

SHEFFIELD PCT
SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST
SHEFFIELD CITY COUNCIL
ST LUKE'S HOSPICE

Identifying Alternatives to Hospital for People at the End of Life

REPORT OF FINDINGS

The Balance of Care Group
in association with the National Audit Office

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5 September 2008

Executive Summary

This report presents the key findings from a project undertaken with Sheffield health and social care organisations, in conjunction with the National Audit Office value for money study on the delivery of end of life care (EOLC) services in England. The aim of the project in Sheffield has been to explore the potential for change in care pathways for people at the end of life, and in particular to consider alternatives to patients dying in hospital.

The central focus of the project was a retrospective survey based on hospital medical records of 348 out of 420 adults in Sheffield PCT who died in October 2007, and were known to Sheffield Teaching Hospitals NHS Trust. Over half the patients died in hospital and the survey was able to identify and review case notes for 200 of the 215 people who died in hospital that month, and to assess whether alternatives to hospital stay might have been possible if appropriate services and clinical processes had been in place. The survey was undertaken by experienced clinical staff with particular interest in issues of end of life care.

Some key findings from the survey were:

- As expected, most people dying were over 65
- Using Gold Standard Framework categories, frailty (42%) was more common as the underlying reason for dying than cancer (30%) or chronic disease (20%). 8% were assessed as dying ‘unexpectedly’.
- Up to 25% of those dying may have had dementia.
- Over half (52%) died in hospital, including 2% on a palliative care unit; of the 18% dying at home about half were cancer patients, and a quarter in the frailty group.
- Surveyors identified alternatives to dying in hospital for 80 out of 200 surveyed (40%), evenly split between home based and bed based alternatives.
 - Cancer patients mainly needed palliative care
 - Frail patients needed services involving general or specialist nursing, with some palliative care as part of their overall end of life care.
 - For chronic disease patients alternatives were only identified for 7 out of 44 patients dying in hospital (16%)
- Care home residents who die in hospital are more likely to have had an admission which might have been avoided than others. Overall over 60% of residents dying did so in their own care home.
- Allowing for people who died but were not included in the survey, only 26% of those living in their own homes died there.
- Clinical decisions about death are often made at a late stage so that there is not enough time to consider alternatives.

Additional data sets from other services with a particular role in end of life care were also obtained and linked to the survey data. These demonstrated that:

- Community and hospital based palliative care nurses had high levels of contact with cancer patients, but not with other patient groups.
- Specialist nurses (COPD, heart failure) had little contact with patients at the end of life, though some had been referred on to general nursing services.

- Social care contact with people at the end of life was high, especially for the frailty group and those for whom alternatives to dying in hospital could be considered.
- There is variability by GP practice in the proportion dying in hospital.

If people are to have greater choice of where they die, especially if they wish to die at home, a number of developments are needed:

- Earlier clinical decisions that the patient is nearing the end of life
- Additional services, in particular nursing led services outside hospital, and some additional palliative care services
- An extended advisory role for palliative care and chronic disease specialists
- An integrated approach to organizing and sharing care of patients, in line with that required to improve general services for patients with frailty and dementia
- Investment in change management related to recently delivered community information systems.

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1. PROJECT BACKGROUND AND METHODOLOGY

Introduction

The National Audit Office (NAO) is undertaking a study of end of life care, particularly around the issue of dignity and dying. examining the health and social care services available to help older people with dementia and their carers to maintain good physical and mental health for as long as possible. The NAO is addressing the following questions:

- Do PCTs have sufficient skills and information to commission end of life services in the most appropriate settings, within an agreed strategy?
- Are services distributed consistently and equitably?
- What barriers do people face in accessing end of life care services in a setting that reflects their personal choice or, if appropriate, their clinical needs?
- Does current provision ensure that a high quality end of life care service that respects patient choice and dignity is delivered to all?

The study has several simultaneous work streams one of which is the project detailed in this report; an in-depth study of all people dying in a single month within a local health and social care economy. This project has been concerned to provide evidence about current access to services at the end of life and in particular:

- An assessment of the extent to which admissions could be avoided or length of stay reduced if alternative approaches to end of life care were introduced
- A description of how the whole system operates and how different services interact with each other
- Evidence regarding good practice, and the potential for more cost-effective approaches

Important issues here are whether appropriate alternative care settings might be identified for future development, and how this might vary between different patient groups, in particular those with cancer, chronic disease, or frailty.

The survey work was undertaken in Sheffield. As well as providing data for the overall NAO study, the project was designed to provide insight and support for local requirements in taking forward end of life care and developing service delivery models. This report summarises key findings from the survey with respect to these local issues, and provides a case study for inclusion in the NAO national report.

Structure of the Report

The report has six main sections, with sections 2-5 covering the main survey results in a series of summary graphs and commentaries (Note that each graph indicates the total number of patients relevant to that particular analysis). The sections cover:

1. The principles and methodology underlying the project including a description of the survey organisation.
2. Characteristics of people who died.
3. Where people died.
4. Potential alternatives to dying in hospital.
5. What affects the end of life experience.
6. Discussion and conclusions.

Methodology

For its PCT baseline review of services, the Department of Health has adopted as a working definition of ‘end of life’ the period of up to 12 months leading to death. Since this can only be determined retrospectively, there is a further ‘surprise’ question to aid consideration of appropriate service responses for individual patients: “Would you be surprised if this patient were to die in the next 12 months?” We note that this includes patients with many different long term conditions and their care needs may include, but not be restricted to, palliative care.

The Balance of Care survey undertaken for the recent NAO report on dementia used a *point prevalence survey* to identify people with dementia in hospital beds, and from this to identify potential alternative approaches to care delivery. For a focussed study of End of Life Care (EOLC) within the time available some adaptation of this methodology was required and instead we set out to undertake a *retrospective* survey of all people dying in a single PCT over a given period. The Balance of Care Group has used such sampling approaches in several recent targeted surveys of emergency short stay admissions to acute hospitals.

We approached Sheffield NHS organisations with a view to undertaking this exercise there. Sheffield was seen as a particularly suitable location because the PCT is fairly ‘self contained’. Most residents use the single local hospital Trust for most general acute services: this has allowed us to use the hospital patient administration system (PAS) to identify not only patients who have died in hospital but also patients who have subsequently died elsewhere (a good medical records service will keep its patient master index updated from death registrations, as is the case in Sheffield). In addition, although there were substantial initiatives underway to improve services for end of life care there, the area was not involved in a Marie Curie Delivering Choice Programme.

In many previous studies of acute hospital activity and bed usage we have used a recognised clinical benchmark tool, the *Appropriateness Evaluation Protocol (AEP)*¹, to identify patients whose care needs might not require an acute hospital setting (see appendix I). This protocol is relevant to end of life care issues but we have recognized that for people at the end of life acuity is not the only factor when alternatives to acute hospital are being considered. In consultation with Sheffield colleagues we set out to collect data that was of particular relevance to considerations of alternative approaches to end of life care. In particular we have aimed to:

- Use the Gold Standard Framework (GSF)² classification of patients at the end of life. The GSF developed in 2001 from clinical experience in primary care, as a grass roots initiative to improve primary palliative care and collaboration with specialists. Since 2004 the framework has been adapted for use in care homes and a new GSF in Care Homes programme has been developed. The GSF classifies people who die into four main groups:
 - Cancer
 - Chronic disease
 - Frailty
 - Unexpected

Full definitions are attached at appendix II.

- Identify the extent to which advance care planning (eg Liverpool Care Pathway) was undertaken for the patient.

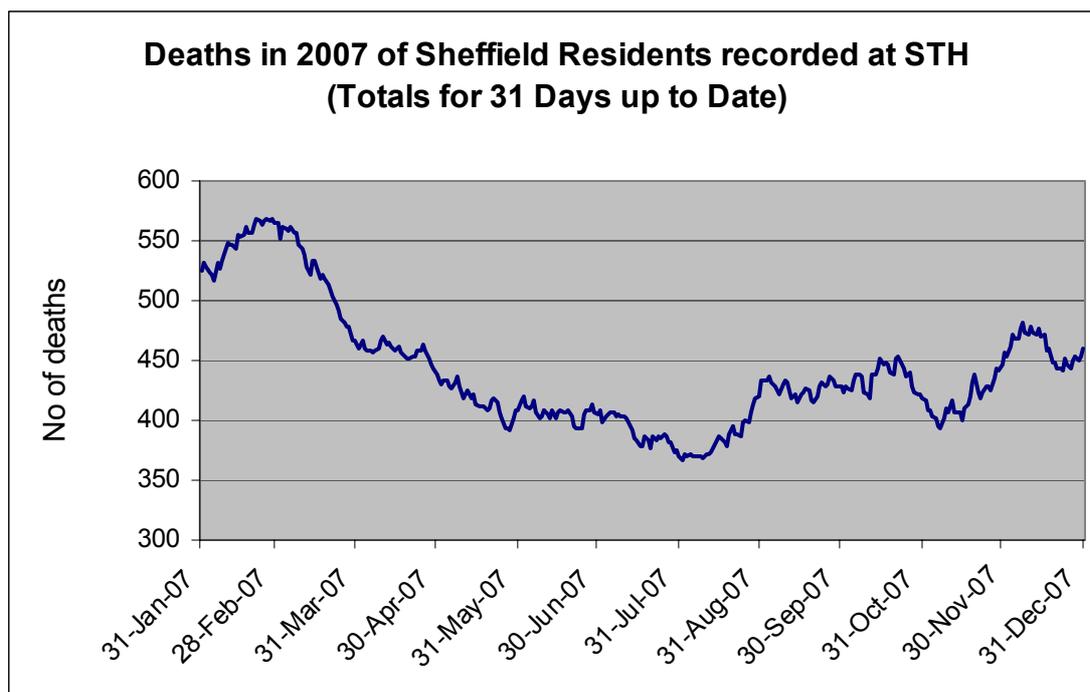
Survey Organisation

The survey was undertaken with the support of the four major organizations involved in Sheffield:

- Sheffield Teaching Hospitals NHS Foundation Trust (STH)
- Sheffield PCT (SPCT)
- Sheffield City Council
- St Luke's Hospice

A Steering Group was set up including representation from all organizations, with substantial clinical interests included. Many of those involved were already members of the Sheffield Palliative Care Committee, the lead collaborative forum for developing services across Sheffield. Membership is listed at appendix III. The first meeting of the group took place on 6 February 2008, with the substantial survey of patient case notes undertaken in the week commencing 7 April 2008. A senior group of clinicians, including many Steering Group members, undertook the survey work, as listed in appendix IV.

To undertake a retrospective study, we needed to choose an appropriate time period for review, and so we followed our normal practice of aiming for a comprehensive survey of all patients within the selected group. Data provided from STH showed an expected level of seasonality with deaths some 25% higher in the winter months. In the event we selected October 2007 as a representative month. There were pragmatic considerations here also in that we needed to ensure good access to medical records, so did not want to undertake the survey too soon after the time of death, but also not too much later as notes might then have been archived.



Altogether 420 deaths in October 2008 of Sheffield PCT patients known to STH were identified, with slightly over half dying whilst in hospital as an inpatient. Our main focus was on people dying in hospital and the potential for alternatives, but there was also considerable interest in the extent to which those dying elsewhere could be considered to be in a desirable pathway. Since many would have had recent contact with STH it was agreed that a suitably modified survey form would be used for these patients also.

Data collected on Survey Forms

As well as identifying patients that were potentially suitable for alternative care settings, the survey also recorded data on:

- when - and by what referral route - the patient was admitted to the hospital and who admitted them.
- reasons for admission; co-morbidities; and any individual risk factors (for example, whether the patient was on a multiple drug therapy or lived alone).
- mental state (dementia; confusion; psychoses; anxiety/ depression; substance misuse)
- whether the patient had a discharge plan and any reasons which appeared to be contributing to delays to their care process.

Many of the items above required clinical expertise to identify the facts from the notes. Clinical judgement was applied only to the assessment of whether alternatives to hospital stay were viable and what these might be. As far as possible these were defined in terms of the care process needed to support the patient rather than a specific service (eg *non-acute bed* rather than *care home*): definitions used are listed at appendix V.

Linked Data Sources

The approach of using hospital case notes to identify patient characteristics and care needs is a productive one and the richest source of information when hospitalisation forms part of the care pathway. However because we were interested in all aspects of care in the last 12 months up to death, we also investigated the potential for supplementary data to be drawn from information systems other than the hospital PAS. We were able to identify and link data from:

- Death certifications as supplied by the Registrar to the PCT
- Palliative care contacts recorded on the *Infoflex* system for
 - Community based palliative care nurses
 - Hospital support palliative care
- Heart failure and COPD (Chronic Obstructive Pulmonary Disease) specialist nurse contacts as recorded on the *TPP SystemOne* community and GP system. In the event the extent of recording, in October 2007 at least, was insufficient, but from the main survey it was possible to identify all patients with heart failure or COPD comorbidities and identify the extent of specialist involvement from office records.
- Social care contacts. The City Council system was able to identify all assessments, supply of equipment and adaptations, home care, support to care home residents and other contacts in the last year of life.
- Chaplaincy contact with inpatients

These data items have been linked to survey data, and analyses are included in the relevant parts of the report

Confidentiality issues

Approval was sought and obtained from the Caldicott Guardians responsible in each of the participating organisations. Data for the survey were abstracted from each patient's medical, nursing and therapy notes. Once entered onto a structured 'Access' database by Balance of Care Group analysts all patient-specific data were anonymised. All surveyors and project team members signed a data confidentiality form designed for the project.

Analyses

In line with our normal practice with analyses based on survey data recorded by clinical colleagues, we first held feedback sessions with surveyors, followed by a full Steering Group session and subsequent meetings and presentations to Sheffield colleagues and key clinical and managerial committees. In this way, survey findings have been subject to extensive discussion and interpretation in a range of feedback sessions, workshops and presentations.

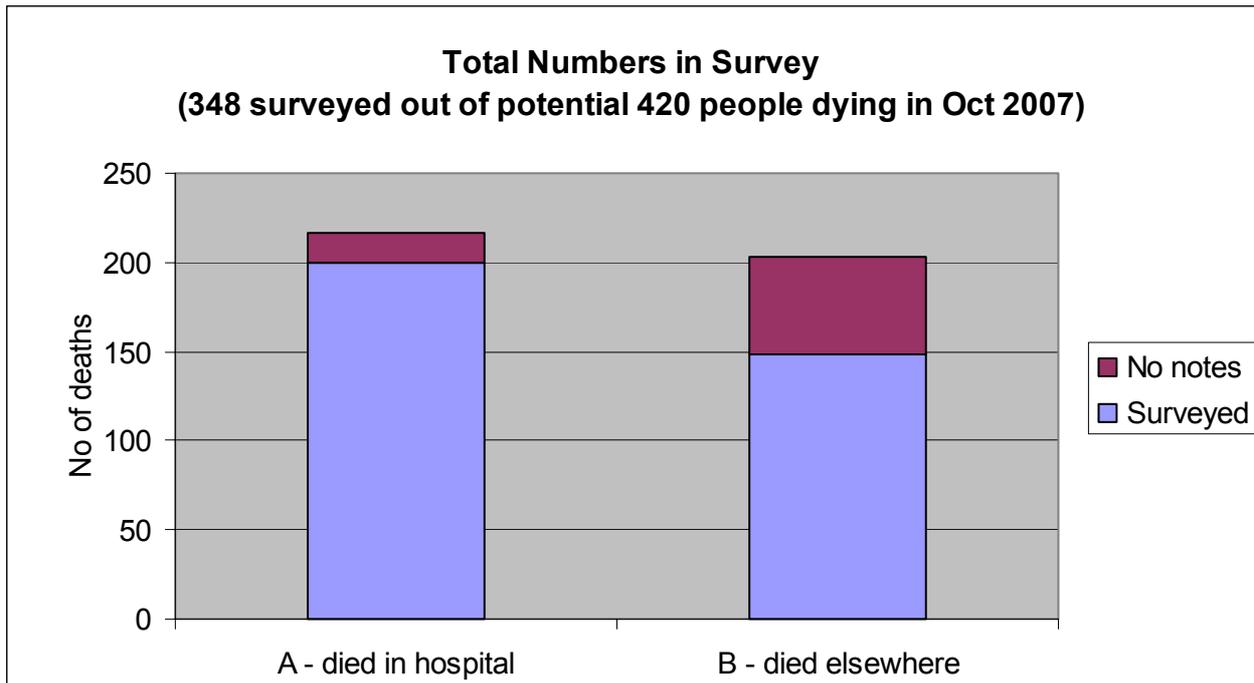
It should be noted that the survey database is rich and can be analysed in many different ways: there is potential for substantial further discussion and evaluation of the implications of the data summaries, and for more detailed review of the interaction of different factors. Results presented here are those we feel contribute most to understanding the potential for change in the current health economy.

SECTION 2: Characteristics of People who Died

Each figure in this section is accompanied by a more detailed commentary, but key points are:

- Hospital case notes were reviewed for 348 out of 420 Sheffield PCT residents who died in October 2007 and who were known to Sheffield Teaching Hospitals, including 200 out of the 215 who died in hospital (figure 2.1).
- The distribution of age at death was in line with most population death statistics (figure 2.2).
- The use of the Gold Standard Framework patient groupings showed 30% with cancer, 20% with chronic disease and 42% in the frailty group (figure 2.3).
- The median age at death was 82, but lower for cancer (75) and chronic disease (73) groups (figure 2.4).
- No deaths were identified of people from Indian or Pakistani ethnic groups, which was within the normal statistical ranges, but highlighted that ethnic groups do not necessarily have higher age adjusted mortality rates (figure 2.5).
- Dementia was present in up to a quarter of the patients who died (figure 2.6).

Figure 2.1



Of Sheffield PCT patients known to the hospitals and registered on the hospital Patient Administration System (PAS), 420 were identified as having died in Sheffield in October 2007. This is close to the 402 identified by the PCT from registrar data. There will be various reasons for the discrepancy: the registrar is recording PCT of residence rather than PCT of the patient's GP, and in Sheffield this is likely to undercount slightly the registered population dying; on the other hand there will be some Sheffield patients not known to the hospitals who died. We have not attempted to fully reconcile the data sets, but note that neither method exactly identifies the registered PCT population.

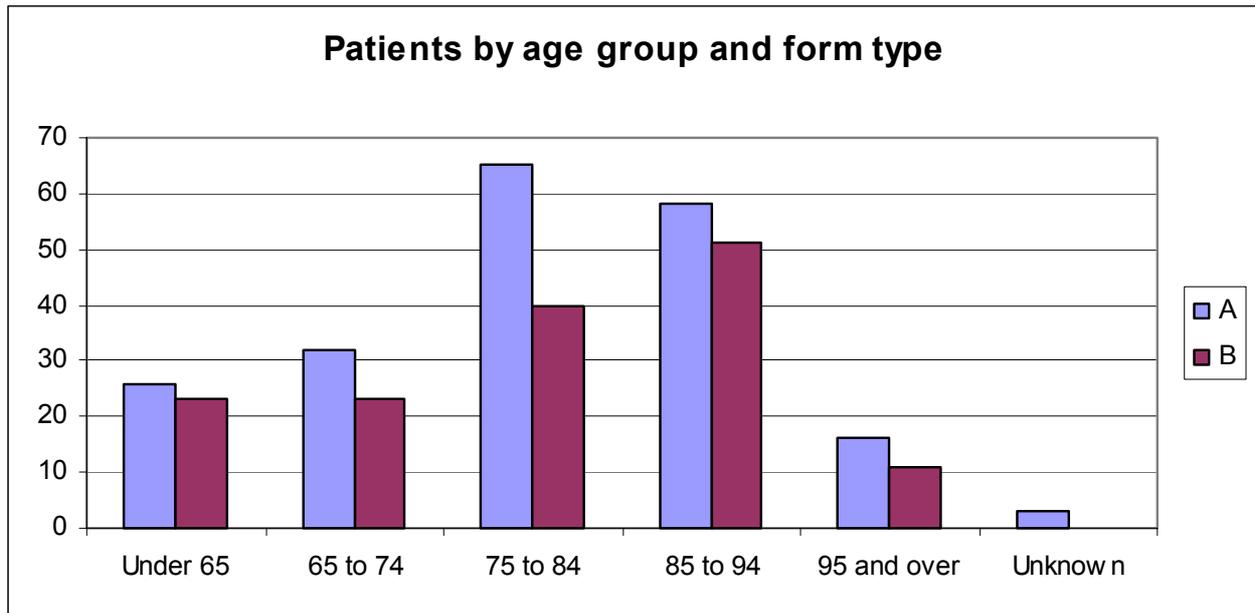
Of the 420 identified, 215 did so in hospital (seven in hospitals other than STH) and, of these, 200 sets of notes were surveyed (92%) and the data recorded on survey 'form A'. The remainder (205) died elsewhere and data were recorded on survey 'form B': this includes patients who died in the A&E department or were certified dead on arrival at hospital (such patients are usually identified as 'dying in hospital' in analyses of registrar data).

In total, across both of these groups 348 patients were surveyed. The coverage of patients dying in hospital was high, with notes not found for only a small number (even after six months it is possible that some notes are still being used for various follow up activities)

More of the notes of patients who died elsewhere will be 'missing' as some will not have had any contact with STH in the twelve months prior to their death (and hence no recent notes). Survey coverage of these patients was 73%.

Because STH uses separate notes in the three main hospitals (Northern General, Royal Hallamshire and Weston Park) there were instances for which details of the final spell were missing or incomplete, as not all the different case note folders could be found. This applied to 26 of those who died in hospital, and 14 of those who died elsewhere but had had a hospital admission in the last 12 months of life. However using our additional data sources (see section 1) it was possible to establish most survey data items.

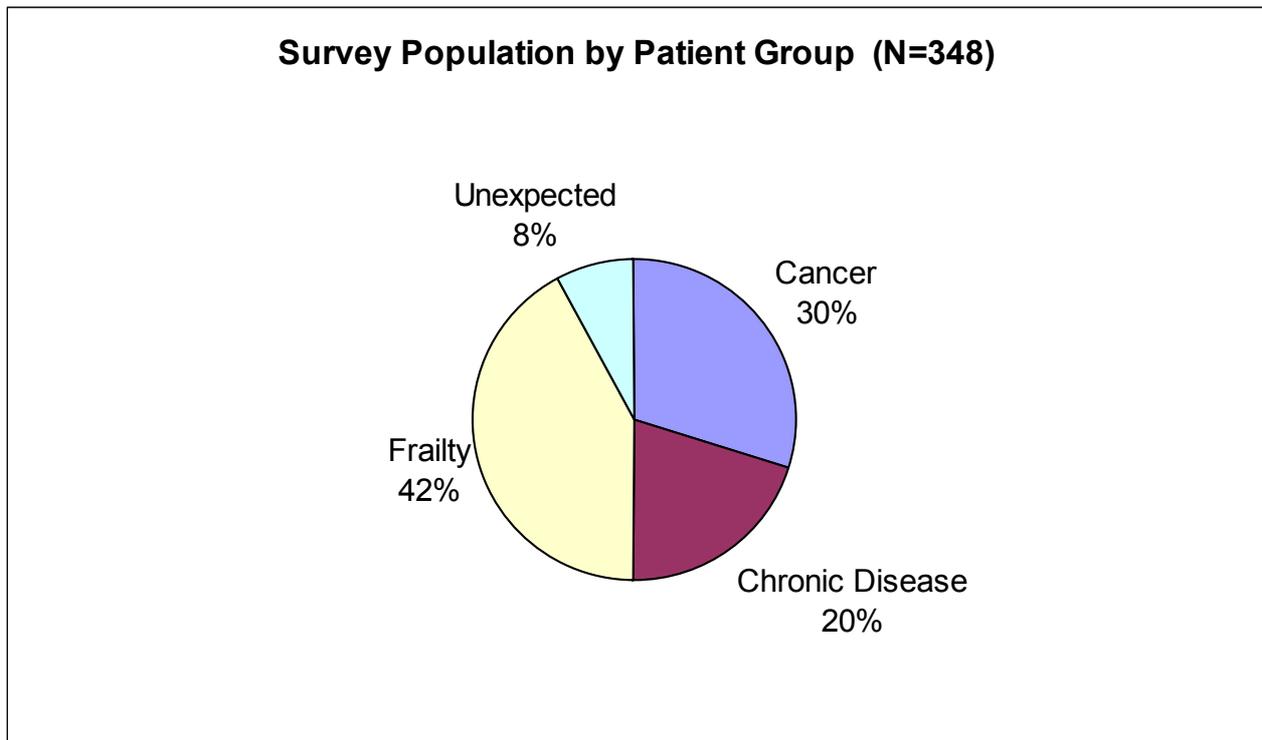
Figure 2.2



The age mix of patients surveyed was as expected, with most people who died over the age of 65.

There are proportionately more 'form B' patients over the age of 85 dying out of hospital, which is a reflection of the age mix of care homes (more details on care home residents at figures 3.6 and 4.5).

Figure 2.3



Using the Gold Standard Framework (GSF, see appendix II), patients were classified into groups by their principal diagnostic category on death.

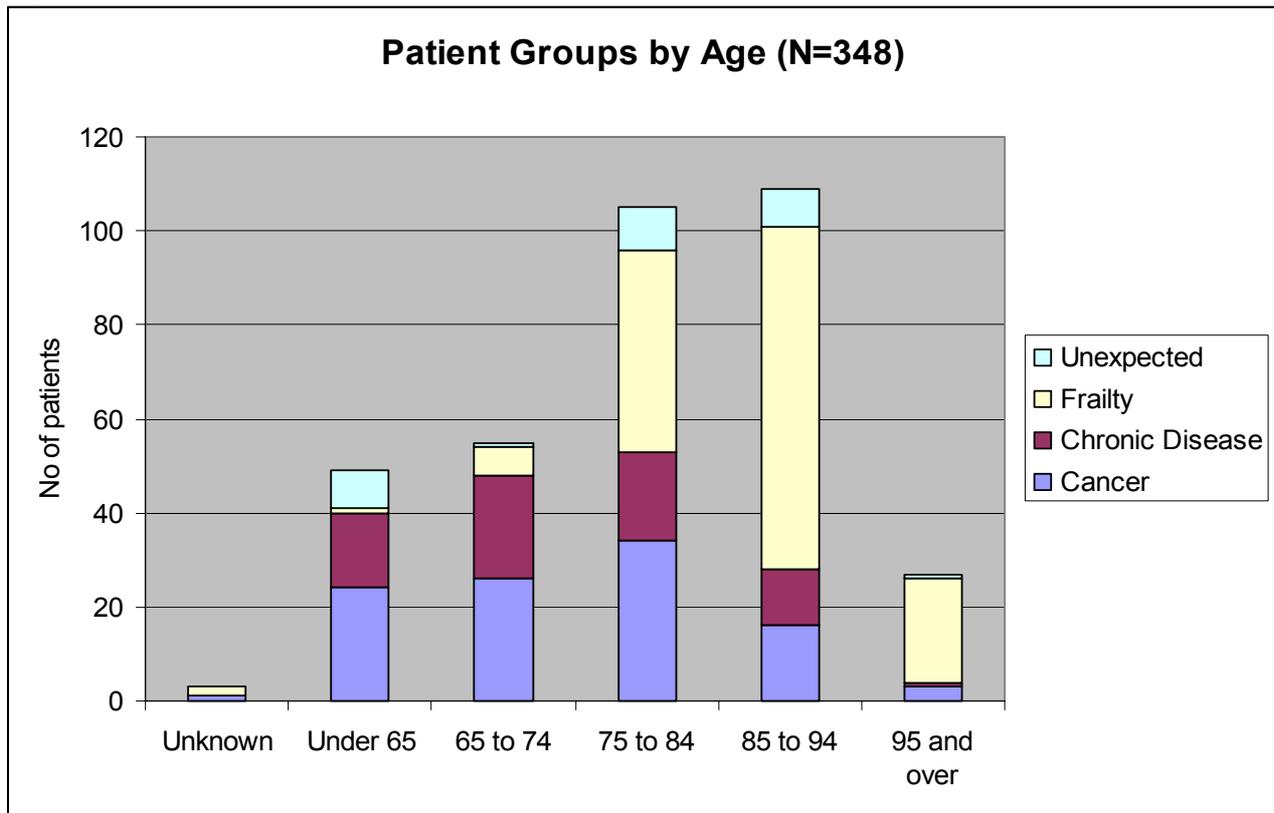
The rule of thumb for the GSF patient groupings is that the three main groups are usually found to be approximately equal. However the survey population shows more patients in the frailty group and fewer solely with a single chronic disease. Grossing up the survey data to allow for the relative under-reporting of ‘form B’ patients does not change these percentage figures.

In part this may reflect the relative success of managing single long term conditions, so that for these individuals it is not until they are older and more frail (and possibly with multiple comorbidities) that they reach the end of life. For example the percentages by patient group for patients with heart failure, chronic obstructive pulmonary disease (COPD) and dementia identified respectively (and note that these groups are not mutually exclusive) were:

Patient Group	Heart failure	COPD	Dementia
Cancer	17%	20%	5%
Chronic Disease	33%	21%	9%
Frailty	46%	51%	83%
Unexpected	4%	8%	3%
Number in survey	48	66	65

As might be expected the majority of people with dementia were in the frailty group, but this was also the case for about half the patients with heart failure or COPD when these were often one of a number of comorbidities.

Figure 2.4



The GSF patient grouping is strongly correlated with age. Most people who become frail are over 75. Deaths in the cancer and chronic disease groups tend to be at younger ages, with median ages at death in our surveyed populations of 75 and 73 respectively, compared to an overall median value of 82.

When interpreting results in this report it is important to recognise the difference between the GSF grouping and those generated by analysis of hospital (HES) or registrar data. Clinical coding in hospital will record the patient's 'main diagnosis' using ICD codes, and death certification will record the main cause of death which can often be the result of subsidiary infections or illness (eg pneumonia, sepsis). These tend to be the dominant variables used to record patient characteristics at death, and this may lead to an emphasis on individual chronic disease rather than frailty.

Further checks of data from death certifications and main diagnoses of surveyed patients show that the surveyed patients tend to follow similar patterns to other published data from these sources (eg 25% of cancer deaths are from lung cancer, pneumonia the recorded cause of death in 20% of cases). These analyses are not included in this report but are available from the authors on request.

Figure 2.5 Ethnicity of Patients Surveyed

Ethnic group	Number	%
White British	321	92%
White European	5	1%
White not specified.	11	3%
Black Caribbean	3	1%
Asian	2	1%
Not identified	6	2%
Total	348	100%

Data on ethnicity was available from the hospital PAS, and this was supplemented where available by information in the patient notes. Unsurprisingly the majority of patients were ‘white British’, and in the few unidentified cases the names suggested that this was also the case.

The surprising feature was the total absence of any Indian, Pakistani or Bangladeshi patients in the survey (the two Asian patients to die were Yemeni and Chinese respectively). Checking the registrar data available to Sheffield PCT for the whole year 2007 identified that 40 had died with monthly totals varying from 0 to 7. Thus no deaths in the month was an extreme value but within the normal range.

Nevertheless relative to the Indo-Pakistani population this would still represent a low death rate, given the younger age range of the population mortality might be standardise to the average, but not to higher level than the rest of the population.

Another possible explanation suggested to us is the so-called ‘salmon effect’ whereby older people in immigrant communities return to their home country at the end of life. This is the subject of epidemiological study elsewhere without any clear conclusions [ref 6].

In line with this ethnicity profile, only Christian religions were identified from both the hospital PAS and the hospital case notes, Christian religions being reported in 234 out of 348 cases (67%). Only two patients were recorded as atheists, and one as a Muslim. No information was available for the remainder.

Figure 2.6 Other Risk Factors

Living alone	76	22%
Housing	7	2%
Carer Incapacity	18	5%
Dementia	65	19%
Confusion (no dementia diagnosis)	43	12%

In line with previous surveys of hospital bed usage we attempted to identify other factors that put people at increased risk of hospitalisation. Whereas we may expect the recording of living alone to be accurately recorded in hospital case notes, it is less likely that information regarding carer incapacity or housing quality would always be entered. Of the former the proportion living alone was the same amongst those dying in hospital and those dying elsewhere (this figure affected by the numbers in care homes).

Again following our normal practice we looked for mental health and cognitive issues amongst the population dying. There was some recording of alcohol or other substance misuse (18, 5%) and psychosis (6, 2%). Depression is often not recorded in hospital notes, and in this case 16 out of 348 (5%) were recorded as having depression.

More substantial is the recording of dementia, a diagnosis being present in 19% of the patients who died. Based on our special study for the NAO on dementia last year [7], we would also expect up to half of those patients identified as having confusion to have undiagnosed dementia. This would imply that as many as a quarter of our survey population were suffering from dementia when they died.

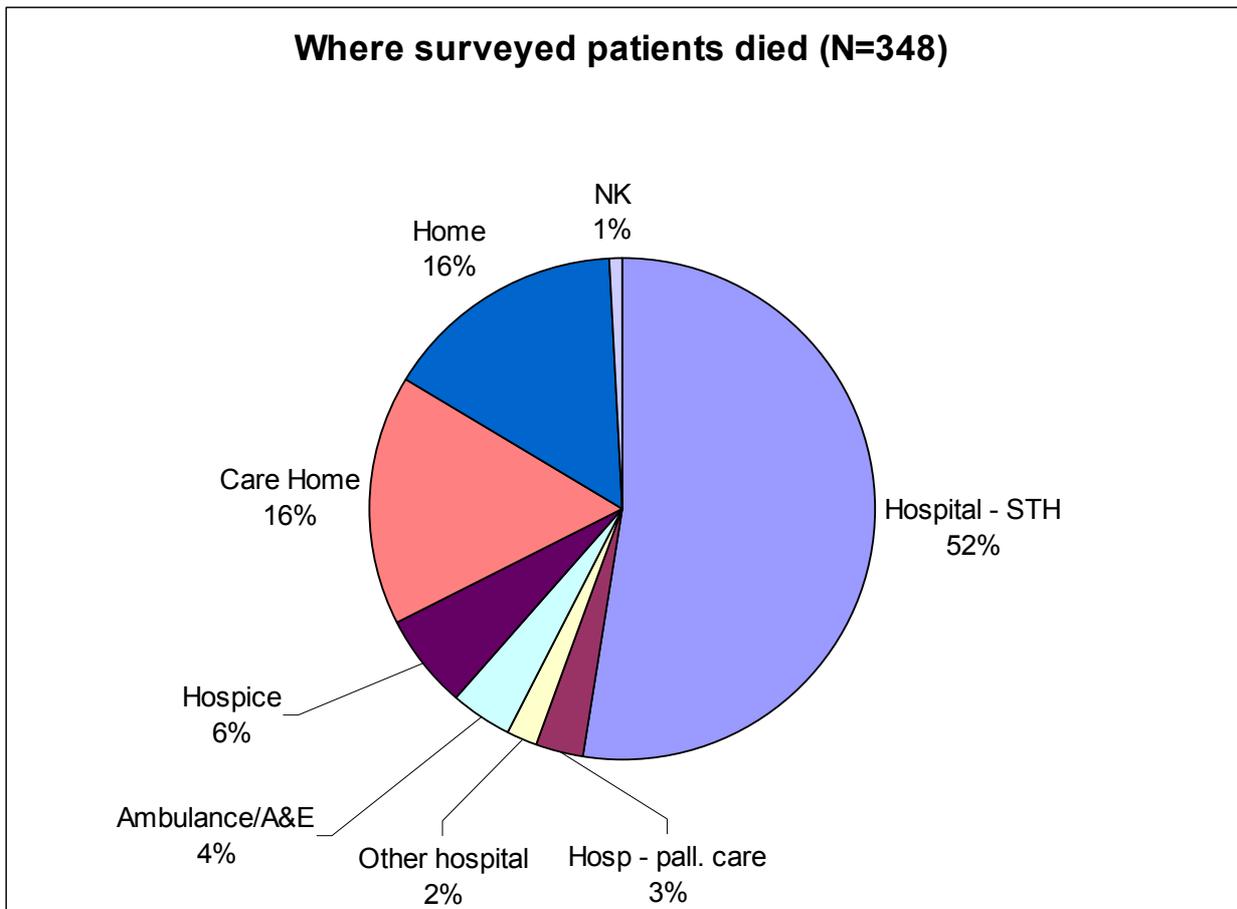
SECTION 3 WHERE PEOPLE DIED

The survey reviewed notes wherever available for patients who died in hospital and those dying elsewhere.

Key points are:

- 50% of Sheffield residents died in hospital, with a further 2% dying in the palliative care unit. A further 19% died in care homes, with 18% dying at home (figures 3.1, 3.2)
- Cancer patients were more likely to die outside hospital, with quarter dying at home and a further 17% in hospice. Only 8% of people in the frailty group died in their own homes, with a further 29% dying in care homes and 59% in hospital (figure 3.3).
- GP involvement in the admission of patients who subsequently died in hospital was limited, but did not appear to be affected to any major degree by the use of out of hours services (figures 3.4, 3.5)
- A quarter of the patients dying in hospital had been admitted from care homes, though a greater number of care home residents either returned or remained in the care home to die.

Figure 3.1



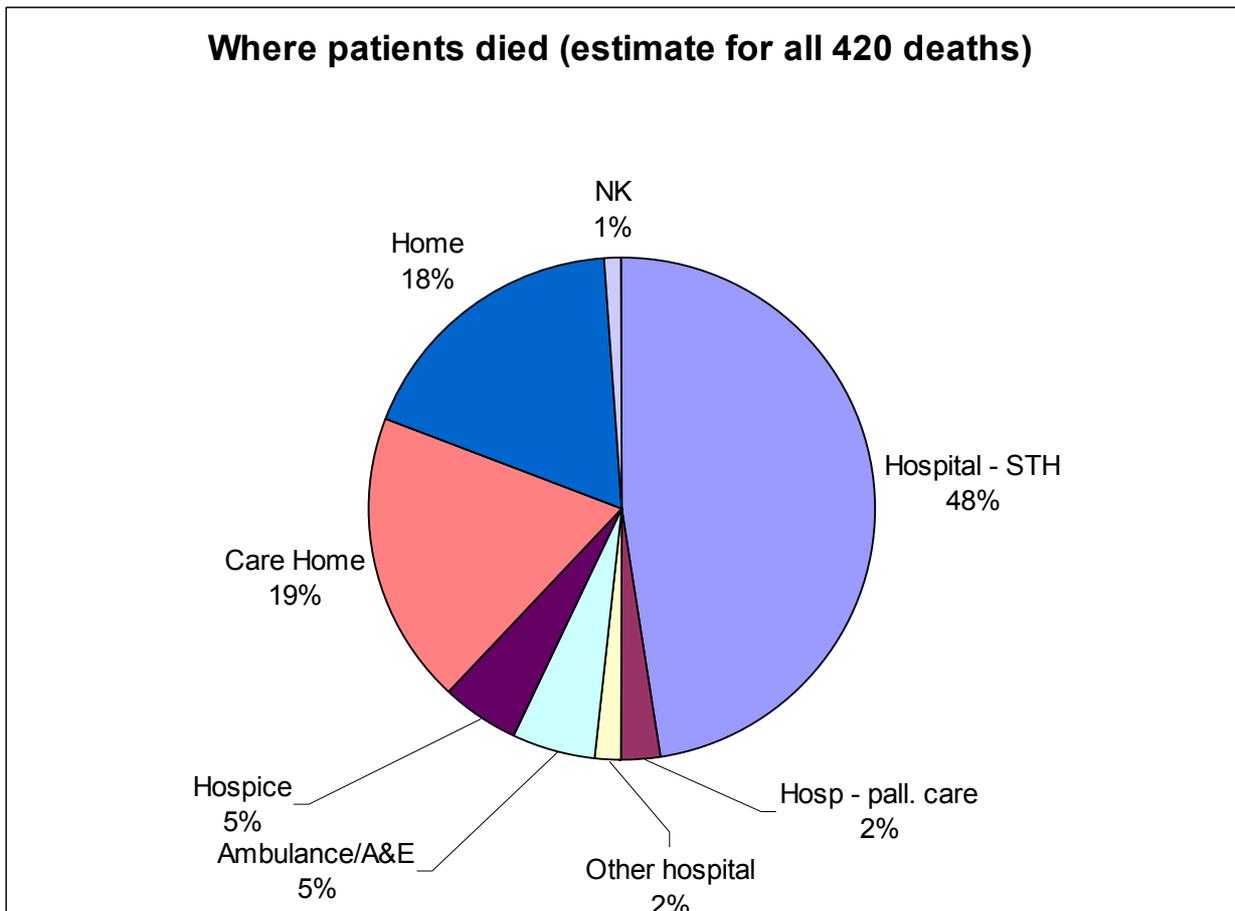
There was little ambiguity about where patients died if the inpatient spell was recorded on PAS. However where we surveyed patients whose death did not come at the end of a spell recorded on the STH PAS, place of death was not usually identifiable from the notes. However using a combination of data from the PCT's record of death registrations and the Council's index of people receiving social care, place of death could be accurately determined in all except 3 of the 348 cases surveyed.

Within the STH hospitals, there is provision for patients to be cared for on the Macmillan Unit a new palliative care ward. 3% of deaths in the survey were on this ward, the low value is the result of the ward being closed for two weeks during October 2007 as the result of infection: in subsequent months the level would have reverted to around 6%, with an equivalent reduction in the numbers dying on the main acute wards.

4% of deaths surveyed have been described as 'Ambulance/ A&E' and include people who died in a public place, were certified dead on arrival at hospital or within A&E (usually following a resuscitation attempt). Most of these patients are classified in analyses of death certifications as dying in hospital though a review of the A&E notes suggests that most died on their way to hospital and after the ambulance was called.

One in six patients surveyed died in their own homes, and a similar number in care homes.

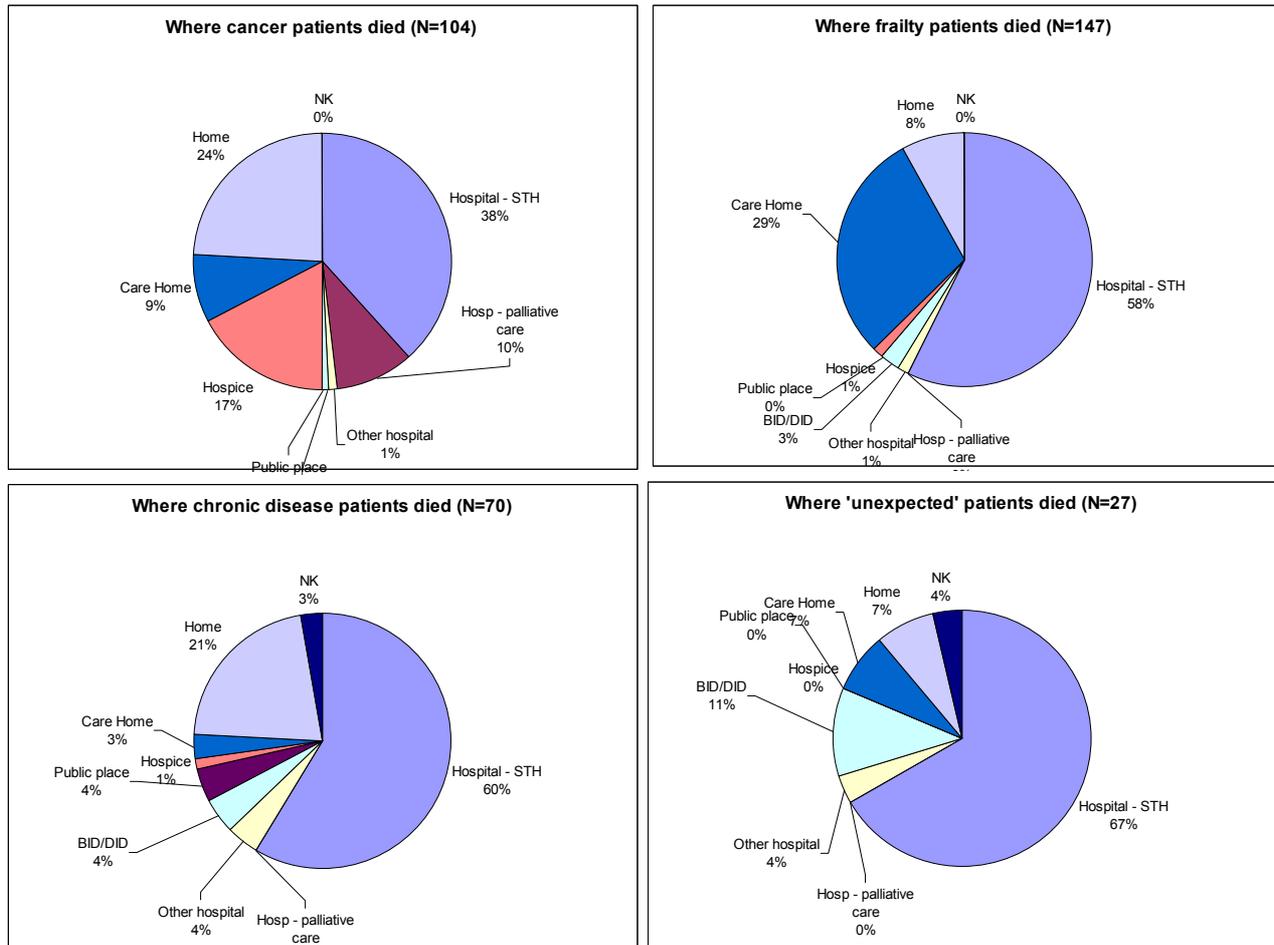
Figure 3.2



Because only 73% of patients dying outside hospital were included in the survey we have grossed up the numbers in figure 3.1 to show estimates the overall pattern in Sheffield in October 2007.

A slightly higher proportion is shown dying at home (18%) or in a care home (19%) than unadjusted survey figures. Altogether 52% died in hospital, and of these 2% were on the Macmillan palliative care ward.

Figure 3.3



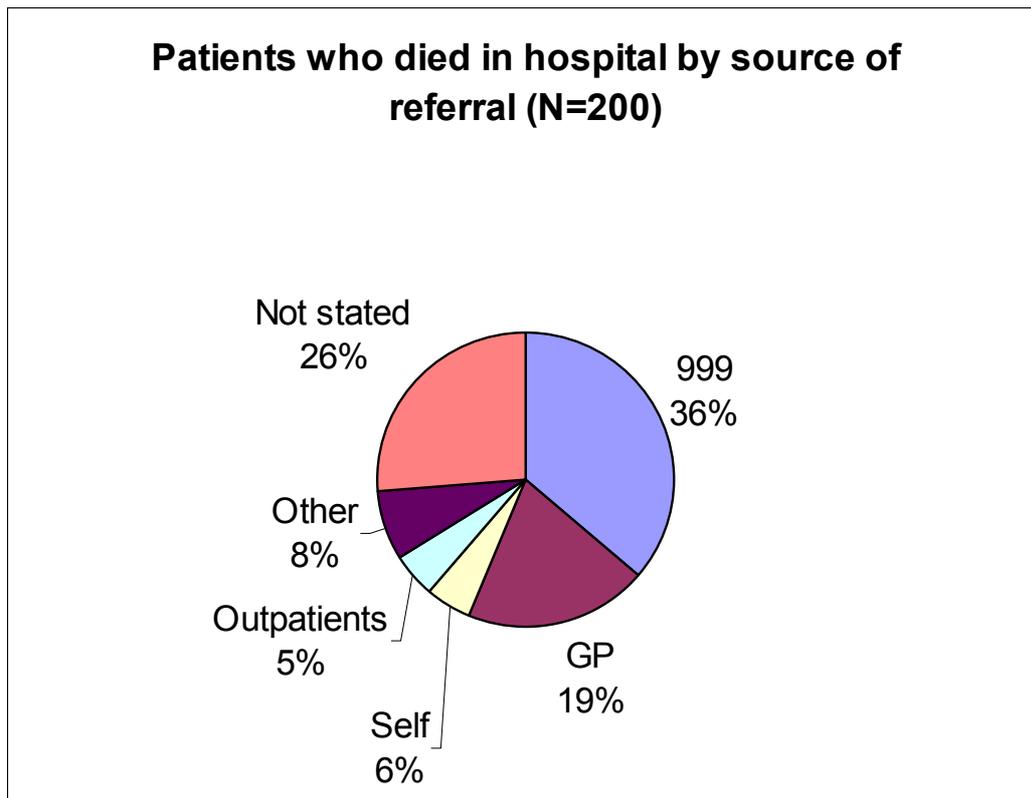
There are substantial and important differences in the pattern of where people die by the four GSF patient groups. The above graphs are based on survey data only (ie without adjustment) so will slightly overestimate the actual proportions in hospital.

For cancer patients, 27% died in hospice or palliative care ward. 39% died on acute hospital wards: this value might have been under 30% if the Macmillan Palliative Care Unit had been open for the full month. Nearly a quarter died in their own homes.

For the larger frailty group, only one patient died in hospice. 59% died on hospital wards, and a further 29% in care homes. Only 8% died in their own homes. Only 2 out of the 65 people with dementia diagnosed died in their own homes

The overall implication of these figures is that half the patients who die at home are from the cancer group, one quarter have a chronic disease and one quarter are frail.

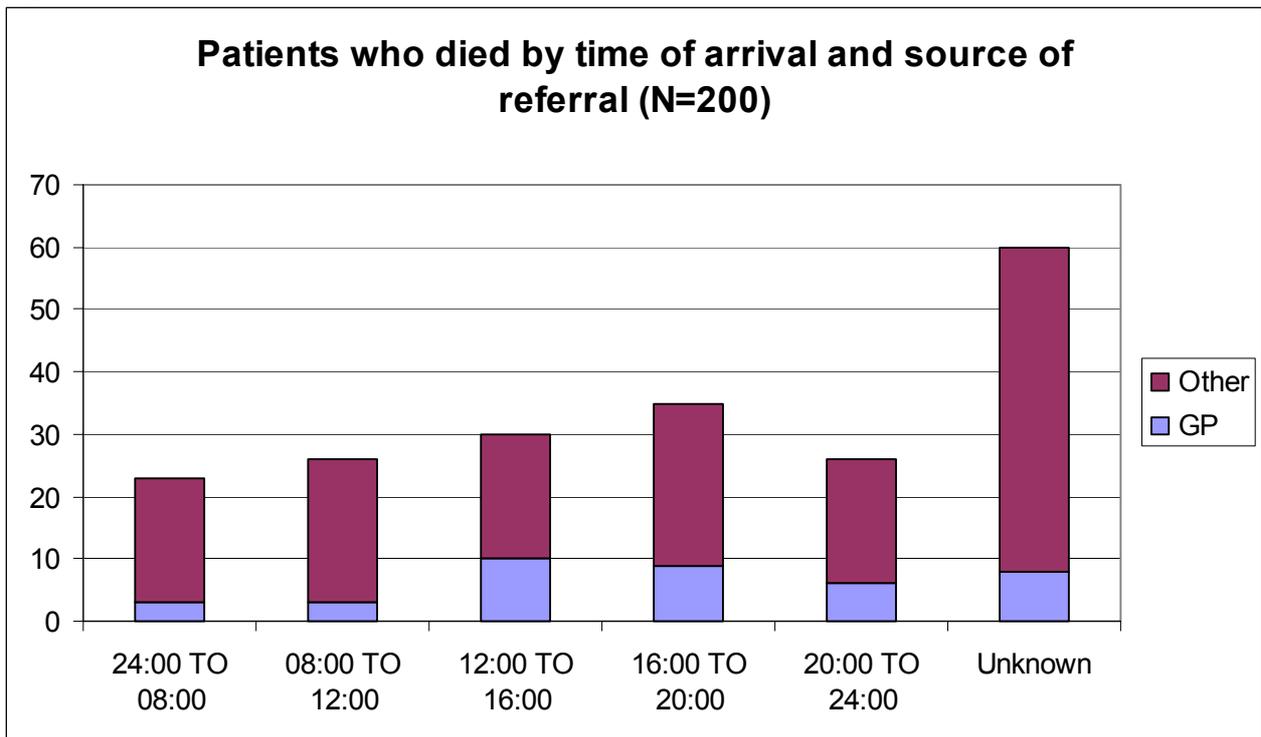
Figure 3.4



Surveyors aimed to identify the source of patient referral for admission, and in particular to see if there was any recorded GP involvement in the admission (This could involve the GP seeing or advising the patient over the phone, but any involvement mentioned is included in the figures shown). Only 19% of admissions involved the GP and most others involved self referral in some form or another, although ambulance notes indicating a 999 call were only identified in 36% of cases.

Note that for the 26% where the source of referral is 'not stated', this is because there is no clear documentation. This implies again that there is no record of GP involvement, nor ambulance record, in the notes.

Figure 3.5

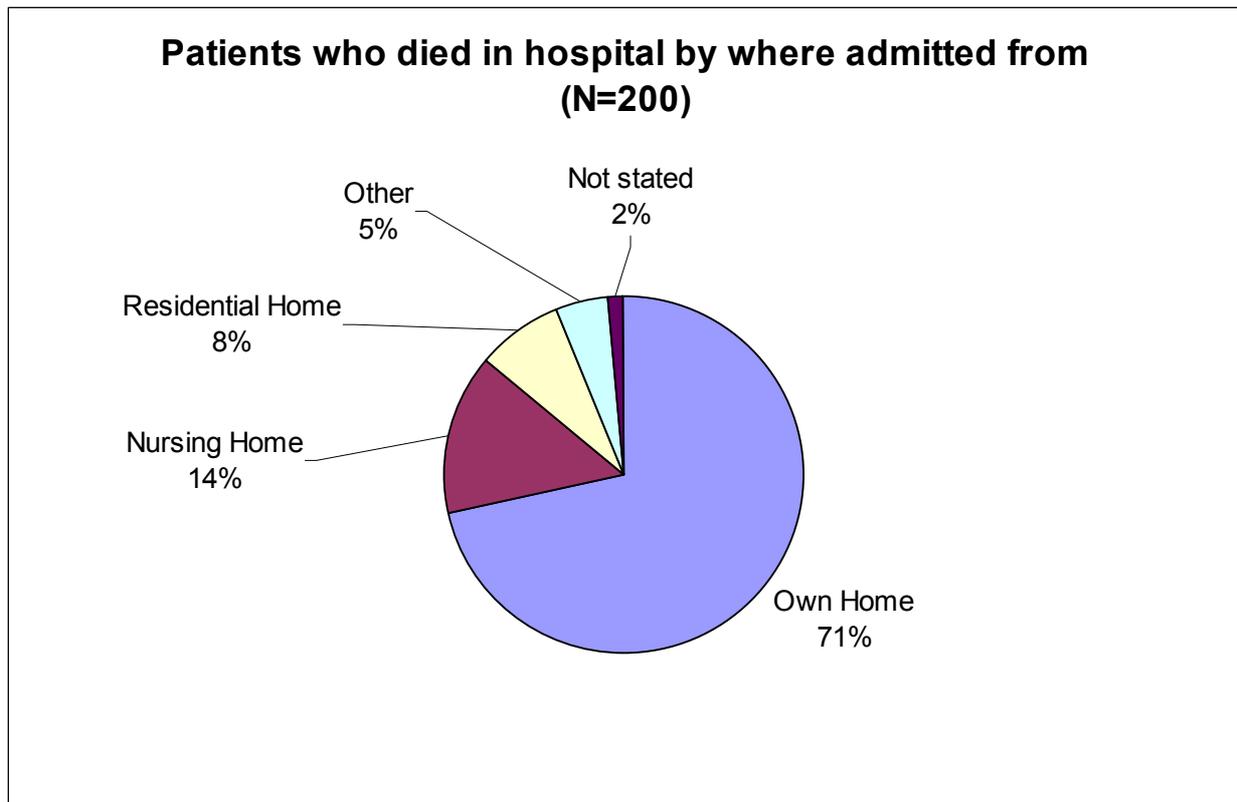


A possible issue for admissions relating to the end of life may be the extent to which the acute event occurs out of hours, hence links to the GP with whom the patient is registered may have broken down.

However figure 3.5 does not indicate any major differences in GP involvement by time of day: there is marginally greater involvement of GPs in the middle of the day, and more admissions generally during the day. But the majority of patients are contacting emergency services direct, hence if alternative responses at the time of admission were appropriate, the patient's own GP would not be in a position to initiate them, whatever the time that the call is made.

Note that the above graph shows patient presentation by time of arrival rather than formal admission. This data item was not recorded in 30% of the notes reviewed.

Figure 3.6



Surveyors identified where patients had been admitted from wherever possible. In a quarter of cases the patient's case notes did not indicate from where they had been admitted: however via the linked social care data it has been possible to identify that all bar three of these patients had been living at private addresses prior to their final admission, and the source of admission will have been the patient's 'own home'.

As can be seen from the chart nearly three quarters of those dying in hospital were recorded as having been admitted from their own homes.

Just under a quarter of people dying in hospital had come from care homes, the majority already receiving nursing care. Whilst this is a substantial number it should be noted that the level, about 50 per month, is still lower than the number dying in care homes, estimated in figure 3.2 at 79 out of 420 (ie 19% of all deaths). Further details are at figure 4.5.

The issue of whether these, and other patients could have avoided dying in hospital, is the subject of the next section.

SECTION 4 ALTERNATIVES TO DYING IN HOSPITAL

In many previous clinically led surveys of hospital inpatients we have used the Appropriateness Evaluation Protocol (AEP) to differentiate between patients whose level of acuity is such that alternatives to hospital were not appropriate and need not be considered. Where patients fall outside AEP criteria surveyors are asked, after training and employing defined criteria, to use their clinical judgement to identify possible alternative ways in which the patient's care and treatment needs could be met.

Many patients at the end of life do develop acute conditions that satisfy AEP criteria. However, clinical colleagues felt that with developments in resuscitation policies and in palliative care that acute care was not always appropriate at the end of life even though they met AEP criteria. However, the survey was unable to discriminate usefully between those that received appropriate acute care or not, even though met the AEP criteria.

We therefore extended the questionnaire approach to allow consideration of alternatives in every case where the patient died in hospital, with the expectation that surveyors would consider these options in terms of the criteria set out in the Gold Standards Framework and the Liverpool Care Pathway.

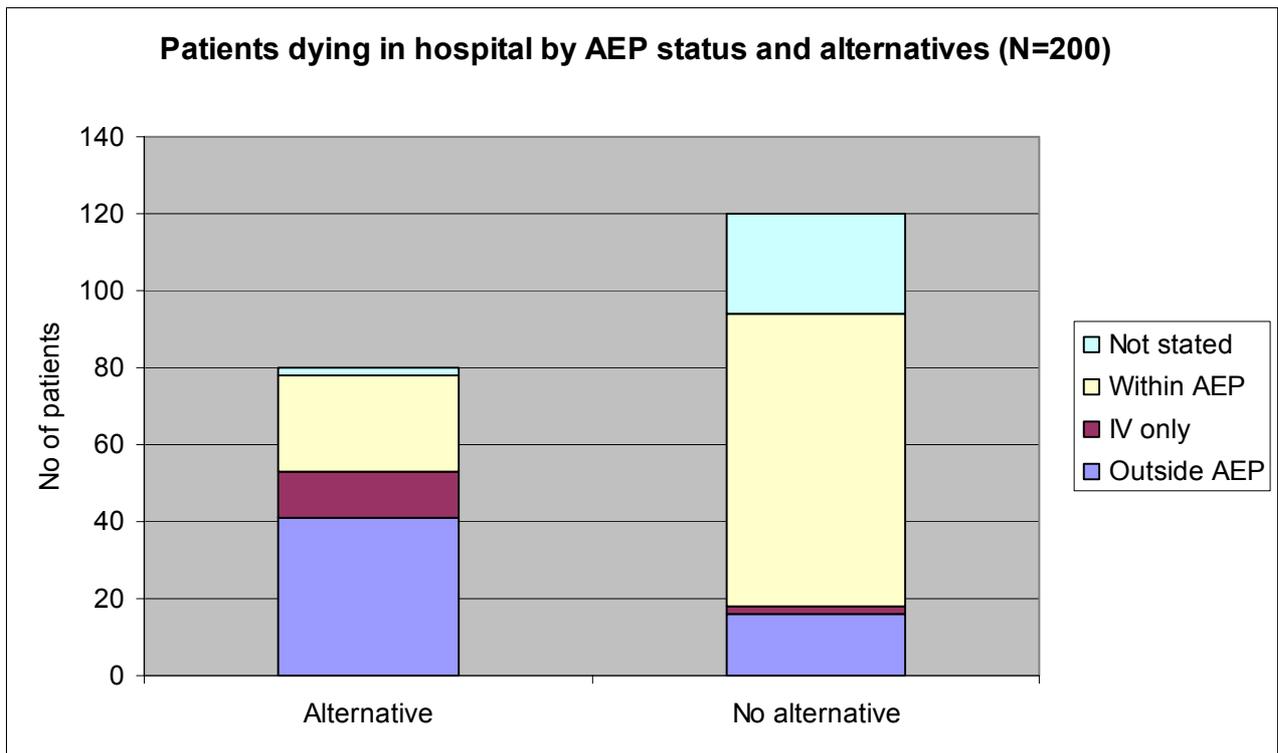
Surveyors were asked to consider 'a blue sky' situation with regard to the availability of alternative resources: hypothetically, patients' alternative needs could always be met. The exercise was not about the availability of resources but rather identifying individual patient's need and from that the needs of the population at the end of the life.

Where an alternative was identified, the surveyor's judgement was validated against other survey data to demonstrate the realistic possibility of that as a potential course of action. For example, if the patient lived alone then sending them home might prove difficult if impossible, or if on admission they had had a procedure that could only be undertaken in hospital then at the time of admission an alternative was unlikely to be appropriate.

Key findings were

- Alternatives to dying in hospital were identified for 80 out of 200 patients (40%) (figure 4.1). This is a conservative figure, in that alternatives were only identified on the basis of sufficient evidence in the notes, and does not allow for patients who were necessarily admitted but might have been discharged elsewhere before death (evidence of discharge planning is reviewed in section 5)
- Roughly half the alternatives involved home based care, half some form of supported bed based provision. Cancer patients tended to require palliative care, chronic and frailty patients more general and specialist nursing support (figure 4.2)
- Overall for those with alternatives, about 40% could have been at home, 40% in a care home and 20% in hospice (figure 4.3)
- Above average numbers of admissions from care homes, especially nursing homes were thought to be avoidable. The 61% of care home residents dying there could be as high as 80% if alternative care pathways were followed. (figures 4.4, 4.5)
- Allowing for people who died but were not included in the survey, an estimated 26% of those living in their own homes died there (figure 4.5).
- Patients dying in hospital are a mix of short and longer stay patients, and alternatives to dying in hospital are possible for both groups (figure 4.6).

Figure 4.1



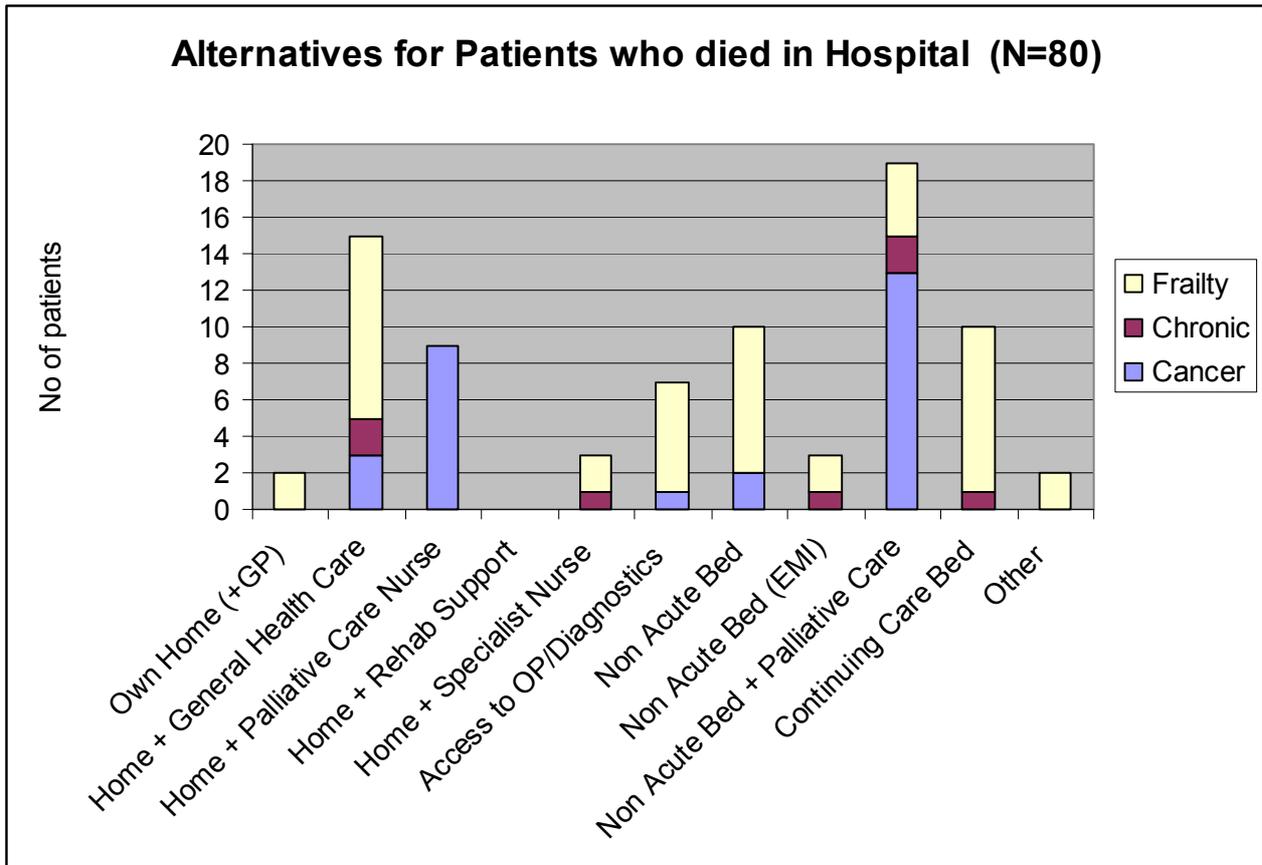
80 out of the 200 patients surveyed who died in hospital (40%) had alternatives identified. The initial findings of surveyors have been cross-checked in the light of the additional data from linked data sets, and in most cases the judgements are robust.

As for the mainstream of acute admissions the majority outside AEP criteria had alternatives to acute hospital admission. But there were almost as many patients within AEP criteria, including nearly all those admitted for intravenous therapy only, for whom alternative approaches were identified.

The overall proportion of 40% has been debated in terms of whether it is on the low side (based on expectation rather than other comparable studies - see Khan et al [5] for a smaller study of palliative care only which identifies about 50%). The approach taken is deliberately on the conservative side, to ensure that alternative approaches are based on clinically robust judgements.

It should also be noted that this approach focuses on alternatives at admission. This may be a desirable strategy for people whose condition is clinically unstable and who might not survive another transfer to an alternative setting once admitted to hospital. It is often difficult for medical staff to prognosticate a patient's condition accurately at the time of presentation and admission is sometimes necessary given the risks. However if the patient's condition stabilises sufficiently, and they so wish, discharge may be possible given a rapid and comprehensive assessment together with good liaison with community and primary care services.

Figure 4.2



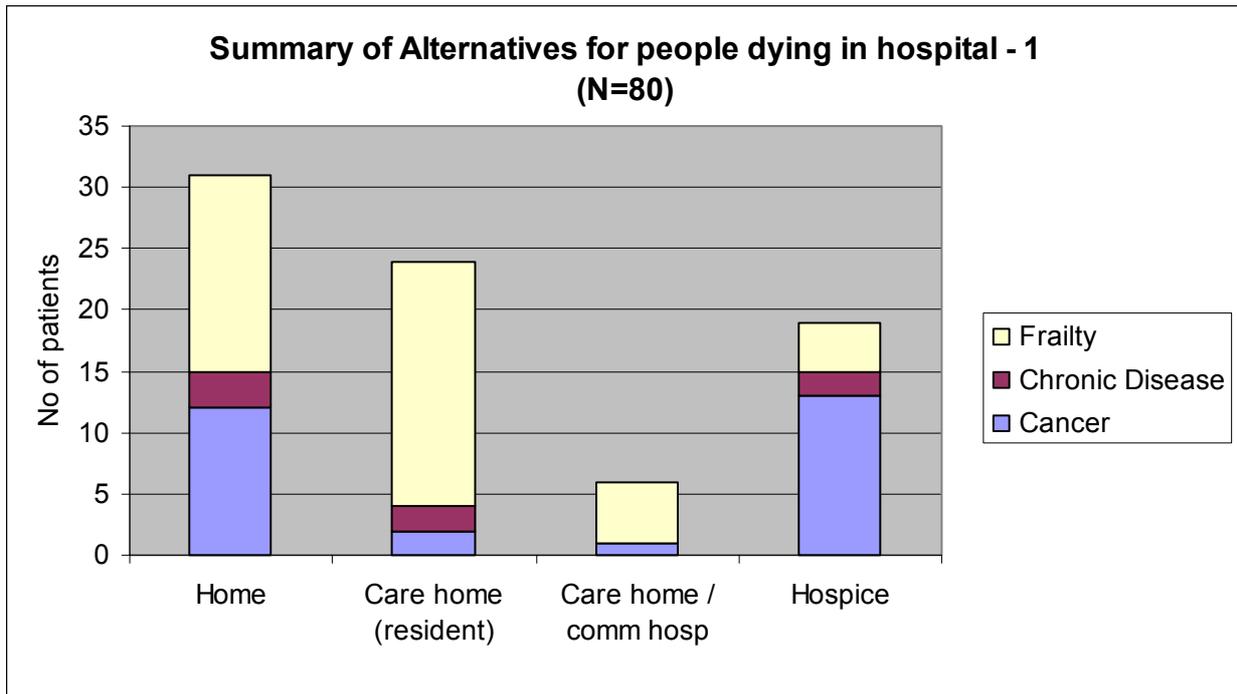
For the 80 patients for whom alternatives were thought possible, surveyors selected from an agreed list of care packages (with the additional option to define new packages if none of these applied).

In the list shown above the home based packages assume complementary services are available eg a ‘general health care’ (district nursing) package is assumed to include social care if needed, similarly palliative or specialist care packages would also include district nursing. Full definitions at appendix V.

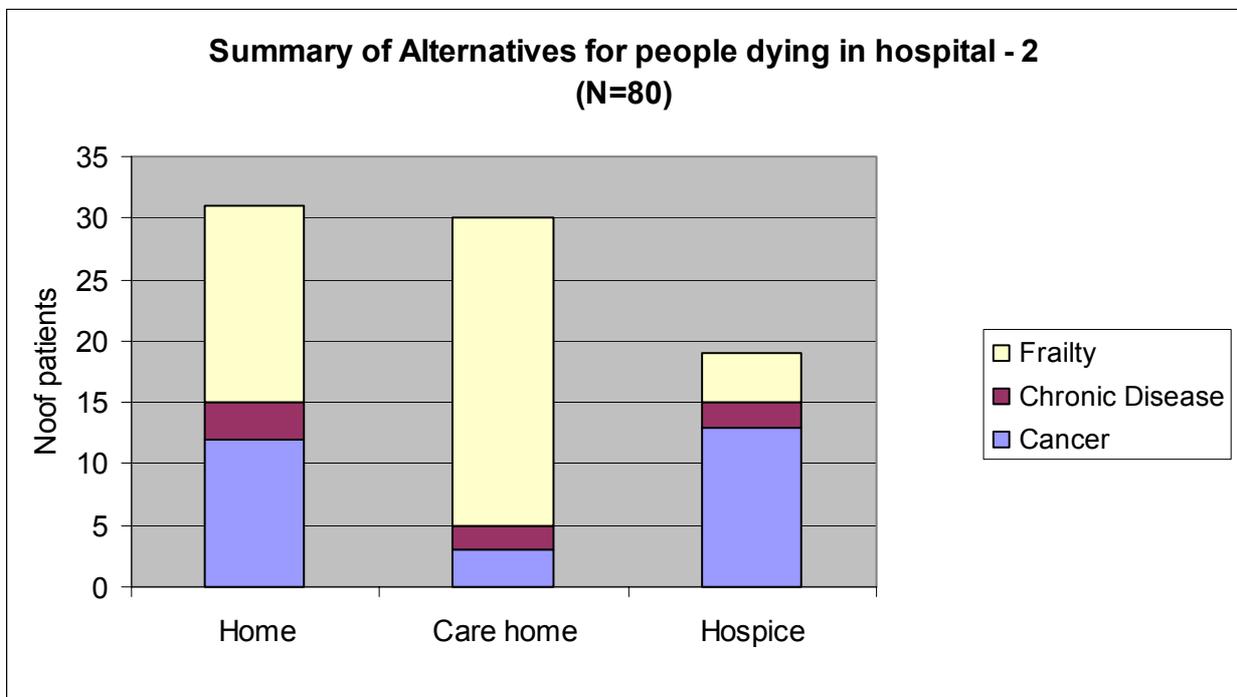
The term ‘non acute bed’ can be any bed based provision not specifically designed to handle acute admissions: in many instances need for non-acute beds might translate into care home provision, with appropriate nursing or therapeutic input. Currently, however, services such as ‘non acute bed with palliative care’ in Sheffield is usually interpreted as hospice or the hospital based Palliative Care Unit whereas in some cases, particularly for those returning to nursing homes, the processes of care provided in hospice could be provided in alternative institutional settings should this be considered desirable.

The alternatives identified split approximately 50:50 between home based and bed based alternatives. There are clear differences between the cancer patients, for whom palliative care approaches are most commonly specified, and the others, nearly all with frailty, for whom general health care and nursing led approaches were mostly specified.

Figure 4.3

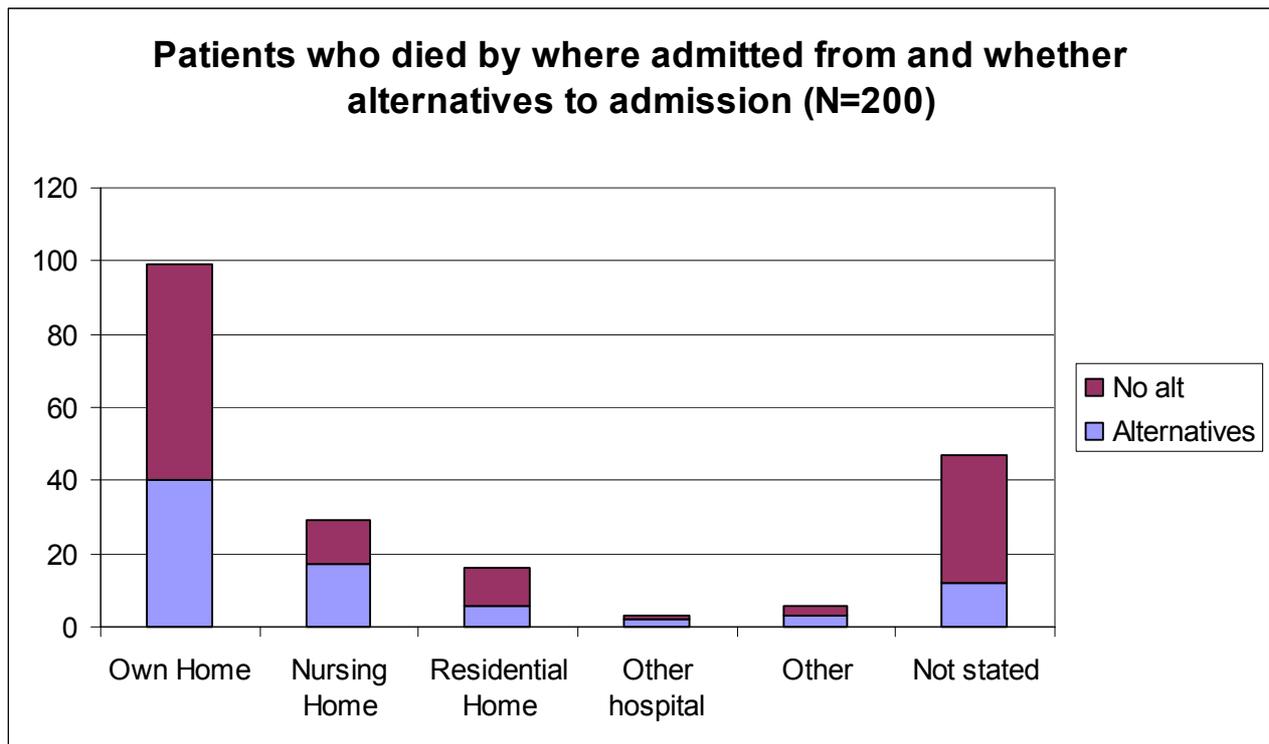


The above graph summarises the more detailed descriptions of figure 4.2, and groups together all home based alternatives. Patients whose care needs have been described as requiring a ‘non-acute bed’ are divided according to whether they are already care home residents. For the remainder a community hospital would be an alternative temporary location.



The above simpler presentation groups the non-acute requirements as ‘care home’ (this would be a sufficient description in Sheffield which has no community hospitals).

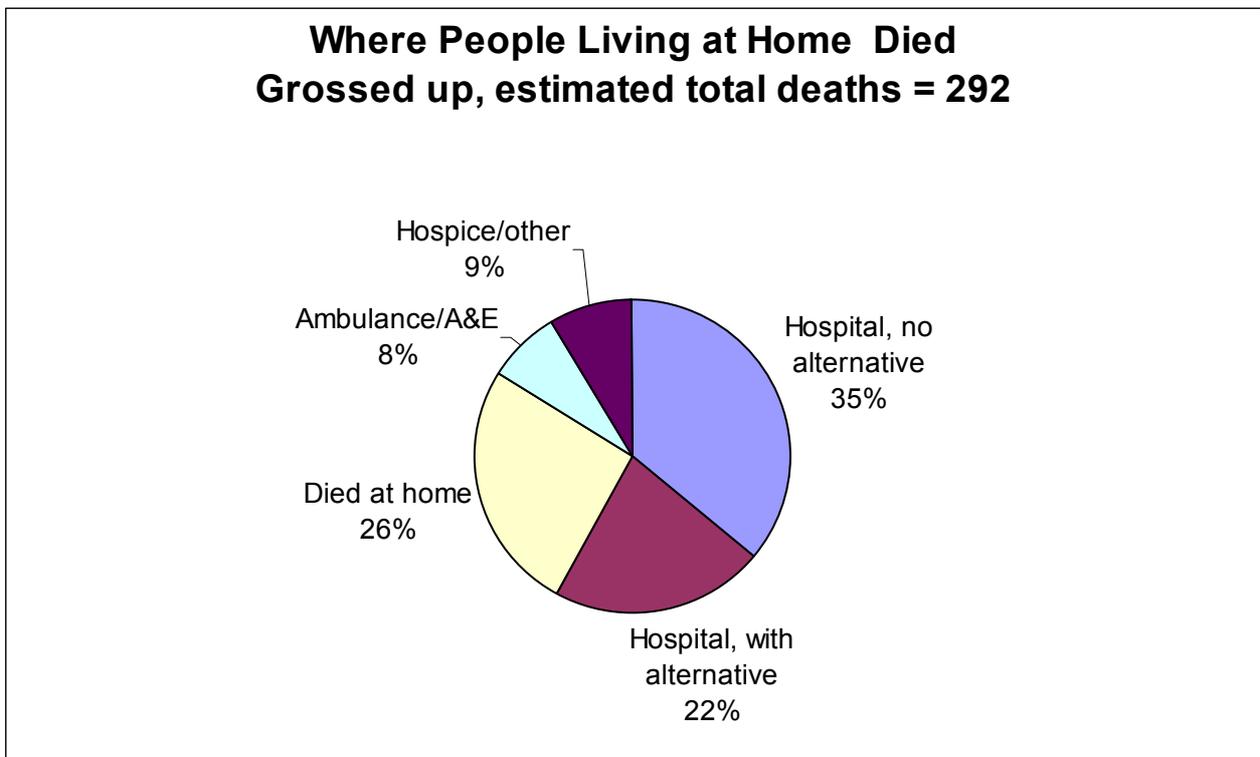
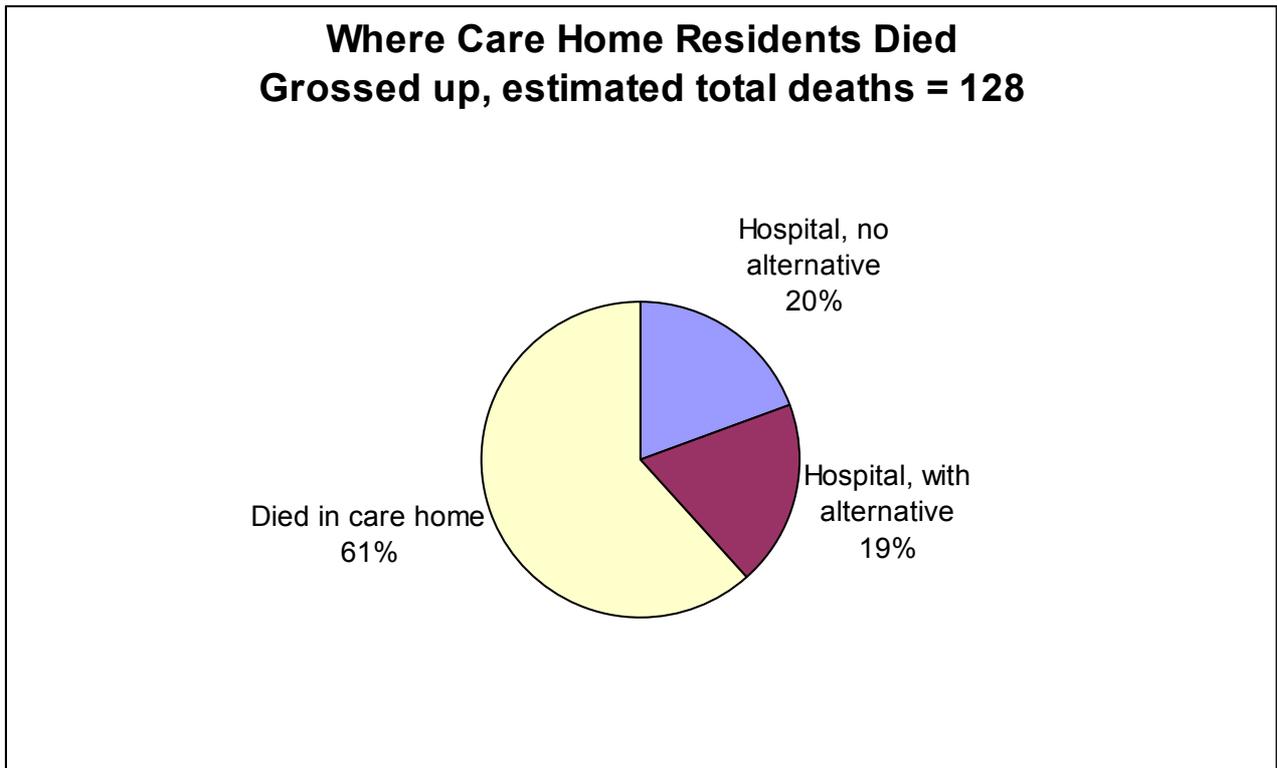
Figure 4.4



In terms of where patients had been admitted from, only the nursing home residents showed an above average proportion who might have avoided admission: 17 out of 29 admissions from nursing homes (59%) might have been avoided. In most cases it was felt that the patient could have remained in the care home, or at least returned there after suitable assessment, in some cases with additional specialist or palliative nursing input.

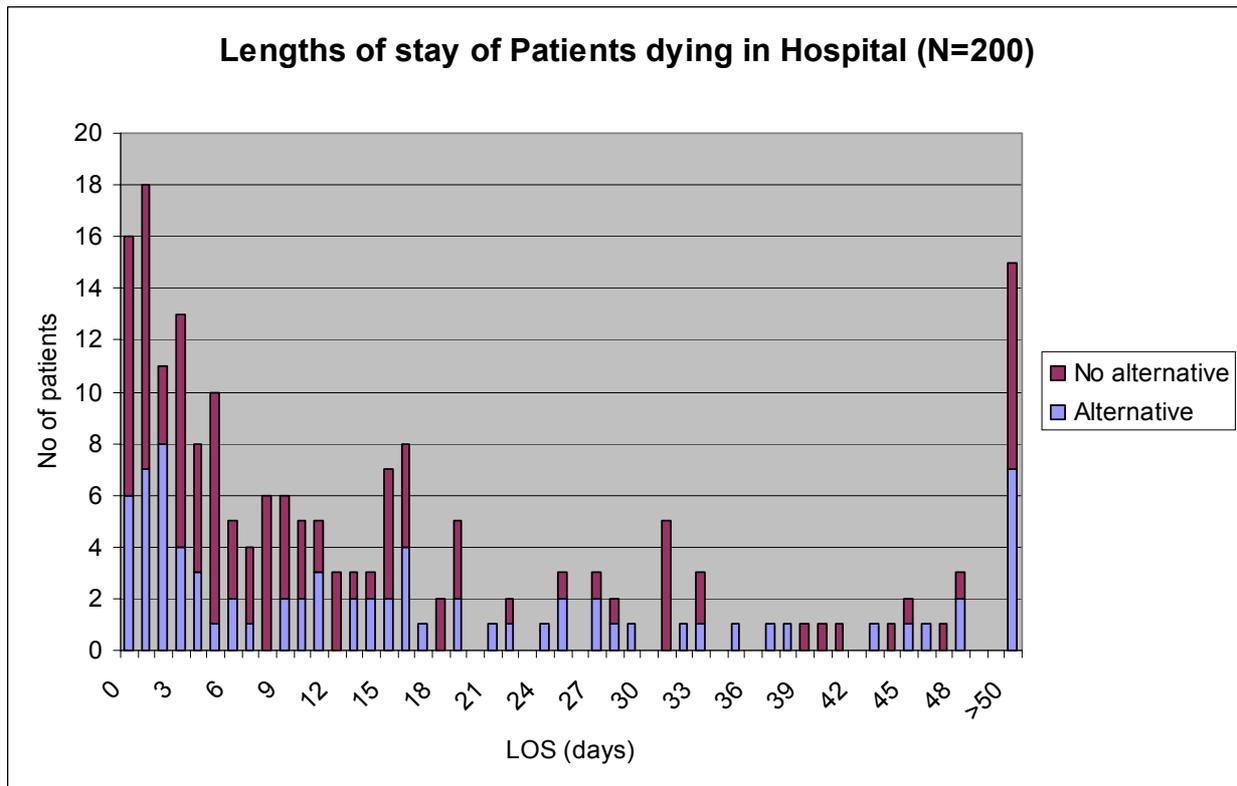
It is also worth noting that over half these admissions were of patients with diagnosed dementia.

Figure 4.5



Bringing the data on alternatives summarised in figure 4.4 together with the grossed up estimates of all Sheffield PCT deaths in October 2007 summarised in figure 3.2, we can estimate the current position for care home residents who die, and the position for the remainder, who had been living in their own homes. Only just over a quarter of those who had been living in their own homes died there.

Figure 4.6



Many patients dying in hospital have long lengths of stay, and those with alternatives identified are found at all lengths of stay.

An important feature of the length of stay distribution shown here is the peak in numbers of patients with alternatives who die within a length of stay of 2 days. Numbers are small but the data would be consistent with some of these patients being near death, and this not being recognised at the time of admission, hence precluding the consideration of alternatives.

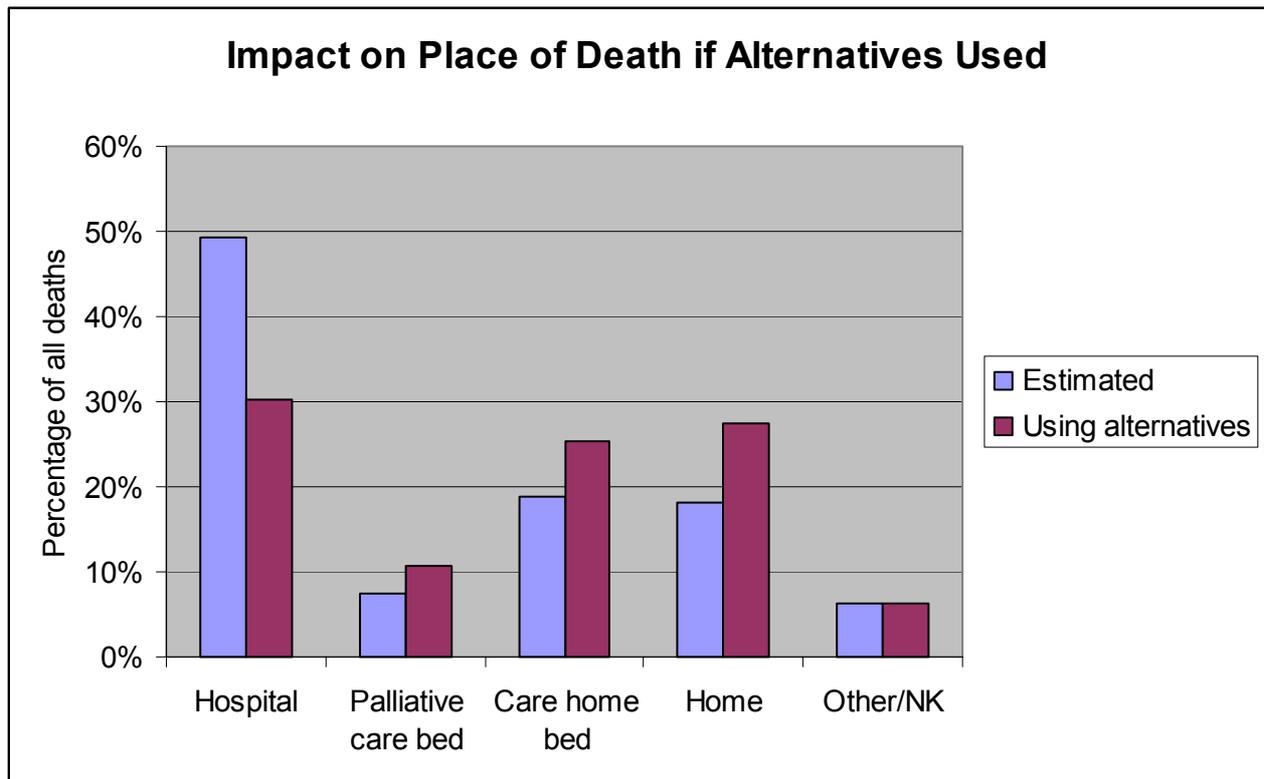
Of the 19 patients with stays over 28 days for whom alternatives were identified, 12 were in the frailty group (63%).

The total bed days occupied by patients who died in hospital was 3367, equivalent to an average 109 occupied beds. The 80 patients for whom alternatives were identified used 1501 bed days, equivalent to 48 occupied beds.

If we assume a cost per inpatient day of £250 the ‘avoidable’ part is worth £375,250 (=1501*250) for what is in effect a month’s costs. If a similar number of bed days could be avoided on average throughout a year, this grosses up to about £4.5million (equivalent say to the running costs of two wards). Sheffield accounts for 1% of England population, so similar reductions in proportions dying in hospital across the country could potentially release revenue of £450million for investment in alternatives to hospital.

Note that, given the small data set, these estimates should be treated as orders of magnitude only. The assumption about cost per inpatient day is in line with Payment by Results tariffs for ‘excess bed days’, which tend to be in the range £200-300. The arithmetic mean across HRGs in 2008-09 is £243, though the overall national average would depend on casemix.

Figure 4.7



Summarising the data presented in this section on alternatives to dying in hospital, the potential for change to the location of death as summarised in figure 3.2 can be shown.

In the above pie charts, hospice and palliative care beds in hospital have been combined in a single category. A majority of the 'Other/ not known' category are those patients dying in ambulance or A&E department.

Overall the proportion dying in acute hospital (excluding palliative care facilities) would have reduced from 49% to 30% if all alternatives identified had been available to patients. Those dying in their own homes would have increased from 18% to 27%.

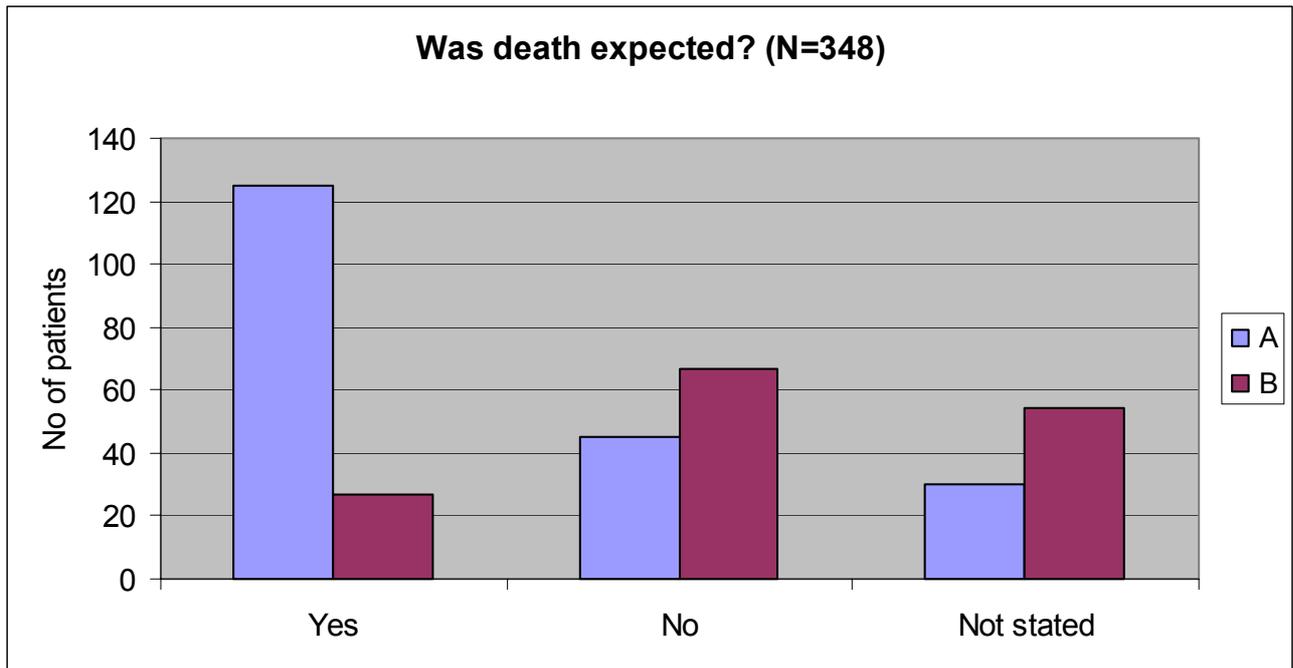
SECTION 5 WHAT AFFECTS THE END OF LIFE EXPERIENCE?

The potential to implement alternative care pathways will inevitably depend on a range of changes in care practices and clinical processes. The survey explored a number of areas which clinical colleagues considered to be important in changing the way people at the end of life are supported.

Key points arising are:

- A decision that death was expected was frequently recorded, including 125 out of 200 patients (63%) dying in hospital. Do not resuscitate (DNR) and other forms of care planning often followed this. Vitally, however the decision was often made too close to death to allow alternative care pathways to be considered (figures 5.1, 5.2)
- Community and hospital based palliative care nurses had high levels of contact with cancer patients, but not other patient groups. Specialist nurses (COPD, heart failure) had little contact with patients at the end of life, though some had been referred on to general nursing services (figure 5.3)
- Social care contact with people at the end of life was high, especially for the frailty group and those for whom alternatives to dying in hospital could be considered (figure 5.4)
- There is some variability in numbers dying in hospital by GP practice, but it is outside the scope of this study to identify the extent to which GPs are able to respond to patient choice (figure 5.5)

Figure 5.1



The ability of the care system to respond flexibly to patient care needs towards the end of life may be affected by the degree to which clinical staff explicitly recognise the stage the patient has reached. For both those dying in hospital (form A) and those discharged from hospital earlier (form B) earlier, surveyed examined notes to identify if there had been a decision regarding death recorded in the notes.

This was the case for 125 out of the 200 surveyed who died in hospital (63%) and a smaller number of those dying elsewhere, 27 out of 148 (18%), only some of whom had an admission in the previous 12 months.

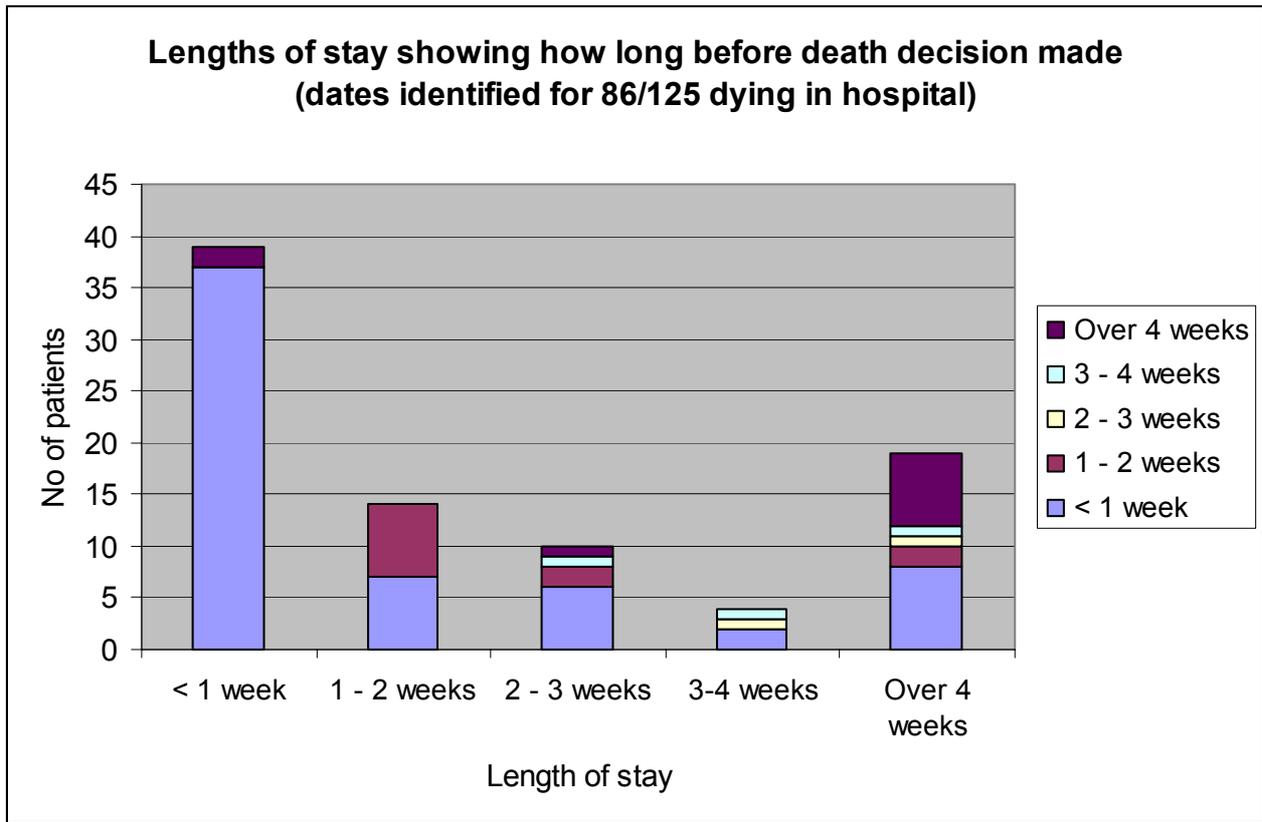
Where stated, the decision was most often recorded by the specialist registrar (36%) or senior house officer (SHO) (25%) than by the consultant (19%) though it was not generally clear from the notes the extent to which consultant advice had been sought directly by the registrar or SHO.

Similar numbers of DNR (do not resuscitate) notes were made. In 106 of 124 DNRs for patients dying in hospital this coincided with the decision that death was expected. Other advanced care planning could be seen in 35 non-curative care plans and 38 referrals to palliative care services.

76 of the 200 patients dying in hospital received general supportive care, and 76 specific symptomatic care. The majority of both groups had also had a decision about death made.

Surveyors also looked for references to patient preference in the notes, and only limited information was available, sometimes recording discussions with family rather than the patient. For the patients dying in hospital 32 out of 200 (16%) had some preference identified, including to go home (9 patients), some form of palliative care (6) and admission to nursing home (5). For people not dying in hospital but previously admitted 40 (out of 111 with a hospital spell earlier in the year) had an identified preference, over half of these to go home.

Figure 5.2

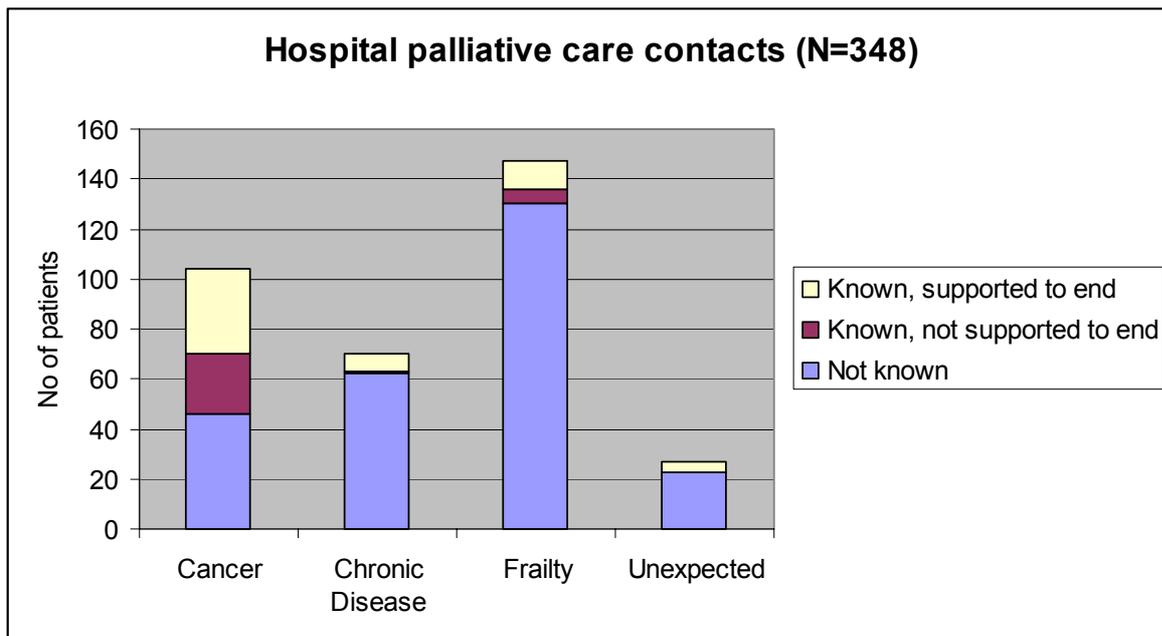
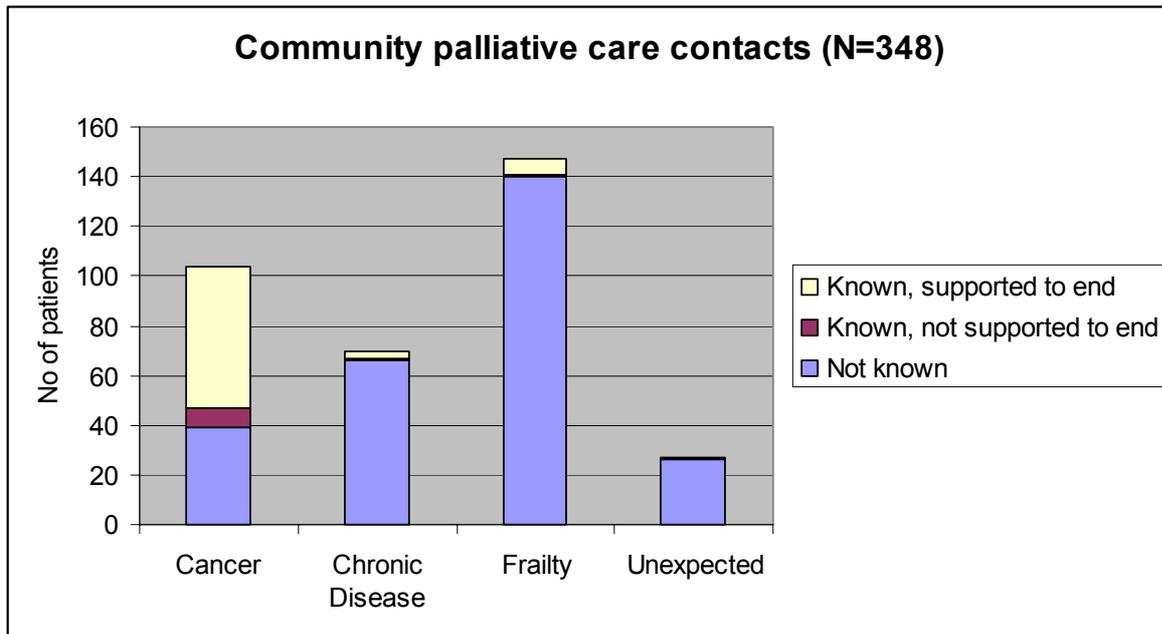


Although a decision regarding death was recorded for 125 of the 200 patients dying in hospital, these were often only made very close to death, so that any alternative approaches to care were difficult to make. The majority of decisions were made less than a week before death, and this was the case even for patients who had stayed in hospital substantially longer.

From further review of the data, it could be seen that for some patients arrangements were in place for discharge to a more appropriate place. There were 15 patients (8%) who died before planned beds or support at home could be arranged (7 of these might have avoided admission), and a further 21 (11%) with some sort of discharge planning in place but whose condition deteriorated (8 of these might have avoided admission).

Altogether this identifies a further 21 patients who could not avoid admission but might have died outside hospital (8 with uncompleted discharge arrangements, 13 with other planning in place). However it is not possible to judge from patient casenotes for what proportion this might have been feasible given service availability, as referenced in the introduction to section 4.

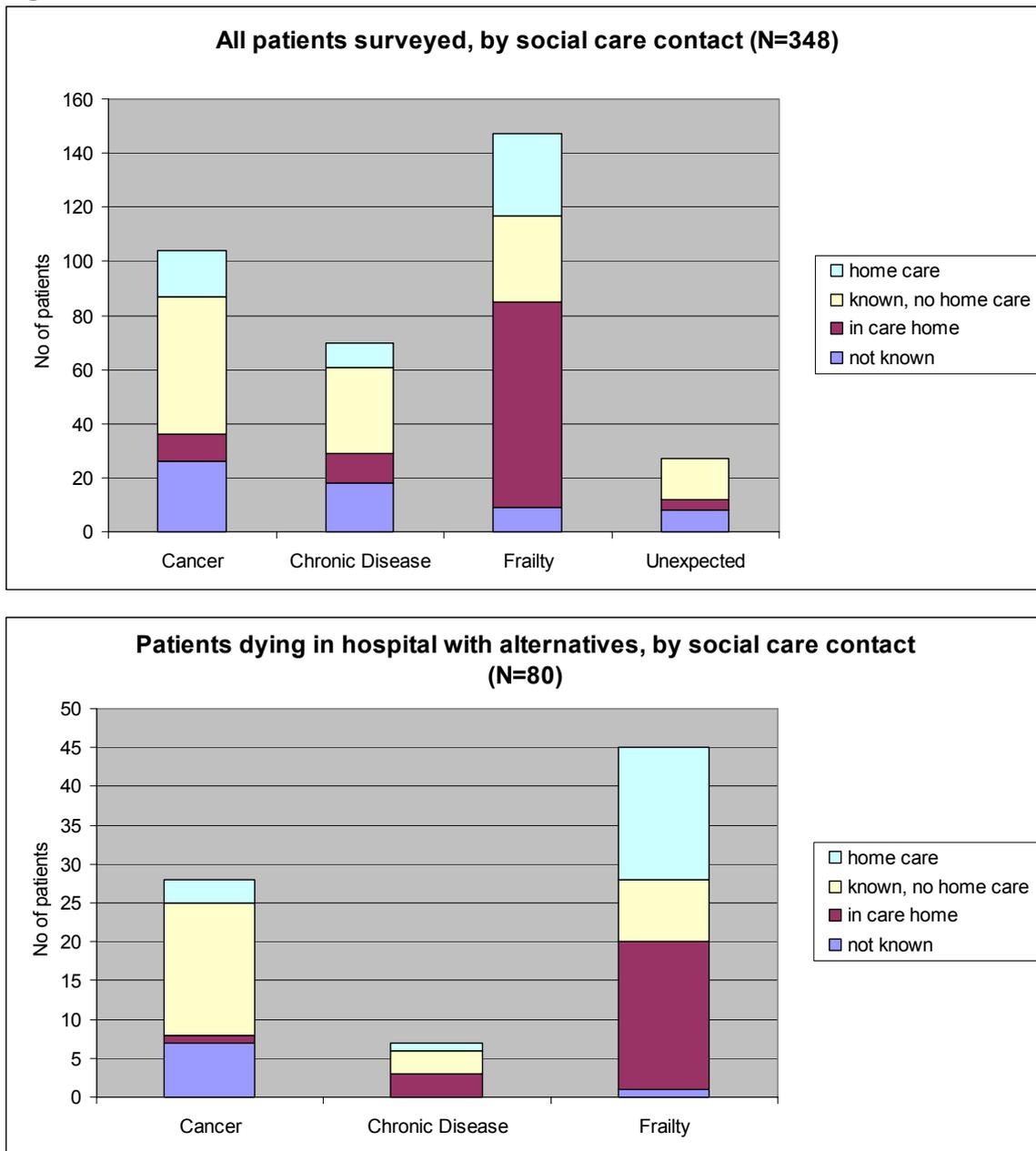
Figure 5.3



Using *Infoflex*, the shared system in Sheffield for palliative care, St Luke’s Hospice was able to identify all patients in the survey who had had support at some stage from any specific palliative care services including hospital referrals and consultations. Many cancer patients were supported, but there was little direct involvement with other patient groups, although some were helped by the hospital support service when inpatient.

Similar exercises were undertaken for COPD and Heart Failure specialist nursing contacts since these now use the newly introduced *SystemOne*. However, recording was insufficiently complete at October 2007, so the data on the patients identified with those conditions was checked through office records. For heart failure only 4 out of 47 had specialist contact, but these were supported to the end. For COPD 8 out of 67 had been supported but referred on, usually to district or practice nurses.

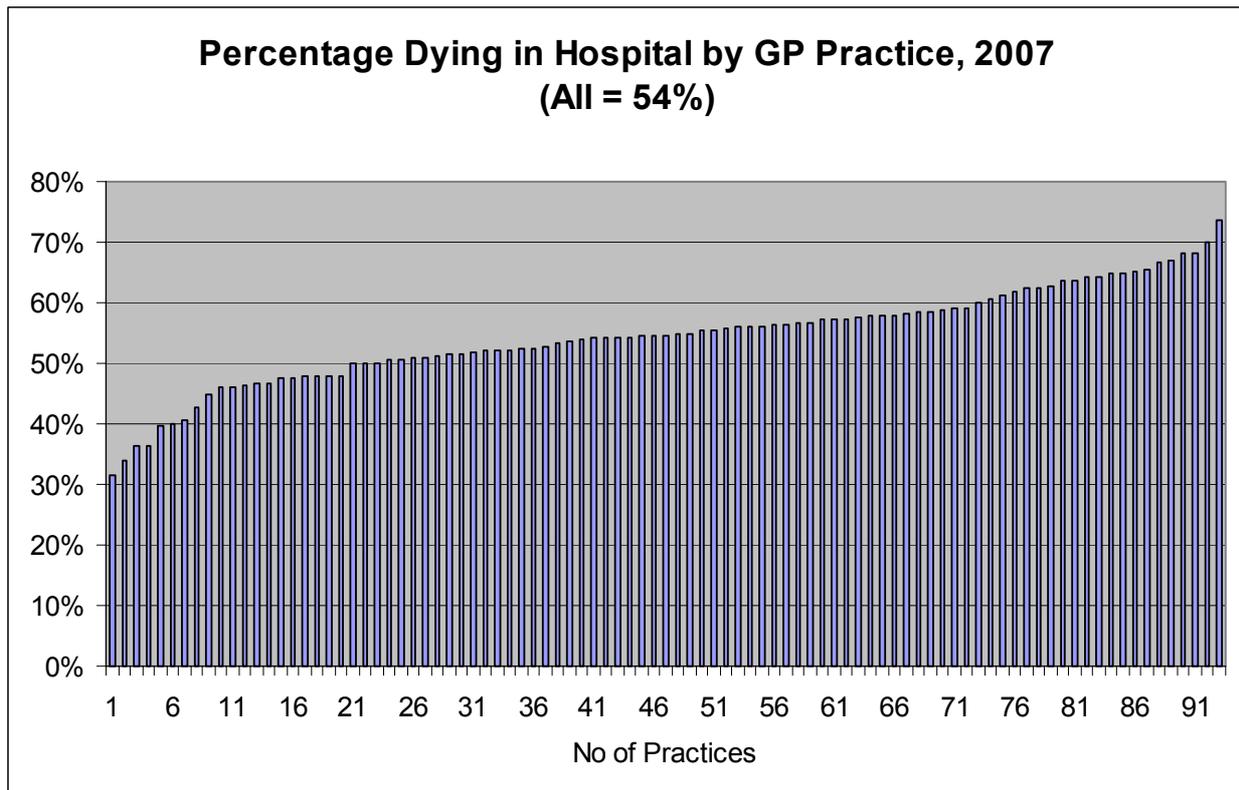
Figure 5.4



In similar fashion to other services the surveyed patients were checked against social care records. Here very high levels of contact were identified, across all patient groups, and especially for the frailty group.

Of note are the equivalent values for the 80 patients dying in hospital for whom alternatives were identified. All but one of the 45 frailty patients were known to social care, and the majority had been receiving social support at home or living in a care home. In the light of this it may be appropriate to review and extend the role of the Social Services in initiating the processes whereby the client and patient and carer choices are made at the end of life.

Figure 5.5



GPs with particular interest in end of life care asked if the survey indicated differences between practices. With over 90 practices our survey would only show a handful of deaths in a month for each practice. We therefore re-analysed the full year data (2007) generated by STH: figure 5.5 shows the percentages from each practice that died in hospital over the year (with the Palliative Care Unit included in the hospital total).

The practice with particular emphasis on giving patient choice recorded 48% dying in hospital, the lower quartile of practices, but it can be seen that variability is quite low, and further examination suggests that the extreme values may have more to do with demography and socio-economic factors, and these factors may also be confounding any interpretation of the distribution. It should also be noted that even with a full year's data, the average (median) practice is still recording fewer than 30 deaths over the year.

There is potential for substantive research to identify the extent to which GP activity can influence outcomes in terms of place of death.

The interest in improving end of life care is associated with the objective of facilitating patient choice of where they die. This exercise has illustrated the complexity and range of issues that need to be addressed together to generate sustainable change.

In this final section some of the implications of the survey findings for service provision and care processes are discussed. It should be stressed that although there has been much helpful discussion with colleagues across the Sheffield health and social care economy, any views expressed and suggestion for further investigation are those of the authors alone.

Numbers and patient type

The small number of people dying ‘unexpectedly’ in Sheffield reflects the wider national picture, and most deaths occur in the older population. However it is of interest that, although the boundaries may overlap, the proportions assessed as being in the *frailty* group was double that of the *chronic disease* group. This will have a significant impact for any strategy for improving end of life care.

The level of frailty amongst those dying is difficult to pick up from routinely available data (eg from Hospital Episode Statistics (HES), death certificates), although both will record a range of diagnoses, so that multiple comorbidities could be identified alongside the main cause of death.

The level of dementia amongst those dying has received some publicity in recent months and the survey finding, if representative of other parts of the country, indicates that dementia is a significant condition in up to 25% of people at the end of life. Usually this will be linked to other issues of frailty.

Locations and alternatives

Cancer patients have an above average prospect of dying at home, and this reflects the range of established palliative care services in Sheffield. Only a minority (38%) died on main hospital wards, and this figure will have been inflated by the closure of the Palliative Care Unit for part of the survey period.

At the other extreme, patients in the frailty group had poor prospects of dying at home. About a third had already moved to a care home and died there without admission to hospital. But the majority died in hospital, including many care home residents. Only 8% of the frailty patients died in their own homes. It is possible that the critical factor of where they die is their frailty rather than that they are at the end of their life. Though these two criteria are inherently linked the management care pathways for each is often separated. In any case, the numbers of people in the frailty group dying hospital has great potential to be reduced and some choice given to frail older people. There was little evidence that the processes of common assessment, the generation of living wills and admission policies to care home were aligned to enable better end of life care.

Across all patient groups 40% of hospital deaths reviewed could have been elsewhere, with roughly equal numbers of bed based and home based alternatives identified by surveyors. Obviously this will be affected by a number of factors, and it is worth noting that the method adopted of requiring surveyors to identify an alternative based on information recorded in the notes is likely to lead to a conservative estimate. A similar but smaller study in East Kent of palliative care patients only found that 52% of admissions might have been avoided [5].

Patients with alternatives tended to be of two types. Firstly, cancer patients for whom palliative care would have been appropriate if it could have been arranged; secondly the frailty group, who were the majority, required some form of nurse led care, either at home or in a non-acute bed setting, which could include care home. Very few alternatives were identified for chronic disease patients.

Changes needed in care pathways

The patterns of services needed to provide appropriate alternatives to dying in hospital use existing services which are either not available in sufficient quantity or are not deployed for people approaching the end of life. It was noteworthy how many frailty patients dying in hospital were already receiving social care packages and may well have been receiving district nursing support (though no tractable data were available about this).

There appear to be significant cultural issues to address also. For example, in subsequent review of the findings it was identified that St Lukes Hospice had been well below full occupancy during the survey month, even though the Palliative Care Unit had been closed for some of that time. Colleagues from the hospice explained that they had stopped taking certain relief admissions in 2005 (as they were deemed an inappropriate use of the service and frequently led to bed shortages). However it was only recently (in 2008) that the opportunity to expand the terminal palliative care service to a wider patient group had begun to be exploited.

We collected data about whether and when decisions on death were made. There was very little evidence in the notes reviewed to suggest the use of scales or measurement tools to systematically assess the patient over time. Much of the recognition of the inevitability of death in this study was done very close to death such that planning for discharge or alternatives to admission was not possible. If the results of using scales and other tools demonstrated deterioration over time then this could be a significant contribution to fewer people dying in hospital. Planning for a good and comfortable death requires the acknowledgement that death is likely to occur in the next few weeks and months. Prognostication of exact time of death is notoriously difficult but it is possible to predict within this period.

Decisions on death are important if choice is to be exercised. However there was little recorded evidence that any choice was offered patients or that they stated a preference for place of death or care. Hospital admission was often precipitated by exacerbation or deterioration of the patient's condition, allied to possible panic on the part of patients or carers, and the risk may have seemed too great for existing care staff with no planned package or referral protocol in place. GPs were only involved in a minority of admissions of this type, and there was little involvement of specialist nurses in end of life care.

For any choice to be meaningful there needs to be the possibility of meeting that preference. Many cancer patients do have that opportunity and palliative care services were notably effective in providing continuous care to the end of life. For the other patient groups an equivalent response would require some nursing and social care services, already involved in the management of chronic disease and frailty, to remain the focus of care much closer to the end of life. A key factor in achieving this may be the ease and speed of information sharing between medical, nursing and care staff.

Changes needed in capacity and organisation

The potential saving in acute bed expenditure in Sheffield if those identified with alternatives were able to die elsewhere could be worth as much as £4.5million, equivalent to £450million if repeated across England. Realistically this would not all be achievable (any retrospective study

has better information available to assess risk than will have been the case at the point of admission) but even a 25% reduction in people dying in hospital could release bed capacity with revenue costs of up to £300million nationally. If linked to other initiatives to free up acute bed capacity, it is reasonable to suppose that substantial revenue to support further service development around end of life care could be released.

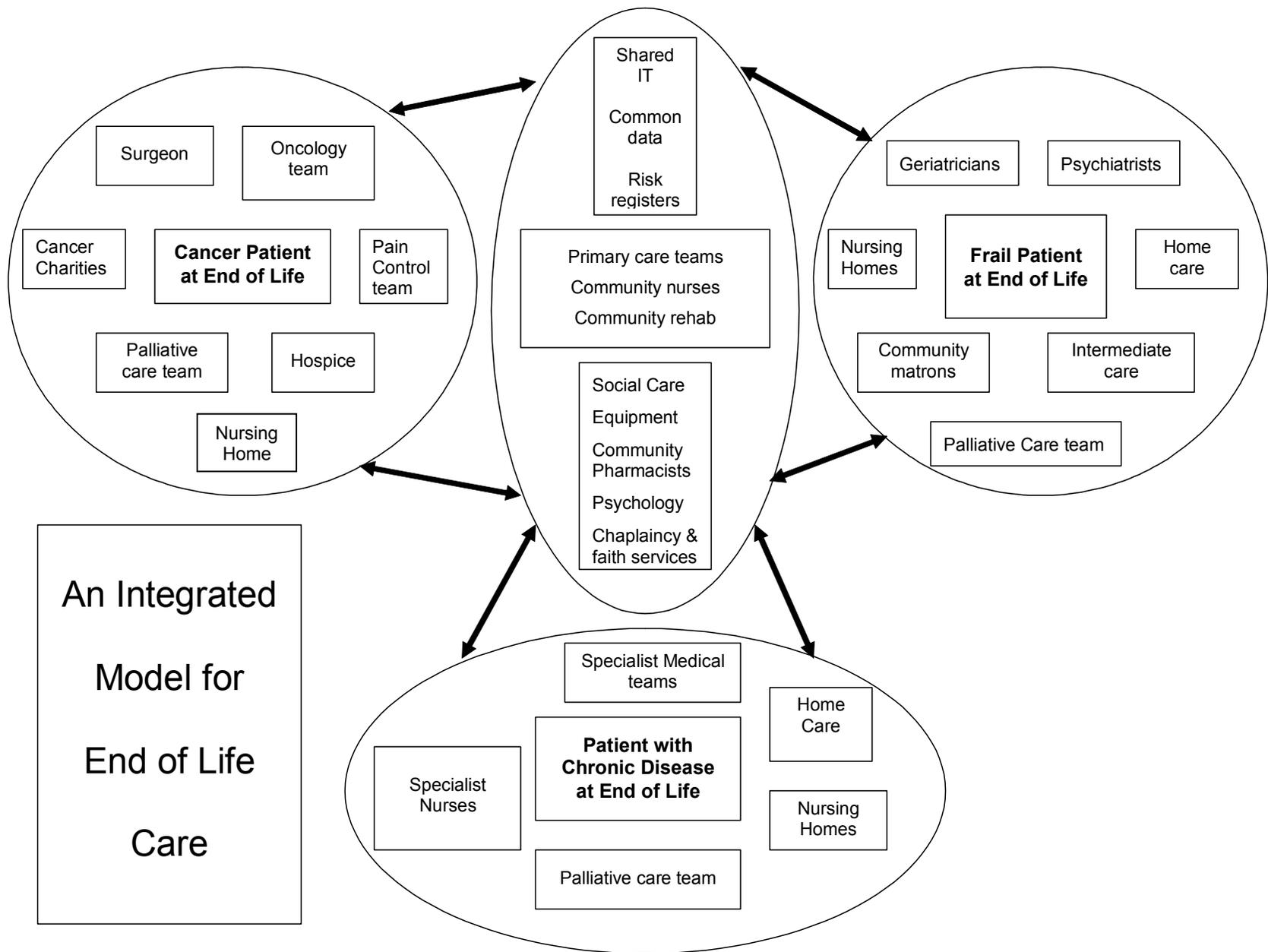
In any event there will need to be some investment in community health and social care, as well as a possible advisory/consultative role for palliative care and chronic disease specialists, both medical and nursing. This mirrors complementary developments needed to support the management of long term conditions, and especially frailty management including dementia

A possible integrative model of end of life care that summarises these issues is attached at figure 6.1. This recognizes that the three main patient groups defined by the Gold Standard Framework have different service needs but some common infrastructure processes that would also support the population management of each category and of those at the end of life. Risk management will involve a balancing act between the individual and the various sub populations.

One particular element here common to meeting dementia and frailty management needs, and essential if all professional groups are able to respond rapidly to care needs at the end of life, is investment on the IT side. The introduction of the NPfIT SystemOne in Sheffield has immediately opened up possibilities for better integration between GPs and general and specialist nurses. Similarly the more established *Infloflex* system is used to record a range of palliative care services. The availability of these data across various out of hospital services has greatly extended the profile of service delivery in this report.

Technically then the potential for data sharing is in place, but in practice the range and timeliness of data recorded was insufficient to sustain the changes in care pathways identified in the survey. Sheffield colleagues involved in system implementation have recognized the sheer scale of the change agenda here but, as elsewhere, the change management resources have not as yet been identified.

The use of measurement scales and the effective sharing of data, taken together with accompanying change in organizational culture, are perhaps the most important developments that will enable significant reductions in the numbers dying in hospital.



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APPENDICES

Appropriateness of Admission Criteria
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Severity of Illness Criteria

- A1.** Sudden onset of unconsciousness or disorientation (coma or unresponsiveness).
- A2.** Pulse rate:
 - a) < 50 per minute
 - b) 140 per minute
- A3.** Blood Pressure:
 - a) Systolic < 90 or > 200 mm Hg.
 - b) Diastolic < 60 or > 120 mm Hg.
- A4.** Acute loss of sight or hearing.
- A5.** Acute loss of ability to move body part.
- A6.** Persistent fever:
 - a) 37.78 C (100 F) orally or
 - b) 38.33 C (101 F) rectally for >5 days
- A7.** Acute bleeding.
- A8.** Severe electrolyte or blood gas abnormality (any of the following):
 - a) Na < 123 mmol/L
Na > 156 mmol/L
 - b) K < 2.5 mmol/L
K > 6.0 mmol/L
 - c) Venous bicarbonate (unless chronically abnormal) < 20 mmol/L
Venous bicarbonate (unless chronically abnormal) > 36 mmol/L
 - d) Arterial pH < 7.30
Arterial pH > 7.45
- A9.** Electrocardiogram evidence of acute ischaemia; must be suspicion of a new myocardial infarction.
- A10.** Wound dehiscence or evisceration.

Medical Procedure

- B1.** Intravenous medications and/or fluid replacement (does not include tube feedings).
- B2.** Surgery or procedure scheduled within 24 hours requiring:
 - a) General or regional anaesthesia, or
 - b) Use of equipment, facilities, or procedures available only in a hospital.
- B3.** Vital sign monitoring every 2 hours or more often (may include telemetry or bedside cardiac monitor).
- B4.** Chemotherapeutic agents that require continuous observation for life-threatening toxic reaction.
- B5.** Intramuscular antibiotics at least every 8 hours.
- B6.** Intermittent or continuous respirator use at least every 8 hours.

Appropriateness of Day of Care Criteria

C. Medical Services

- C1.** Procedure in operating theatre that day.
- C2.** Scheduled for procedure in operating theatre the next day, requiring pre-operative consultation or evaluation.
- C3.** Cardiac catheterisation that day.
- C4.** Angiography that day.
- C5.** Biopsy of internal organ that day.
- C6.** Invasive central nervous system diagnostic procedure (eg. lumbar puncture, cisternal tap, ventricular tap).
- C7.** Any test requiring strict dietary control for the duration of the diet.
- C8.** New or experimental treatment requiring frequent dose adjustments under direct medical supervision.
- C9.** Close medical monitoring by a doctor at least 3 times daily (observations must be documented in record).
- C10.** Operative day for any procedure covered in numbers 1, or 3-7 above.

D. Nursing/ Life Support Services

- D1.** Respiratory care – intermittent or continuous respirator use and/or inhalation therapy (with nebuliser, intermittent positive pressure breathing) at least three times daily.
- D2.** Parenteral therapy – intermittent or continuous intravenous fluid with any supplementation (electrolytes, protein, medications).
- D3.** Continuous vital signs monitoring, at least every 30 minutes, for at least 4 hours.
- D4.** Intramuscular and/or subcutaneous injections at least twice daily.
- D5.** Intake and output measurement.
- D6.** Major surgical wound and drainage care (eg. chest tubes, T-tubes, haemovacs, penrose drains).
- D7.** Close medical monitoring by nurse at least 3 times daily, under doctor's orders.

E. Patient's Condition

Within 24 hours on or before day of review:

- E1.** Inability to void or move bowels (past 24 hours) not attributable to neurological disorder.

Within 48 hours on or before day of review:

- E2.** Transfusion due to blood loss.
- E3.** Ventricular fibrillation or electrocardiogram evidence of acute schamaemia, as stated in progress notes or in electrocardiogram report.
- E4.** Fever at least 37.78 C (100 F) orally or at least 38.22 C (101 F) rectally, if patient was admitted for reason other than fever.
- E5.** Coma – unresponsive for at least one hour.
- E6.** Acute confusional state not due to alcohol withdrawal.
- E7.** Acute haematological disorders, significant neutropenia, anemia, thrombocytopenia, leucocytosis, erythrocytosis, or thrombocytosis, yielding signs or symptoms.
- E8.** Progressive acute neurological difficulties.

APPENDIX II Gold Standard Framework - Definitions of Patient Groups

These clinical prognostic indicators³ are an attempt to estimate when patients have advanced disease or are in the last year or so of life. They have been drawn and referenced from a number of sources including from specialist centres in the UK and abroad but will be updated regularly. Some in other countries e.g. USA use such indicators routinely, to assess patients' need for palliative/supportive/hospice care. Although these are intrinsically only a very approximate guide to prognosis, these clinical indicators can therefore act as a rough guide to indicate to those in primary care and in specialist secondary services that patients may be in need of palliative or supportive care.

General Predictors of End Stage Illness / 2

- Multiple co-morbidities
- Weight loss - Greater than 10% weight loss over 6 months
- General physical decline
- Serum Albumin < 25 g/l
- Reducing performance status / Karnofsky score (KPS) < 50%. Dependence in most activities of daily living (ADL's)

1. Cancer Patients

Cancers

Any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from diagnosis e.g. lung cancer. 'The single most important predictive factor in cancer is performance status and functional ability' – if patients are spending more than 50% of their time in bed/lying down, prognosis likely to be about 3 months or less

2. Organ Failure Patients

2.1 Heart Disease - CHF 4

At least two of the indicators below :-

- CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
- Patient thought to be in the last year of life by the care team - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

2.2 Chronic Obstructive Pulmonary Disease – COPD 5

- Disease assessed to be severe e.g. (FEV1 <30%predicted – with here caveats about quality of testing)
- Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)
- Fulfils Long Term Oxygen Therapy Criteria
- MRC grade 4/5 – shortness of breath after 100 meters on the level or confined to house through breathlessness
- Signs and symptoms of Right heart failure
- Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression

2.3 Renal Disease

- Patients with stage 5 kidney disease who are not seeking or are discontinuing dialysis or renal transplant. This may be from choice or because they are too frail or have too many co-morbid conditions.
- Patients with stage 4 or 5 chronic kidney disease whose condition is deteriorating and for whom the 'surprise question' is applicable ie overall you would not be surprised if they were to die in the next year?
- Clinical indicators:
 - CKD stage 5 (eGFR <15 ml/min)
 - Symptomatic renal failure (anorexia, nausea, pruritus, reduced functional status, intractable fluid overload)

2.4 Neurological Disease

a) Motor Neurone Disease

MND patients should be included from diagnosis, as it is a rapidly progressing condition

Indicators of rapid deterioration include:

- Evidence of disturbed sleep related to respiratory muscle weakness in addition to signs of dyspnoea at rest
- Barely intelligible speech
- Difficulty swallowing
- Poor nutritional status
- Needing assistance with ADL's
- Medical complications eg pneumonia, sepsis
- A short interval between onset of symptoms and diagnosis
- A low vital capacity (below 70% of predicted using standard spirometry)

b) Parkinson's Disease

The presence of 2 or more of the criteria in Parkinson disease should trigger inclusion on the Register

- Drug treatment is no longer as effective / an increasingly complex regime of drug treatments
- Reduced independence, need for help with daily living
- Recognition that the condition has become less controlled and less predictable with "off" periods
- Dyskinesias, Mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

c) Multiple Sclerosis

Indications of deterioration and inclusion on register are:-

- Significant complex symptoms e.g. pain
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive difficulties
- Swallowing difficulties/poor nutritional status
- Breathlessness + aspiration
- Medical complication e.g. recurrent infection

3. Patients with Frailty and Dementia

Frailty

- Multiple comorbidities with signs of impairments in day to day functioning
- Deteriorating Karnofsky score
- Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, weight loss, self-reported exhaustion

Dementia

- Unable to walk without assistance, and
- Urinary and fecal incontinence, and
- No consistently meaningful verbal communication, and
- Unable to dress without assistance
- Barthel score < 3
- Reduced ability to perform activities of daily living

Plus any one of the following:

10% weight loss in previous six months without other causes, Pyelonephritis or UTI, Serum albumin 25 g/l, Severe pressure scores eg stage III / IV, Recurrent fevers, Reduced oral intake / weight loss, Aspiration pneumonia

Stroke

- Persistent vegetative or minimal conscious state / dense paralysis / incontinence
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia

Karnofsky Performance Status Score

The Karnofsky score, measures patient performance of activities of daily living

Score Function

- 100 Normal, no evidence of disease
- 90 Able to perform normal activity with only minor symptoms
- 80 Normal activity with effort, some symptoms
- 70 Able to care for self but unable to do normal activities
- 60 Requires occasional assistance, cares for most needs
- 50 Requires considerable assistance
- 40 Disabled, requires special assistance
- 30 Severely disabled
- 20 Very sick, requires active supportive treatment
- 10 Moribund

Appendix III

Local Steering Group Members

Dr Sam Ahmedzai – Professor of Palliative Medicine

Sara Bradley – PCT Lead, End of Life Care

Louise Brewins – Consultant in Public Health, Sheffield PCT

Maggie Campbell, PCT Lead, Long Term Neurological Conditions

Dr Andy Ferguson – G.P

Tracey Hardcastle – Cardiac Failure Specialist Nurse STH

Dr Sophie Harrison – Consultant in Palliative Medicine

Simon Kirk – Director of Strategy, Sheffield PCT

Steve Kirk – Chief Executive, St Lukes Hospice; Chair, Sheffield Palliative Care Collaborative

Dr Jane Liddle – Consultant in Elderly Medicine (Hospital)

Collette Longford – Project Manager, CHD Collaborative

Dr Survira Madan – Consultant in Elderly Medicine (Hospital)

Rebekah Matthews Community nurse manager , Sheffield PCT

Dr Al Mohammed – Consultant Cardiologist

Cath Roff – Director of Adult Services, Sheffield City Council

Hilary Scholefield – Chief Nurse, STH

Dr Kay Stewart – Consultant in Palliative Medicine

Sue Thackeray – PCT Lead, COPD

Dr Vandana Vora - Consultant in Palliative Medicine

Dr Claire Whitehead - Consultant in Elderly Medicine (Community)

Mandy Yates – Assistant Director of Nursing, STH

APPENDIX IV**List of Surveyors, Sheffield, 7 – 11 April 2008**

Sue	Barnston	(STH)
Sara	Bradley	End of Life Project Consultant (PCT)
Alison	Humphrey	Palliative Care Liaison Nurse (STH)
Anne	Jennings	Practice Development Coordinator (Information) (STH)
Debbie	Kendray	Renal specialist nurse (STH)
Colette	Longford	CHD/ heart failure nurse specialist (PCT)
Diane	Marquand	Staff nurse, Intensive home nursing service (PCT)
Rebekah	Matthews	Community Nurse Manager (PCT)
Becky	McGeehan	(STH)
Pete	Saunders	Palliative Care Liaison Nurse (STH)
Kay	Stewart	Consultant in Palliative Care Medicine (STH)
Sue	Thackray	COPD nurse specialist (PCT)
Shirley	Thompson	End of Life Co-ordinator (STH)
Tracy	Ward	COPD Specialist Nurse (PCT)

Appendix V Survey form definitions of alternative care settings

The table below provides definitions of the potential care alternatives specified on the survey forms. All definitions were discussed in depth with surveyors during the training sessions.

Own home only (+GP)	At home (alone, or living with a carer/ family) but with no additional supporting services other than normal GP support
Home with social care	At home with Care Assistant support (only) for social care tasks. Social care can also include meals on wheels and voluntary sector support Includes respite care where provided at home
Home + general health care	At home with general community nursing support (and with or without any necessary social care support as required)
Home with rehab support	Support at home from therapy services (with or without social care and / or nursing support as required)
Home with specialist nurse	Specialist nurse skills - eg diabetes, stroke, CPN (and with or without social care and / or general community nursing support).
Home with palliative care nurse	Palliative care nurse skills (and with or without social care and / or general community nursing support).
Non-acute bed	Placement in residential or nursing care home (excluding mental health facility)
Non-acute bed + palliative care	Placement in hospice or residential or nursing care home with direct input from palliative care services
Non-acute bed (EMI)	Placement in residential or nursing care home which is a specialist mental health facility
Continuing care bed	Long-term placement in a care home (includes both EMI and non-EMI patients)
Access to outpatient clinic and/or diagnostics	At home (alone or with carer and with or without social care support) with access to outpatient clinic and/or diagnostic services as rapidly as required
Other	As specified by surveyor, if not included above

NB: ‘Own home’ or ‘home’ options mean that the person could be living on their own (or with their partner or family) in the community. It does not mean ‘care home’. A care home placement of any type would be covered here by ‘non-acute bed’ options.

This also applies if the patient was originally admitted from a care home. If the preferred alternative option is still a care home environment, then one of ‘non-acute bed’ options should be selected (not ‘own home’).