

# EVALUATION OF PILGRIMS HOSPICES RAPID RESPONSE HOSPICE AT HOME SERVICE

*Summary of findings*  
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**Laura Holdsworth**

Research Fellow, Centre for Health Services Studies, University of Kent

**Annette King**

Kent Academic Lead for NIHR Research Design Service South East Kent,  
Centre for Health Services Studies, University of Kent

**Claire Butler**

Medical Director, Pilgrims Hospices in East Kent

**Heather Gage**

Professor of Health Economics, School of Economics, University of Surrey

**Simon Coulton**

Professor of Health Services Research, Centre for Health Services Studies,  
University of Kent

# HOSPICE AT HOME SERVICE: BACKGROUND AND DEVELOPMENT

**When faced with a life-limiting illness, most people say they would prefer to spend the end of their lives and die at home.<sup>1</sup> However, we know that about half the people with cancer or long-term illnesses still die in hospital. Fewer than a quarter die in their own home.<sup>2</sup> Patients are often admitted to hospital because of a crisis such as uncontrolled symptoms, carer fear or stress, or not having medication available when needed.<sup>3</sup> Community based palliative care teams can help in such situations.<sup>4</sup>**

In 2008 Pilgrims Hospices commissioned a review of the literature to understand what kinds of home care services provide the most benefit to patients at the end of their lives and their families.<sup>5</sup> Though good quality evidence was scarce, the findings of the review suggested that successful services are able to respond rapidly, focus on supporting family carers at home and are available 24 hours a day seven days a week.

Following these conclusions, Pilgrims Hospices developed the Rapid Response Hospice at Home service (Hospice at Home) to support people who are at the end of life and would like to die at home. The Hospice at Home service operates in addition to established hospice community services and is staffed by healthcare assistants (HCAs) who have been trained at the hospice. The HCAs are available day and night at four hours' notice to support patients in the last days of their lives or when they experience a crisis.

A research project was undertaken to contribute to our knowledge of hospice at home services. The study was carried out by Pilgrims Hospices and the Universities of Kent and Surrey, and was funded by the NIHR Research for Patient Benefit scheme.

## **What was the research about?**

The study aimed to find out whether the Hospice at Home service enabled more patients to die where they wished. To do this, we identified where patients preferred to die and where they actually died as recorded in hospice notes. In addition, we investigated:

- Family carers' physical and mental quality of life and their activities as caregivers. This was done through postal questionnaires sent out when patients were referred to the hospice and eight months later to see if there were any changes over time.

## **Acknowledgements**

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- The costs of the Hospice at Home service which we compared to costs of usual care.
- The experiences of bereaved family carers through interviews.

### How the research was carried out

The Hospice at Home service was introduced in stages across each of Pilgrims Hospices' three sites at six monthly intervals (see Figure 1). This was the most practical approach so that new staff could be recruited and trained. NHS and social care service providers were made aware of the service as it became available in their area. We collected data across all areas during the study period so we could compare what happened in areas where the new service was available (intervention group) to those where it was not (control group).

Throughout the study, all patients received usual services from all providers of health and social care. Whether or not patients in the intervention group actually received the Hospice at Home service depended on their individual needs.

An advisory group of patients and carers from Pilgrims Hospices met regularly to provide guidance to the research team throughout the study. We are grateful for their support.

**Figure 1: Timeline of service delivery by area**

	Jan 2010	July 2010	Jan 2011	July 2011
Canterbury	<b>Intervention</b> (Hospice at Home + usual care)	<b>Intervention</b> (Hospice at Home + usual care)	<b>Intervention</b> (Hospice at Home + usual care)	
Thanet	<b>Control</b> (Usual care)	<b>Intervention</b> (Hospice at Home + usual care)	<b>Intervention</b> (Hospice at Home + usual care)	
Ashford	<b>Control</b> (Usual care)	<b>Control</b> (Usual care)	<b>Intervention</b> (Hospice at Home + usual care)	

# SUMMARY OF THE RESEARCH FINDINGS

## Outcomes for patients

A total of 953 patients referred to the hospice during the 18 month study period recorded a preferred place of death by the time they died (70% of all referred hospice patients). Table 1 summarises the characteristics of patients in both the control and intervention groups. Bar charts 1 and 2 show where patients preferred to die and where they actually died.

**Table 1: Characteristics of patients in the study**

	Intervention n=688	Control n=265
<b>Average age</b>	75 years	74 years
<b>Gender</b>		
Male	388 (56.4%)	160 (60.4%)
Female	300 (43.6%)	105 (39.6%)
<b>Diagnosis</b>		
Cancer	617 (89.7%)	239 (90.2%)
Non-Cancer	70 (10.2%)	26 (9.8%)
Unknown	1 (0.1%)	0
<b>Occupancy<sup>1</sup></b>		
Lives at home with others	382 (65.2%)	163 (66.3%)
Lives at home alone	151 (25.8%)	69 (28.0%)
Lives in a care home	53 (9.0%)	14 (5.7%)

<sup>1</sup> Data missing for occupancy for 121 patients, intervention n=586 and control n=246

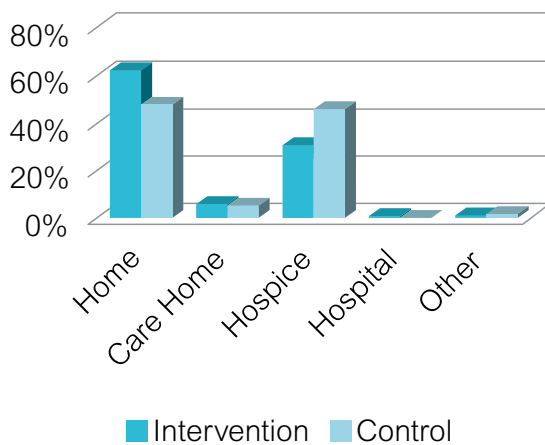
We found the following:

- The number of people achieving their preferred place of death was high in both the intervention and control groups (about 60% in each). Availability of the Hospice at Home service did not affect whether patients died in their preferred place or not.
- Patients who had specified *care home* or *hospice* as their preferred place of death were significantly more likely to achieve their preference.
- Patients who *lived at home alone* were less likely to achieve their preference, regardless of whether the Hospice at Home service was available in their area.
- When the Hospice at Home service was available, significantly more patients stated a preference to die at *home* (62% intervention vs 48% control) and were able to do so (41% intervention vs 26% control).
- Only 36% of patients in the intervention group actually received the Hospice at Home service.

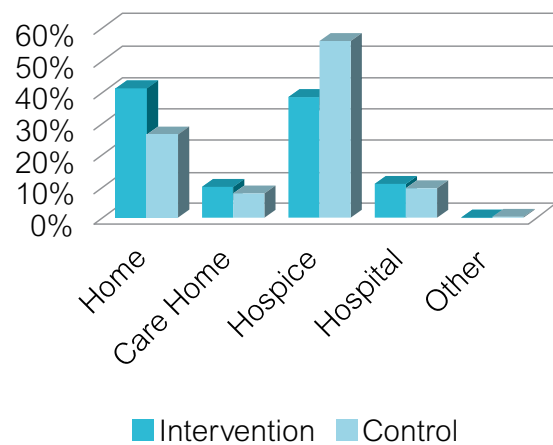
The availability of the Hospice at Home service did not improve patients' chances of dying in their preferred place. We think this is because patients under hospice care already receive a high level of input from services operating in the community which means they are likely to achieve their wishes in any case. However, more patients wished to die at home when the Hospice at Home service was available and were enabled to do so. This could indicate that the availability of such a service make a death at home seem more achievable.

Our study also highlights the important role that family play in helping patients achieve their wishes. People living on their own and who therefore may rely mainly on formal care services for support were less likely to achieve their preferences. This suggests that family carers are an important part of the support that many patients need. Our work affirms previous research which also found that the presence of relatives increases the chances of patients being able to die at home.<sup>4</sup>

Bar chart 1. Where patients preferred to die



Bar chart 2. Where patients actually died



## Outcomes for family carers

Questionnaires were sent to 403 carers; 155 responded to the first questionnaire and 64 completed the follow-up questionnaire. Most carers who responded were the patients' spouse or partner (72%) with patients' children making up the second largest group (23%) and the remainder were other family and friends (5%).

Outcomes for family carers with regards to physical health and depression were largely similar between those who had access to the Hospice at Home service and those who did not. This finding suggests that the Hospice at Home service itself did not have much of an impact on these outcomes. There was one difference – carers in the intervention group had worse mental health than those who did not have access to the service. We cannot be entirely sure what caused this difference, but it may be that more carers in the intervention group cared for a patient who died at home, which involved a higher burden of care and greater stress. Nevertheless, we need to be cautious about these results because overall only 16% of carers in the study responded at the two time points.

## Family experiences of caring at the end of life

We carried out 44 interviews with bereaved family carers between six and ten months after the patient's death. Carers were either the spouse of the patient (87%) or child (13%) and were mostly female (62%). We asked them to reflect on what happened in the time leading up to death and what they thought about the quality of care and how their loved one died. We were particularly interested in how people made the choices they did and what constitutes a 'good death.'

## The importance of preferences

When faced with decisions about end of life care and where to die, each individual and family is unique in what they wish for or indeed whether they consider place of death important at all. Some carers said that patients were not particularly concerned about this, while other patients were. For carers, it tended to be important. In our interviews we identified four common themes that shaped the preferences that carers had: previous experience of caring for someone; wishes and values; ability to cope with the physical and emotional aspects of caring; and social and personal circumstances.

## SUMMARY OF THE RESEARCH FINDINGS (CONT)

Preferences and choices were not set in stone, but were reviewed throughout the last weeks and days of life. Sometimes the progression of the illness meant that priorities had to be reconsidered. Whilst this was sometimes difficult, particularly when it appeared that the expressed wishes of a loved one could not be fulfilled, carers said that they were mostly happy with the choices that had been made about the place of death. This was more often the case when carers had support in changing their plans and felt it had been in the best interest of the patient. Thus whilst achieving preferences was important for many, the most important thing was for patients to die well.

### Carers' views on a 'good death'

We wanted to find out what carers thought made for a good end of life experience and a 'good death' for their loved one. For carers in our study, a 'good death' meant that the patient was able to maintain meaningful relationships and a connection to their identity as a self-determining person up until death. This meant continuing to be involved in family life, maintaining 'normality', dignity, and control. Our definition of a good death from a family point of view comes from eight separate themes that were identified in contributing to a good end of life experience. Some of these themes are illustrated by quotes taken directly from the interviews.

- 1 It was essential for carers and patients to be able to maintain a **normal life** despite the presence of illness as much as possible.
- 2 Carers wanted to be able to have meaningful contact with both the patient and other friends and family; therefore **maintaining relationships and a connection to their identity** as a wife, husband, or child and not a 'carer' was essential.

*"The hospice... enabled me to become [patient's] partner again as opposed to his carer ... so that was priceless"*

10CM, patient's partner, patient died at home

- 3 Having confidence and being able to **trust in the support given by care professionals** was essential. Many patients and carers were reliant on professionals for managing the patient's illness and helping with caring activities which made carers feel vulnerable.

*"you build up this relationship of trust and love, really, and, you know, [the district nurses] care for you and they put their arm around you and that's vitally important"*

38IF, patient's wife, patient died in hospice



4 Carers expressed concern that they lacked the **ability to provide care** to patients, but when they were able to support the patient's choices they felt satisfaction with their efforts.

*"I'm pleased that everybody helped me to help [patient] to die where he really wanted to die and I feel he... maybe it's a funny thing to say, but I think he died happy because he died where he wanted to be. And I think I felt if I'd sent him to hospice to give myself a break, I couldn't live with that because I would have felt that I broke my promise to him"*

16CF, patient's partner, patient died at home

5 Being **prepared, aware, and accepting** of death was identified by many carers as helping them to cope with caring for their dying relative.

*"if you accept that you fought this illness for three-and-a-bit years and it's come back again and this time you won't be able to fight it. ... if you accept that and if everyone around you accepts it as well then the caring is very easy"*

05IF, patient's wife, patient died at home

6 Carers felt that the best environment at the time of death was one which was **peaceful, private, dignified**, and where the patient could be **surrounded by family and friends**. Above all carers did not want the patient to die alone.

*"there is no comparison to the hospice spirit and feel and kindness and you're a person. You're actually not a number. You're a person. You're a real person."*

02CF, patient's wife, patient died at home

7 The **control of distressing symptoms** was a priority throughout the patient's illness, but particularly at the time of death.

8 A few carers spoke about the importance of having **time to reflect and grieve** immediately after death and how care professionals could help them to transition back to a life not dominated by a care routine.

*"The aftercare, after it's happened, the nurses came back to see me. That was wonderful. Because the [Hospice at Home] couldn't but the nurses came back to see if I was all right. .... A day later and then a week later they popped in. 'Just passing, thought we'd pop in and see if you're all right.'"*

38IF, patient's wife, patient died in hospice

CONTINUED OVERLEAF



## SUMMARY OF THE RESEARCH FINDINGS (CONT)

### **How care professionals can better support patients and their families**

The interviews also highlighted a number of ways in which care professionals can better support patients and their families at the end of life. This included:

- Explaining what options and support are available in an evolving situation.
- Sharing in the responsibility of making decisions about care and place of dying. This means neither leaving families to make decisions in isolation nor making decisions on their behalf.
- Keeping the conversation about wishes and what to expect going as long as it is needed.

### **The cost of the service**

To find out the cost of the Hospice at Home service compared to usual care, we collected information about what services patients used including: hospice care, hospital care, GP care, community nursing, social services, Marie Curie services, and out of hours services.

We found the following:

- Overall costs were the same for the group of patients who had access to the Hospice at Home service and the group receiving usual care. This indicates that the new service was cost neutral.
- How and what services were received by patients in the days and weeks prior to death varied greatly and expenditure on the Hospice at Home service was a relatively small proportion of total service costs. For those who used the service, Hospice at Home accounted for between 4% and 10% of their total service use cost.
- On average, the Hospice at Home team made 11 visits to patients.

Whilst overall the new service did not add to the cost of end of life care in the area, different cost drivers came into play at different periods before death. There was no simple shift in service use, such as from inpatient hospital costs to home care, which means that funding for the service cannot easily be shifted from one provider to another.



# CONCLUSIONS

While the availability of the Hospice at Home service did not significantly increase the number of patients who were able to die in their preferred place, significantly more patients died at home when the service was available. The interviews indicated that all supportive medical and nursing care received at home was appreciated. The Hospice at Home service enabled more people to receive compassionate care at home.



## CONCLUSIONS (CONT)

### **The case of Mr and Mrs Roberts – an example of Hospice at Home in action based on experiences from the interviews**

Mr Roberts is a 76 year old man with lung cancer who was referred to Pilgrims Hospices by his GP and has since been having weekly visits with a hospice Community Nurse Specialist (CNS). Mr Roberts has decided that he would like to die at home as long as his wife can cope. Mrs Roberts had been coping fairly well with her husband's care needs, but recently he has deteriorated and now requires her help to get out of bed, to wash and go to the toilet. One night he experiences very intense pain and the next day has a visit from his GP who sees that Mrs Roberts is struggling to help her husband. The GP arranges to have a district nurse visit once a day and at the same time makes a referral to the Hospice at Home team who arrange to have two Healthcare Assistants (HCAs) visit Mr Roberts the very same day. The district nurse organises a hospital bed to be delivered to Mr Roberts' home and some additional equipment, and the Hospice at Home team arrange to have two HCAs visit three times a day for one to two hours. When they arrive, Mrs Roberts likes to use the time for herself; she'll take the dog out for a walk or perhaps do the shopping.

The HCAs help Mr Roberts to use the toilet, wash him, and make sure his bedding and clothes are clean. When Mrs Roberts returns, they make her a cup of tea and have a chat with her about how she's coping. She says she is exhausted and hasn't been sleeping, so the team arrange to have someone stay that night so she can have a full night's sleep. The next day Mr Roberts is very unwell so a district nurse puts him onto a syringe driver and he hasn't woken up since.

The Hospice at Home team continue to visit and still chat to Mr Roberts as they clean him even though he is not conscious, which Mrs Roberts really appreciates. They have arranged to have Sally, an HCA stay for a second night and in the middle of the night Sally notices that Mr Roberts' breathing has changed. She makes sure Mr Roberts is clean and comfortable and then goes to wake Mrs Roberts to let her know that Mr Roberts is dying. When she comes down stairs, her husband looks peaceful and she is able to spend his last hours holding his hand, but feels confident knowing that Sally is in the next room if she needs her. Mr Roberts is able to die in his own home with his wife by his side.

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