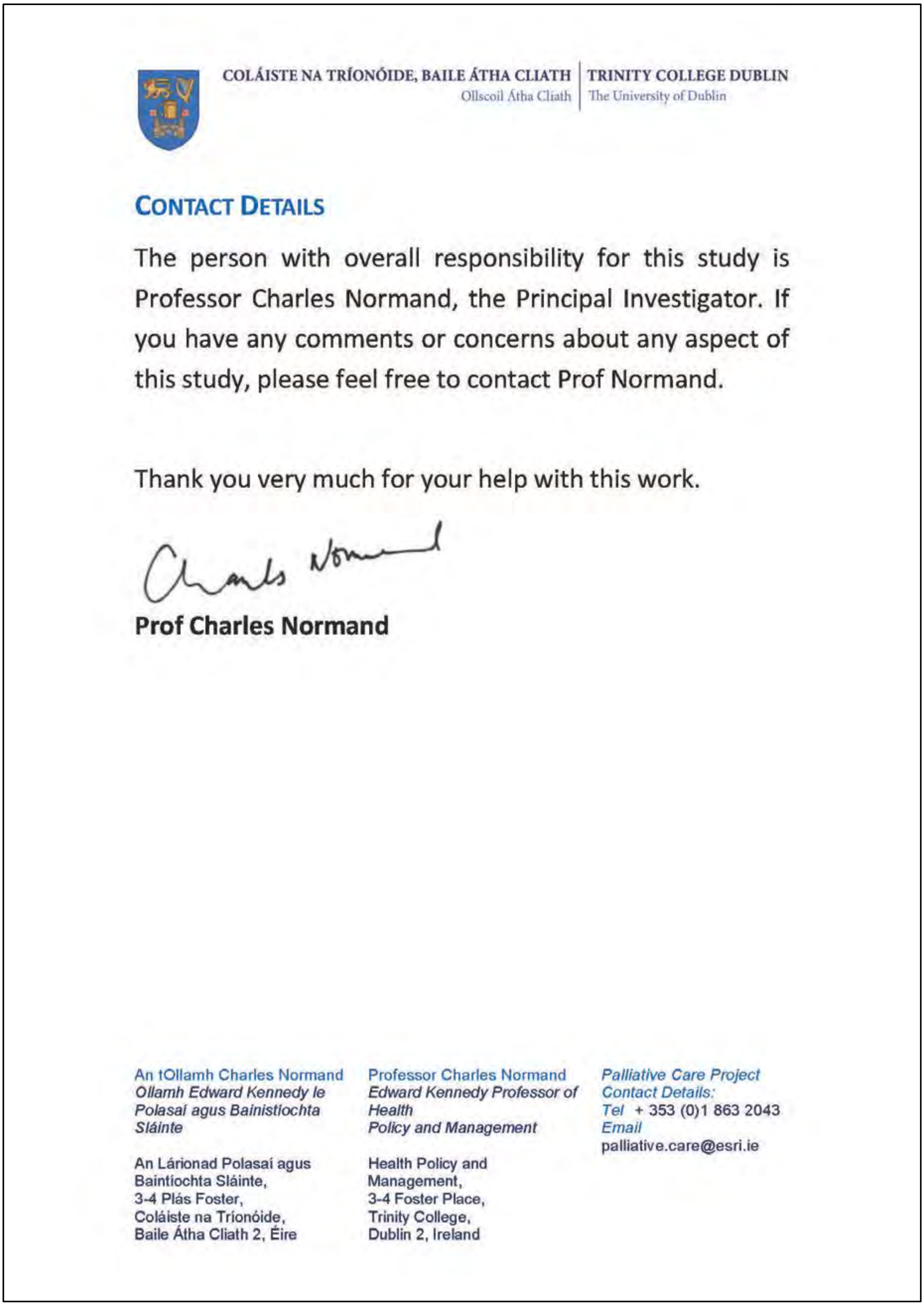
STUDY TEAM

This study is funded by the charity, The Atlantic Philanthropies. It is being carried out by an independent research team led by Professor Charles Normand of Trinity College, Dublin. The research team includes researchers from Trinity College, Dublin and the Economic & Social Research Institute (ESRI). The project is being managed locally by the specialist palliative care teams based in the Midlands (Dr Michael Cushen, Consultant in Palliative Medicine, Midland Regional Hospitals), the Mid West (Dr Feargal Twomey, Consultant in Palliative Medicine, Milford Hospice & Midwestern Regional Hospital, Limerick) and in the South East (Dr Brian Creedon, Consultant in Palliative Medicine, HSE South East).



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CONTACT DETAILS

The person with overall responsibility for this study is Professor Charles Normand, the Principal Investigator. If you have any comments or concerns about any aspect of this study, please feel free to contact Prof Normand.

Thank you very much for your help with this work.

Charles Normand

Prof Charles Normand

An tOllamh Charles Normand
Ollamh Edward Kennedy le Polasaí agus Bainistíochta Sláinte

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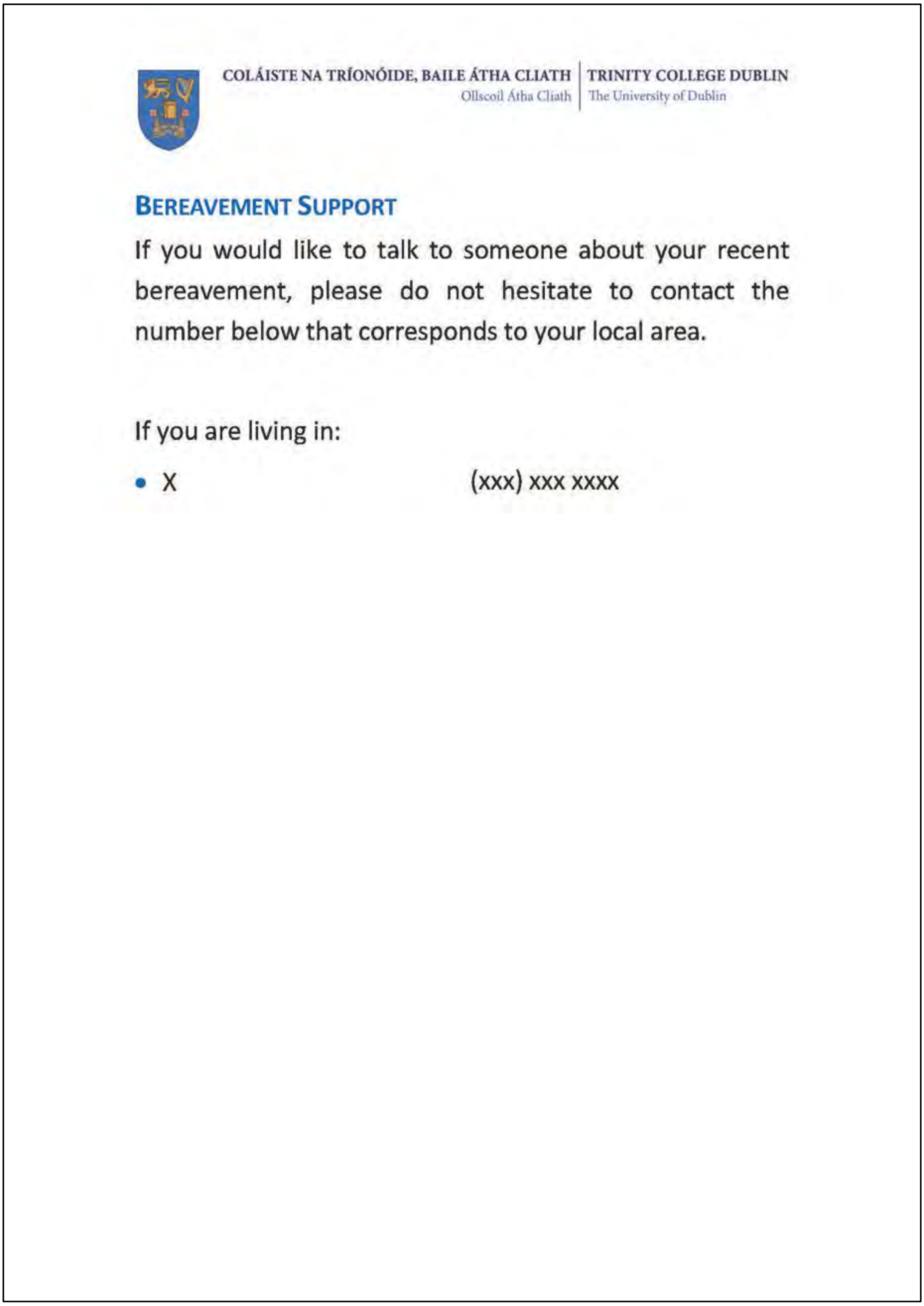

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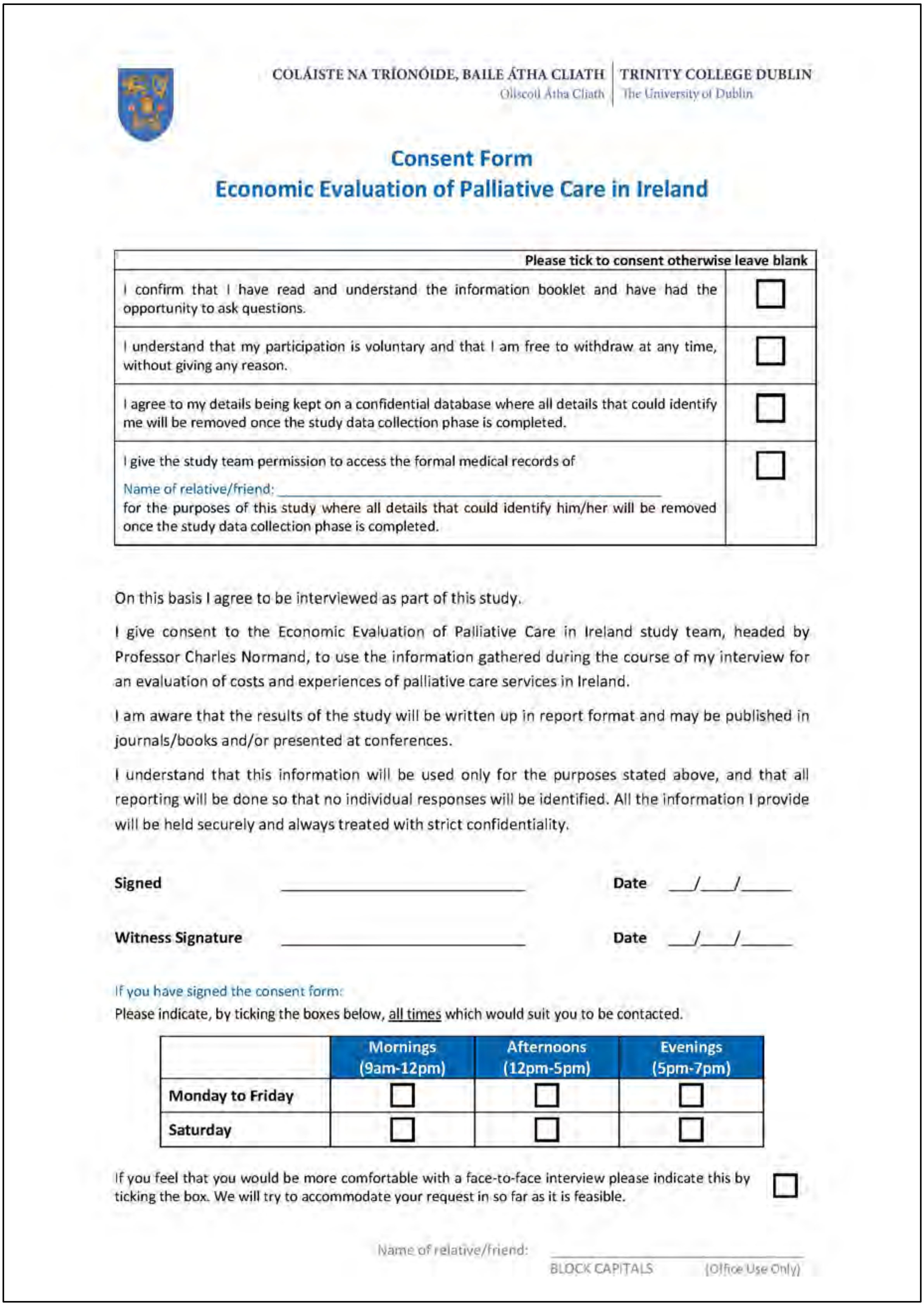
BEREAVEMENT SUPPORT

If you would like to talk to someone about your recent bereavement, please do not hesitate to contact the number below that corresponds to your local area.

If you are living in:

- X (xxx) xxx xxxx

A2.3 CONSENT FORM



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Consent Form
Economic Evaluation of Palliative Care in Ireland

Please tick to consent otherwise leave blank	
I confirm that I have read and understand the information booklet and have had the opportunity to ask questions.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	☐
I agree to my details being kept on a confidential database where all details that could identify me will be removed once the study data collection phase is completed.	☐
I give the study team permission to access the formal medical records of Name of relative/friend: ______________________ for the purposes of this study where all details that could identify him/her will be removed once the study data collection phase is completed.	☐

On this basis I agree to be interviewed as part of this study.

I give consent to the Economic Evaluation of Palliative Care in Ireland study team, headed by Professor Charles Normand, to use the information gathered during the course of my interview for an evaluation of costs and experiences of palliative care services in Ireland.

I am aware that the results of the study will be written up in report format and may be published in journals/books and/or presented at conferences.

I understand that this information will be used only for the purposes stated above, and that all reporting will be done so that no individual responses will be identified. All the information I provide will be held securely and always treated with strict confidentiality.

Signed ______________________ **Date** ___/___/_____

Witness Signature ______________________ **Date** ___/___/_____

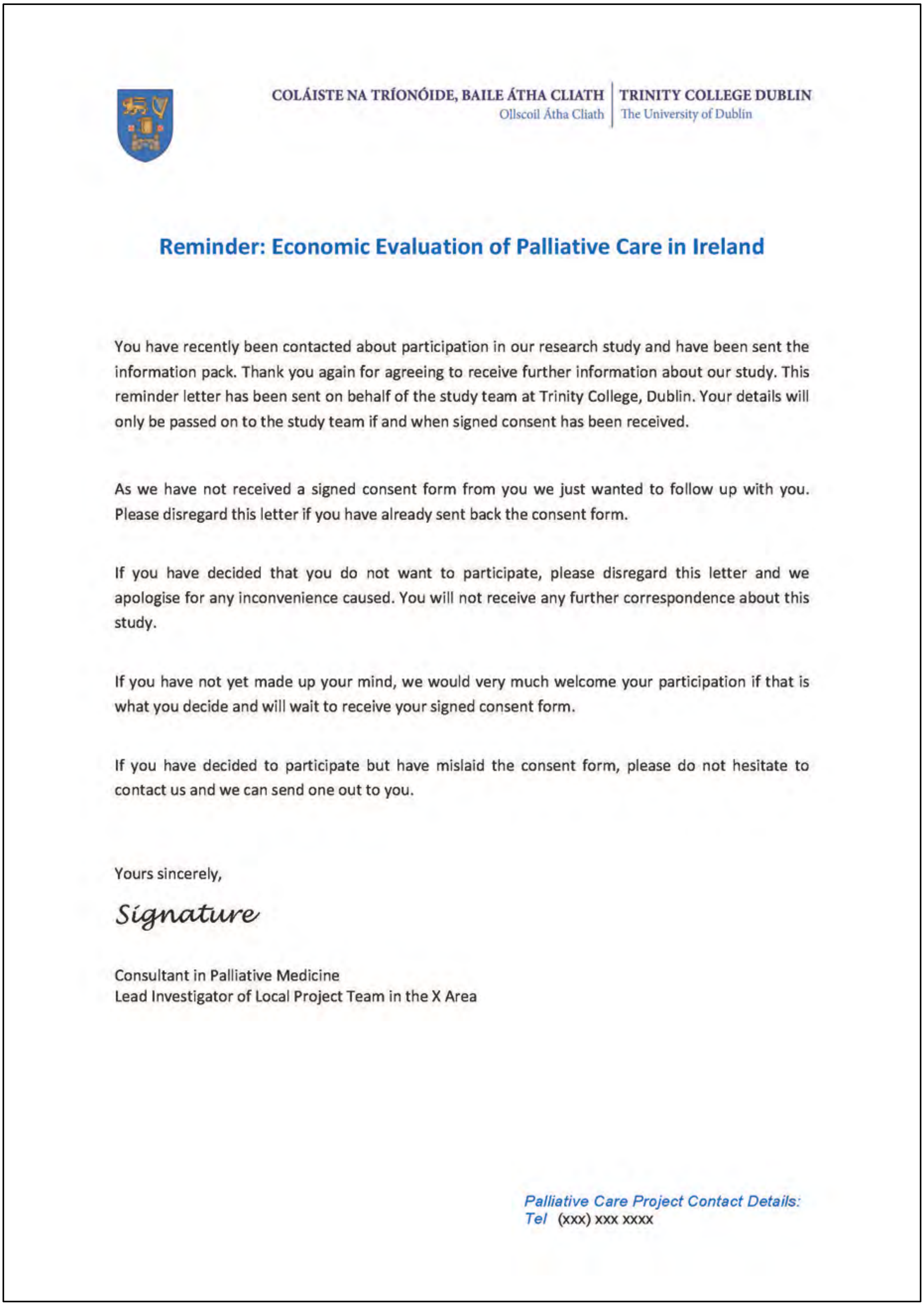
If you have signed the consent form:
Please indicate, by ticking the boxes below, <u>all times</u> which would suit you to be contacted.

	Mornings (9am-12pm)	Afternoons (12pm-5pm)	Evenings (5pm-7pm)
Monday to Friday	☐	☐	☐
Saturday	☐	☐	☐

If you feel that you would be more comfortable with a face-to-face interview please indicate this by ticking the box. We will try to accommodate your request in so far as it is feasible. ☐

Name of relative/friend: ______________________
BLOCK CAPITALS (Office Use Only)

A2.4 REMINDER LETTER



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Reminder: Economic Evaluation of Palliative Care in Ireland

You have recently been contacted about participation in our research study and have been sent the information pack. Thank you again for agreeing to receive further information about our study. This reminder letter has been sent on behalf of the study team at Trinity College, Dublin. Your details will only be passed on to the study team if and when signed consent has been received.

As we have not received a signed consent form from you we just wanted to follow up with you. Please disregard this letter if you have already sent back the consent form.

If you have decided that you do not want to participate, please disregard this letter and we apologise for any inconvenience caused. You will not receive any further correspondence about this study.

If you have not yet made up your mind, we would very much welcome your participation if that is what you decide and will wait to receive your signed consent form.

If you have decided to participate but have mislaid the consent form, please do not hesitate to contact us and we can send one out to you.

Yours sincerely,

Signature

Consultant in Palliative Medicine
Lead Investigator of Local Project Team in the X Area

Palliative Care Project Contact Details:
Tel (xxx) xxx xxxx

Appendix 3

Service Profiles

The purpose of the following appendix is to assist with the interpretation of the primary data collected from the KIs during the interviews. The service profiles describe the structure of the specialist palliative care services (SPC) available in each of the study areas during the period in which the decedents died. In particular the local teams were asked to provide data for June 2012. Given the range of dates of death for decedents included in the study it may be that the services differed during a particular decedent's time in that service than the picture presented here. Local teams were however given the opportunity to add footnotes to the service profile tables on any important developments since June 2012.

- Table A3.1 outlines the SPC infrastructure available in each of the three study areas. The local teams were asked to provide details on infrastructure such as community SPC, in-patient hospital care, palliative care support beds, hospice facilities, and various day and outpatient services where relevant.
- Table A3.2 outlines, where known, the source of patient referrals to SPC in each area.
- Table A3.3 outlines the different categories of SPC personnel whole time equivalents (WTEs) working with each team.
- Table A3.4 outlines the availability and role of each category of SPC team personnel.
- Table A3.5 outlines the role of SPC consultants in each area.
- Table A3.6 outlines how the community SPC teams operate in each region. The purpose of this exercise was not to audit or describe all subtle difference between the services, but rather, to identify any major differences in service provision across the regions.

TABLE A3.1 Specialist Palliative Care Infrastructure by Study Area, June 2012

Midlands		Mid West		South East	
Location	Number of Allocated Beds	Location	Number of Allocated Beds	Location	Number of Allocated Beds
Community SPC					
- St. Fintan's Hospital Campus, Dublin Road, Portlaoise, Laois - The Health Centre, Arden Road, Tullamore, Offaly - Team Leader Office, Cloneygowan, Offaly - The Health Centre, Dublin Road, Longford - St. Loman's Campus, Mullingar, Westmeath - South Westmeath Hospice, Cossan Road, Athlone, Westmeath	n/a	Milford Care Centre Hospice at Home Team: - Milford Care Centre, Castletroy, Limerick - St. Ita's Hospital, Newcastle West, Limerick - Quin Road Business Park, Ennis, Clare - 63 Ormond Street, Nenagh, Tipperary - Hospital of the Assumption, Thurles, Tipperary	n/a	- South Tipperary Home Care Team [South Tipperary Hospice Movement] - Waterford Home Care Team [Waterford Hospice Movement]	n/a
SPC In-Patient Care (Hospital)					
- Midland Regional Hospital at Tullamore, Arden Road, Tullamore, Offaly	0	- Mid-Western Regional Hospital, Limerick[a]	0	- South Tipperary General Hospital, Clonmel, Tipperary	0
- Midland Regional Hospital Portlaoise, Dublin Road, Portlaoise, Laois	0	- St. John's Hospital, Limerick	0	- Waterford Regional Hospital, Dunmore Road, Waterford	2
- Midland Regional Hospital Mullingar, Longford Road, Mullingar, Westmeath	0	- Mid-Western Regional Hospital, Ennis General Hospital[a,b]	0		
		- Mid-Western Regional Hospital, Nenagh General Hospital[a,b]	0		
Palliative Care Support Beds (Hospital/Community/Long-Stay Unit)					
- Midland Regional Hospital Portlaoise, Dublin Road, Portlaoise, Laois	1	- Milford Care Centre, Castletroy, Limerick	2	- St. Teresa's Hospital, Clogheen, Tipperary	1
- St. Vincent's Hospital, Mountmellick, Laois	2	- Raheen Community Hospital, Tuamgraney, Scariff, Clare	2	- St. Brigid's District Hospital, Carrick-on-Suir, Tipperary	3
- Midland Regional Hospital at Tullamore, Arden Road, Tullamore, Offaly	1	- Regina House, Kilrush, Clare	2	- Cluainn Arainn Welfare Home, Tipperary	1
- Community Nursing Unit, Birr, Offaly	1	- Ennistymon Community Hospital, Dough, Ennistymon, Clare	1	- Waterford Regional Hospital, Dunmore Road, Waterford	n/a
- Ofalia House, Edenderry, Offaly	1	- Cahercalla Community Hospital, Ennis, Clare	5	- Dungarven Community Hospital, Waterford	2
- Birr District Hospital, Offaly	1	- Hospital of the Assumption, Thurles, Tipperary	2		
- St. Joseph's District Hospital, Longford	1	- Dean Maxwell Community Nursing Unit,	1		

Midlands		Mid West		South East	
Location	Number of Allocated Beds	Location	Number of Allocated Beds	Location	Number of Allocated Beds
		Roscrea, Tipperary			
- Laurel Lodge Nursing Home, Glebe, Longford	1	- St. Conlan's Community Nursing Unit, Nenagh, Tipperary	2[c]		
- Midland Regional Hospital Mullingar, Longford Road, Mullingar, Westmeath	2				
- South Westmeath Hospice, Palliative Care Unit, Athlone, Westmeath	4				
- St. Camillus Nursing Centre, Killucan, Westmeath	2				
SPC – In-Patient Care (Hospice)					
-	-	Milford Care Centre (MCC), Castletroy, Limerick	30[d]	Waterford Regional Hospital, Dunmore Road, Waterford	2
If applicable:					
SPC – Day-Patient Care (Hospice and Hospital)					
-	-	Milford Care Centre, Castletroy, Limerick	10 places (2 days per week)	-	-
SPC – Out-Patient Care (Hospice and Hospital)					
- Midland Regional Hospital at Tullamore, Arden Road, Tullamore, Offaly - Midland Regional Hospital Mullingar, Longford Road, Mullingar, Westmeath - South Westmeath Hospice, Cossan Road, Athlone, Westmeath	n/a	- Milford Care Centre, Castletroy, Limerick - Mid-Western Regional Hospital, Limerick - St. John's Hospital, Limerick	n/a	- Waterford Regional Hospital, Dunmore Road, Waterford[e] - South Tipperary General Hospital, Clonmel, Tipperary[f]	n/a
Other					
-	-	- Haematology oncology day ward and Radiation oncology centre (Hospital) - Mid-Western Regional Hospital, Limerick[g]	n/a	- Day oncology care (Hospital) - South Tipperary General Hospital, Clonmel, Tipperary - Waterford Regional Hospital, Dunmore Road, Waterford	n/a

Notes: n/a=not applicable

a The hospitals were known as Mid Western Regional Hospital, Ennis General Hospital and Nenagh General Hospital during this period. The name change to UL Hospitals occurred in 2013.

b Both Ennis and Nenagh provided SPC input delivered by Clinical Nurse Specialists.

c These beds were closed to admissions during the period covered by this report.

d 28 beds are in operation.

e 1st and 3rd week (day of week depends on schedule) outpatient department in WRH, patients could be seen outside of these arranged hours.

f If there are patients that require to be seen this is facilitated every Monday at STGH outpatient department. The patients are seen by the SPC Consultant.

g Although it is not a dedicated service for patients with palliative care needs, the hospital's SPC team sees patients here.

TABLE A3.2 Source of Referral to SPC by Study Area, 2012[a]

	Midlands		Mid West	South East	
	Laois/Offaly Home Care Team (n=461)	Longford/ Westmeath Home Care Team (n=390)	Milford Care Centre (n=868)	South Tipperary Hospice Movement (n=148)	Waterford Hospice Movement (n=570)
	%	%	%	%	%
Source of Referral to Community SPC					
Consultant (palliative medicine)	-	12.1	-	-	17.9
Consultant (other)	32.5	44.4	44.0	-	1.1
GP	21.7	31.0	51.0	100[b]	20.0
Public health nurse	2.8	2.1	-	-	-
Oncology team (Hospital)	18.4[c]	-	-	-	11.0[d]
Nursing staff (hospital)	12.8	-	-	-	-
Community nursing unit/nursing home	5.0	-	-	-	-
Unknown	3.3	9.2	-	-	50.0
Nursing staff – palliative care	1.5	0.3	-	-	-
Family/Self	0.7	-	-	-	-
Another SPC service	0.7	1.0	-	-	-
Allied health professional	0.4	-	-	-	-
Other	0.2	-	5.0	-	-

Notes:
a Referral dates were retrieved for 95.8% of all decedents and of these 23.7% were referred prior to 2012.
b Although not all referrals are initiated by the GP, no record of source of referral is available.
c Midland Regional Hospital, Tullamore
d Waterford Regional Hospital

TABLE A3.3 SPC Team Personnel by Study Area[a], June 2012

	WTEs												
	Midlands				Mid West					South East[b]			
	Community	Acute Hospital Care[c]	Palliative Support-Bed Care	Total	Community	Acute Hospital Care	Palliative Support-Bed Care	Hospice Care	Total	Community	Acute Hospital Care	Palliative Support-Bed Care	Total
Medical Staff													
Consultant	0.2	0.7	0.1+	**1**	0.1	0.7		2.2	**3**[d]				**3**[e]
Specialist Registrar					0.6	0.4		1	**2**[f]				**1**
Registrar								1	**1**[f]				**1**
SHO								3	**3**				**2**
Nursing Staff													
Director of Nursing					0.5			0.5	**1**[g]				
Deputy Director of Nursing					0.5			0.5	**1**[g]				
Nursing Team Manager/Leader	2			**2**	2.0			5.6[h]	**6.6**	2			**2**
Clinical Nurse Specialist	13.56	0.5	0.5	**14.56**	16.75	5			**21.75**	8.2			**8.2**
Staff Nurse	1.27			**1.27**	6.7			31.8[h]	**38.4**	1.4			**1.4**
Care Assistant					7			16.2[h]	**7**				
Allied Health Professionals													
Occupational Therapist					2			2.5[h]	**5**[i]	1			**1**
Occupational Therapy Assistant								1	**1**				
Physiotherapist	1.75			**1.75**[j]	3[k]			2.5[h]	**6.5**[l]				
Physiotherapy Assistant								1	**1**				
Social Worker	1			**1**[j]	2			2.5[h]	**5.5**[j]				
Pastoral Carer					1[m]				**2**				
Dietician								1	**1**				
Pharmacist								1	**1**				
Pharmacy Technician								1	**1**				
Aromatherapist													
Music Therapist								1.6[n]	**1.6**				
Art Therapist								1.1[n]	**1.1**				
Art Facilitator								2[n]	**2**				
Bereavement Counsellor													[o]
Complementary Therapist								1.5[n]	**1.5**	0.6			**0.6**
Administrative Staff (Nursing)	2			**2**[p]	1.8			3	**4.8**				
Administrative Staff (Medical)								3	**3**		1.5		**1.5**

Notes:
a The teams were asked to provide data about the number of Whole Time Equivalents (WTEs) available across all care settings in June 2012.
b The WTE data is for the South Tipperary and Waterford regions only.
c Laois/Offaly: There are no dedicated nurses to cover level 2 beds. The 3 WTE CNSs from Laois rotate into the Midland Regional Hospital Portlaoise depending on referrals, workload and who is on duty. The WTE numbers remained unchanged in the home care team because the CNSs were backfilled from HSE staff funded by the Hospice.
d 1 in 3 on-call for home care service, in terms of providing senior medical support and attending two home care multidisciplinary team meetings.

e Details on how the consultants’ time is split between the two services were not provided.

f One registrar post is allocated to Hospice at Home/ Midland Regional Hospital at a time to be that specialist registrar or registrar.

g Director and Deputy Director of Nursing also manage the Outpatient and Day Care services.

h Includes WTEs for Specialist Palliative Day Care.

i Includes OT manager.

j Laois/Offaly: The senior social worker and the specialist physiotherapist see level 2 bed patients on a needs basis.

k 1 WTE assigned to Lymphoedema.

l Includes Physio Manager.

m Limited pastoral care support is available for the Hospice at Home service if required.

n These WTEs also provide elderly services.

o South Tipperary: The bereavement counsellor has their own practice and the STHM funds visits if this service is required.

p Administrative staff for the home care team is funded through voluntary contributions.

TABLE A3.4 Community SPC Team Availability and Role by Study Area, June 2012

	Mon-Fri In-Hours[a]		Mon-Fri Out-of-Hours[b]		Weekends/ Bank Holidays		Role
	Hrs Per Day	Days per Wk	Hrs Per Day	Days Per Wk	Hrs Per Day	Days per Wk	
Midlands							
Medical Staff							
Consultant	09.00-17.00	5	[c]				1) Participation in a weekly MDT meeting in the Team Leader Office, Cloneygowan, Offaly and in the South Westmeath Hospice, Cossan Road, Athlone, Westmeath. 2) Provides telephone advice to CNSs on both community SPC teams, which would take up at least half to one hour per team per day. 3) Undertakes occasional home visits or clinic appointments as necessary. The number of home visits varies widely from month to month; On average over the year: 1/month in Laois/Offaly and 2/month in Longford/Westmeath.
Nursing Staff							
Nursing Team Manager/Leader	09.00-17.00	5	0	0	09.00-17.00	2	1) Is responsible for the management and co-ordination of the community SPC team. 2) Liaises with Director of PHN. 3) Manages multidisciplinary team. 4) Takes responsibility for financial, human resource and strategic elements of the service. 5) Facilitates learning and practice development of all staff. 6) Encourages research among staff. 7) Provides care to patients on the caseload of the SPCT when necessary. 8) Is responsible for providing direct telephone access to patients, family members and related Health and Social Care professionals as part of the out-of-hours telephone advisory service.
Clinical Nurse Specialist	09.00-17.00	5	0	0	09.00-17.00	2	1) Assesses, plans and initiates palliative care for patients. 2) Provides advice, support and information to patients and their carers. 3) Works collaboratively with SPC teams, primary care teams, hospital teams and other agencies. 4) Educates and supports other professionals providing palliative care. 5) Manages caseloads and maintain accurate records. 6) Engages in continuing professional development. 7) Has limited participation in audit and research. 8) Is responsible for providing direct telephone access to patients, family members and related Health and Social Care professionals as part of the out-of-hours telephone advisory service.
Staff Nurse	09.30-16.30	5	0	0	0	0	1) Assesses, plans, implements and evaluates care within the nursing model. 2) Works collaboratively with SPC teams, primary care teams, hospital teams and other agencies 3) Engages in learning and teaching. 4) Manages caseloads. 5) Delegates to other members of the care team, e.g. care assistant, home help.
Allied Health Professionals							
Physiotherapist	09.30-17.00	5	0	0	0	0	1) Assesses, plans and implements a treatment programme for patients appropriately referred and prioritised.

	Mon-Fri In-Hours[a]		Mon-Fri Out-of-Hours[b]		Weekends/ Bank Holidays		Role
	Hrs Per Day	Days per Wk	Hrs Per Day	Days Per Wk	Hrs Per Day	Days per Wk	
							2) Evaluates patient progress and outcomes. 3) Provides educational and practical support to patients and families. 4) Liaises with members of the community SPC team and the primary care team in the community in relation to the needs/progress of patients and attend MDT meetings/case conferences as appropriate. 5) Maintains accurate records. 6) Participates in continuing education courses and professional development. 7) Participates in professional supervision. 8) Participates in education, audit and research.
Social Worker	09:00-18:00	4	0	0	0	0	1) Is responsible for the delivery of a direct social work service: (i) Provides guidance and assistance to individuals, families and friends in communicating with each other at times of severe emotional distress (ii) Provides support and advice to parents in recognising and managing the specific needs of children (iii) Helps service users and families access health, personal social services and welfare entitlements in the community (iv) Provides bereavement support and counselling (v) Assists with discharge planning (vi) Manages caseloads and maintain accurate records. 2) Works closely with and support other disciplines, medical and nursing staff in the community SPC team. 3) Contributes to the support and development the staff of the Social Work Department. 4) Works closely with community and other HSE services and other statutory bodies and appropriate voluntary bodies, agencies and individuals. 5) Participates in professional development. 6) Participates in teaching, research and audit.
Administrative Staff (Nursing)	09.00-17.00	5	0	0	0	0	1) Is responsible for managing referrals: (i) Taking referrals from GPs, PHNs and hospital consultants. (ii) Registering new patients on database. (iii) Organising charts and following up on all relevant test results. (iv) Ensuring that referrals are given to the relevant team members. 2) Provides secretarial support to team members. 3) Handles telephone enquiries within service hours and passes these on to various members of the nursing team. 4) Maintains statistical data and management of information using the ‘Pall Care System’. 5) Is responsible for management of filing system.

	Mon-Fri In-Hours[a]		Mon-Fri Out-of-Hours[b]		Weekends/ Bank Holidays		Role
	Hrs Per Day	Days per Wk	Hrs Per Day	Days Per Wk	Hrs Per Day	Days per Wk	
Mid West							
Medical Staff							
Consultant	09.00-17.00	5	24hr	5	24hr	2	1) Second line of responsibility in providing senior medical support to the community SPC team registrar, community SPC team, and first on-call NCHD. 2) Participation in two MDT meetings during the week on-call [1 in 3].
Specialist Registrar	09.00-17.00	5	24hr	5	24hr	2	When assigned to the role or on-call [1 in 6]: 1) First line of responsibility in providing medical support to the community SPC team 2) Provides telephone advice to CNSs on the community SPC team, GPs and other disciplines 3) Undertakes home visits.
Registrar	09.00-17.00	5	24hr	5	24hr	2	
SHO	09.00-17.00	5	24hr	5	24hr	2	1) Provides on-call support to community SPC team.
Nursing Staff							
Director of Nursing	09.00-17.00	5	0	0	0	0	1) Provides strategic and clinical leadership for nursing staff and related services. 2) Provides direction for the development and advancement of nursing and related services 3) Plans, organises and supervises the nursing service. 4) Is responsible for monitoring and evaluation of nursing and related services patient care 5) Take an active part in the delivery of care: (i) Liaises with the primary care team in the community (ii) Is responsible for providing direct telephone access to patients, family members and related Health and Social Care professionals as part of the out-of-ours telephone advisory service. 6) Prepares an annual report in relation to the nursing area, covering areas such as activities and expenditure, objectives and actions plans. 7) Promotes professional development. 8) Initiates, encourages and participates in relevant nursing research and promotes the awareness of on-going and current research into issues affecting patient care.
Deputy Director of Nursing	09.00-17.00	5	0	0	0	0	1) Assists the Director of Nursing Services with the organisation and co-ordination of the Nursing Services within the designated areas, i.e. Day Care/ community SPC/Palliative Care In-patient Unit and Nursing Home. 2) Deputises for the Director of Nursing Services in her/his absence or when required. 3) Receives and disseminates information through the attendance at meetings within and outside the Centre. 4) Participates when appropriate with the recruitment, selection, deployment and management of all Nursing Staff. 5) Assists the Director of Nursing with developing, reviewing and co-ordinating Nursing Services in the areas of the SPC Unit, Nursing Home, Day Care and Community SPC. 6) Takes an active part in the delivery of care:

	Mon-Fri In-Hours[a]		Mon-Fri Out-of-Hours[b]		Weekends/ Bank Holidays		Role
	Hrs Per Day	Days per Wk	Hrs Per Day	Days Per Wk	Hrs Per Day	Days per Wk	
							(i) Liaises with Community SPC Team, attends Community SPC meeting weekly and report to Director of Nursing all matters of significance (ii) Liaises with the primary care team in the community (iii) Is responsible for providing direct telephone access to patients, family members and related Health and Social Care professionals as part of the out-of-hours telephone advice Service,' when providing 'Centre Cover' as per the Centre Cover Rota. 7) Supervised and participated in the work undertaken in Audit and Monitoring. 8) Is involved in organising in-service training as required by the Director of Nursing.
Nursing Team Manager/Leader	09.00-18.00	5	0	0	0	0	1) Is responsible for the management and co-ordination of the community SPC team. 2) Takes an active part in the delivery of care: (i) Manages caseloads and maintain accurate records (ii) Liaises with the primary care team in the community (iii) Is responsible for making decisions in the area of pain and symptom management (iv) Is responsible for the safe custody, ordering and administration of drugs. 3) Takes responsibility for financial, human resource and strategic elements of the service. 4) Co-ordinates and plans admissions to the in-patient unit. 5) Participates in team meetings on patient/family care, management and progress. 6) Deals promptly with and report appropriate patient care problems/issues to the Director of Nursing Services, as well as staff complaints and grievances. 7) Promotes professional development. 8) Encourages research among staff. 9) Participates in continuing education courses and professional development. 10) Participates in education, audit and research.
Clinical Nurse Specialist	09.00-17.00	5	0	0	3 to 4	2 to 3	1) Assesses, plans and initiates palliative care for patients. 2) Provides advice, support and information to patients and their carers. 3) Works collaboratively with SPC teams, primary care teams, hospital teams and other agencies 4) Manages caseloads and maintain accurate records. 5) Supervises and manages healthcare assistants in their role in the community setting and provides feedback to the healthcare coordinator in the compilation of proficiency assessments for healthcare assistants. 6) Provides support and acts as an information link to the community SPC co-ordinator. 7) Co-operates in the rostering of nursing and support staff. 8) Shares in the responsibility for the safe custody, ordering and administration of drugs 9) Co-ordinates and plans admissions to the in-patient unit. 10) Investigates and discusses untoward incidents/accidents involving patients, staff and/or equipment. 11) Participates in continuing education courses and professional development. 12) Participates in education, audit and research.
Staff Nurse	09.00-	5	0	0	1	2 to 3	1) Provides advice, support and information to patients and their carers with regarding their

	Mon-Fri In-Hours[a]		Mon-Fri Out-of-Hours[b]		Weekends/ Bank Holidays		Role
	Hrs Per Day	Days per Wk	Hrs Per Day	Days Per Wk	Hrs Per Day	Days per Wk	
	17.00						short- or long-term care needs. 2) Works collaboratively with the CNS and PHN. 3) Acts as an information link to the CNS and CNM and consult when necessary. 4) Shares in the responsibility for the administration of drugs. 5) Maintains accurate records. 6) Investigates and discusses untoward incidents/accidents involving patients, staff and/or equipment. 7) Co-operates in the rostering of nursing and support staff. 8) Participates in continuing education courses and professional development. 9) Participates in teaching/training/supervision of staff/students. 10) Participates in audit and research.
Care Assistant	09.00-17.00	5	0	0	1	2 to 3	1) Visit patients in their home and carry out duties assigned by the CNS and Staff Nurse. 2) Assist with the cleaning and storage of community SPC medical equipment. 3) Assist with keeping stocks of community SPC clinical supplies and documentation at optimal levels. 4) Attend study days and in-service training.
Allied Health Professionals							
Occupational Therapist	09.00-17.00	5	0	0	0	0	1) Assesses, plans and implements a treatment programme for patients appropriately referred and prioritised. 2) Evaluates patient progress and outcomes. 3) Researches and prescribes equipment and technical aids in accordance with the patient's assessed needs. 4) Instructs the patient and/or carer in use of equipment. 5) Maintains accurate written and electronic records. 6) Reports on occupational therapy interventions either routinely or by request. 7) Reports any incidents/accidents involving patients and/or staff in accordance with relevant policies/procedures. 8) Liaises with members of the MDT in MCC and the primary care team in the community in relation to the needs/progress of patients and attend meetings/case conferences as appropriate. 9) Liaises with the patient, carer and/or Local Authorities relating to recommended housing modifications to maximise access, independence and safety of patient and/or carer. 10) Participates in health promotion activities, continuing education courses and professional development.
Physiotherapist	09.00-17.00	5	0	0	0	0	1) Assesses, plans and implements a treatment programme for patients appropriately referred and prioritised. 2) Evaluates patients progress and outcomes. 3) Provides educational and practical support to patients and families. 4) Liaises with members of the community SPC team and the primary care team in the

	Mon-Fri In-Hours[a]		Mon-Fri Out-of-Hours[b]		Weekends/ Bank Holidays		Role
	Hrs Per Day	Days per Wk	Hrs Per Day	Days Per Wk	Hrs Per Day	Days per Wk	
							community in relation to the needs/progress of patients and attend MDT meetings/case conferences as appropriate. 5) Maintains accurate records. 6) Liaises with members of the MDT in MCC and the primary care team in the community in relation to the needs/progress of patients and attend meetings/case conferences as appropriate. 7) Participates in continuing education courses and professional development. 8) Participates in education, audit and research.
Social Worker	09.00-17.00	5	0	0	0	0	1) Is responsible for the delivery of a direct social work service. (i) Provides guidance and assistance to individuals, families and friends in communicating with each other at times of severe emotional distress. (ii) Provides support and advice to parents in recognising and managing the specific needs of children. (iii) Helps service users and families access health, personal social services and welfare entitlements in the community. (iv) Provides bereavement support and counselling. (v) Assists with discharge planning. 2) Works closely with and support other disciplines, medical and nursing staff in the community SPC team. 3) Manages caseloads and maintain accurate records. 4) Contributes to the support and development the staff of the Social Work Department. 5) Works closely with community and other HSE services and other statutory bodies and appropriate voluntary bodies, agencies and individuals. 6) Participates in professional development. 7) Participates in teaching, research and audit.
Pastoral Carer	09.00-20.00	5	0	0	0	0	1) Responds to the spiritual needs of patients and ensure that respect for religious freedom and personal convictions is always maintained. 2) Works closely with local clergy, the wider churches and the community. 3) Carries out pastoral visitation in the MCC and community environments, providing accompaniment and pastoral counselling to patients, their families and friends receiving SPC 4) Notifies the Chaplain if the patient requests the sacrament. 5) Provides continuity in pastoral care and counselling at the time of death, and offering guidance and support in funeral arrangements. 6) Plans and organises memorial services and masses. 7) Evaluates the service annually.
Administrative Staff (Nursing)	09.00-17.00	5	0	0	0	0	1) Is responsible for organising bookings of ICS night nurse. 2) Handles telephone enquiries within service hours and pass these on to various members of the nursing team. 3) Maintains accurate records using relevant databases and storing them in a safe and

	Mon-Fri In-Hours[a]		Mon-Fri Out-of-Hours[b]		Weekends/ Bank Holidays		Role
	Hrs Per Day	Days per Wk	Hrs Per Day	Days Per Wk	Hrs Per Day	Days per Wk	
							confidential manner. 4) Maintains statistical data and contributing to the preparation of submissions, annual reports and research data.
South East							
Medical Staff							
Consultant	09.00-17.00	5	24	5	24hr	2	1) Provides on-call support to community SPC team on a 1st on basis Mon-Friday, and 2nd on for weekends. 2) Attends weekly MDT in each homecare area (South Tipperary and Waterford).
Specialist Registrar	09.00-17.00	5	0	0	24hr	2	1) All NCHDs participate in a weekend on-call rota as 1st on from 4pm on Friday until Monday at 9am.
Registrar	09.00-17.00	5	0	0	24hr	2	1) All NCHDs participate in a weekend on-call rota as 1st on from 4pm on Friday until Monday at 9am.
SHO	09.00-17.00	5	0	0	24hr	2	1) All NCHDs participate in a weekend on-call rota as 1st on from 4pm on Friday until Monday at 9am.
Nursing Staff							
Director of Nursing	0	0	0	0	0	0	-
Nurse Team Manager/Leader	09.00-17.00	5	24hr	5	24hr	2	1) Is responsible for the management and co-ordination of the community SPC team. 2) Liaises with community services/GPs. 3) Manages multidisciplinary team. 4) Takes responsibility for financial, human resource and strategic elements of the service. 5) Facilitates learning and practice development of all staff. 6) Encourages research among staff. 7) Provides care to patients on the caseload of the SPCT when necessary. 8) Is responsible for providing direct telephone access to patients, family members and related Health and Social Care professionals as part of the out-of-hours telephone advisory service.
Clinical Nurse Specialist	09.00-17.00	5	24hr	5	24hr	2	1) Assesses, plans and initiates palliative care for patients. 2) Provides advice, support and information to patients and their carers. 3) Works collaboratively with SPC teams, primary care teams, hospital teams and other agencies. 4) Educates and supports other professionals providing palliative care. 5) Manages caseloads and maintain accurate records. 6) Engages in continuing professional development. 7) Has limited participation in audit and research. 8) Is responsible for providing direct telephone access to patients, family members and related Health and Social Care professionals as part of the out-of-hours telephone advisory service.
Staff Nurse	09.00-17.00	5	0	0	0	0	1) Assesses, plans and initiates palliative care for patients. 2) Provides advice, support and information to patients and their carers. 3) Works collaboratively with SPC teams, primary care teams, hospital teams and other agencies. 4) Educates and support other professionals providing palliative care. 5) Manages caseloads and maintain accurate records.

	Mon-Fri In-Hours[a]		Mon-Fri Out-of-Hours[b]		Weekends/ Bank Holidays		Role
	Hrs Per Day	Days per Wk	Hrs Per Day	Days Per Wk	Hrs Per Day	Days per Wk	
							6) Engages in continuing professional development. 7) Has limited participation in audit and research.
Allied Health Professionals							
Occupational Therapist	09.00-17.00	5	0	0	0	0	1) Assesses, plans and implements a treatment programme for patients appropriately referred and prioritised. 2) Evaluates patient progress and outcomes. 3) Researches and prescribes equipment and technical aids in accordance with the patient's assessed needs. 4) Instructs the patient and/or carer in use of equipment. 5) Maintains accurate written and electronic records. 6) Reports on occupational therapy interventions either routinely or by request. 7) Reports any incidents/accidents involving patients and/or staff in accordance with relevant policies/procedures. 8) Liaises with members of the primary care team in the community in relation to the needs/progress of patients and attend meetings/case conferences as appropriate. 9) Liaises with the patient, carer and/or Local Authorities relating to recommended housing modifications to maximise access, independence and safety of patient and/or carer. 10) Participates in health promotion activities, continuing education courses and professional development.
Bereavement Counsellor	Occasional		0	0	0	0	1) Provides therapeutic intervention to patients or bereaved relatives of the hospice care team on an individual and/or group basis. 2) Provides education/awareness training to professionals and the general public. 3) Liaises effectively with other professionals. 4) Works within the MDT in planning and developing a bereavement service. 5) Maintains patient records.
Complementary Therapist	09.00-17.00	3	0	0	0	0	1) Provides emotional and physical support through hands on therapy.
Administrative Staff (Nursing)	09.00-17.00	5	0	0	0	0	1) Is responsible for managing referrals: (i) Takes referrals from GPs (ii) Registers new patients on database (iii) Organises charts and following up on all relevant test results (iv) Ensures that referrals are given to the relevant team members. 2) Provides secretarial support to team members. 3) Handles telephone enquiries within service hours and pass these on to various members of the nursing team. 4) Maintains statistical data and management of information using the Pallcare System. 5) Is responsible for management of filing system.
Administrative Staff (Medical)	0	0	0	0	0	0	1) Is responsible for the development and maintenance of databases i.e. Patient Database, Minimum Data Set Project (Patient Activity Data – Monthly returns to HSE).

	Mon-Fri In-Hours[a]		Mon-Fri Out-of-Hours[b]		Weekends/ Bank Holidays		Role
	Hrs Per Day	Days per Wk	Hrs Per Day	Days Per Wk	Hrs Per Day	Days per Wk	
							2) Compiles and distributes both scheduled and periodic reports. 3) Is responsible for the processing and certification of payroll for staff via H.S.E. computer system fortnightly. 4) Provides Secretarial support to the Nursing Team as required.

Notes:

a In-hours refers to Monday–Friday between the hours of 9am and 5pm.

b Out-of-hours outlines availability of services or staffing arrangements that extend beyond this.

c There is no official arrangement, but can answer calls and offer advice out-of-hours and during weekends and Bank Holidays.

TABLE A3.5 SPC Consultant Role by Study Area, June 2012

Type	Location	Each Consultant		Description of Role
		Hrs/Wk	Days/Wk	
Midlands – 1 SPC Consultant				
Community	St. Fintan's Hospital Campus, Dublin Road, Portlaoise, Laois	4	1	1) Participates in the weekly MDT meetings - 1 in the Team Leader Office, Cloneygowan, Offaly and 1 in the South Westmeath Hospice, Cossan Road, Athlone, Westmeath. 2) Provides telephone advice to CNSs on the team, which would take up at least half to one hour per day. 3) Undertakes occasional home visits or clinic appointments as necessary. The number of home visits varies widely from month to month. On average over the year, 1 per month in Laois/Offaly and 2 per month in Longford/Westmeath.
	Team Leader Office, Cloneygowan, Offaly			
	The Health Centre, Arden Road, Tullamore, Offaly			
	The Health Centre, Dublin Road, Longford	4	1	
	St. Loman's Campus, Mullingar, Westmeath			
	South Westmeath Hospice, Cossan Road, Athlone, Westmeath			
Acute Hospital Care	Midland Regional Hospital at Tullamore	16	2	See some palliative care referrals in the hospital, liaises with referrers, carers and nursing and medical staff, changes treatment.
	Midland Regional Hospital at Portlaoise	4	0.5	
	Midland Regional Hospital at Mullingar	6	1	
Palliative Support-Bed Care	Midland Regional Hospital at Tullamore	0.1	<1	All hospital support beds are visited at least weekly if occupied; sometimes on a daily basis in Midland Regional Hospital at Tullamore.
	Midland Regional Hospital at Portlaoise	0.1	<1	
	Midland Regional Hospital at Mullingar	0.1	<1	
	South Westmeath Hospice	3	<1	There are weekly ward rounds in unit and occasional patient admissions (usually done by GPs).
	St. Vincent's Hospital, Mountmellick, Laois	0.1	<1	Some of the home visits mentioned above would be to one of the palliative support beds. Visits the support beds in Mountmellick and Longford the most and occasionally sees patients at Birr and Killucan. Less than 1 hour per week is spent between the other palliative care support beds. Ofalia House is not visited.
	St. Joseph's District Hospital, Longford	0.1	<1	
	Birr District Hospital, Offaly	0.1	<1	
	Community Nursing Unit, Birr, Offaly	0.1	<1	
	St. Camillus Nursing Centre, Killucan, Westmeath	0.1	<1	
	Laurel Lodge Nursing Home, Glebe, Longford	0.1	<1	
	Ofalia House, Edenderry, Offaly	0	0	
Mid West – 3 SPC Consultants				
Community	Limerick City Community SPC Team - Milford Care Centre, Castletroy, Limerick	1.5	Meetings on 2 days of week on call	Takes a second line of responsibility in providing senior medical support to the Hospice at Home registrar, Hospice at Home team [to discuss patients very well known to the consultant/recently seen by the consultant if necessary] and first-on-call NCHD, as well as attending two Hospice at Home MDT meetings on the week on call [1 in 3].
	Limerick County Community SPC Team - St. Ita's Hospital, Newcastle West, Limerick			
	Clare Community SPC Team - The Nurses' Home, Ennis General Hospital, Clare			
	Tipperary North Community SPC Team, 63 Ormond Street, Nenagh, Tipperary			
	Tipperary North Community SPC Team - Hospital of the			

Type	Location	Each Consultant		Description of Role
		Hrs/Wk	Days/Wk	
	Assumption, Thurles, Tipperary			
Acute Hospital Care	Mid-Western Regional Hospital, Limerick	10	1.25	2 consultants each provide: 1) an advisory consultant service to other consultants' in-patients on a sessional basis 2) a SPC out-patient service on alternate weeks.
	St. John's Hospital	9	1	1 consultant provides: 1) an advisory consultant service to other consultants' in-patients on a sessional basis 2) a joint specialist palliative medicine/pain medicine out-patient service weekly.
Palliative Support-Bed Care	Milford Care Centre, Castletroy, Limerick			There is no formal commitment to palliative-support beds. Provides support if a member of the Hospice at Home team is treating a patient in one as is provided for a patient at home.
	Raheen Community Hospital, Tuamgraney, Scariff, Clare			
	Regina House, Kilrush, Clare			
	Ennistymon Community Hospital, Dough, Ennistymon, Clare			
	Cahercalla Community Hospital, Ennis, Clare			
	Hospital of the Assumption, Thurles, Tipperary			
	Dean Maxwell Community Nursing Unit, Roscrea, Tipperary			
Hospice Care	Milford Care Centre, Castletroy, Limerick	25.5/ 26.5	3.75	Breakdown of approximately 28hrs across MCC services is a little arbitrary: 1) Looks after own MCC in-patients 2) Two consultants provide a SPC out-patient service on alternate weeks. One consultant attends the specialist palliative day-care service thrice weekly. 3) There is a 1 in 3 on-call rotation for all services.
South East – 3 SPC Consultants				
Community	South Tipperary Community SPC Team [South Tipperary Hospice Movement]	2	1	1) Participates in the weekly MDT. 2) Provides telephone advice to CNSs on the team 3) Provides out-patient services at South Tipperary General Hospital/Waterford Regional Hospital (as required).
	Waterford Community SPC Team [Waterford Hospice Movement]	2	1	
Acute Hospital Care	South Tipperary General Hospital, Clonmel, Tipperary	9	2	1) Provides in-patient consultations.
	Waterford Regional Hospital, Dunmore Road, Waterford	20-29	4	2) Provides outpatient service.
	St. Teresa's Hospital, Clogheen, Tipperary			There is no formal commitment to palliative-support beds.
	St. Brigid's District Hospital, Carrick-on-Suir, Tipperary			
	Dungarven Community Hospital, Waterford			
	Cluainn Arainn Welfare Home, Tipperary			
SPC In-Patient Beds	Waterford Regional Hospital, Dunmore Road, Waterford	2	1	This is part of acute hospital workload.

TABLE A3.6 Community SPC Team Operation by Study Area, June 2012

		Midlands	Mid West	South East
Assessment Procedure				
Q. 1	To whom are referrals directed in the home care team?	**Laois/Offaly:** Referrals are usually directed to the CNS for the area the patient lives in, but they can also be directed to the physiotherapist and the social worker. **Longford/Westmeath:** Referrals are mainly directed to the clinical nurse specialist [CNS].	Referrals are directed towards the Milford hospice at home nursing team and come directly to the office where they are triaged by members of the nursing team.	Referrals are directed towards the community SPC nursing team.
Q. 2	How long does the patient have to wait before he/she is assessed?	A patient is usually seen within 24 to 48 hours.	A patient is usually seen within 24 to 48 hours.	A patient is usually seen within 24 to 48 hours.
Q. 3	How is the assessment process initiated?	The CNS begins the assessment process by ringing the PHN to collect additional information about the patient and their medical history. This is followed by a phone call to the patient/family to schedule an appointment for a visit.	The CNS begins the assessment process by ringing the PHN to collect additional information about the patient and their medical history. This is followed by a phone call to the patient/family to schedule an appointment for a visit.	**South Tipperary:** The CNS begins the assessment process by ringing the PHN to collect additional information about the patient and their medical history. This is followed by a phone call to the patient/family to schedule an appointment for a visit. **Waterford:** Patients are generally referred by the palliative care consultant and the CNS has direct access to recent medical information through the hospital's IT system. This is followed by a phone call to the patient/family to schedule an appointment for a visit.
Q. 4	Where does the assessment take place?	Assessment takes place wherever the patient is staying.	Assessment takes place wherever the patient is staying.	Assessment takes place wherever the patient is staying.
Q. 5	Who assesses the service need?	**Laois/Offaly:** The CNS carries out the assessment, except for physiotherapy and social service needs, which are assessed by the physiotherapist and social worker, respectively. **Longford/Westmeath:** The CNS carries out the assessment.	In most cases, service need is assessed by the CNS. However, there are occasions when referrals come to other components of the team for more specific involvement and those therapists make the first contact.	The CNS carries out the assessment.
Q. 6	How long does this assessment take?	Assessment takes 1–2 hours.	Assessment takes 1–2 hours.	Assessment takes 1–2 hours.
Q. 7	Does this assessment involve multiple meetings/visits from each individual involved?	It may not always be possible to collect all of the information needed during the first visit. In those cases, some of the assessment will happen on a follow-up visit.	It may not always be possible to collect all of the information needed during the first visit. In those cases, some of the assessment will happen on a follow-up visit.	The CNS will try and collect all relevant information during the initial visit.

		Midlands	Mid West	South East
Assessment Outcome				
Q. 8	Is a meeting then held to discuss this assessment?	Every new patient who has been assessed is discussed at a multi-disciplinary team meeting (MDT). These meetings are held once per week.	Every new patient who has been assessed is discussed at an MDT. These meetings are held once per week.	Every new patient who has been assessed is discussed at an MDT. These meetings are held once per week.
Q. 9	If so, how soon after this assessment does a meeting take place?	Newly assessed patients are usually discussed within one week of referral, maximum two weeks.	At the next MDT.	At the next MDT.
Q. 10	Where is the meeting held?	MDTs are held in the team office.	MDTs are held in the team office.	MDTs are held in the team office.
Q. 11	Who is present at the meeting?	All members of the team attend the clinical meeting.	The entire team for the Limerick base meets once a week. The teams at other bases hold separate meetings once a week.	All members of the team attend the clinical meeting.
Q. 12	Is this discussion part of a general team meeting on current community SPC patients or is it separate?	Discussion of all newly referred patients is a regular part of the MDT meeting.	Discussion of all newly referred patients is a regular part of the MDT meeting.	Discussion of all newly referred patients is a regular part of the MDT meeting.
Q. 13	Who reports the assessment of the patient at the meeting?	**Laois/Offaly:** Each CNS has their own caseload and reporting during the meeting is the responsibility of the team member who made the assessment. **Longford/Westmeath:** The team works a collaborative caseload; the CNS who first met the patient is considered the key worker and, if present at the meeting, they are responsible for reporting the case, otherwise another CNS will report.	Reporting during the meeting is the responsibility of the team member who made the assessment.	Reporting during the meeting is the responsibility of the CNS who made the assessment.
Q. 14	Who makes the final decision on the service need of the patient?	The team makes the decision about the care needs, sometimes they might look to the consultant or the physiotherapist or the social worker for specific input depending on the issues. The aim of clinical meetings is to support the CNS in making their own decisions.	Each discipline takes a large degree of responsibility for addressing the needs that fall within their domain and will contribute to the formation of a treatment plan whenever appropriate.	The consultant in palliative care would make the final decision about service need.
Standard Community SPC Services				
Q. 15	Are there standard community SPC services that each patient receives?	This depends on the patient's needs.	This depends on the patient's needs.	This depends on the patient's needs.
Q. 16	If so, can you explain?	Not Applicable	Not Applicable	Not Applicable
Coordination of Community SPC Services				

		Midlands	Mid West	South East
Q. 17	Who informs the healthcare professionals, outside of the core multidisciplinary community SPC team, of their degree of involvement in the patient's care?	The CNS would contact the PHN after the initial assessment to discuss the patient's service needs.	Referrals for AHP involvement are primarily for members of the core homecare team. With respect to Occupational therapy, some of the OTs on the home care team would make a referral outwards to another colleague in the community because the patient has needs that do not require specialist input.	**South Tipperary:** The CNS would contact the PHN by telephone after the initial visit to discuss the patient's service needs. **Waterford:** The CNS would make direct contact with the physiotherapist or GP, if required.
Q. 18	Is this achieved through a separate meeting with these healthcare professionals or via phone/email contact etc.?	This can be achieved via letters, telephone contact or by fax.	This can be achieved via meetings, telephone contact or by fax.	**South Tipperary:** This can be achieved via meetings, telephone contact or by fax. **Waterford:** The physiotherapist would be contacted by letter and GPs are contacted via telephone.
Q. 19	Who is responsible for coordinating the various services required by the patient, in terms of the following:			
	* The core multidisciplinary community SPC team services?	**Laois/Offaly:** The CNS will refer patients to the physiotherapist or social worker when required. The AHPs are then responsible for coordinating the services required by the patient. **Longford/Westmeath:** The CNS will discuss referrals with the physiotherapist during the MDTs, in addition to completing a referral form.	The CNS is responsible for sending referrals to other members of the community SPC team. The CNS will document in the notes that a referral had been made and confirm that it has been activated. The AHP managers are involved in referrals but not on a day to day basis.	**South Tipperary:** The CNS will discuss referrals with the OT during the MDTs, in addition to completing a referral form. **Waterford:** The CNM3 is responsible for coordinating the various services.
	* The community services offered by healthcare professionals?	**Laois/Offaly:** The CNS will inform the PHN, who then sends a referral to the appropriate AHP. **Longford/Westmeath:** The CNS sends a referral to the appropriate AHP.	The CNS is responsible for communicating with the PHN. The AHP managers are involved in activating referrals to AHPs outside the community SPC team, but not on a day to day basis. The community SPC team's OT would be responsible for coordinating OT services.	The CNS will inform the PHN, who then sends a referral to the appropriate AHP.
Q. 20	How are the community SPC visits [home and nursing home] coordinated:			
	* Between members of the core multidisciplinary community SPC team?	**Longford/Westmeath:** In addition to weekly MDTs, there is regular telephone communication between members of the community SPC team.	In addition to weekly MDTs, there is regular communication between members of the community SPC team.	**South Tipperary:** In addition to weekly MDTs and nursing team meetings, there is regular communication between members of the community SPC team. **Waterford:** The CNM3 is responsible for coordinating the various services.
	* Between this team and the community:			
	... Allied health professionals?	**Laois/Offaly:** Once a patient is referred to the AHP, they would manage the frequency of their visits. If the CNS knows that a patient	Coordination of OT services would be organised by the community SPC team's occupational therapist.	The PHN or GP would be responsible for coordinating visits and managing communication between members of the

		Midlands	Mid West	South East
		has an appointment with an AHP outside of the core community SPC team, they can ring and follow up with either the PHN or the patient. **Longford/Westmeath:** Once a patient is referred to the AHP, they would manage the frequency of their visits. There would be regular communication between the AHPs and the team.		community SPC team and AHPs in the community. There is regular telephone and written communication between the CNS and AHPs.
	... GPs?	The CNS will ring the GP after receiving the referral and advise that they are going to see the patient. There is regular telephone and written communication between the CNS and patient's GP.	The CNS will need the GP's permission to be involved from the outset if the referral was not generated by the GP. There is regular telephone and written communication between the CNS and patient's GP.	The CNS will need the GP's permission to be involved from the outset if the referral was not generated by the GP. The CNS will ring the GP after receiving the referral and advise that they are going to see the patient. There is regular telephone and written communication between the CNS and patient's GP.
	... PHNs?	The CNS will ring the PHN before the initial visit to the patient and will follow up as frequently as required. There is regular telephone and written communication between the CNS and PHN.	There is regular telephone and written communication between the CNS and PHN. The two will share work and coordinate visits to the patient accordingly.	**South Tipperary:** There is regular telephone and written communication between the CNS and PHN**.** **Waterford:** Communication between CNS and PHN occurs, as needed. This communication is always by telephone.
	... Care assistants?	Not applicable	Visits between the nurses and care assistants within the Hospice at Home Nursing Team are co-ordinated by Manager, in consultation with the Key Nurse (s) for each patient and geographical patch/base. This occurs on a weekly and as needed basis.	Not Applicable
	... Night nurses employed by the Irish Cancer Society?	The ICS night nurses are usually booked by the CNS looking after the patient. This can be arranged by either email or telephone call, but a referral form for each new patient must be submitted by fax.	The ICS night nurses are usually booked by the CNS looking after the patient.	**South Tipperary:** The administrative staff arrange bookings for ICS night nurse via email. **Waterford:** The ICS night nurses are usually booked by the CNS looking after the patient. The CNM3 can also make these arrangements.
	... Pharmacists, particularly for medicines out-of-hours?	The CNS will ring the patient's pharmacist in order to ensure adequate stock of medications.	Any changes to medications would be organised through the patient's GP.	The CNS will ring the patient's pharmacist in order to ensure adequate stock of medications.
Q. 21	How frequent are these community SPC visits [home and nursing home]?			
	* When the service has been initiated?	The frequency of community SPC visits depends on the needs of the patient.	The frequency of community SPC visits depends on the needs of the patient.	The frequency of community SPC visits depends on the needs of the patient.

		Midlands	Mid West	South East
	* When death is imminent?	The frequency of community SPC visits depends on the needs of the patient.	The frequency of community SPC visits depends on the needs of the patient.	The frequency of community SPC visits depends on the needs of the patient.
Patient's Record System				
Q. 22	What system is in place to manage the patient's record, in terms of documenting both the number of service visits and the health status of the patient on each of those visits as well as his/her medication update?	**Laois/Offaly:** Case notes are written by hand and stored in the office. Nursing staff and AHPs keep separate notes, but regularly discuss service visits and the patient's health status so that each set of notes can be updated. Notes are made available to every member of the team. Communication with AHPs outside of the community SPC team is coordinated by the PHN. **Longford/Westmeath:** Case notes are written by hand and stored in the office. Some information is inputted into iCare system, e.g. telephone call and contact with patients or communication with AHPs from the community SPC team. Case loads are shared, so whoever has had the contact will input/update the record.	Each patient will have a central nursing file in which team members incorporate nursing notes, medical information, medical letters, our assessments, referrals to other disciplines. In addition, care assistants keep a set of notes and the other disciplines (AHPs) also document their interaction the patient. Notes are made available to every member of the team. All bases also have their own patient files, which will follow the patient when necessary.	Patients' records are written by hand and stored in the office. The CNS updates their notes after any discussion with the OT, PHN, the CNS on-call or the patient's GP. The CNS will also add copies of all written communication about the patient received from hospital consultants or other healthcare professionals.
Community SPC Nurse Shifts				
Q. 23	What protocol is in place to manage the transfer of information between community SPC nurse shifts?	Case notes are available to nurses and on-call nurses. A weekend handover form is filled in so the weekend nurse will know what has happened during the week. There is a meeting first thing Monday morning so information from the weekend is shared and weekend notes are given to the CNS responsible for the patient. In the evening, the CNS leaves a voicemail on the ICS night nurse's mobile phone. The night nurse hands over to the team each morning.	The ICS night nurse is given the information they need about the patient they are looking after and will be linked up with the CNS on the base. Each patient has an electronic record on the system that contains information about their contacts, carers, the number of community SPC team visits per week and who has carried out the visits. The night nurse will hand over to the CNM each morning.	**South Tipperary:** The nursing team hold meetings on a regular basis. Additionally, the CNSs hand over to the nurse on duty every evening. The ICS night nurse and community SPC CNS both hand over to the team each morning. **Waterford:** The community SPC team does not have direct, on-going contact with the out-of-hours service, Caredoc, and may not receive updates about patients from their GP. The ICS nurse leaves a voicemail for the team each morning.
Out-of-Hour Service				
Q. 24	What procedure is in place to manage the out-of-hours service?	**Laois/Offaly:** This out-of-hours telephone advisory service is available Saturday, Sunday and Bank Holidays between the hours of 09:30 and 17:00. There is one nurse on-call for each county. **Longford/Westmeath:** A telephone advisory service is available out of hours and	A telephone advisory service is available between 17.00 and 09.00, including weekends and Bank Holidays. In the first instance, the call will be put through to a night nursing manager – either from the hospice or a nursing home. A nursing manager from a nursing home will be backed up by one of their nursing colleagues in the	**South Tipperary:** A nurse from the community SPC team is available for telephone consultation outside of business hours and during weekends and Bank Holidays. The nurse on duty will also make a home visit whenever necessary. **Waterford:** There is a recorded message on the mainline advising patients and carers to

		Midlands	Mid West	South East
		weekends 9.00-17.00. There is always a CNS on-call in Athlone, Longford and Mullingar.	hospice or the on-call doctor. If required, a visit from a doctor can be arranged.	contact the out-of-hours GP service, Caredoc.
Equipment Needs				
Q. 25	Who determines if the patient needs equipment?	Equipment needs can be identified by members of the community SPC team, the PHN and allied health professionals outside of the community SPC team.	Equipment needs can be identified by members of the community SPC nursing team.	**South Tipperary:** Equipment needs could be identified by members of the community SPC team or the PHN **Waterford:** Equipment needs can be identified by members of the community SPC team, the PHN and allied health professionals outside of the community SPC team.
Q. 26	How is this equipment organised?	The occupational therapist, physiotherapist or PHN will contact the community care services to organise equipment, depending on the needs of the patient. The CNS organises syringe pumps. If a patient needs a pump, the CNS will bring one to the home. If a patient is using a pump provided by the hospital, the CNS will bring a new one during the initial visit.	The occupational therapist or physiotherapist organises certain equipment, e.g. a walker or a walking stick. If a patient needs a bed and a mattress, the CNS will organise these. In North Tipperary, equipment will be supplied by the North Tipperary Hospice Foundation. For patients living outside of the North Tipperary area, the CNS will put in a request to the HSE for a bed. However, because the waiting lists are long, arrangements are made to rent beds on a weekly basis from a company based in Dublin.	**South Tipperary:** The PHN or OT will contact the community care services to organise equipment, depending on the needs of the patient. **Waterford:** The CNS, PHN or OT will contact the community care services to organise equipment, depending on the needs of the patient. Syringe drivers are provided by the community SPC team.
Team Meetings				
Q. 27	Are team meetings held to discuss the care needs of the patient?	Yes, clinical meetings are held to discuss deaths, new referrals, discharges, transfers and other matters.	Yes, clinical meetings are held to discuss deaths, new referrals, discharges, transfers and other matters.	**South Tipperary:** Yes, clinical meetings are held to discuss deaths, new referrals, discharges, transfers and other matters. Immediately after the MDT, members of the nursing team hold an additional meeting. **Waterford:** Yes, clinical meetings are held to discuss deaths, new referrals, discharges, transfers and other matters.
Q. 28	If so, how often?	Clinical meetings are held every week.	Clinical meetings are held every week.	Clinical meetings are held once a week. The nursing team also meets throughout the week.
Q. 29	Where are these meetings held?	The meetings are held in the team office.	The meetings are held in the team office.	The meetings are held in the team office.
Q. 30	Who is present at these team meetings?	Everyone from the team.	Everyone from the team.	Everyone from the team.
Q. 31	For those who are unable, or disallowed, to attend the meeting, what procedure is in	**Laois/Offaly:** There is no formal system for sharing this information; however, one is currently being developed.	There is no formal system for sharing this information.	The CNM or deputy would be responsible for sharing this information.

		Midlands	Mid West	South East
	place to inform these individuals?	**Longford/Westmeath:** There is no formal system for sharing this information.		
Q. 32	Following each meeting, who is responsible for updating the patient's record?	The CNS looking after the patient updates their records.	The CNS looking after the patient updates their records.	The CNS looking after the patient updates their records.
Q.33	If an emergency meeting/consultation is necessary, what steps are taken and who is involved?	During office hours, a patient or their carer would ring the CNS looking that is responsible for them.	During office hours, a patient or their carer would ring the main office in the first instance. Depending on the nature of the situation, the CNS would either offer advice or make arrangements to visit the patient.	**South Tipperary:** During office hours, a patient or their carer would ring the main office in the first instance. The details would then be forwarded on the CNS responsible for the patient, who would then ring and either offer advice or make arrangements to visit the patient. If an out-patient appointment with the palliative care consultant is necessary, the CNS will contact the GP to arrange for a referral. **Waterford:** The CNS would triage the call, assess need, and identify capacity to address the patient's situation. The response will depend on the patient's needs. The CNS can refer directly to an out-patient clinic, if necessary.
Protocol at Admission				
Q. 34	If the patient becomes ill and needs to be admitted to the hospice/hospital, what protocol is in place to facilitate this referral?	The patient's needs are identified by the CNS in discussion with the family (intermediate care bed policy). The availability of level 2 beds has been identified from the team meeting. The request for admissions goes through the CNM3. If the patient is receiving chemo, the protocol is for them to ring the ward in their hospital and arrange admission. The PHN or GP would refer a patient to the Emergency Department (ED) if they required immediate treatment.	Admissions to the hospice do not happen out-of-hours. If the on-call GP for the area visits the patient and they deem that inpatient care is needed, then the patient will be transferred to hospital. If possible, the patient may be transferred from hospital to the hospice. If the GP goes out on call and finds that a patient is very unwell but cannot be transferred to hospital, the GP may be equipped to deal with that situation themselves or they may choose to ring and speak the on-call doctor at Milford Care Centre.	**South Tipperary:** The patient is under the care of the GP when at home and the routine protocols are followed if they need to be admitted to hospital/hospice. If the community SPC team is notified by the family that the patient is being taken to hospital, the CNS will follow-up with a phone call, email or fax to inform the palliative care team in-hospital and the ED department and provide staff with all relevant information about the patient's medical history. **Waterford:** The patient would be assessed through oncology day ward, if known to that team. If a patient becomes unwell out of hours, arrangements should be made to visit the ED and the patient's GP can arrange for an ambulance. Non-malignant patients or their carers would contact the GP or arrange a visit to the ED in such instances.
Q. 35	Who is responsible for informing	The CNS would inform other members of the	A CNM would inform members of the core	The CNS would inform other members of the

		Midlands	Mid West	South East
	the core community SPC team of this change in the patient's care need?	core community SPC team about changes in the patient's care needs.	community SPC team about any patients recently admitted to the in-patient unit. If admission to hospital occurs out of hours, the information usually comes through our out-of-hours telephone advisory service and the CNM will log these changes and inform the CNS who has been looking after the patient. The CNS would inform other members of the core community SPC team about changes in the patient's care needs.	core community SPC team about changes in the patient's care needs.
Q. 36	Who is responsible for informing the community services of this change in the patient's care need?	There is regular communication between the patient's GP, the PHN, and the community SPC team.	There is regular communication between the patient's GP, the PHN, and the community SPC team.	There is regular communication between the patient's GP, the PHN, and the community SPC team.
Protocol at Death				
Q. 37	In the event of the patient dying at home, who is responsible for informing the core community SPC team of this news?	There is regular communication between the homecare team, the patient's family, the public health nursing team, and the GP when a patient is actively dying. If a patient dies during the night, the night nurse or family would provide these details to the out-of-hours telephone service or relay the information to the CNS looking after the patient. The CNS would inform the core community SPC team and all deaths are discussed during the weekly MDTs.	There is regular communication between the homecare team, the patient's family, the public health nursing team, and the GP when a patient is actively dying. If the patient dies during the night, the night nurse or family would provide these details to the out-of-hours telephone service and the CNM would relay the information to the CNS looking after the patient. The CNS would inform the core community SPC team and all deaths are discussed during the weekly MDTs.	There is regular communication between the homecare team, the patient's family, the public health nursing team, and the GP when a patient is actively dying. If a patient dies during the night, the night nurse or family would provide these details to the out-of-hours telephone service or relay the information to the CNS looking after the patient. The CNS would inform the core community SPC team and all deaths are discussed during the weekly MDTs.
Q. 38	In the event where the patient dies at home, who is responsible for informing the community services of this news?	The CNS would be responsible for informing the community services, when necessary.	The CNS would be responsible for informing the community services, when necessary.	The CNS would be responsible for informing the community services, when necessary.
Follow-Up Visits				
Q. 39	Does the team carry out follow-up visits with the bereaved family of the deceased patient?	Yes, the community SPC team carry out follow-up visits.	Yes, the community SPC team carry out follow-up visits.	Yes, the community SPC team carry out follow-up visits.
Q. 40	If so, what is the time interval between death and follow-up?	Bereavement follow-up visits take place immediately following the death.	Bereavement follow-up visits take place immediately following the death. The second point of contact might be that another member of the team who has been involved would call out to see how the relatives are doing. Once those initial contacts are made, the bereavement follow-up may not happen	**South Tipperary:** Bereavement follow-up visits take place immediately following the death and four weeks thereafter. Contact is also made, usually via a card, at Christmas and on the first anniversary of death. **Waterford:** The CNS looking after the patient will always phone the family/carer but may

		Midlands	Mid West	South East
			for a number of weeks and will depend on the CNSs caseload.	not always have the opportunity to visit.
Q. 41	Who is responsible for carrying out these follow-up visits?	**Laois/Offaly:** Members of the community SPC team responsible for looking after patient would carrying out these follow-up visits. **Longford/Westmeath:** The CNS who was primarily responsible for looking after the patient would carry out these follow-up visits.	Members of the community SPC team responsible for looking after patient would carrying out these follow-up visits.	**South Tipperary:** The CNS who was primarily responsible for looking after the patient would carry out these follow-up visits. If more than one CNS was involved in the patient's care, each one would visit the bereaved family. **Waterford:** The CNS who was primarily responsible for looking after the patient would carry out these follow-up phone calls and/or visits.
Q. 42	How frequent are these visits?	The time interval between death and the second visit will be determined by the needs of the bereaved relatives.	The time interval between death and the second visit will be determined by the needs of the bereaved relatives.	Additional follow-up visits are carried out as frequently as required.
Bereavement Support				
Q. 43	What other arrangements of bereavement support are made available to the bereaved family of the deceased patient?	At follow up meetings with the families, bereavement support may be initiated. The CNS might either refer the family to the community SPC team's social worker or they could be referred to a counselling service offered by the hospice foundation. However, referrals would not be sent any sooner than nine months after the patient had died.	For more routine cases, where there is no obvious sign of special risk, the social work department would schedule a bereavement visit three months after the patient's death. If bereavement risks have been identified, social workers would make the bereavement visit sooner than this.	**South Tipperary:** The CNS could refer the family to a counselling service funded by the STHM, if necessary. **Waterford:** The CNS would notify the GP about the need for follow-up if bereavement risks have been identified by the community SPC team.
Equipment Collection				
Q. 44	How soon after the death of the patient is the equipment collected at his/her home?	Equipment can be collected at any time. It depends on individual families, with some wanting equipment collected as soon as possible, while others prefer to wait to have it collected.	Equipment can be collected at any time. It depends on individual families, with some wanting equipment collected as soon as possible, while others prefer to wait to have it collected.	The length of time waiting for equipment collection can range from one week up to one month.
Q. 45	Who is responsible for collecting the equipment?	Occupational Therapy and Stores are responsible for collecting the equipment, with the exception of syringe drivers, which are collected by the community SPC team.	Beds and mattresses will be collected by the supplier. The community SPC team organise collection of the syringe drivers.	**South Tipperary:** Community Care/Stores is responsible for collecting equipment. **Waterford:** The community SPC team organise collection of all equipment provided by the service. Community Care/Stores is responsible for collecting all other equipment.

Appendix 4

Supplementary Data Analysis

A.4.1 INTRODUCTION

As part of the data collection process for this study it was deemed necessary to collect supplementary data from secondary sources. These data included a selection of utilisation data from decedent healthcare records and community SPC nurse time-use diaries.

Utilisation Data

Decedent healthcare records were obtained for two reasons.[1] Firstly, it was acknowledged that some KIs may have difficultly remembering, or may never have known, details of service utilisation by the decedent. It was deemed important to investigate whether differences existed between KI reported utilisation and utilisation reported in the formal healthcare records. Such differences had the potential to fundamentally affect the cost estimates.

Secondly, it is important to check for telescoping in the responses during the interview. Telescoping refers to the phenomenon in questionnaire responses whereby respondents pull in activity referring to a period outside of the period under review. For example, where the focus is on the last 12 months of life, respondents may pull in events that occurred within the last 18 months.

Given time constraints and issues of accessibility, it was not possible to collect secondary data for all service providers (e.g., GPs, public health nurses). It was decided to focus on public hospital discharge data (HIPE) and community SPC team data, focusing particularly on community SPC visits.[2] With respect to the community SPC team data, the data provided to the study varied across areas for reasons of local availability.

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[1] Consent was sought from key informants to access healthcare records that pertained to the decedent. Eight KIs did not give permission to access records.

[2] Data were collected for other members of the community SPC team, including physiotherapists, occupational therapists, and complementary therapists where available. These data are not compared to the KI reported data, as it may not be an accurate comparison. Decedents may have had visits from these healthcare professionals which took place in private healthcare settings or elsewhere, which would not be captured in the data provided by the local SPC team.

The data used for this comparison exercise were obtained from

- HIPE Discharge Data – day patient and in-patient public hospital records for public and private patients across all areas
- Milford Care Centre – community SPC team and hospice discharge data
- Midlands – Laois/Offaly and Longford/Westmeath community SPC team data
- South East – Wexford, Waterford, and South Tipperary community SPC team data.

Time-Use Diaries

Time-use diaries were compiled by community SPC nurses in each study area to allow for the estimation of the proportion of time spent carrying out direct and indirect duties (see section A4.5). These data provide important information for the cost estimation process (see Appendix 5).

A.4.2 HOSPITAL DATA

The Hospital In-Patient Enquiry (HIPE) scheme is the principal source of national data on discharges from acute public hospitals in Ireland. It contains data relating to all in-patient and day patient visits which are subsequently costed for Casemix purposes (see Appendix 5). It was decided that the most accurate way to cost hospital visits for decedents in the study was to calculate their Casemix cost from their HIPE record (see Appendix 5).[3] For completeness the day and in-patient visits reported in the study are those reported in the HIPE record rather than those reported by the KI.

Comparisons between the number of visits recorded in HIPE and the KI reported visits were only made when the KI reported a valid number of visits (answer was not 'don't know'). Comparisons with KI reported visits were not possible for visits recorded in hospitals for which hospital managers did not provide permission to access the HIPE data.

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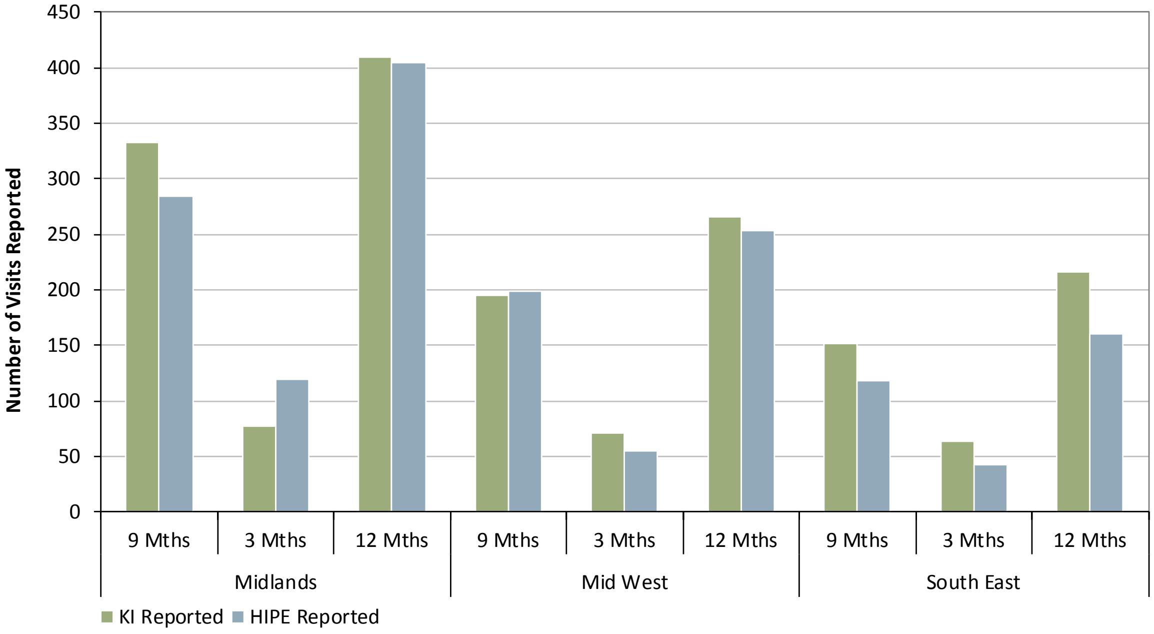
[3] It was necessary to get the consent of individual hospital managers to access the HIPE records of decedents for whom the KI had given their consent. Access was granted by 24 acute public hospital managers while 4 did not grant permission.

A.4.2.1 Day Patient Visits

Figure A4.1 shows the total number of day patient visits reported by the KI and the number of visits reported by HIPE for the nine-month and three-month periods; these were summed to provide the total number of day patient visits over the last year of life (12 months).

KIs mainly reported a higher number of day patient visits in the nine-month period, and reported a smaller number in the three-month period when compared with that reported in HIPE; this was mainly driven by the reporting of fewer day patient visits in the Midlands.

FIGURE A4.1 Comparison of Day Patient Visit Reporting

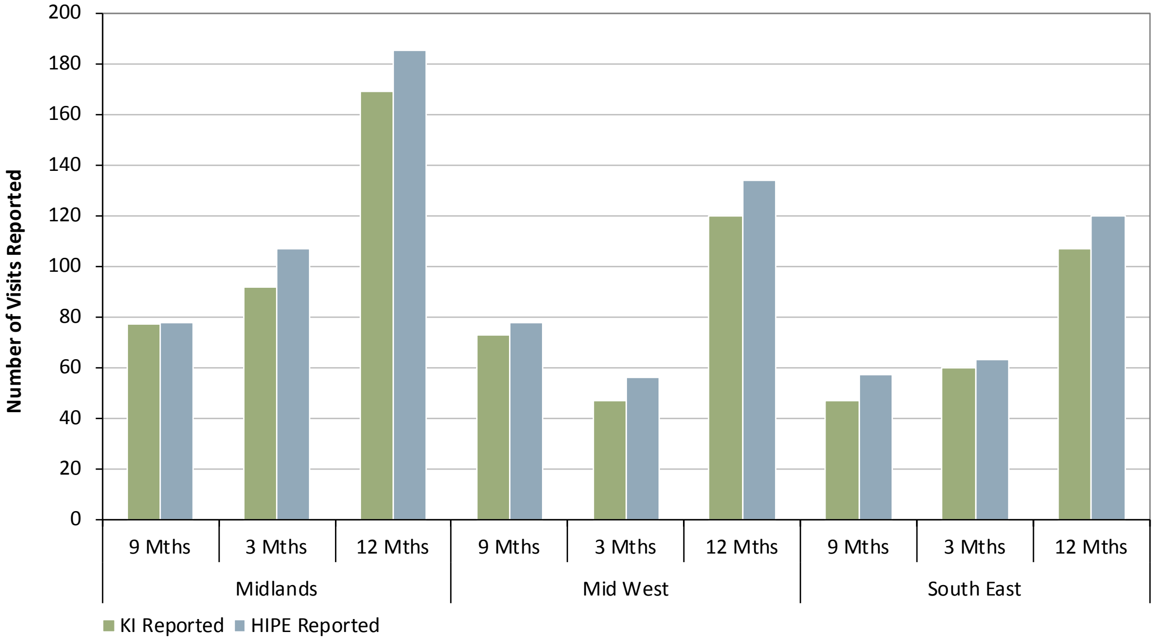


Note: It should be noted that these tables reflect the overall aggregate number of visits reported, and may underestimate individual differences between what the KI reported and what was recorded in HIPE for particular cases.

A.4.2.2 In-Patient Visits

Figure A4.2 shows the total number of in-patient visits reported by the KI and the number of visits reported by HIPE for the nine-month and three-month periods; these were summed to provide the total number of in-patient visits over the last year of life (12 months). KIs mainly reported a lower number of in-patient visits in all time periods relative to the number of visits recorded by HIPE .

FIGURE A4.2 Comparison of In-Patient Visit Reporting



Note: It should be noted that this figure reflects the overall aggregate number of visits reported, and may underestimate individual differences between what the KI reported and what was recorded in HIPE for particular cases.

A.4.3 Community SPC Team Data – Nurse Visits

Where available, decedent records held by community SPC teams were provided to the study team, subject to permission by the KI and the relevant data gatekeepers. Data are reported for community SPC nurse visits.[4,5] Due to differences in data collection systems and the capacity of each team to provide the data, the data collected varied across each study area as shown in Table A4.1.

TABLE A4.1 Community SPC Nurse Visits – Supplementary Data

	9 Mths	3 Mths	12 Mths
Midlands	✓	✓	✓
Laois/Offaly	✓	✓	✓
Longford/Westmeath	✓	✓	✓
Mid West	n/a	✓	
South East			✓
Waterford[a]	✓	✓	✓
Wexford	✓	✓	✓
South Tipperary	n/a	n/a	✓

Note: n/a= not available

No comparisons were made between the data sources when the answer from the KI was 'don't know', or when the local community SPC team could not find a record for the decedent.

Figure A4.3 shows that:

- In all time periods and across all study areas KIs reported more community SPC nurse visits compared to the number recorded by the community SPC team.
- In the Midlands, data were available for all time periods. The largest differences between KI reported visits and community SPC team reported visits was in the nine-month period, where the KI reported 55.3% more visits than the community SPC team compared to a 32.7% difference in the three-month period.
- In the South East, where data for all areas were available for the 12-month period only, the difference between KI reported visits and community SPC team reported visits was lower than in any other area or time period at 17.4% more visits.

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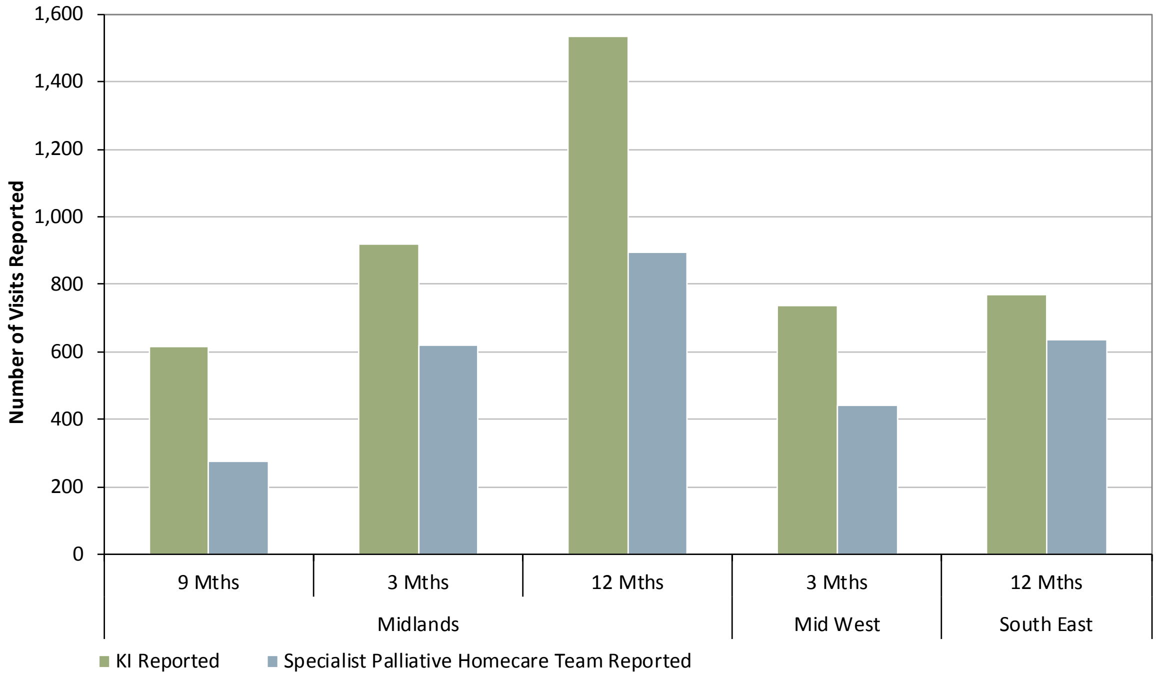
[4] Data were collected for other members of the community SPC team, including physiotherapists, occupational therapists, and complementary therapists where available. These data are not compared to the KI reported data, as it may not be an accurate comparison. Decedents may have had visits for these healthcare professionals which took place in private healthcare settings or elsewhere, which would not be captured in the data provided by the local palliative care team.

[5] Detailed data on telephone contact between community SPC nurses in the Mid West and decedent/family in the last year of life showed less than half of contacts were more than five minutes in duration. In the interview, 'Telephone contact refers to the decedent or someone on their behalf having a consultation over the phone; it excludes calls to make an appointment'. For this reason it does not appear that the KI data were comparable with that provided by the local team in the Mid West. It was assumed that the data provided by other local teams consisted of a similar mix of phonecall types and so KI data are not compared to that provided by the local team for any of the study areas.

FIGURE A4.3 Comparison of Community SPC Nurse Visit Reporting



Note: It should be noted that this figure reflects the overall aggregate number of visits reported, and may underestimate individual differences between what the KI reported and what was recorded in HIPE for particular cases.

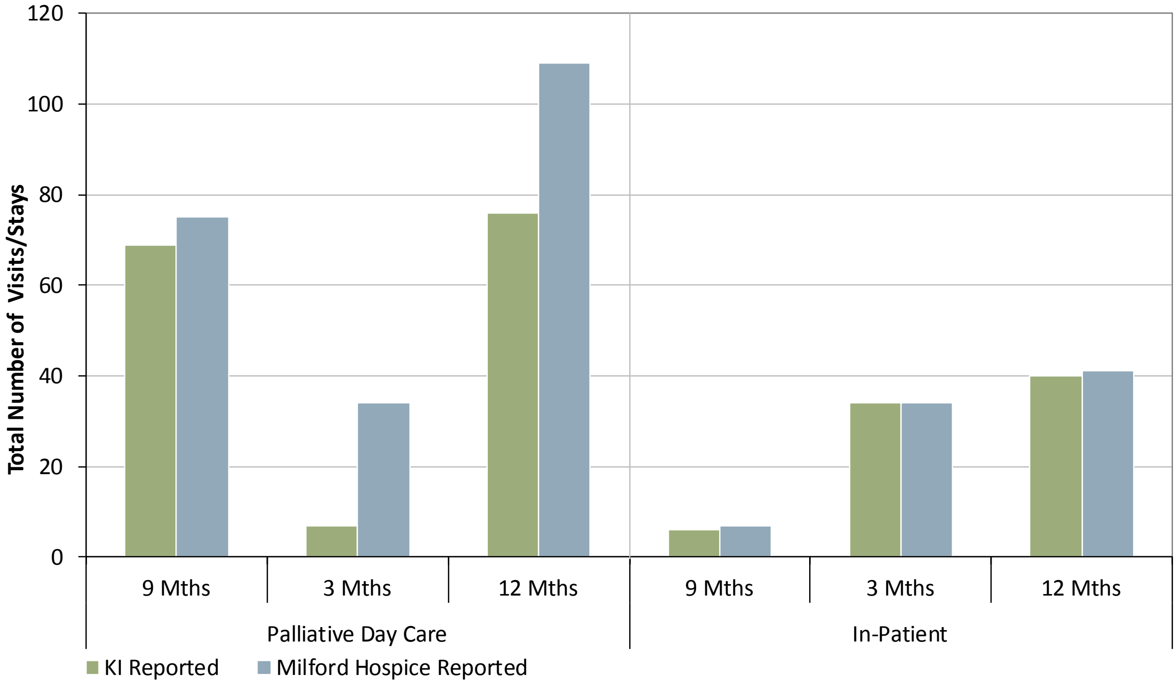
A.4.4 MILFORD HOSPICE DATA

A.4.4.1 Comparison of KI and Milford Reported Activity – Palliative Day Patient and In-Patient Hospice

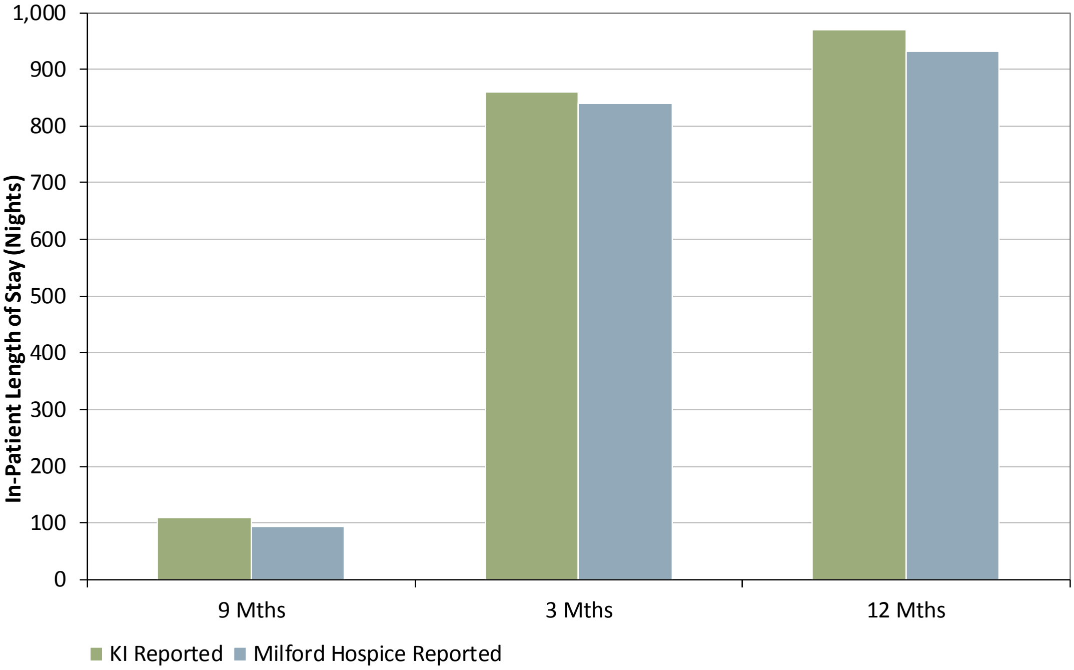
Milford Care Centre in Limerick record all palliative day care and in-patient hospice stays on the I-CARE system. Using this, it was possible to compare the number of palliative day care visits, in-patient hospice stays, and the length of stay reported by the KI in the last year of life with those reported for the same decedents on the Milford system. Figure A4.4 shows that there was a lower level of agreement for palliative day care visits compared to in-patient stays. KIs reported 43.4% fewer palliative day patient visits over the 12 months, while they reported only 2.5% fewer in-patient stays over the 12 months relative to the Milford system data. For in-patient length of stay KIs reported 3.9% more nights over the 12 months relative to the Milford system data.

FIGURE A4.4 Comparison of Palliative Day Patient Visits and Hospice In-Patient Stays Reporting

Number of Stays



In-Patient Length of Stay (Nights)



Notes: The assumption was made that all hospice stays recorded in the Mid West were in Milford Hospice as it is the only hospice in the catchment area. Also, in the validation exercise it was shown that four patients who recorded hospice stays had stays in Caherhalla which is a private hospital and nursing home. These stays were subsequently recoded as nursing home stays.

It should be noted that this figure reflects the overall aggregate number of visits reported, and may underestimate individual differences between what the KI reported and what was recorded in Milford for particular cases.

A.4.4.2 Utilisation of Allied Health Professional Services in the Milford Palliative Day Care and In-Patient Hospice Settings

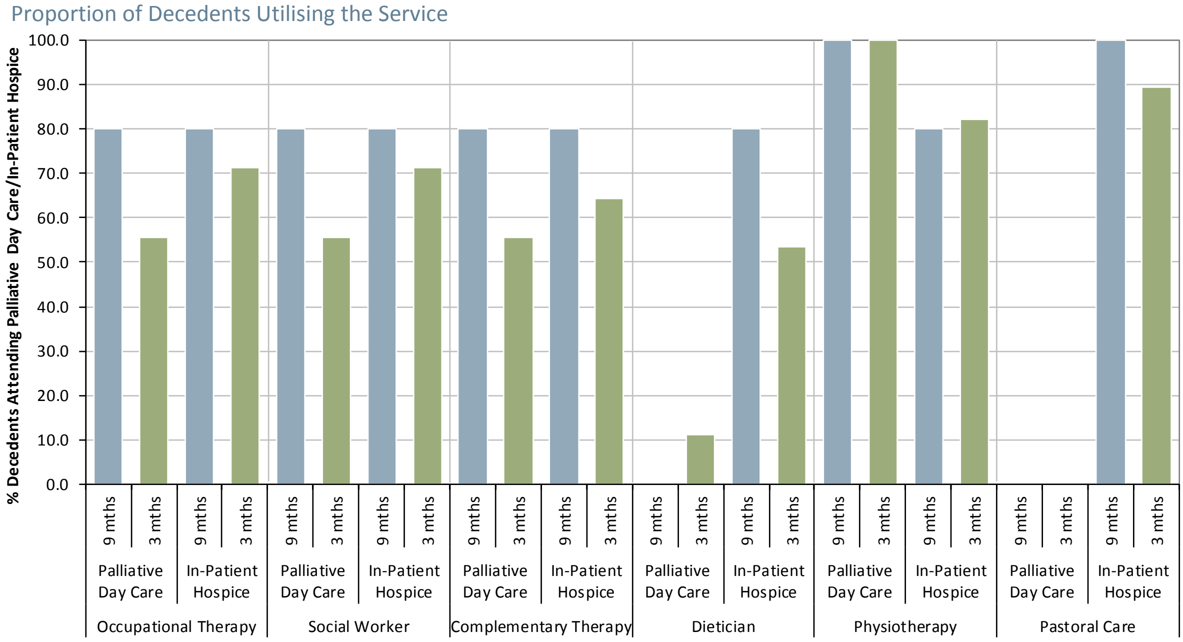
When collecting data from KIs on allied health professional utilisation in the last year of life only data on community visits were collected. It was assumed that KIs would not know what types of visits decedents had when they went into palliative day care or in-patient hospice. In addition, when calculating costs of palliative day care and in-patient hospice a unit cost per visit (see A.5.3.3.2) or nightly rate (see A.5.3.5) was used for each patient i.e. each individual encounter within, for example, a palliative day care visit was not separately costed for the purposes of this study.

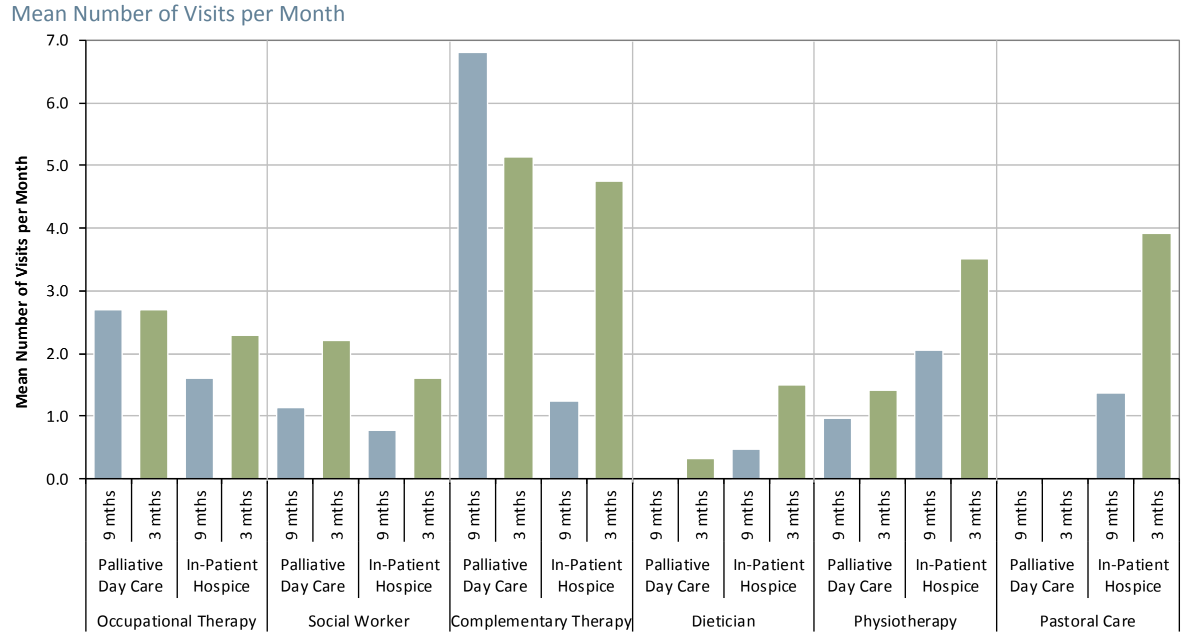
To illustrate the level of utilisation of these services as part of the palliative day care and in-patient hospice services the team returned to the I-CARE records provided by Milford Care Centre.

According to I-CARE, five decedents from the study sample attended palliative day care in the first nine months of their last year of life and nine decedents accessed palliative day care in the last three months of life. Hospice in-patient attendances were recorded for 5 decedents in the first nine months of their last year and 28 in the last three months.

Figure A4.5 illustrates that for those attending Milford Care Centre high proportions of decedents utilised allied health services as part of their attendances and of those who received the services the mean number of visits was high. For example, of decedents attending the palliative day care centre in the last three months of life, all decedents received treatment from a physiotherapist, with a mean of 1.4 visits per month. The most intensively used allied health professionals are complementary therapists in both the nine-month period and the three-month period.

FIGURE A4.5 Allied Health Professional Visits at Milford Care Centre – Palliative Day Care and In-Patient Hospice





Note: 6.7% of decedents in the Mid West visited the SPC day care service in the first nine months of the last year of life, while 2.7% of decedents visited in the last three months of life (see section 4.2.2).
4.0% of decedents in the Mid West had in-patient hospice stays in the first nine months of the last year of life, while 42.7% of decedents had visits in the last three months of life (see section 4.2.2).

A.4.5 Time-Use Diaries

Each community SPC team were asked if one or more of the nurses on the team would complete a time-use diary for a typical working week. The research team provided the form to the team which categorised the time each nurse spent carrying out tasks into direct time and indirect time.

Direct time was understood to be any of the following:

- Patient/family visit (A)
- Patient/family telephone contact (B)
- Contact with other healthcare providers directly related to individual patient care (face-to-face/telephone) (C and D)
- Education (E)

Indirect time was understood to be any of the following:

- Other administration (F)
- Audit and research (G)
- Driving (H)
- Break time (I)

The working day was divided into 15 minute intervals as shown in Table A4.2. If two ticks were applied to the same 15 minute interval (e.g., other administration and telephone contact with other) these were apportioned by dividing the 15 minutes in half, with similar adjustments made if more than two activities were ticked.

TABLE A4.2 Time-Use Diary Form

	Direct Time					Indirect Time			Other
	A	B	C	D	E	F	G	H	I
Hour 1									
0.15			✓						
0.30		✓	✓						
0.45								✓	
1.00	✓								

The time spent carrying out direct and indirect activities were very similar across the three areas as seen in Table A4.3.

TABLE A4.3 Direct and Indirect Time Reported by Community SPC Nurses

	Direct Time	Indirect Time
	%	%
Midlands	61.8	38.2
Mid West	60.9	37.9
South East	59.6	40.4
Total	**61.8**	**39.5**

When time spent driving was analysed, this also showed a similar proportion across the areas with an overall average time spent driving of 14.7% in a typical working week.[6] Patient visits ranged between half-an-hour and an hour in all areas.[7]

The diaries highlight the wide range of activities undertaken by community SPC nurses. Their working hours show that they have various working arrangements including job-sharing and on-call arrangements, and despite overall similarities in the split between direct and indirect activities, each day showed a different working pattern. The community SPC nurses also conduct a wide range of activities outside of direct patient care including education, and interaction with a wide range of healthcare professionals including GPs, public health nurses, other nursing staff, and hospital consultants.

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[6] This proportion is used to calculate the overall unit cost of a SPC nurse visit in Appendix 5.

[7] For the purposes of costing a community SPC nurse visit, a duration of 45 minutes per visit was applied. See Appendix 5.

Appendix 5

Unit Cost Methods and Data

A.5.1 INTRODUCTION

This appendix outlines in detail the methods and data for calculating total direct and indirect costs of care received by decedents over their last year of life. It also outlines the methods used for obtaining unit costs in an Irish context.

A.5.2 BOTTOM-UP COSTING METHODS

As outlined in Section 3.1.1, this study adopts a bottom-up approach to generating the cost estimates. Where possible, for each decedent recorded in the primary data collection process, utilisation of services is multiplied by the unit cost for each service.[1]

Equation 1 illustrates the method, taking the example of GP costs:

$$\mathrm{GP}_{\mathrm{cost},i,3} = \mathrm{GP}_{\mathrm{unit}} \times \mathrm{GP}_{\mathrm{use},i,3} \qquad (1)$$

where $\mathrm{GP}_{\mathrm{cost},i,3}$ refers to the total cost of GP care for decedent *i* in the last three months of life, $\mathrm{GP}_{\mathrm{unit}}$ refers to the unit cost per GP visit and $\mathrm{GP}_{\mathrm{use},i,3}$ refers to the number of GP visits for decedent *i* in the last three months of life. The method in equation 1 is repeated for each of the services outlined in Table A5.2. As will be explained in their respective sections, alternative methods were employed to estimate costs for other services such as in-patient and day patient hospital visits (see A.5.3.2.3), expenditure on medications (see A.5.3.6), cost of home modifications (see A.5.3.9) and others.

The total cost of care in the last three months of life for each individual is obtained using equation 2:

$$\mathrm{Total}_{\mathrm{cost},i,3} = \mathrm{GP}_{\mathrm{cost},i,3} + \mathrm{PHN}_{\mathrm{cost},i,3} + \ldots\ldots + \mathrm{Informal}_{\mathrm{cost},i,3} \qquad (2)$$

where $\mathrm{Total}_{\mathrm{cost},i,3}$ refers to the total cost of direct and indirect care received by decedent *i* in the last three months of life, PHN refers to public health nurse care, and so on to include all services for which utilisation data/expenditure were obtained for the sample of decedents included in the study.

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[1] For particular services, supplementary data were collected directly from the service providers, which was used in place of KI reported data, and multiplied by the unit cost.

The above methods are repeated to calculate the total cost of care received by each decedent in the first nine months of the last year.

After all costs are estimated in the three-month and the nine-month periods, total costs of care over the last year of life ($\text{Total}_{\text{cost},i,12}$) are calculated using equation 3:

$$\text{Total}_{\text{cost},i,12} = \text{Total}_{\text{cost},i,3} + \text{Total}_{\text{cost},i,9} \qquad (3)$$

All costs are quoted in 2011 prices, consistent with the time period during which the decedents were using the services, and being the most up-to-date year for which all the relevant data were available at the time of cost estimation.

A.5.3 Methods for Estimating Unit Costs

A.5.3.1 Health Care Professionals' Costs

A.5.3.1.1 PSSRU Methodology

The Personal Social Services Research Unit (PSSRU) in the UK compiles estimated unit costs for a range of health and social care services on an annual basis. This study applies the methods used by the PSSRU (Curtis, 2012) to estimate unit costs for the following health care professionals:

- Palliative care nurse
- Palliative care consultant
- Public health nurse
- Pastoral carer
- Chiropodist
- Complementary therapist
- Dietician
- Occupational therapist
- Physiotherapist
- Psychiatrist
- Psychologist
- Social worker
- Speech and language therapist.

Using the example of an occupational therapist, Table A5.1 outlines the components of the unit cost for a health professional based on the PSSRU methodology. The data sources for each component are also presented.

TABLE A5.1 PSSRU Methodology: Occupational Therapy Unit Cost Calculation (2011 €s)

		2011 Value	Source	Notes
		€		
Cost Component				
A	Wages/salary	62,439	HSE	Mean total earnings for Occupational Therapist (Senior - largest WTE). Mean total earnings are calculated by dividing total earnings earned by staff in the group by the total worked whole time equivalent (WTE) for those staff. Total earnings include basic salary, overtime, on-call, allowances, weekend pay, night duty pay, arrears. Employers' PRSI contributions are also included.
B	Salary oncosts	11,757	Author's calculations	Notional cost of superannuation of 18.83%. Based on a real cost of government borrowing of 2%, assuming half-pay pensions at the age of 65, based on 30 years' service.
C	Qualifications	n/a		
D	Overheads	45,467	PSSRU 2012	PSSRU (2012) estimates an overhead of 19.31% of direct care salary costs (i.e., 19.31% of A+B) for management & other non-care staff costs; and 41.6% of direct care salary costs (i.e., 41.97% of A+B) for non-staff costs.
E	Capital overheads	6,244	PSSRU 2012	Based on a 10% increase in unit costs to account for capital costs The average increase used for capital in the PSSRU for community-based staff is 10%. Based on the new-build and land requirements of NHS facilities, but adjusted to reflect shared use of both treatment and non-treatment space. Capital costs have been annuitised over 60 years at a discount rate of 3.5 per cent.
F	Travel	N/A		
Total costs		125,907		
Working Time				
G	Weeks per annum	42.8	HSE HR Circular 005/2009	Based on Senior Occupational Therapist, annual leave of 29 days
H	Hours per week	35	HSE HR Circular 005/2009	
I	Hours per annum	1,500	(G*H)	
J	Ratio of direct to indirect time	60:40	PSSRU 2012	Assuming 50 per cent in patient's own home; 10 per cent in clinics; 20 per cent on non-contact time; and 20 per cent on travel. Information derived from consultation with NHS Trusts (PSSRU, 2012)
K	Client contact hours per annum	900		
L	Duration of contact	n/a	Based on reported times provided by service providers	1 hour for the initial visit and 30 minutes for subsequent visits
Unit Costs				
M	Unit cost per hour	€84		
N	Unit cost per hour of client contact	€140		
O	Unit cost per contact	€140 (initial visit) €70 (subsequent visits)		1 hour for the initial visit and 30 minutes for subsequent visits

Note: n/a= Not Applicable

Cost Component:

- **A** Wages/salary costs – were obtained from the HSE, based on national data (excluding the South and South East)[2, 3] and included the following:

  Mean total earnings per WTE:
  - Mean basic salary per WTE
  - Mean overtime expenditure per WTE
  - Mean on-call expenditure per WTE
  - Mean allowances expenditure per WTE
  - Mean weekend expenditure per WTE
  - Mean night duty expenditure per WTE
  - Mean arrears / other per WTE
  - Mean employer PRSI payments per WTE

  Where more than one grade was provided by the HSE, the grade with the largest number of WTEs employed was selected for inclusion. Milford Care Centre provided salary data for a complementary therapist and PRSI at 4% was then added to this figure.

- **B** Salary oncosts – Included a notional cost of superannuation of 18.83%, assuming a real cost of government borrowing of 2% and half-pay pensions at the age of 65, based on 30 years' service.

- **C** Qualifications – Although qualifications were taken into account in the PSSRU methodology, for this project they were not deemed relevant. This is because in general, health professionals are not paid a premium if they have extra qualifications but it is reflected in their grade and seniority, which in turn is reflected in their salary.

- **D** Overheads – Based on estimates by Curtis (2012), an overhead of 19.31% of direct care salary costs (i.e., 19.31% of wages plus salary oncosts) for management and other non-care staff costs; and 41.6% of direct care salary costs (i.e., 41.97% of wages plus salary oncosts) for non-staff costs was applied.

- **E** Capital overheads – In order to account for capital overheads a 10% increase was applied to the wages/salary cost for each health professional. This is based on the average increase of 10% used for capital in the PSSRU for community-based staff.

- **F** Travel – Travel costs were taken into account for a public health nurse, palliative care nurse and home help. Time-use diaries from the study were used to estimate the proportion of working time spent driving by nurses (14.7%). The same proportion was applied for home help in the absence of any other information. The total number of kilometres travelled over one year for these cadres (43.23 weeks) was calculated assuming an average

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[2] Salary data from the South and South East were not available from the HSE at the time of the analysis.

[3] HSE, personal communication, 3 April 2013.

travel speed of 50km per hour.[4] This resulted in a total of 275km travelled per week (11,888km per year). Flat-rate kilometric allowances for civil servants were applied assuming an engine capacity of between 1,201 cc and 1,500 cc (42.65c up to 6,437km and 23.62c over 6,437km), giving a total annual travel cost of €4,033 for these cadres.

Working Time:

- **G** Weeks per annum – The number of weeks worked per annum was calculated taking into account the relevant annual leave entitlements for the different cadres (HSE, 2011), including sick leave and Bank Holidays. Sick leave was estimated using the HSE national sick leave target of 3.5% based on the number of days per year, minus Bank Holidays and annual leave.
- **H** Hours per week – The number of working hours per week for each health professional was calculated for nurses from the HSE Circular 111/99, for consultants from the HSE Consultant contract, for chaplains from the HSE HR Circular 013/2006, and for other cadres from the HSE HR Circular 005/2009.
- **I** Ratio of direct to indirect time – For the ratio of direct to indirect time, the main data sources came from previous PSSRU reports (Curtis and Netten, 2005, 2006; Curtis, 2007, 2010, 2011, 2012). Where no information was available in these reports, the direct and indirect ratio was assumed to be the same as other community cadres, in particular for the dietician and chiropodist. The time-use diaries from this study provided information for the public health nurse and palliative care nurse unit costs. In the absence of any other data, a ratio of 80% of direct contact was assumed for the pastoral carer and health care assistant based on information provided by service providers.

Using the same methodology Table A5.2 shows the unit costs calculated for other occupations for which data were available.

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[4] This assumes a speed limit of 50 km/h for towns, and city speed limits of 50 km/h in place in built-up areas (Department of Transport Tourism and Sport, 2013).

TABLE A5.2 Unit Costs: Health Care Professionals– PSSRU Methodology (2011 €s)

Variable	Cost per Hour 2011 (€)	Cost per Visit 2011 (€)	Cost per Telephone Contact	Methodology	Unit Cost Assumptions[a]	Source of Cost Data
Public health nurse	122.8	92.1	30.7	PSSRU	Client visit – 45 mins Telephone contact – 15mins	HSE-Finance Shared Services
Palliative care consultant (Home Care)	426.9	213.4	106.7	PSSRU	Client visit – 30 mins Telephone contact – 15 mins	
Palliative care nurse (Home Care)	134.0	100.5	33.5	PSSRU	Client visit – 45 mins Telephone contact – 15 mins	
Occupational therapist	139.9	139.9 or 70	-	PSSRU	Initial client visit – 1 hour Subsequent visits – 30 mins	
Physiotherapist	142.3	71.2	-	PSSRU	Client visit – 30 mins	
Dietician	146.8	146.8 or 73.4	-	PSSRU	Initial client visit – 1 hour Subsequent visits – 30 mins	
Social worker	102.5	102.5 or 51.3	-	PSSRU	Initial client visit – 1 hour Subsequent visits – 30 mins	
Psychologist	282.0	282.0	-	PSSRU	Client visit – 1 hour	
Psychiatrist	419.2	209.6	-	PSSRU	Client visit – 30 mins	
Speech and language therapist	135.1	135.1	-	PSSRU	Client visit – 1 hour	
Complementary therapist	63.1	63.1	-	PSSRU	Client visit – 1 hour	
Chiropodist	136.8	68.4	-	PSSRU	Client visit – 30 mins	
Pastoral carer	42.8	21.4	10.7	PSSRU	Client visit – 30 mins Telephone contact – 15 mins	

Note: Where data were available on duration of visits these were used but in other cases information was supplied by service providers that formed the basis of these estimates.

A.5.3.1.2 Other Methodology

For some services, it was not possible to estimate the costs using the PSSRU methodology due to data limitations. Costs were estimated for particular services using alternate methodologies.

GP

GP costs were calculated separately for medical card and non-medical card (private) visits.[5] For medical card visits, utilisation data were obtained from the Quarterly National Household Survey (Central Statistics Office, 2011) a large-scale, nationwide survey of households. The average number of GP consultations for medical card holders was 5.4 for those over 18 years in the last 12 months. Using the average payment made by the Primary Care Reimbursement Service

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[5] GP costs for non-medical card holders were estimated from the point of view of the service user, which may not take into account the overall opportunity cost of a visit.

(2012) to GPs per eligible person of €257.93, a unit cost of €48 per GP visit by a medical card holder was calculated.

For private GP visits, an independent price survey conducted via telephone in 2013 randomly selected 12 GP surgeries from each of three regions of the study i.e. South East, Midlands, Mid West.[6] Four GPs were selected from each of the following counties: Tipperary, Waterford, Wexford, Laois, Offaly, Westmeath, Clare, Limerick and North Tipperary. The average private GP consultation fee across the 36 GPs surveyed was €47.[7]

Dentist

Similar to the GP unit cost, the dentist unit cost was calculated separately for medical card and private visits. For the cost of medical card visits, the scale of fees payable under the Dental Treatment Services Scheme (DTSS) as at 31 December 2011 (Primary Care Reimbursement Service, 2012) was assessed. The DTSS payment for an oral examination for a medical card holder is €33.

For private dental visits, data from a National Consumer Agency price survey in 2010 were utilised (National Consumer Agency, 2010). The average fee charged per private oral examination was €44 across 11 regions.

TABLE A5.3 Unit Costs: Health Care Professionals – Other Methodology (2011 €s)

Variable	Cost per Visit 2011 (€)	Cost per Telephone Contact	Assumptions	Source
GP (Private)	47	23.5	Consultation only	Independent price survey 2013[a]
GP (Medical Card)	48	24	Consultation only	Central Statistics Office, 2011; Primary Care Reimbursement Service, 2012
Dentist (Medical Card)	33	n/a	Consultation only	Primary Care Reimbursement Service, 2012
Dentist (Private)	44	n/a	Consultation only	National Consumer Agency, 2010

Note: a Survey conducted by research team over the phone, March 2013.

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[6] Survey conducted by research team over the phone, March 2013.

[7] A similar price survey was conducted in 2008 by The Competition Authority, which revealed the cost of GP visits at approximately €50–€55 in urban areas, with slightly lower charges in rural areas (The Competition Authority, 2009). This survey was based on fees charged by 51 GPs in rural and urban locations throughout Ireland. It is acknowledged that the cost of €47 utilised in this study may be slightly lower than other estimates but provides a more conservative up-to-date cost.

Formal Care in the Community

Costs for night nursing, home help, health care assistants and formal paid helper are outlined in Table A5.4.

TABLE A5.4 Unit Costs: Formal Care in the Community (2011 €s)

Variable	Cost per Hour/Shift	Cost per Telephone Contact	Methodology	Unit Cost Assumptions	Source of Cost Data
	2011 (€)				
Night nurse	350.0	n/a	-	Cost per night shift	Irish Cancer Society[a]
Home help	21.5	n/a	Average of weekend and weekday hourly cost	Client visit – 1 hour	HSE Home Care Provider[b]
Health care assistant	21.5	n/a		Client visit – 1 hour	
Other paid help	21.5	n/a		Client visit – 1 hour	

Note: a ICS, personal communication, 14 January 2013.
b Bluebird Care (Home Care Provider), personal communication,5 October 2012.

A.5.3.2 Hospital Costs

A.5.3.2.1 Emergency Department Visits

The unit cost for a visit to a public emergency department (ED) was calculated by dividing total public hospital ED expenditure for non-admitted ED attendances by the total number of non-admitted ED attendances in 2011. These data were available from the HSE (HSE, 2013).

TABLE A5.5 Unit Cost: Emergency Department (2011 €s)

Variable	Cost per Visit	Source
	2011 (€)	
Emergency Department	268	HSE National Casemix Programme Ready Reckoner 2013

A.5.3.2.2 Outpatient Department Visits

- Public – The unit cost for a public outpatient department (OPD) specialist visit was calculated by dividing the total public hospital OPD expenditure by the total number of OPD attendances in 2011. These data were available from the HSE.
- Private – The unit cost for a private OPD visit is not publicly available. The study team conducted an independent price survey of four private hospital clinics across a range of specialties. The average price obtained from this survey is based on the price of first consultation, and therefore may overestimate where a patient was attending for additional follow-up visits.[8]

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[8] The cost of charges to the service user is a reasonable estimate of the cost of the visit, but may not fully represent the opportunity cost.

- Specialist Palliative – The unit cost for a specialist palliative OPD visit is not readily available in Ireland at present, due to commercial sensitivities. Information was provided by St. Francis Hospice on the length of visits for palliative OPD,[9] in order to calculate a unit cost.

TABLE A5.6 Unit Cost: Outpatient Department (2011 €s)

Variable	Cost per Visit 2011 (€)	Assumptions/Source
Public	130	HSE National Casemix Programme Ready Reckoner 2013
Private	154	Independent price survey 2013
Specialist Palliative	260	Based on outpatient public cost*2

A.5.3.2.3 Day Patient Visits and In-Patient Stays

The costs of day patient visits and in-patient stays are calculated using Casemix costs,[10] using data recorded in the Hospital In-Patient Enquiry (HIPE). This method of costing is a top-down approach which allocates total hospital costs across all discharges on the basis of Casemix units rather than solely on length of stay. Access to HIPE data was granted by the hospital managers in each of the participating hospitals. Assisted by a hospital administrator and HIPE personnel, patient visits were identified, and HIPE data were downloaded for each hospital. When data for all decedents were collected, they were grouped and costed by the HIPE IT team in the ESRI using the method below.[11]

- Each discharge was assigned to a Diagnosis Related Group (DRG). These are homogenous groups that are based on similar treatment processes and incur similar levels of resource use.[12]
- Once the data are grouped, each visit is assigned a Casemix Unit (CMU) which measures the complexity (in terms of resource use) of the DRG to which a case has been assigned, relative to all other DRGs and is adjusted to take into account the specific length of stay of the case.
- The CMU is multiplied by the Base Price, which is the national average inlier[13] cost per case, which is calculated separately for in-patients (€4,580) and day patients (€637).

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[9] Personal communication with Dr Karen Ryan, Consultant in Palliative Medicine.

[10] The Irish Casemix system has adopted the Australian system of diagnosis-related groups (Australian Refined Diagnosis Related Groups, AR-DRG).

[11] In some cases, the number of visits reported by the KI did not match the number of visits returned by HIPE. In such cases HIPE data was used to calculate costs. Triangulation of the KI reported and HIPE reported admissions is undertaken in Appendix 4.

[12] For further information on the National Casemix Programme, HSE, see www.casemix.ie

[13] An inlier is a standard case where no additional per diem payment has been included for a long-stay patient.

TABLE A5.7 Cost: Day Patient and In-Patient – Public Hospital (2011 €s)

Variable	Cost per Visit/Night	Assumptions/Source
	2011 (€)	
Day Patient – Public Hospital		
Public patient	-	Casemix Base Price per case (€637) multiplied by the associated CMU [HSE National Casemix Programme Ready Reckoner 2013 (2011 Costs)]
Private patient	-	
In-Patient – Public Hospital		
Public patient	-	Casemix Base Price per case (€4,580) multiplied by the associated CMU [HSE National Casemix Programme Ready Reckoner 2013 (2011 Costs)]
Private patient	-	

For a small number of decedents hospital records for particular visits, as reported by the KI in the interview, were not available for one of the following three reasons:

1) The KI did not grant permission to the project to access the decedent's medical records.
2) The relevant public hospital did not grant permission to the project to access the HIPE data.
3) HIPE data are not available for private hospitals.

To estimate a cost for these visits CMUs for the available HIPE data were stratified by age (<65 years/≥65 years) and diagnosis (cancer/non-cancer). An average CMU for each strata was then calculated (Table A5.5). This CMU value was then multiplied by the Casemix Base Price per case (2011 costs) to provide an estimate of the cost per visit.

TABLE A5.8 Estimated Casemix Unit Values (2011 €s)

	Casemix Base Price 2011 (€)	Estimated Casemix Units			
		<65 years		≥65 years	
		Cancer	Non-Cancer	Cancer	Non-Cancer
Day Patient	637	1.46	0.62	1.60	0.88
In-Patient	4,580	2.08	2.02	1.77	1.61

Note: For example, the cost applied to one in-patient visit for a decedent with a cancer diagnosis aged < 65 years was €4,580 * 2.08 = €9,526.4.

A.5.3.3 Day Care

A.5.3.3.1 Day Care Centre

The unit cost of a day care visit was estimated from data collected for ten day care centres in the HSE Midlands area. The total cost of running the selected day care centres was divided by an estimated total number of visits in 2011. The total number of visits was estimated from the maximum number of visits based on each day care centre's capacity, multiplied by the number of days per week and the number of weeks per year for which the day care centres were operational. Total costs were based on pay and non-pay expenditures, and included user charges. This estimated day care unit cost has been applied to day care visits for the Midlands and the South East area. Milford Care Centre also provided day care centre costs. It became clear from information from the service providers that a range of different costs were estimated for day care services, probably related to differences in models of care.

A.5.3.3.2 Palliative Day Care Centre

The unit cost for a palliative day care visit was provided by Milford Care Centre in Limerick.

TABLE A5.9 Cost per Visit: Day Care (2011 €s)

Variable	Cost per Visit	Source
	2011 (€)	
Day care centre	36/115	HSE Midlands/Milford Care Centre
Palliative day care centre	385	Milford Care Centre

A.5.3.4 Nursing Home

The maximum weekly prices for both public and private nursing homes were obtained from the HSE. Under the Nursing Home Support Scheme, prices charged by private nursing homes are agreed between each Private Nursing Home and the National Treatment Purchase Fund. As this list changes on a monthly basis a mid-year list was obtained for June 2011. A weekly price list for the cost of care in public homes is also provided which was effective from August 2010 to July 2011. Both of these lists were combined to give a total weekly average charge for nursing home care.[14,15]

TABLE A5.10 Cost per Week: Nursing Home (2011 €s)

Variable	Cost per Week	Source
	2011 (€)	
Nursing home	958	HSE Nursing Homes Support Scheme

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[14] KIs were asked about stays in public and private nursing homes separately, but analysis of the data indicated that the distinction between public and private was not always clear to KIs. As a result, the public and private nursing home utilisation data have been merged for the cost calculations.

[15] Stays in community hospitals, which were reported in the hospital section of the questionnaire were costed as nursing home stays.

A.5.3.5 In-Patient Hospice

In-patient hospice costs were provided by Milford Care Centre in Limerick and the total cost per night is €890.

TABLE A5.11 Cost per Night: Hospice (2011 €s)

Variable	Cost per Night	Source
	2011 (€)	
Hospice	890	Milford Care Centre

A.5.3.6 Drugs

A.5.3.6.1 Prescribed Drugs

Monthly prescription costs were estimated using data from the Primary Care Reimbursement Service (2012, p115–17) on the national average cost of medicines per year for medical card holders, by age group, as at December 2011. Evidence suggests that patterns of drug use in the last year of life differ significantly from those who are of the same age but are not in the last year of life. The national average cost of medicines are based on the general medical card population and do not account for higher medication use among patients in the last year of life. The costs were adjusted using the following methodology:

- The mean GMS (General Medical Services) cost per decedent for the last 12 months of life for individuals 65 years or older who died in 2009 was calculated using the PCRS database of reimbursed drugs.[16]
- The data were analysed to see whether there was an increasing or decreasing trend between the same age groups in the general medical card population, and those who were in the last year of their life. The following table displays the ratios calculated.

TABLE A5.12 Methodology: Prescribed Drug Cost Calculation (2011 €s)

	Age Group		Source
	65–69 Years	70–74 Years	
Average cost of medications per decedent for the last 12 months of life (A)	€2,153.0	€2,158.6	PCRS (2009)
Average cost of medications by age group for medical card holders (B)	€1,370.9	€1,403.0	PCRS (2011)
Ratio	0.637	0.650	(A/B)

- A ratio was calculated for the ages 65–69 years and 70–74 years as these two age groups were directly comparable to the Primary Care Reimbursement Service (2012) age groups. The percentage increase was calculated as 0.0208.

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[16] The authors are grateful to Patrick Moore, PhD Scholar in health services research for assistance in gaining access and analysis of prescribing data from the PCRS, 2009.

- This 0.0208 was then applied on a decreasing basis to the age groups under 65 who were not in the last year of their life.
- A new cost for each age group was calculated using the formula: 1 divided by the corresponding ratio.
- This cost was divided by 12 to estimate a monthly prescription drug cost.

TABLE A5.13 Cost per Month: Prescribed Drugs by Age Group (2011 €s)

Age Group	Monthly Cost	Age Group	Monthly Cost	Source
	2011 (€)		2011 (€)	
Under 5 Years	21	55-64 years	157	Calculated as per methodology using data from PCRS.
5-11 years	15	65-69 years	179	
12-15 years	16	70-74 years	180	
16-24 years	31	75-79 years	180	
25-34 years	46	80-84 years	169	
35-44 years	62	85-89 years	161	
45-54 years	104	90+ years	134	

A.5.3.6.2 Non-Prescribed Drugs

The monthly cost of non-prescribed drugs was directly reported in the interview by the key informant.

TABLE A5.14 Cost per Month: Non-Prescribed Drug (2011 €s)

Variable	
Non-Prescribed Drugs	Cost per month as reported by the key informant in the interview

A.5.3.7 Meals-On-Wheels

The cost per meal provided by a meals-on-wheels service was based on a survey of four meals-on-wheels centres in the HSE Midlands area. Two of the centres operate as private providers (i.e. a meal is purchased by the HSE from a private provider and delivered by a home help or other community support staff member). The other two centres are run by community organisations whereby the HSE provides an annual grant towards the cost of purchasing the food for preparation, and the prepared meal is delivered by volunteers. Costs included food costs, salary costs for chefs and co-ordinators, overhead costs, and also estimated costs for volunteers' time and travel. The total costs in each centre were divided by the number of meals supplied by each centre per year to give an average cost per meal. The final unit cost per meal is based on an average of these cost estimates.

TABLE A5.15 Cost per Meal: Meals-on-Wheels (2011 €s)

Variable	Cost per Meal	Source
	2011 (€)	
Meals-on-wheels	10.6	HSE Midlands

A.5.3.8 Equipment Costs

Equipment costs (with the exception of oxygen equipment and commode) are valued in terms of equivalent annual values, including the cost of maintenance where possible/relevant. This follows the PSSRU methodology and takes into account the fact that equipment is often re-used (e.g., return of a wheelchair to the HSE following the patient's death).

TABLE A5.16 Cost per Item: Equipment (2011 €s)

Variable	Cost per Item	Methodology	Assumptions	Source
	2011 (€)			
Wheelchair (manual)	74.3	PSSRU	Annualised cost (incl. maintenance costs)	HSE Procurement
Wheelchair (electric)	460.7	PSSRU		
Feeding pump	1560	PSSRU		
Special bed	416.4	PSSRU		
Hoist	591	PSSRU		
Electric Chair Riser Recliner	146	PSSRU		
Air Mattress Overlay	314.3	PSSRU		
Oxygen equipment	576	Actual Price	Annualised cost (rental cost)	
Commode	26.6	Actual Price	Annualised cost (no maintenance cost)	

Table A5.17 outlines the methods for estimating the annual cost of equipment, taking the example of an electric wheelchair. This method is adopted for the following items of equipment:

- Wheelchair (manual)
- Wheelchair (electric)
- Oxygen equipment
- Feeding pump sets[17]
- Commode
- Special bed
- Hoist
- Electric chair riser recliner
- Air mattress overlay

TABLE A5.17 Methodology: Wheelchair (Manual)[a] Cost Calculation (2011 €s)

Total Value 2011	Expected Useful Life	Discount rate	Annualisation factor[b]	Annual Cost 2011	Maintenance Costs	2011 Value	Source
€	Years			€	€	€	
200	5	0.035	4.515	44.30	30	74.30	HSE Procurement

Notes: a Costs are applied on the basis of annual costs even if the patient did not have the item of equipment for the full year – potential over-estimation of the costs.

b The annualisation factor is calculated based on the discount rate and the number of expected useful life years to reflect the opportunity cost of tying-up funds in purchasing the capital equipment (Walker and Kumaranayake, 2002)

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[17] Oxygen equipment and feeding pump sets are not annuitised as they are paid for on a monthly basis by the HSE. Oxygen equipment is costed at the monthly rental cost of €48 for a home concentrator, while a feeding pump set is the cost of a standard person's monthly supply (cost of monthly supply is €130 and feeding pumps are supplied free of charge to the HSE).

A.5.3.9 Home Modifications

The cost of home modifications was directly reported in the interview by the key informant in the nine-month and three-month periods. This was divided by the number of months to get the cost per month.

TABLE A5.18 Cost: Home Modifications (2011 €s)

Variable	
Home modifications	Total cost of all modifications undertaken in the period as reported by the key informant in the interview

A.5.3.10 Informal Care

There are a number of ways in which the value of informal care has been estimated in the literature. The cost of informal care in this study refers to the replacement value of informal care provided by the family/friends of the decedent. The unit cost obtained for home help was used as the replacement value (see Section A.5.3.1.2).

The number of hours of assistance with tasks including:

- Personal Care
- Eating and Drinking
- Going to the Toilet
- Mobility Indoors
- Taking Medications
- Household Tasks
- Administrative Tasks

that were reported by the KI in the nine-month and three-month periods were multiplied by the unit cost for home help.

TABLE A5.19 Cost: Informal Care (2011 €s)

Variable	Cost per Hour	Source
	2011 (€)	
Informal Care	21.50	Refers to the replacement value of informal care provided by the family/friends of the decedent using the cost of home help. See Table A5.4.

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Appendix 6

Cost Results

A.6.1 COMPONENTS OF TOTAL COST

Table A6.1 presents the mean cost per month in the first nine months and last three months of the last year of life for all components of the total cost of health-care utilisation.[1] Results are discussed in Section 4.

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[1] All costs are quoted in 2011 prices, consistent with the time period during which the decedents were using the services.

TABLE A6.1 Detailed Costs of Health Care Utilisation by Time Period and Area

	Cost per Month (€)						Statistical Testing						
	Midlands		Mid West		South East		ANOVA[a]	Independent Samples T-Test[b]			Paired Samples T-Test[c]		
							Across Areas	Across Areas			9mth v 3mth		
								ML v MW	ML v SE	MW v SE	ML	MW	SE
	Mean	Median	Mean	Median	Mean	Median	p-value	p-value	p-value	p-value	p-value	p-value	p-value
1 Community Services Costs													
GP													
Visit													
9 months	47.02	26.67	51.71	48.00	48.21	42.67	0.835	0.584	0.887	0.672	0.000	0.000	0.000
3 months	109.93	80.00	103.05	48.00	101.53	64.00	0.916	0.749	0.694	0.945			
Phone Call													
9 months	6.97	0.00	9.99	0.00	7.47	0.00	0.675	0.443	0.881	0.525	0.001	0.008	0.012
3 months	13.67	0.00	18.11	0.00	15.71	0.00	0.670	0.391	0.682	0.663			
Total													
9 months	52.50	26.67	59.89	48.00	55.42	48.00	0.743	0.479	0.769	0.649	0.000	0.000	0.000
3 months	120.39	88.00	117.88	64.00	116.69	80.00	0.987	0.914	0.872	0.959			
Public Health Nurse													
Visit													
9 months	139.48	20.47	94.44	10.23	89.68	20.47	0.344	0.236	0.251	0.886	0.000	0.000	0.007
3 months	384.54	138.15	234.36	92.10	198.03	107.45	0.019	0.048	0.018	0.500			
Phone Call													
9 months	3.80	0.00	5.65	0.00	1.92	0.00	0.410	0.543	0.399	0.177	0.003	0.002	0.000
3 months	28.54	0.00	19.44	0.00	20.47	0.00	0.598	0.401	0.478	0.890			
Total													
9 months	141.24	23.88	100.08	10.23	86.87	20.47	0.326	0.284	0.197	0.692	0.526	0.570	0.403
3 months	406.43	133.03	253.53	92.10	204.14	148.38	0.018	0.059	0.014	0.372			
Pastoral Care[d]													
Visit													
9 months	21.75	2.38	17.12	2.38	19.06	2.38	0.789	0.459	0.721	0.776	0.000	0.000	0.000
3 months	61.11	28.53	44.64	21.40	49.33	14.27	0.607	0.329	0.530	0.774			
Phone Call													
9 months	0.23	0.00	1.31	0.00	1.09	0.00	0.421	0.164	0.260	0.836	0.986	0.438	0.347
3 months	1.01	0.00	2.45	0.00	3.81	0.00	0.353	0.375	0.120	0.557			
Total													
9 months	21.66	1.19	17.92	2.38	20.11	2.38	0.862	0.545	0.842	0.759	0.000	0.000	0.000
3 months	61.21	24.97	46.42	21.40	52.25	14.27	0.690	0.381	0.639	0.732			
Day Care Centre													
9 months	32.20	0.00	34.24	0.00	8.20	0.00	0.332	0.920	0.168	0.138	0.304	0.673	0.007
3 months	10.63	0.00	10.73	0.00	0.00	0.00	0.388	0.992	0.187	0.152			

	Cost per Month (€)						Statistical Testing						
	Midlands		Mid West		South East		ANOVA[a]	Independent Samples T-Test[b]			Paired Samples T-Test[c]		
							Across Areas	Across Areas			9mth v 3mth		
								ML v MW	ML v SE	MW v SE	ML	MW	SE
	Mean	Median	Mean	Median	Mean	Median	p-value	p-value	p-value	p-value	p-value	p-value	p-value
Home Help[d]													
9 months	57.51	0.00	129.25	0.00	82.64	0.00	0.172	0.093	0.437	0.273	0.041	0.800	0.185
3 months	94.99	0.00	137.35	0.00	129.79	0.00	0.679	0.396	0.481	0.895			
Health Care Assistant[d]													
9 months	40.04	0.00	38.67	0.00	33.38	0.00	0.979	0.969	0.838	0.873	0.158	0.258	0.270
3 months	74.21	0.00	31.06	0.00	79.97	0.00	0.604	0.363	0.928	0.316			
Formal Paid Helper[d]													
9 months	100.12	0.00	30.98	0.00	60.73	0.00	0.528	0.306	0.611	0.388	0.720	0.108	0.343
3 months	112.75	0.00	166.98	0.00	206.26	0.00	0.838	0.617	0.593	0.828			
Meals-on-Wheels[d]													
9 months	3.43	0.00	1.33	0.00	3.66	0.00	0.760	0.549	0.958	0.350	0.321	0.608	0.279
3 months	2.29	0.00	2.22	0.00	1.02	0.00	0.854	0.981	0.628	0.541			
2 Specialist Palliative Care													
Palliative Care Consultant (Home Care)													
Visit													
9 months	1.25	0.00	0.32	0.00	0.00	0.00	0.378	0.376	0.274	0.382	0.032	0.028	0.103
3 months	11.23	0.00	18.27	0.00	9.99	0.00	0.616	0.444	0.867	0.433			
Phone Call													
9 months	0.47	0.00	1.12	0.00	0.00	0.00	0.351	0.449	0.241	0.215	0.128	0.163	-
3 months	2.34	0.00	0.00	0.00	0.00	0.00	0.042	0.060	0.096				
Total													
9 months	1.72	0.00	1.44	0.00	0.00	0.00	0.375	0.847	0.186	0.137	0.022	0.041	0.103
3 months	13.57	0.00	18.27	0.00	9.81	0.00	0.671	0.619	0.629	0.420			
Palliative Care Nurse (Home Care)													
Visit													
9 months	90.36	0.00	77.76	0.00	71.04	0.00	0.820	0.690	0.566	0.806	0.000	0.000	0.000
3 months	428.99	234.50	365.56	217.75	347.40	134.00	0.607	0.449	0.373	0.830			
Phone Call													
9 months	5.84	0.00	6.29	0.00	10.57	0.00	0.626	0.916	0.429	0.435	0.000	0.000	0.010
3 months	31.75	0.00	30.67	0.00	42.71	0.00	0.634	0.923	0.482	0.383			
Total													
9 months	94.65	0.00	83.79	0.00	81.61	0.00	0.913	0.743	0.718	0.943	0.000	0.000	0.000
3 months	435.65	228.92	385.11	234.50	371.83	134.00	0.745	0.559	0.498	0.877			
Night Nurse Service													
3 months	181.65	0.00	208.44	0.00	161.39	0.00	0.826	0.720	0.783	0.536	n/a	n/a	n/a
Specialist Palliative Day Care[e]													

	Cost per Month (€)						Statistical Testing						
	Midlands		Mid West		South East		ANOVA[a]	Independent Samples T-Test[b]			Paired Samples T-Test[c]		
							Across Areas	Across Areas			9mth v 3mth		
								ML v MW	ML v SE	MW v SE	ML	MW	SE
	Mean	Median	Mean	Median	Mean	Median	p-value	p-value	p-value	p-value	p-value	p-value	p-value
9 months	-	-	39.36	0.00	-	-	0.028	0.043		0.080	-	0.169	-
3 months	-	-	11.98	0.00	-	-	0.159	0.148		0.210			
Specialist Palliative Outpatient Care[e]													
9 months	-	-	1.58	0.00	-	-	0.218	0.185		0.256	-	0.820	-
3 months	-	-	1.19	0.00	-	-	0.388	0.297		0.371			
In-Patient Hospice													
9 months	-	-	143.72	0.00	16.48	0.00	0.200	0.153	0.250	0.277	-	0.000	0.282
3 months	-	-	3,433.42	0.00	178.00	0.00	0.000	0.000	0.175	0.000			
3 Allied Health Professionals													
Chiropodist													
9 months	10.96	0.00	9.35	0.00	8.74	0.00	0.812	0.665	0.520	0.866	0.586	0.110	0.301
3 months	9.48	0.00	6.10	0.00	6.79	0.00	0.651	0.425	0.564	0.795			
Complementary Therapy													
9 months	8.09	0.00	12.71	0.00	5.94	0.00	0.598	0.524	0.689	0.357	0.600	0.120	0.123
3 months	9.98	0.00	5.05	0.00	11.76	0.00	0.593	0.446	0.813	0.288			
Dentist													
9 months	0.61	0.00	1.01	0.00	1.77	0.00	0.111	0.244	0.061	0.261	0.925	0.722	0.811
3 months	0.56	0.00	0.84	0.00	1.65	0.00	0.384	0.639	0.234	0.363			
Dietician													
9 months	4.02	0.00	4.64	0.00	1.38	0.00	0.244	0.780	0.153	0.074	0.134	0.474	0.516
3 months	8.38	0.00	3.06	0.00	2.90	0.00	0.203	0.145	0.176	0.956			
Occupational Therapy													
9 months	11.82	0.00	3.56	0.00	10.93	0.00	0.178	0.057	0.888	0.087	0.011	0.006	0.033
3 months	23.32	0.00	18.00	0.00	19.64	0.00	0.759	0.463	0.637	0.833			
Physiotherapy													
9 months	14.32	0.00	3.68	0.00	10.32	0.00	0.217	0.075	0.615	0.172	0.198	0.059	0.533
3 months	23.72	0.00	9.98	0.00	6.54	0.00	0.112	0.147	0.104	0.491			
Psychiatry													
9 months	1.21	0.00	2.17	0.00	1.16	0.00	0.858	0.672	0.968	0.693	0.760	0.321	0.643
3 months	1.81	0.00	0.00	0.00	2.33	0.00	0.565	0.325	0.860	0.265			
Psychology													
9 months	8.03	0.00	0.42	0.00	4.18	0.00	0.331	0.171	0.565	0.176	0.262	0.185	0.450
3 months	3.62	0.00	7.62	0.00	1.57	0.00	0.489	0.477	0.453	0.324			
Social Work													
9 months	1.08	0.00	1.40	0.00	0.20	0.00	0.457	0.762	0.248	0.220	0.437	0.346	0.452
3 months	2.08	0.00	0.47	0.00	0.88	0.00	0.385	0.195	0.429	0.661			

	Cost per Month (€)						Statistical Testing						
	Midlands		Mid West		South East		ANOVA[a]	Independent Samples T-Test[b]			Paired Samples T-Test[c]		
							Across Areas	Across Areas			9mth v 3mth		
								ML v MW	ML v SE	MW v SE	ML	MW	SE
	Mean	Median	Mean	Median	Mean	Median	p-value	p-value	p-value	p-value	p-value	p-value	p-value
Speech and Language Therapy													
9 months	10.88	0.00	2.00	0.00	2.75	0.00	0.311	0.225	0.330	0.749	0.422	0.615	0.798
3 months	5.07	0.00	1.20	0.00	3.75	0.00	0.515	0.229	0.759	0.406			
4 Hospital Costs													
Emergency Department													
9 months	11.22	0.00	8.45	0.00	9.43	0.00	0.836	0.564	0.747	0.815	0.552	0.511	0.199
3 months	15.08	0.00	6.04	0.00	26.80	0.00	0.231	0.178	0.419	0.129			
Outpatient Department													
Public													
9 months	42.55	0.00	29.26	0.00	29.94	14.44	0.362	0.237	0.308	0.935	0.131	0.705	0.333
3 months	28.31	0.00	25.63	0.00	37.36	0.00	0.598	0.801	0.452	0.349			
Private													
9 months	9.20	0.00	8.91	0.00	9.44	0.00	0.994	0.951	0.958	0.914	0.853	0.849	0.204
3 months	10.27	0.00	9.84	0.00	19.14	0.00	0.516	0.951	0.376	0.323			
Day Patient													
Public – Public Hospital													
9 months	392.26	0.00	148.48	0.00	208.17	0.00	0.066	0.031	0.139	0.557	0.734	0.098	0.488
3 months	422.43	0.00	76.74	0.00	151.56	0.00	0.001	0.000	0.018	0.325			
Private – Public Hospital													
9 months	76.27	0.00	65.13	0.00	84.51	0.00	0.954	0.854	0.908	0.706	0.698	0.346	0.668
3 months	90.63	0.00	89.61	0.00	101.25	0.00	0.980	0.985	0.865	0.859			
Private – Private Hospital													
9 months	67.24	0.00	121.03	0.00	23.23	0.00	0.473	0.538	0.453	0.239	0.921	0.326	0.236
3 months	61.43	0.00	73.07	0.00	206.54	0.00	0.423	0.850	0.300	0.359			
Total													
9 months	535.78	0.00	334.63	0.00	315.91	0.00	0.252	0.196	0.164	0.889	0.753	0.157	0.442
3 months	574.48	0.00	239.41	0.00	459.35	0.00	0.108	0.010	0.556	0.216			
In-Patient													
Public – Public Hospital													
9 months	731.08	152.59	692.58	0.00	551.30	0.00	0.695	0.863	0.365	0.517	0.000	0.009	0.008
3 months	2,802.14	1,397.00	1,520.51	0.00	3,427.87	0.00	0.118	0.050	0.579	0.056			
Private – Public Hospital													
9 months	338.69	0.00	461.30	0.00	265.68	0.00	0.775	0.676	0.811	0.308	0.004	0.071	0.010
3 months	1,185.48	0.00	822.34	0.00	725.49	0.00	0.542	0.439	0.360	0.770			
Private – Private Hospital													
9 months	144.56	0.00	82.56	0.00	64.25	0.00	0.541	0.457	0.329	0.762	0.732	0.088	0.801

	Cost per Month (€)						Statistical Testing						
	Midlands		Mid West		South East		ANOVA[a]	Independent Samples T-Test[b]			Paired Samples T-Test[c]		
							Across Areas	Across Areas			9mth v 3mth		
								ML v MW	ML v SE	MW v SE	ML	MW	SE
	Mean	Median	Mean	Median	Mean	Median	p-value	p-value	p-value	p-value	p-value	p-value	p-value
3 months	180.81	0.00	0.00	0.00	52.91	0.00	0.188	0.108	0.339	0.265			
Total													
9 months	1214.33	530.16	1236.45	550.65	881.23	421.46	0.532	0.951	0.351	0.204	0.000	0.003	0.002
3 months	4168.43	2850.01	2342.85	1643.93	4,206.27	2,175.88	0.087	0.016	0.974	0.062			
5 Nursing Home Costs													
9 months	552.85	0.00	342.75	0.00	94.03	0.00	0.033	0.269	0.009	0.082	0.003	0.290	0.004
3 months	738.46	0.00	383.20	0.00	455.05	0.00	0.145						
6 Medication Costs													
Non-Prescription Medication													
9 months	2.97	0.00	4.62	0.00	2.55	0.00	0.450	0.366	0.758	0.293	0.489	0.090	0.971
3 months	2.39	0.00	5.51	0.00	2.54	0.00	0.109	0.075	0.901	0.155			
Prescription Medication													
9 months	158.04	165.00	163.01	179.00	160.88	169.00	0.494	0.257	0.503	0.640	-	-	-
3 months	158.04	165.00	163.01	179.00	160.88	169.00	0.494	0.257	0.503	0.640			
7 Equipment Costs													
Manual Wheelchair													
9 months	0.93	0.00	1.10	0.00	1.79	0.00	0.209	0.695	0.095	0.203	0.000	0.000	0.051
3 months	6.19	0.00	6.93	0.00	4.62	0.00	0.452	0.675	0.377	0.210			
Electric Wheelchair													
9 months	0.00	0.00	0.00	0.00	0.85	0.00	0.278	-	0.250	0.268	-	-	0.321
3 months	0.00	0.00	0.00	0.00	0.00	0.00	-	-	-	-			
Oxygen Equipment													
9 months	3.20	0.00	8.53	0.00	6.40	0.00	0.201	0.071	0.259	0.555	0.001	0.015	0.007
3 months	31.20	0.00	28.16	0.00	35.20	0.00	0.850	0.787	0.748	0.570			
Feeding Pump													
9 months	6.50	0.00	2.31	0.00	2.89	0.00	0.565	0.346	0.468	0.875	0.442	0.321	0.532
3 months	13.00	0.00	0.00	0.00	8.67	0.00	0.410	0.170	0.738	0.265			
Commode													
9 months	0.63	0.00	0.24	0.00	0.64	0.00	0.042	0.020	0.953	0.023	0.000	0.000	0.045
3 months	3.03	0.00	2.76	0.00	1.63	0.00	0.105	0.686	0.038	0.093			
Special Bed													
9 months	7.52	0.00	3.70	0.00	6.17	0.00	0.298	0.119	0.635	0.316	0.000	0.000	0.000
3 months	50.31	0.00	48.12	0.00	47.05	0.00	0.957	0.838	0.776	0.927			
Hoist													
9 months	4.93	0.00	1.75	0.00	4.38	0.00	0.390	0.176	0.851	0.266	0.023	0.375	0.374
3 months	22.16	0.00	5.25	0.00	9.85	0.00	0.083	0.038	0.194	0.479			

	Cost per Month (€)						Statistical Testing						
	Midlands		Mid West		South East		ANOVA[a]	Independent Samples T-Test[b]			Paired Samples T-Test[c]		
							Across Areas	Across Areas			9mth v 3mth		
								ML v MW	ML v SE	MW v SE	ML	MW	SE
	Mean	Median	Mean	Median	Mean	Median	p-value	p-value	p-value	p-value	p-value	p-value	p-value
Recliner (chair)													
9 months	1.22	0.00	0.22	0.00	0.27	0.00	0.079	0.065	0.119	0.875	0.058	0.070	0.038
3 months	4.26	0.00	2.60	0.00	4.06	0.00	0.690	0.411	0.931	0.491			
Other Equipment													
9 months	0.87	0.00	0.47	0.00	2.33	0.00	0.200	0.601	0.231	0.105	0.007	0.070	0.374
3 months	10.48	0.00	5.59	0.00	5.33	0.00	0.419	0.280	0.292	0.949			
Home Modifications													
9 months	12.71	0.00	17.78	0.00	102.52	0.00	0.017	0.685	0.030	0.050	0.875	0.182	0.075
3 months	2.08	0.00	15.11	0.00	13.89	0.00	0.612	0.321	0.332	0.950			
8 Informal Care Costs[d]													
Personal Care													
9 months	196.52	0.00	312.22	0.00	288.36	0.00	0.245	0.098	0.550	0.768	0.001	0.001	0.001
3 months	434.50	217.39	487.10	326.08	495.05	244.56	0.794	0.562	0.333	0.938			
Eating and Drinking													
9 months	22.38	0.00	203.73	0.00	50.05	0.00	0.009	0.011	0.884	0.055	0.000	0.016	0.002
3 months	191.05	0.00	324.35	0.00	201.25	0.00	0.205	0.118	0.941	0.209			
Toilet													
9 months	143.30	0.00	210.33	0.00	139.32	0.00	0.377	0.256	0.699	0.243	0.001	0.006	0.005
3 months	349.92	99.46	320.47	163.04	314.63	101.90	0.903	0.713	0.564	0.943			
Mobility Indoors													
9 months	148.74	0.00	209.83	0.00	115.45	0.00	0.327	0.369	0.291	0.139	0.012	0.121	0.049
3 months	344.40	53.80	274.39	71.74	238.14	0.00	0.537	0.479	0.452	0.682			
Medications													
9 months	137.03	54.35	90.94	0.00	110.10	45.29	0.362	0.177	0.519	0.518	0.004	0.007	0.036
3 months	207.56	135.87	161.99	54.35	173.43	108.69	0.644	0.359	0.033	0.826			
Household Tasks													
9 months	199.59	0.00	238.51	0.00	430.76	0.00	0.055	0.642	0.698	0.078	0.000	0.002	0.177
3 months	490.98	163.04	568.06	7.76	549.64	31.06	0.871	0.619	0.243	0.910			
Administrative Tasks													
9 months	33.71	0.00	32.05	0.00	56.06	0.00	0.317	0.909	0.688	0.183	0.064	0.009	0.346
3 months	63.12	0.00	77.29	0.00	74.03	0.00	0.858	0.569	0.216	0.915			

Notes:

a ANOVA is used to determine if there are any significant differences in the mean costs across the three areas.
b Independent samples t-tests are used to determine if there are any significant differences in the mean costs across the three areas by examining each individual pair.
c Paired samples t-tests are used to determine if within each area there is a significant difference in the mean costs, for those using a service in both the nine month and the three month periods.
d Where decedents lived in an institution for the entire last year of their life these questions were not asked.
e Milford Care Centre only.

A.6.2 COST ADJUSTMENT ANALYSIS

A.6.2.1 Utilisation Adjustments

In Appendix 4 a comparison of KI-reported data to supplementary data is conducted. Where a unit cost is available it is possible to calculate how the costs in the individual categories would change depending on the source of the utilisation data. It is only possible to conduct this comparison for palliative home care nurse visits and hospice in-patient stays.

Palliative Home Care Nurse Visits

Table A6.2 shows that using KI-reported community SPC nurse visits results in a higher mean cost per month reported across all study areas.

- In the three-month period in the Midlands and the Mid West, the estimated mean cost per month is approximately one-third higher than the mean cost based on visits reported by the community SPC team.
- The South East reported the lowest differential in the mean cost per month in the last year, with KI-reported utilisation yielding costs which were 17.4% higher than utilisation reported by the community SPC team.

TABLE A6.2 Cost Comparison for Community SPC Nurse Visits using KI-Reported and Community SPC Team Reported Visits

	KI-Reported Utilisation	Specialist Palliative Home Care Team Reported Utilisation
	Mean Cost per Month (€)	Mean Cost per Month (€)
Midlands		
9 Months	91.57	40.94
3 Months	434.08	292.06
12 Months	181.07	105.45
Mid West		
3 Months	364.07	239.92
South East		
12 Months	131.44	108.53

Notes: Supplementary data were not available for all time periods in all three study areas for reasons of local availability. See Appendix 4.

Permission to access decedent records was not provided by eight KIs; for this reason the visits for these decedents were not included for comparison in the above table and therefore the mean cost per month differs slightly to the costs that are presented for palliative home care nurse visits in Table A6.1.

In-Patient Hospice Stays

In-patient hospice stays comprise a large component of SPC costs in the Mid West.[2] Table A6.3 shows that the costs of in-patient hospice stays based on KI-reported utilisation of hospice visits are very similar to those based on the data provided by Milford Hospice. Costs based on KI-reported visits exceed costs based on the data provided by Milford Hospice by 2.6%.

TABLE A6.3 Cost Comparison for In-Patient Hospice using KI-reported and Milford Hospice Reported Stays

	KI-Reported Utilisation	**Milford Hospice Reported Utilisation**
	Mean Cost per Month (€)	Mean Cost per Month (€)
Mid West		
9 Months	149.71	127.73
3 Months	3,547.64	3,456.99
12 Months	999.19	960.05

Note: Permission to access decedent records was not provided by three KIs; for this reason the visits for these decedents were not included for comparison in the above table and therefore the mean cost per month differs slightly to the costs that are presented for in-patient hospice costs stays in Table A6.1.

A.6.2.2 Unit Cost Adjustments

Costs are presented adjusting the total costs (including informal care) presented in Section 4 and applying a multiplier of 10% (above and below). This is to allow for any possible under- or over-estimations in the unit cost calculations that were applied to the data.

Using the lower bound, the Table A6.4 shows that the total costs (including informal care) range from €50,556.2 in the South East to €59,907.9 in the Mid West in the last year. Using the upper bound, total costs (including informal care), range from €61,790.9 in the South East to €73,220.8 in the Mid West.

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[2] Table A6.1 shows the components of specialist palliative care costs by time period and area. The Mid West is the only region with an in-patient hospice unit within its catchment area, thus comprising a larger component of its overall costs compared to the other areas.

TABLE A6.4 Total Costs (Incl. Informal Care): Cost Adjustment Analysis (€)

	Midlands		Mid West		South East	
	Mean	Median	Mean	Median	Mean	Median
(1–8) Total Costs (Incl. Informal Care) - 10%						
9 months						
Cost per month	3,475.3	3,492.4	3,626.0	2,624.7	2,927.7	2,708.9
Total cost – 9 months	31,277.3	31,431.4	32,633.8	23,622.6	26,348.9	24,380.2
3 months						
Cost per month	8,127.7	6,855.3	9,091.4	7,574.2	8,069.1	6,662.9
Total cost – 3 months	24,383.0	20,565.9	27,274.1	22,722.7	24,207.3	19,988.6
12 months						
Cost per month	4,638.4	4,212.3	4,992.3	4,234.8	4,213.0	3,866.7
Total cost – 12 months	55,660.3	50,547.7	59,907.9	50,817.1	50,556.2	46,400.7
(1–8) Total Costs (Incl. Informal Care) + 10%						
9 months						
Cost per month	4,247.5	4,268.5	4,431.7	3,208.0	3,578.2	3,310.9
Total cost – 9 months	38,227.8	38,416.2	39,885.7	28,872.1	32,204.2	29,798.0
3 months						
Cost per month	9,933.8	8,378.7	11,111.7	9,257.4	9,862.2	8,143.5
Total cost – 3 months	29,801.4	25,136.2	33,335.1	27,772.2	29,586.7	24,430.6
12 months						
Cost per month	5,669.1	5,148.4	6,101.7	5,175.8	5,149.2	4,726.0
Total cost – 12 months	68,029.2	61,780.5	73,220.8	62,109.8	61,790.9	56,712.0

A.6.3 COSTS AND OUTCOMES – EXPLORATORY ANALYSIS

As discussed in Section 4.7, the POS and Quality of Life outcome measures used in this study failed to find valid significant differences across study areas. It was not considered appropriate to present a joint analysis of costs and POS/Quality of Life outcomes across the three study areas in the main report, given that any differences would be driven by differences in costs. A possible methodology for considering this type of joint analysis is however presented here, which may contribute toward carrying out such an analysis if valid differences are detected in these outcome measures in other studies. For this analysis, the focus is on the Palliative Outcomes Score presented in Section 4.5.3.

A.6.3.1 Methodology

Cluster Analysis

While full multivariate analysis is beyond the scope of this study, in order to control for patient characteristics to some degree the comparison of costs and POS outcomes for subsets of the sample is categorised by decedent relative wellbeing in the first nine months of the last year of their life. This is done to facilitate comparison of similar groups of decedents across areas. The responses to the five dimensions used to assess the decedent's quality of life (Section 4.7.2) in the nine-month period were used to divide the decedents into groups using hierarchical cluster analysis. This process resulted in two groups of decedents, those with:[3]

1) relatively *poor* quality of life in the nine-month period (117 decedents)
2) relatively *better* quality of life in the nine-month period (88 decedents).

Similar proportions of decedents in each area were found in each cluster, that is 41.4% of decedents in the Mid West, 45.3% in the Midlands, and 41.6% in the South East were allocated to the 'better' outcomes cluster (p=0.869).

Cost-Outcomes Score

Each cost and outcome measure was scaled to values between zero and four, where zero refers to the lowest possible cost and the best possible outcomes. Therefore the best possible outcome is zero on the cost scale and zero on the outcomes scale i.e., the decedent achieved a good outcome with no cost. For this analysis figures were generated for POS measures which showed some indication of significant differences across the three areas (see Section 4.7.2) The figures illustrate the relationship between costs and outcomes in each of the study areas.

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[3] 10 decedents were excluded as responses were not provided for the quality of life indicators in the nine-month period.

A *cost-outcome score* is also calculated for each decedent by combining the re-scaled cost and outcome values. Lower cost-outcome scores can indicate more cost-effective care (lower cost score combined with better outcome score).[4] The mean cost-outcome score across all decedents is presented for each area.

A.6.3.2 Comparison of Formal Care Costs in the Last Year of Life with POS Scores in Last Week of Life

Figures A6.1 to A6.3 present an analysis of formal care costs in the last year of life compared to the outcomes for POS 1 (Affected by pain), POS 3 (Decedent anxious or worried) and POS 7 (Feeling depressed) in the last week of life.[5] [6] Figures are presented for total decedents, and for the clusters of decedents; those with poor and relatively better outcomes in the first nine months of the year.

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[4] sqrt (Cost^2 + Outcome^2) where the worst cost or outcome value is four. The lowest possible cost-outcome score is zero and the highest is 5.66

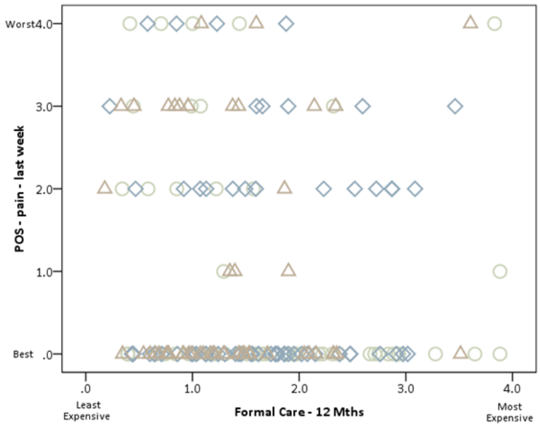
[5] Decedents who were in a coma or unconscious in the last week of life were not included.

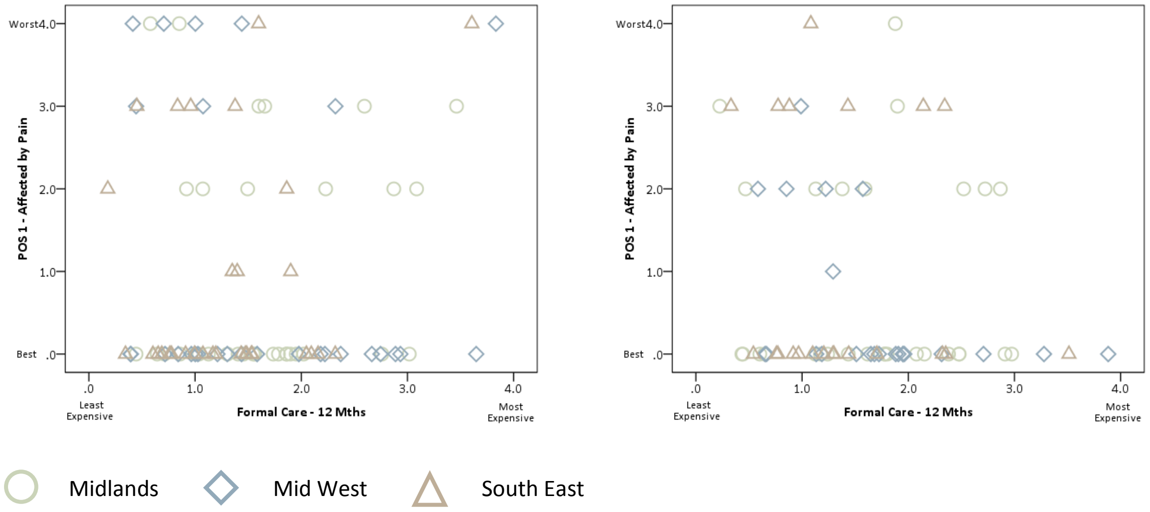
[6] Analysis was also run for costs in the last three months of life but there was no difference in the results.

For total decedents and within the two clusters of decedents, the outcomes are mainly very good for the majority of decedents i.e. concentrated at 0 on the y-axis (see Section 4.6). However, the costs for formal care are seen to vary substantially.

FIGURE A6.1 Formal Care Costs (12 Mths) and POS 1 (Affected by Pain) Outcome Scores

Total Decedents

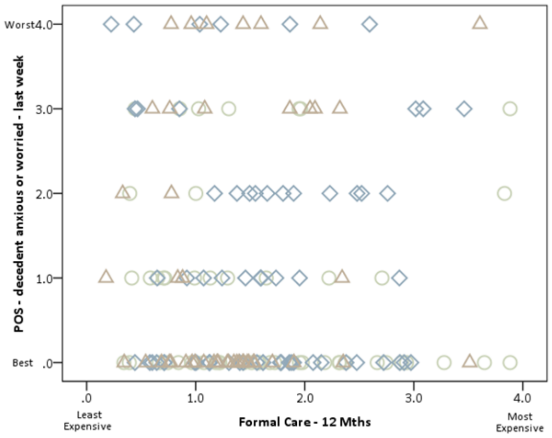


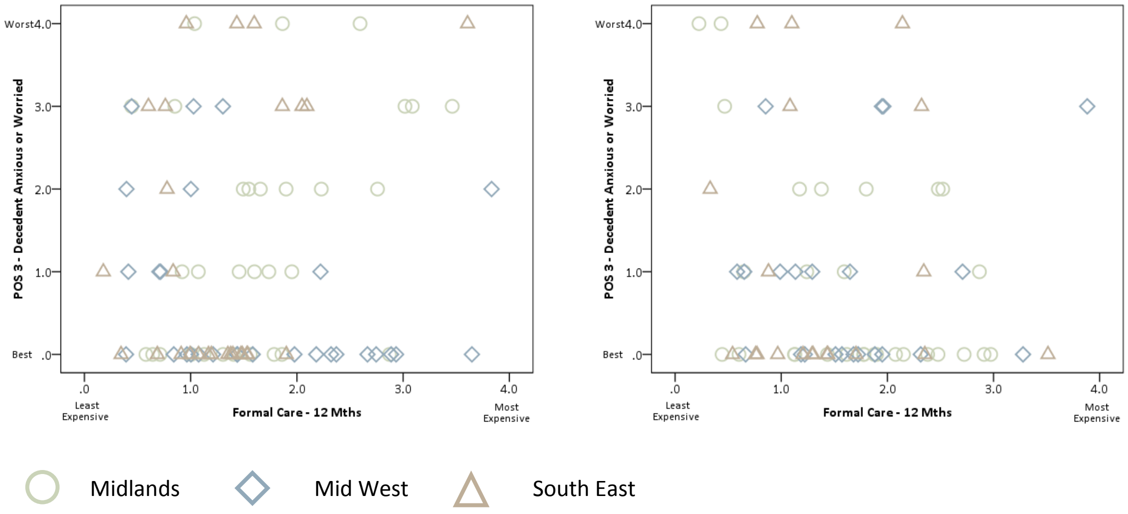

Relatively poor outcomes in nine-month period

Relatively better outcomes in nine-month period

FIGURE A6.2 Formal Care Costs (12 Mths) and POS 3 (Decedent anxious or worried) Outcome Scores

Total Decedents

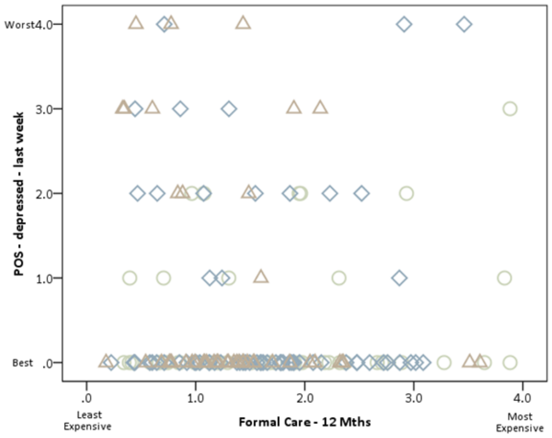



Relatively poor outcomes in nine-month period

Relatively better outcomes in nine-month period

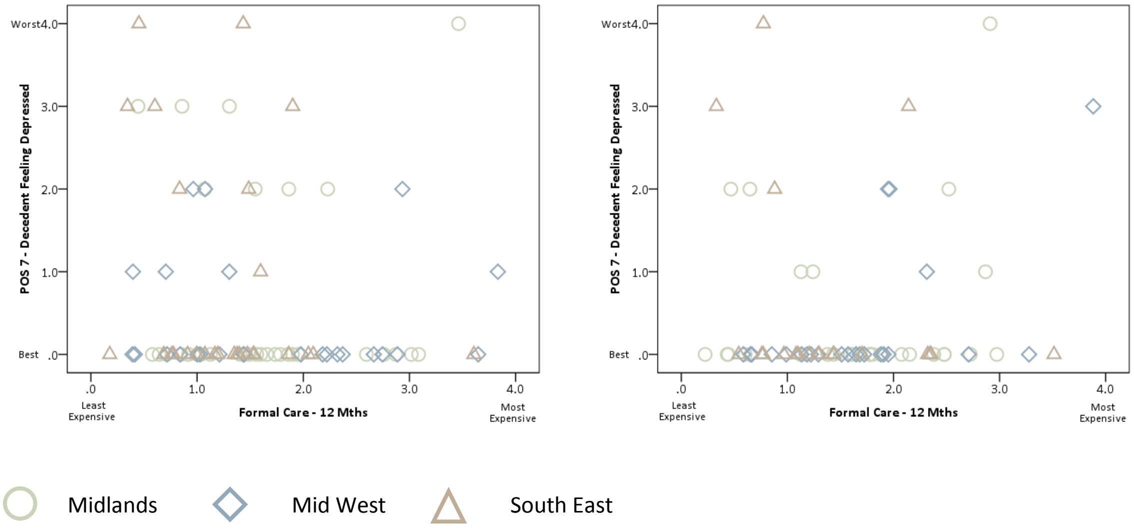
FIGURE A6.3 Formal Care Costs (12 Mths) and POS 7 (Feeling Depressed) Outcome Scores

Total Decedents



Relatively poor outcomes in nine-month period

Relatively better outcomes in nine-month period



There are however no significant differences in the cost-outcomes scores for the POS items presented in Table A6.5 across the three study areas. What is clear from the cost-outcome scores is that for the POS items presented, the difference in scores between those in the poor outcomes cluster and those in the relatively better outcomes cluster is small with the relatively better outcomes group having slightly lower (i.e., better) summary scores. For POS 3 and POS 7, the Midlands had a slightly higher (i.e. worse) summary score; however these differences were not statistically significant.

In the absence of evidence of better outcomes, the ratios of costs and outcomes are effectively determined by differences in costs. The issues around the measurement of outcomes and assessing cost-effectiveness in this study are discussed further in Section 5.

TABLE A6.5 Summary Cost-Outcome Score – Costs (12 Mths) and Palliative Outcome Score (Last Week)

		Midlands	Mid West	South East	ANOVA p-value
POS 1 Affected by Pain	Total Decedents	2.18	2.22	1.97	0.454
	Relatively poor outcomes	2.20	2.38	1.87	0.262
	Relatively better outcomes	2.14	2.00	2.11	0.878
POS 3 Decedent Anxious or Worried	Total Decedents	2.30	2.05	2.15	0.503
	Relatively poor outcomes	2.42	2.06	2.15	0.496
	Relatively better outcomes	2.21	2.09	2.15	0.922
POS 7 Feeling Depressed	Total Decedents	1.97	1.84	1.86	0.775
	Relatively poor outcomes	2.03	1.90	1.87	0.824
	Relatively better outcomes	1.89	1.80	1.85	0.950

While this analysis may not have shown any statistically significant results, the cost-outcome score it is a potentially a useful summary tool for presenting costs and outcomes in a joint analysis.

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