



## **Achieving seamless care**

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**A review of Hospiscare services  
May 2007**

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## Executive Summary

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### Foreword

Hospiscare is 25 years old and is widely respected for the standard of palliative care it delivers in the community, in the hospice and in the acute hospitals. A pivotal point in its development has now been reached with recent and impending change at all levels. It is therefore, a very appropriate time to stand back and look at the services Hospiscare provides and, importantly, plan a strategic way forward.

I would like to thank all the patients, carers and professionals who have responded and contributed to this report and I look forward to seeing these plans come to fruition.

**Hugh Savill**

**Chairman of the Service Review Group**

### Introduction

This review was carried out by a Service Review Group whose members included Hospiscare staff and trustees and also PCT staff and representatives from neighbouring hospices. Its deliberations were held in the context of major change both nationally, with the imminent publication of an End of Life Strategy, and locally following the instigation of a strategic review by the newly established Devon PCT. The Group considered feedback from stakeholders; including the results of a postal survey to local health and social care professionals and focus groups with patients and carers. It has made 20 recommendations that it intends will provide the basis for the strategic development of Hospiscare's services over the next 5 to 10 years.

### Purpose of the review

The review was set up to achieve these outcomes:

- Patients experience a seamless service from Hospiscare
- Patients experience smooth transitions between Hospiscare and other service providers
- Patients are able to access the services they need, when and where they need them
- A financially sustainable model of service provision

### Key findings

The stakeholder consultation found that Hospiscare's current practice was very highly valued. There was a common perception by professionals that they undertook a very wide range of roles *in partnership* with Hospiscare, rather than seeing it simply as a service provider. Whilst most respondents had experience of patients dying in a number of environments, the Hospice was regarded as offering the best experience, with death at home seen as their next preferred choice. Most respondents would like to refer more non-cancer patients to Hospiscare but are concerned that this would

stretch Hospiscare's resources and dilute its offering to patients. Some respondents were not sure how appropriate their referral would be.

Respondents were asked their opinions on a wide range of potential improvements to Hospiscare's services. The most popular were:

- Education for staff working with palliative care patients, information, advice and support to professionals
- Extending services to more non-cancer patients
- Meeting the needs of patients with complex psychological and emotional needs
- Leading the development of palliative care in Exeter, mid and east Devon
- Locality based day-care services and carer support
- Out of hours 'hospice at home'

### **Service Review Group conclusions**

The Service Review Group identified three themes that ran through its deliberations.

#### **Theme 1: Equity of access for patients to timely and responsive services**

The Group considered whether factors such as locality, the time of day service was required, diagnosis, social context, preference for place of care and, or death, had an effect on equity of access to services. They made a number of recommendations to enhance access identifying however that the majority of these issues were not within Hospiscare's direct control and thus required partnership working with Community Hospitals, Primary Care and the PCT. They also thought that labelling patients by their diagnosis was problematic because they believed that the most important issue was meeting patients' individual needs.

#### **Theme 2: Hospiscare's role**

The Group valued the finding from the survey that Hospiscare was seen as a partner by local professionals and seeks, in its recommendations, to build on that platform. They identified that Hospiscare has a key role in raising awareness and understanding of care of the dying with both the public and health and social care professionals. There was a strong desire for Hospiscare to develop the education and information services it provides for practitioners. The Group recognised that this would be particularly important in supporting the government's proposed End of Life Strategy and identified that to do so Hospiscare would need to strengthen its relationship with the PCT and Social Services, both in their commissioner and provider roles.

#### **Theme 3: Resourcing and sustainability**

The Group identified that their recommendations have implications for the way in which Hospiscare applies its resources and configures its workforce. It was aware that a number of stakeholders had identified that service development must be sustainable and not affect adversely on the current quality of Hospiscare's work. The Group identified the need for flexibility in the workforce of staff and volunteers and individual development and learning opportunities. It also acknowledged that access to IT and accommodation were particular issues for the community based teams and that these needed to be addressed. Lastly, the Group recognised that some of their recommendations for service development, such as 'hospice at home' would require new funding and that discussions about implementing the government's End of Life Strategy must include how it will be funded.

## **Conclusion**

The Service Review Group believes that its recommendations provide a strategic framework for Hospiscare to improve patient experience and choice at the end of their lives. It looks forward to supporting the implementation of its recommendations in partnership with its local communities.

## **Summary of recommendations**

### **Theme 1: Equity of access for patients to timely and responsive services**

#### **Location**

Explore with the PCT Hospiscare's role in supporting Community Hospital inpatient provision.

Explore options for greater choice in day-care provision including flexible locality based day-care that encompasses carer support, access to complementary therapy, advice and information.

Explore ways in which to work more closely with out of hour's services to avoid unnecessary acute admissions.

Work with partners to scope and develop 'hospice at home' provision.

#### **Diagnosis**

Clarify Hospiscare's referral criteria and the ways in which it might respond to referrals, and disseminate this guidance appropriately.

Develop partnerships with non-cancer specialist clinical teams and continue to support the implementation of the Gold Standards Framework, the Liverpool Care Pathway and other relevant care pathways.

#### **Social inclusion**

Highlight Hospiscare's commitment to social inclusion in referral criteria and consider how this should be audited and monitored.

#### **Choice of place of end of life care**

Engage with the PCT, Social Services and relevant providers to co-ordinate and support patients' choice of place of end of life care.

#### **Access to full range of palliative care services**

Adopt a generic approach to enhancing psychological support by enabling front-line staff to develop appropriate skills.

## Theme 2: Hospiscare's role

### **Awareness and information**

Develop Hospiscare's role in raising public awareness about care of the dying; including building understanding about hospices and palliative care; breaking down the taboos around talking about death and encouraging higher expectations of quality of care at end of life.

Review Hospiscare's patient and carer information in consultation with users.

### **Education**

Review and enhance information and education for professionals, in association with local partners, to support the implementation of End of Life Strategy.

### **Partnerships**

Review and enhance communication and liaison with local health and social care professionals.

Fully engage as a partner in the development and implementation of the End of Life Strategy in this locality.

Strengthen relationships with the new PCT (both commissioners and providers) and with Social Services.

Explore with nursing homes how to support them better.

## Theme 3: Resourcing and sustainability

### **Workforce**

Prepare a workforce development plan to implement report recommendations.

### **Physical resources**

Include accommodation and ICT needs in service development planning.

### **Funding**

Ensure funding issues are on the agenda for implementing an End of Life Strategy locally.

### **Evaluation**

Discuss with commissioners and other partners appropriate measures and put in place mechanisms to collect the required quantitative and qualitative data.

# Achieving seamless care

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## A review of Hospiscare services May 2007

### **Forward**

Hospiscare is 25 years old and is widely respected for the standard of palliative care it delivers in the community, in the hospice and in the acute hospitals. A pivotal point in its development has now been reached with recent and impending change at all levels. Nationally, there is the end of life strategy due out this year as well as the drive to roll out the Gold Standard Framework and Liverpool Care Pathway to all settings where palliative care may be delivered. Locally, the former PCTs have been amalgamated into one large organisation which includes other providers of hospice facilities; this will bring change to the way in which the service is commissioned and will be facilitated by greater dialogue between ourselves and other local providers. Finally, within Hospiscare, we have seen a new extension built and further major improvements to our buildings and services are planned.

It is, therefore, a very appropriate time to stand back and look at the service we provide and, importantly, plan a strategic way forward for the next five or ten years – taking into account all the recent and anticipated developments at national and local level. This service review report aims to lay the foundation for this development, leaving the detail to be worked through by our clinical and administrative committees. The Service Review Group has been very fortunate to include representatives from other hospice services, (Bath and North Devon) the PCT and social services and we plan to continue to meet in order to monitor the progress of these strategic proposals.

I would like to thank all the patients, carers and professionals who have responded and contributed to this important Group and we all look forward, with anticipation, to seeing these plans come to fruition and for Hospiscare to develop new and exciting pathways.

Hugh Savill

**Chairman of the Service Review Group**

## Introduction

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Hospiscare celebrates 25 years of providing palliative care services in 2007. This anniversary is an opportunity to celebrate a successful and well-regarded service and also to look to the future to meet new challenges.

Following a strategic review early in 2006, which primarily involved staff and volunteers, Hospiscare began a consultation with patients and carers, local health and social care practitioners, and funders, as a precursor to reviewing its services. The resulting data was then analysed by the Service Review Group (appendix I) and their conclusions are presented in this report.

### Purpose of the review

The review was set up to achieve these outcomes:

1. Patients experience a seamless service from Hospiscare
2. Patients experience smooth transitions between Hospiscare and other service providers
3. Patients are able to access the services they need, when and where they need them
4. A financially sustainable model of service provision

### Local context

Hospiscare serves a population of 361,908 (2006) in Exeter, mid and east Devon (see map, appendix 2). This accounts for 48% of Devon PCT's population. This population is primarily white but there are significant minority ethnic populations in Exeter.

PCT	All People	White	Black	Asian	Chinese	Other Ethnic
East Devon	118894	118027	77	125	153	426
Exeter	129706	126902	240	750	403	1033
Mid Devon	90474	89813	55	110	114	314
North Devon	146490	145064	130	267	280	616
South Hams	111907	110859	177	152	107	519
Teignbridge	106977	105924	117	140	256	452

(2001 Census)

Hospiscare provides palliative care for people living with any advanced incurable progressive illnesses and for those close to them. Referral to the service may be at the time of diagnosis for some patients, at the time of recurrence or relapse, or towards the end of their life. The Hospiscare's multi-professional team includes nurses, care managers, doctors and a chaplain, supported by trained volunteers. Hospiscare offers this care in a variety of settings: -

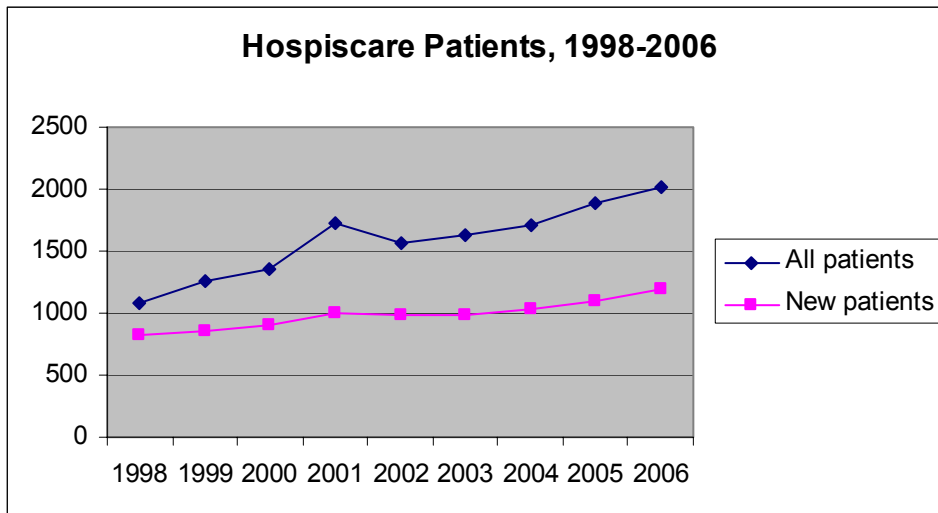
- in the community alongside primary care
- at the Royal Devon & Exeter Hospital (RD&E)
- in the hospice in-patient unit and day-care facility

- at hospice out-patient appointments
- through carer and patient support groups

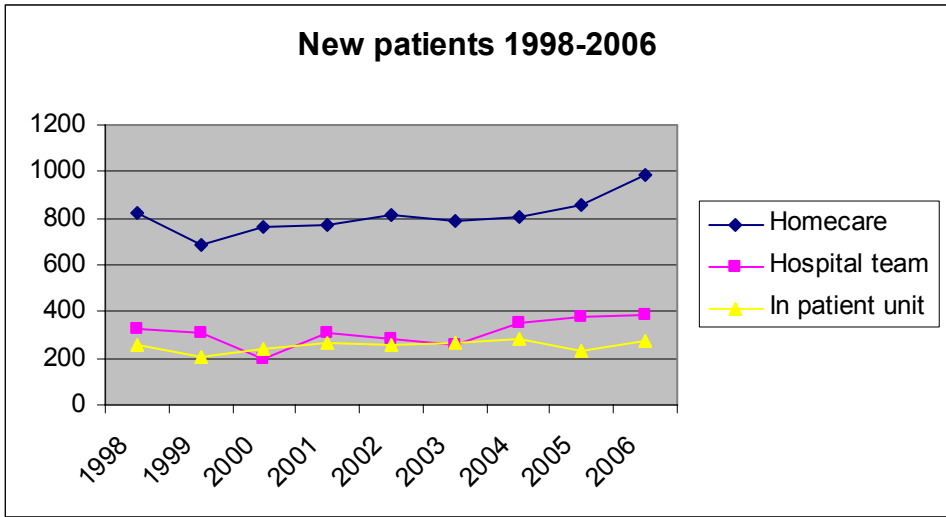
Patient and, or family referral may be for:

- management of difficult symptoms and, or complex care management
- emotional support
- discussion of treatment options
- difficult communication issues
- practical advice and information
- spiritual care
- planning for future care needs
- bereavement

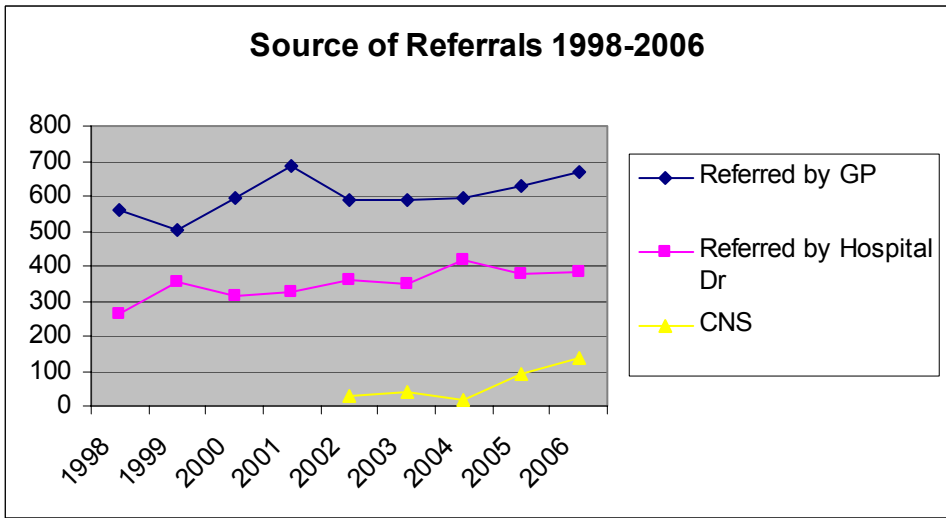
In total 2013 patients were in Hospiscare’s care in 2006; 1186 of these were new patients. Total patient numbers have almost doubled since 1998 and the length of time they remain with Hospiscare has increased, suggesting earlier referral in recent years.



The majority of Hospiscare patients are in the care of homecare teams and referral to this team has been rising steadily. The average length of stay in the 12 bedded in-patient unit was 9 days in 2006 and the throughput was 26 patients per bed, per year. The Hospital team, which serves the RD&E Hospital, has also seen a consistent increase in referrals.



Patients are referred to Hospiscare mainly by GPs but there has been an increase in referrals from site specific clinical nurse specialists recently as these posts have become established.

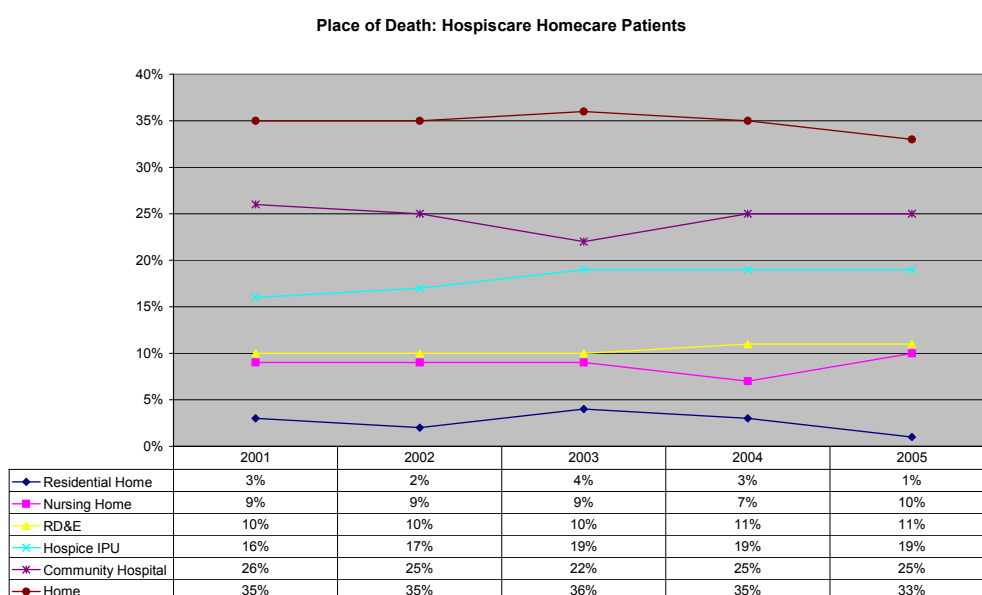


Nationally statistics demonstrate that patients prefer to be cared for and to die at home but are more likely to die in hospital.

## Preferences versus reality – where people want to be cared for and where they actually die<sup>1</sup>

Place of death	Preferred place of death	Actual place of death – all causes	Actual place of death – cancer principal cause
Home	56%	20%	25%
Hospice	24%	4%	17%
Hospital	11%	56%	47%
Care Home	4%	20%	12%

Hospiscare's analysis of place of death of *patients in the care of its homecare teams* indicates that on average 60% die in a community setting; either at home, 35%, or in a community hospital 25%.



## Regional and national context

Until recently Hospiscare served three PCTs; Exeter, east Devon and mid Devon. These were combined in October 2006, along with 3 other PCTs to create Devon PCT. Commissioning arrangements are still being worked through but clearly there will be implications for the way in which services are commissioned and delivered throughout the new PCT area which will require greater collaboration with other providers, particularly neighbouring hospices. PCTs are being given a strong steer to improve commissioning practice, including developing practice based commissioning; and moving services from the secondary to primary care through applying the concept of 'contestability'.

<sup>1</sup> Tebbit P. (2005), Palliative Care Needs Assessment For South West Peninsula Cancer Network

The government has tasked Prof Mike Richards, the National Cancer Director, with producing an 'End of Life Strategy'. This is expected in September 07 and its aim is to encompass all conditions with an emphasis on enabling patient choice in the location of care. One model often quoted is the Marie Curie 'Delivering Choice' programme<sup>2</sup> which aims to enable more people to die at home (if that's their wish) through the co-ordination and integration of end of life services within a given locality. A key measure that the programme adopts is the reduction in acute admissions.

'Payment by results', via a tariff system, appears to no longer be on the agenda for hospices although remains a possibility for hospital based services. The government have pledged to review hospice funding in the End of Life Strategy. 'Full cost recovery', as envisaged by the 2002 Treasury cost-cutting review<sup>3</sup>, remains a subject for negotiation between commissioners and providers<sup>4</sup>.

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<sup>2</sup> [The Supporting the Choice to Die at Home campaign in England](#)

<sup>3</sup> Full cost recovery (FCR) refers to the inclusion of overheads in contracts for services as well as direct costs.

<sup>4</sup> "...the Department's focus has been on encouraging fair pricing of contracts with all providers that reflect the principles of FCR, and emphasising the importance of effective negotiation between contracting partners as contracts and service level agreements are created or come up for renewal." Letter from Rt. Hon Rosie Winterton MP, Minister of State for Health, to David Prail, Chief Executive of Help the Hospices, 2<sup>nd</sup> March 2007.

## **Hospiscare review process**

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Hospiscare engaged an independent researcher to manage and report on the consultation with stakeholders. An initial meeting to identify themes for consultation was held with 24 representatives from stakeholder groups<sup>5</sup>. This meeting reviewed current services, identified gaps in provision and contributed ideas for improving services. Key themes from this meeting were used to design a questionnaire survey.

The questionnaire was circulated to 320 individuals, including GP practices, hospital doctors, district nurses, and nursing home managers. 117 completed returns were received, with an average of 39% of returns from each professional group.

Two focus groups were held with patients and carers and, in addition, the researcher interviewed four patients and one carer at the hospice.

The report on the consultation with stakeholders<sup>6</sup> was considered by the Service Review Group in the spring of 2007 alongside an activity audit collected by Hospiscare's team of community based clinical nurse specialists<sup>7</sup> and market research data on public awareness of Hospiscare<sup>8</sup>.

### **Key findings**

#### **Stakeholder consultation**<sup>9</sup>

The vast majority of respondents were very satisfied with the services provided by Hospiscare.

Current practice was extremely highly valued, with differences between localities or professionals marginal. All aspects of the service received positive comments and scores. Patients in the care of the community nurse specialists were very complimentary about the support they received and anxious that any suggestions they made did not increase the pressure on the nurses.

The area with most potential for improvement appears to be providing better information to professionals and the public on the range of services available from Hospiscare. The issue as to whether or not those services are provided equitably was also identified by survey respondents.

There was a common perception by professionals that they undertook a very wide range of roles *in partnership* with Hospiscare, rather than seeing it simply as a service provider.

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<sup>5</sup> Including local GPs, hospital doctors and nurses, social services, neighbouring hospices, lead nurses from the PCTs, representatives from the coastal town charities, senior Hospiscare staff and trustees.

<sup>6</sup> Hospiscare Report on Consultation with Stakeholders 2006

<sup>7</sup> Community Palliative Care Team Audit of Nurse Activity October 2006

<sup>8</sup> Hospiscare Awareness Research, Power Marketing, March 2007

<sup>9</sup> Summarised from Hospiscare Report on Consultation with Stakeholders 2006

Whilst most respondents had experience of their patients dying in a number of environments, the Hospice was regarded as offering the best experience, with death at home being their next preferred choice.

Most respondents would like to be able to refer more non-cancer patients to Hospiscare. The most common reason they gave for not referring these patients was that they believed Nurse Specialists were already fully occupied and were anxious not to detract from the quality of the services they offered to patients. The second most common reason was that respondents were not sure how appropriate their referral would be.

Respondents were asked their opinions on a range of potential changes in the services delivered by Hospiscare. The most popular of these are set out below in order of preference:

- **Education for staff working with palliative care patients, information, advice and support to professionals.**  
This included giving information about current services, explaining the ethos and principles of hospice care, training for those involved in delivering the Liverpool Care Pathway, in community hospitals and nursing homes and support for carers. This was supported by the patient and carers.
- **Extending services to more non-cancer patients**  
This was supported by patient and carers.
- **Meeting the needs of patients with complex psychological and emotional issues**
- **Leading the development of palliative care in Exeter, mid and east Devon**  
Respondents, patients and carers also indicated that they would like agencies to work more effectively together, to share information, hold joint planning meetings and speed up transmission of information from one organisation to another. The majority felt that Hospiscare was well placed to take the lead in these developments, building on its expertise in palliative care.
- **Locality based day-care services**  
This was supported by respondents to the questionnaire and focus group members. Patients and carers felt they would benefit from the opportunity to make short journeys to a local meeting place where they could make use of complementary therapies and other services.

The Consultation Report concluded:

“The response rate<sup>10</sup> was 36.5%, so that these conclusions and recommendations should be treated with some caution, although the rate of returns compares well with other,

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<sup>10</sup> To the questionnaire survey

similar surveys which had return rates of between 22% and 48%. The very high levels of approval and support for Hospiscare shown by respondents do, however, suggest that these conclusions are valid. This level of response is also comparable with those undertaken by the NHS on the subject of palliative care.

On the basis of the findings described above and detailed in Section 5 of the main body of the report, a number of conclusions and recommendations have been made for consideration by the management and review group. These include the following:

- The vast majority of respondents were extremely satisfied with the services provided by Hospiscare
- Many of the themes identified by professionals were also highlighted by carers, although from different perspectives
- It will be important to engage with PCT commissioners and Social Services, since no representatives from either group returned questionnaires<sup>11</sup>
- A small number of respondents, mainly from east Devon, felt that services were not accessible equally. While there was not enough information to identify whether this referred to specific social groups or geographical groups, comments attached to the questionnaire by respondents suggest that staff levels and particularly out-of-hours cover were perceived to be lower here than in other areas
- 24 hour telephone advice, usually from Nurse Specialists was considered to be important
- A number of recommendations around education, training and support imply the need to review and strengthen the education function of Hospiscare
- There was substantial support for Hospiscare taking a lead role in developing palliative care. This, together with relatively low levels of awareness about the Liverpool Care Pathway and the Gold Standards Framework, suggest that there is potential to engage in *systematic* development of services. This role is dependent upon support from healthcare commissioners
- Amongst all contributors to the study there was awareness of the limited existing capacity of Hospiscare nurse specialists as well as keen interest in that organisation (Hospiscare) developing services.”

### **Audit of Community Team Nurse Activity**<sup>12</sup>

During October 06 Hospiscare took a ‘snapshot’ audit of the activity of its community palliative care team<sup>13</sup>.

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<sup>11</sup> In fact they did but were classified according to their profession rather than employer – however it was a small number and therefore the point remains valid

<sup>12</sup> Community Palliative Care Team Audit of Nurse Activity, October 2006

<sup>13</sup> Described in appendix 3

This indicated very similar average caseloads per nurse in each of the former PCT areas; Exeter 29; mid Devon 33; and east Devon 31. This can be benchmarked against average caseloads for similar (although not identical services<sup>14</sup>) as follows:

St Margaret's Hospice, Somerset	30 patients
Weldmar Hospicecare Trust, Dorset	30 patients
North Devon Hospice	20-25 patients
Dorothy House, Bradford on Avon	20 patients

Likewise there was little variation in the number of visits per patient, per month; Exeter 1.9; mid Devon 1.6; and east Devon 1.7.

Face to face contact with professionals was higher in east Devon; on average 1.6 contacts per patients compared to one in Exeter and mid Devon. One reason for this is that, on average, the east Devon teams each work with a smaller number of GP practices. Exeter nurses, who work with the largest number of practices, attended considerably more meetings; including referral meetings, team meetings and multi-disciplinary meetings. Nurses in mid and east Devon also made a proportionally higher number of bereavement telephone contacts than Exeter.

The time spent on travelling, particularly in outlying areas was notable. It ranged from an average of 35 minutes a day to 2¼ hours a day.

Time spent on paperwork also varied and requires further consideration, although is affected by the availability of administrative support in some areas.

### **Market Research**<sup>15</sup>

In February 2007 Hospiscare commissioned market research to assess what people in its catchment area knew about hospices and Hospiscare. This survey mirrored, to some extent, a national awareness survey undertaken by Help the Hospices in 2006<sup>16</sup>. It found:

- Unprompted, over a quarter of people thought Hospiscare were the 'experts' at providing care for the dying in this area
- 80% of people described hospices as 'caring' and 'supportive'; this was higher than the national perception. 'Professional', 'trustworthy' and 'give hope' also scored highly, whilst 'sad' and 'frightening' were lower than the national perception
- Most people became aware of Hospiscare through our shops; this rises with the younger age group. Having had a friend or relative looked after was the second highest prompt for awareness and this was higher with older age groups

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<sup>14</sup> A number of factors account for different caseloads between services; including admission criteria, discharge criteria, care planning and dependency scoring

<sup>15</sup> Hospiscare Awareness Research, Power Marketing, March 2007

<sup>16</sup> Public Perceptions of Hospice Care, Help the Hospices, 2006

- 32% of people agreed that Hospiscare was a local independent charity but 56% of people thought it was the branch of a national charity
- The majority of people expect that care involves a stay at the hospice (71%) and almost half (44%) understand that care can be provided in people's own homes – this was much higher than the national survey (29%)

These findings indicate that, in addition to professional education, Hospiscare must continue to educate the public about care of the dying and its role.

## Theme I: Equity of access to services

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Fair and timely access to services was a recurring theme from the stakeholder consultations. The Review Group identified five contexts which influenced equity of access to services; these were:

- Locality
- Time of day e.g. access to 'out of hours' services
- Diagnosis
- Social inclusion
- Choice of place of care and death
- Range of services available

### Locality

Access to 'end of life' services varies across the area that Hospiscare serves. Access to out of hours district nursing, for example, varies from 24 hour access in Exeter and Exmouth to day-time and twilight provision in the remainder of east Devon and a day-time only service in mid Devon. The Review Group understands that Devon PCT is reviewing district nursing but frustration with this inconsistency was evident in some of the responses to the survey; *"Practical help is not available currently over 24 hours often results in hospital admission"*. There were a number of comments from district nurses that they could enable people to stay at home if the resources were provided; *"As I work in a rural community, access to 24 hour hands-on service at home would both benefit patients and carers, supporting them through the final days of life. At present we have no nurse cover out of hours and inequalities seem unfair depending on where you live in Devon."*

There were indications of a preference to see more services delivered locally; 76% of respondents supported locality based day-care, *"Lots of patients are put off by the long drive to Exeter"*; and there was a strong demand for hospice at home type services. *"From the point of view of the coastal towns, devolution of some services towards east Devon would benefit patients."*

In terms of Hospiscare's services one might have expected locality to have been an issue in two respects; access to specialist palliative care in-patient beds and to palliative day-care services, both of which are only available at the hospice in Exeter. There were few indications from the survey that locality was an issue for in-patient beds; less than 50% of respondents thought that Hospiscare should put more emphasis on in-patient services<sup>17</sup>. This is likely to be because of ease of access to community hospitals in rural Devon, which, with support from Hospiscare clinical nurse specialists, provide good care to the majority of palliative patients<sup>18</sup>.

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<sup>17</sup> There were three comments that raised concerns about hospice bed availability

<sup>18</sup> Seamark, D.A. et al, (1998) 'Palliative terminal cancer care in community hospitals and a hospice: a comparative study', *British Journal of General Practice*, 48, 1312-1336

The Review Group discussed Hospiscare's role in supporting Community Hospital in-patient provision and agreed that this should be sustained and explored with the PCT in conjunction with the PCT's planned strategic review.

The idea of locality based day-care was supported by patients and carers with some provisos. "People tended not to want to simply meet socially – the potential for sadness and making friends only to see them go was too great. Complementary therapy sessions and other day-care provision were seen, by contrast, as a reason for people to attend, with the opportunity to meet other people socially on a casual basis, with an enjoyable focus. It was stressed that these should perhaps be half-day, rather than full day, as some patients tired easily. It was suggested that patients could accompany their carers to carers' meetings and have an opportunity to access services while carers were meeting<sup>19</sup>."

The Review Group supported providing greater choice in day-care provision, including the option of flexible locality based day-care that could also be linked to carer support and access to complementary therapies, advice and information. It was felt that the community nurses could see less ill patients at these 'drop-ins' and thus reduce their travelling and visiting time.

## Out of hours

Over 60% of a patient's time is 'out of hours' and access to services during these times was a key theme from the consultation. It was raised by a number of respondents in relation to district nursing and to the desirability of a 'hospice at home service'. 76% of respondents supported the development of 24 hour hands-on care in the last few days of life, with 9% disagreeing. *"There needs to be more consistent care 24 hours a day so patients can die in their own homes with full support."* 12 respondents cited hospice at home at end of life as the most beneficial single action for patients, for example; *"The ability to discharge patients to care at home quickly when palliation has been decided on."*

District nurses expressed concern that if Hospiscare were to develop this service it could deskill them; *"Can be met by district nurse teams if resources were improved. Providing 24 hour Hospiscare would decrease DN clinical skills and enthusiasm for nursing palliative patients."*

Patients indicated that their first choice would be to die at home, where they were not living alone. "The key feature for them was having their own things around them and being with their loved ones – human or animal<sup>20</sup>." Patients and carers also expressed concerns about having to deal with out of hours doctors who didn't know them or their circumstances.

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<sup>19</sup> Hospiscare Report on Consultation with Stakeholders 2006

<sup>20</sup> Hospiscare Report on Consultation with Stakeholders 2006

74% of survey respondents prioritised enhancing out of hours services in terms of Hospiscare intervention or visiting. “*Out of hours crisis intervention and telephone advice are sometimes a problem we see in the Emergency Department with changes to out of hours GP services .... Patients may be inappropriately sent in/referred to the Emergency Department from home, nursing home etc.*” “Respondents from the mid Devon PCT area were the only people who did not think that this was the role of Hospiscare, but 42.8% of respondents from this area thought that this was a gap in service. In each area, some thought this service was not needed, and these individuals were Nurses in Management<sup>21</sup>. There was a tendency for more respondents from east Devon to see this as Hospiscare’s role<sup>22</sup>.”

Hospiscare provides an out of hours telephone advice line which is used primarily by patients. 65% of calls to the line are from patients, friends and relatives and the remainder from professionals.

The Review Group supported further exploring ways in which to work more closely with out of hour’s services (Devon Docs, DNs, intermediate care services, etc) to avoid unnecessary acute admissions.

The Group also recommended working with partners to scope and develop ‘hospice at home’ provision.

## Diagnosis

Hospiscare’s referral policy has always been based on need rather than diagnosis and thus the question posed in the survey was ‘Would you like to be able to refer *more* non-cancer patients?’ and ‘If so, what currently deters you from doing this?’

“Of the 96 individuals who answered the question on whether or not they would like to be able to refer more non-cancer patients to Hospiscare, 75% said ‘yes’ and 24% ‘no’. 7 individuals (one GP, 2 Hospital doctors, one Nurse in Management, 2 District Nurses and one Community Hospital Nurse) commented that some non-cancer patients are already being referred to the Hospice. One had been informed ‘previously’ that they could not refer these patients and two said that staff did not always think of Hospice when dealing with non-cancer patients. One of these respondents suggested that more information was needed to encourage referrals, whilst one noted how busy the Community Nurse Specialists were.

Respondents were asked to give reasons for not currently referring non-cancer patients. 72% of those who would like to be able to refer such patients responded. The most common reason given (32%) was concern for the Hospiscare Nurse Specialists, who were seen to be already over-stretched and under pressure. Individuals from all areas and professions gave this as a reason. The second most common answer was that respondents were not sure how appropriate their referral would be (21%). Those who

<sup>21</sup> The majority of whom were nursing home managers

<sup>22</sup> Hospiscare Report on Consultation with Stakeholders 2006

worked in 'all PCTs' (predominantly hospital doctors) did not identify this as a problem. A further 6 (14%) individuals said they needed more information about the services available through Hospiscare, but none of these came from the Exeter area. Other concerns raised were around patients' reluctance to use services which are often seen by the public as being about dying, the need for respite care for patients who do not have cancer and the worry that existing funds cannot be stretched to cover a large new area of work<sup>23</sup>."

The comments that this question generated reflect the complexity of this area;

Perception of 'overload' and concern about diluting the quality of the service

"Workload for already stretched team"

"Perception that it would swamp you, e.g. heart failure/dementia/WPD"

"Can't stretch service any further without more investment"

"Fear of overwhelming the service"

"Working in an area with a high percentage of elderly patients with end stage diseases, this would involve a large increase in referrals and the hospice team have been working with reduced numbers and this would probably make the workload too heavy"

and, appropriateness of referrals in terms of what is palliative

"Heart failure is/is not a terminal illness"

"These are 'heart sink' patients who can be very challenging to manage"

"Variability of conditions means that prognosis is not always clear and can be difficult to discuss palliative care with patient/family when they do not perceive themselves to have a terminal illness"

"Generally we will refer a patient who has a life limiting illness such as cardiac failure. However, a lot of staff do not make the link of Hospiscare unless a patient has cancer"

and, lack of information about what is appropriate

"Not sure of the appropriateness of my referrals"

"Probably lack information on what is available and acceptable"

"Unsure of who to refer"

"Lack of understanding re: Hospice role in this area. Are they keen/able to accept this type of patient?"

although, a number of respondents indicated that they were referring appropriately

"I feel Hospiscare is open to these referrals – it may help to produce some guidelines as to when a non-cancer patient might be referred"

"I already refer those non-cancer patients I think would benefit"

"We do phone for advice on analgesia for non-cancer patients from Hospiscare nurses and they have been really helpful"

"I think non-cancer patients with palliative care problems usually are accepted by Hospiscare"

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<sup>23</sup> Hospiscare Report on Consultation with Stakeholders 2006

The Review Group was aware that non-cancer patients are referred to the service regularly but they remain a small proportion of all referrals; 65 in 2006/7, 6% of all patients. The recognition that Hospiscare already supports non-cancer patients may explain why the main concern was Hospiscare's capacity rather than competency to help these patients.

The Group discussed whether it was more helpful to draw a distinction between patients requiring palliative care (with advanced, progressive and incurable illnesses) and patients with chronic conditions; rather than between cancer and non-cancer patients. They thought that this might enable Hospiscare to provide clearer guidance to referrers and was less likely to result in an overwhelming increase in referrals. This understanding is particularly relevant to the implementation of and support for the Gold Standards Framework in primary care.

It was identified that the models of care developed for cancer may not be transferable to some non-cancer patients because of differences in disease trajectories which involve longer periods of chronic illness with intermittent crises. The Group recognised that different needs might entail different patterns of intervention from Hospiscare clinical nurse specialists; involving initial assessments and engagement at periods of crisis followed by discharge until/or if required again.

The Group identified that this was an area where it would be helpful to develop partnerships with condition specific specialists (e.g. heart specialist nurses) and to support education in palliative care for primary care and nursing homes. An example of the latter has been the implementation of the Liverpool Care Pathway by Hospiscare nurses. This benefited more non-cancer than cancer patients in the acute hospital but the reverse in the community.

The Review Group supported Hospiscare clarifying its referral criteria and the ways in which it might respond to referrals; and disseminate this guidance appropriately.

The Group recommended developing partnerships with non-cancer specialist clinical teams and continuing to support the implementation of the Gold Standards Framework, the Liverpool Care Pathway and other relevant care pathways.

## **Social inclusion**

Hospiscare endorses Help the Hospices Statement of Intent on Equity of Access to Hospice Care<sup>24</sup>. It recognises that this includes Hospiscare's value<sup>25</sup> of 'respect for the individual' and issues already discussed in this report such as geography and diagnosis but also that there are wider social factors that can present barriers to patients access to hospice care. These are collectively described in the Help the Hospices' Statement as

<sup>24</sup> Widening Access to Hospice Care, Help the Hospices, November 2006

<sup>25</sup> Hospiscare 'Our Values', 2005

'identity and life experience' and include things like ethnicity, religion, sexual orientation, being homeless, mentally ill, having learning disabilities or a prisoner.

The Review Group recommends that Hospiscare highlights its commitment to being socially inclusive in its referral criteria and considers how it can audit and monitor this commitment.

### **Choice of place of care at end of life**

Surveys<sup>26</sup> have consistently indicated that people prefer to die at home – although it is also known that this preference changes as people become more ill and dependent<sup>27</sup>. The patients interviewed confirmed this preference – with the proviso that they were not alone; *“Patients and carers were very clear that they did not want to go into hospital as their condition worsened. The reasons given were largely about wanting to retain their personality, to be someone, for as long as possible. For this reason, they wanted to have their things around them, to be close to their loved ones, without limitations placed on visits and contact. They wanted to continue to have pets close to them, and they did not want to be looked after by people who did not know them, only their illness<sup>28</sup>.”*

A number of respondents to the survey reflected this view; *“preferred place of care is usually home and (access to 24hour care) from some agencies is less than desirable”;* and *“The thing I feel that would be most beneficial to patients is having someone caring for them 24hours or for long periods of time. This, I feel is what carers find most difficult – ‘the responsibility’ – and which takes patients into hospice/RD&E.”*

The Hospiscare survey asked professionals about their impressions of quality of care at end of life. Unsurprisingly the hospice scored highest with 96% of respondents saying the care was either excellent or good; home was rated as second choice (88%), followed by community hospitals (77%); nursing homes (48%) and acute hospital (45%).

The Review Group identified that access to choice of place of care, particularly given the preference for staying at home, is related to the issues already discussed such as access to out of hours services and 24 hour care at home in the last days of life. Providing and co-ordinating such services would enable more patients to be cared for and die in their preferred place of care.

The Review Group recommends that Hospiscare engages with the PCT, Social Services and relevant providers to co-ordinate and support patients' choice of place of end of life care.

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<sup>26</sup> Views about dying at home: Survey of the UK general public, February 2004, KRC Research, Marie Curie Cancer Care

<sup>27</sup> Gomes B, Higginson I. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006; 332: 515-518

<sup>28</sup> Hospiscare Report on Consultation with Stakeholders 2006

## Accessing comprehensive and integrated palliative care services

The NICE guidance on palliative care<sup>29</sup> recommends patients with palliative care needs should be able to access;

- Comprehensive and co-ordinated assessments (including physical, psychological, social, spiritual and financial needs)
- Continuity of care including the concept of a key worker
- Involvement in care planning
- Effective and sensitive communication of significant news
- High quality information
- Psychological support
- Social support
- Spiritual support
- 24/7 nursing care for the dying
- Specialist services including
  - In-patient facilities
  - Hospital teams
  - Community teams
  - 24/7 advice
- Rehabilitation services
- Complementary therapies
- Bereavement care
- Carer support

The survey asked professionals to identify whose role it was to meet these needs and whether there were gaps in the service.

The roles most likely to be seen as those of Hospiscare were:

I expect Hospiscare to meet this need	%
Access to hospice beds	71.2
Access to day-care	61.7
Out of hours telephone advice	54.2

**Fig. 5 Roles most commonly ascribed to Hospiscare**

Generally, professionals were more likely to see the range of tasks as shared. Where 'shared' scores are the highest, they are also higher by a wider margin than where 'Hospiscare' scores are highest. The table below shows the role most commonly described as 'shared'.

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<sup>29</sup> Improving Supportive and Palliative Care for Adults with Cancer, National Institute of Clinical Excellence, 2004.

<b>I share this role with Hospiscare staff</b>	<b>%</b>
Emotional support to patients	88.3
Support and information to carers	84.5
Advice on symptom control	82.7
Information for patients on the illness and treatment options	77.1
Information for patients on the progress and likely prognosis of the illness	75

**Fig. 6 Roles most commonly described as 'shared'**

.....The table below shows the roles that were most commonly thought to be a gap, or insufficient services.

<b>This is a gap in service provision</b>	<b>%</b>
Access to complementary therapy	22.9
Out of hours crisis intervention	14
Nurse prescribing	11.6

**Fig. 7 Most commonly identified gaps in service**<sup>30</sup>

Nurse prescribing is a way of providing the service that could support preferred place of care and should be considered as part of workforce development.

A key impression from the stakeholder consultation was the extent to which Hospiscare was seen as a partner in providing palliative care rather than an independent provider; "There appears to be widespread agreement that most of the needs of patients were met jointly between Hospiscare staff and the other professionals involved. Respondents were more likely to identify a specific role as being shared and being a gap than as a gap only<sup>31</sup>." This is pleasing because it reflects the value of working co-operatively<sup>32</sup> that Hospiscare has sought to apply to its relationships with other agencies. It is demonstrated by a strong degree of integration with local healthcare providers; shared posts (e.g. consultants, chaplain); generic approaches to patient care (e.g. care management) and partnerships with primary care and other hospices. The consultation report did identify however, that there was a need to strengthen relationships with social services and the PCT; "It is recommended that a dialogue be established with these two groups, using the information gathered from this study, to establish the nature of the partnership with these agencies<sup>33</sup>."

Patients and carers were particularly concerned about the co-ordination of services; when asked about the 'worst aspects of their treatment' their greatest concern was the management of their cases by other agencies.

"Initial diagnosis had been traumatic for most, although the majority said that their treatment from that point onward had been excellent. There were concerns about the position of the carer, with some patients and carers saying that their consultants would not talk to the carer, or even allow some in to the consulting room. Carers found this difficult, since the majority appeared to be dealing with the illness as a team and they felt that this was unnecessary and divisive.

<sup>30</sup>Hospiscare Report on Consultation with Stakeholders 2006

<sup>31</sup> Hospiscare Report on Consultation with Stakeholders 2006

<sup>32</sup> "Hospiscare is committed to working co-operatively as the best means of meeting the needs of patients and their families ...." Hospiscare, Our Values, 2005

<sup>33</sup> Hospiscare Report on Consultation with Stakeholders 2006

The single biggest issue, however, was around the management of their cases by other agencies. Group members found it impossible to believe that it really needed to take five or six weeks to get results, particularly on initial diagnosis, or to pass notes from one hospital to another. Many found that they were expected to attend hospital on three, four or even five days of the week, with all the associated problems of travelling, parking and waiting at times when they are ill and tired. Their carers found this round of journeys, and their impact upon the patient, exhausting too. If there was one thing they could change, they would like to have a sequence of appointments at the same time, so that they could have some normality at other times<sup>34</sup>.”

The Review Group considered access to the range of services that Hospiscare provided. It did not identify any issues in relation to access to Hospiscare’s core range of services; professionals indicated very high levels of satisfaction with the responsiveness of the service (95% saying that Hospiscare was either good or very good at responding to referrals). The Review Group considered whether Hospiscare could address patients’ desire for better co-ordination of out patient appointments and treatments. The Group identified that Hospiscare staff should (and did) act as advocates for patients in this respect and that it was appropriate for Hospiscare to make senior management at the RD&E aware of patients’ concerns.

The Group noted that ‘meeting the needs of patients with complex psychological and emotional issues’ scored highly in survey respondents ‘wish list’ of service developments (79%) and was also raised at the initial stakeholders meeting.

The Review Group supported enabling front-line staff to enhance these skills in line with Hospiscare’s emphasis on a generic approach.

The Group noted that Hospiscare does not provide planned in-patient respite and whilst this was not identified by stakeholders as a gap they identified this as an area which could be provided through supporting community provision.

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<sup>34</sup> Hospiscare Report on Consultation with Stakeholders 2006

## Theme 2: Hospiscare's role

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This section of the report focuses on Hospiscare's role in influencing the development of palliative care through education, providing information, and working with partners to co-ordinate and develop services.

### Awareness and information

Hospiscare's market research indicated that 49% of people identified hospice care with care of the dying – compared to 38% in the national survey. A higher proportion (31% compared to 15%) thought that hospices are places where people go to die. These proportions increased with age.

Most people had associated positive words with hospice care; supportive (80%), caring (79%), professional (49%) and 'give hope' (46%). A much smaller proportion associated words such as sad (9%) and frightening (4%). Most people associated hospice care with cancer (87%) or terminal illness (73%). In terms of specific diagnoses, the next most recognised as being cared for at a hospice was Motor Neurone Disease (44%) with other life-limiting conditions being identified by around 30% of respondents.

In relation to Hospiscare specifically 71% of respondents thought care involved a stay at a hospice, 44% said it could involve care in people's own homes, 29% as day-care and 24% at the RD&E. Over three-quarters of people thought that Hospiscare provided emotional support for patients, families and carers and a high proportion thought that medical care and bereavement support was available. There was lower awareness of spiritual care, social care and complementary therapy, however on the whole Devon responses were noticeably higher than the national survey.

The Review Group recognised that Hospiscare has a key role in raising public awareness about care of the dying; including building understanding about hospices and palliative care; breaking down the taboos around talking about death and encouraging higher expectations of quality of care at end of life.

Patients and carers raised the need for better information for themselves; their suggestions included:

“A leaflet for relatives and friends, explaining some of the implications of the illness e.g. appetite, principles of pain control, types of equipment available and responsibilities of each discipline.

A leaflet for patients, explaining the principles of different groups of medication and the rationale of recommending certain items<sup>35</sup>.”

The Review Group recommends that Hospiscare reviews its patient and carer information in consultation with users.

<sup>35</sup>Hospiscare Report on Consultation with Stakeholders 2006

## Education for practitioners

The desire for Hospiscare to provide education and information about palliative care came out strongly from the stakeholder survey. The response to the question 'How good are we at informing you on the range of services we provide?' attracted the least positive response in the section about 'working with you'.

*"This was the lowest-scoring area in that it had the highest proportion of 'Variable' (12.8%) and 'Poor' (3.4%) grades, although it still attracted positive grades from 78.6% of respondents. It was also the only issue about which more individuals assessed the service as 'Good' rather than 'Very Good'. A number of comments made by respondents in margins, or within different comment boxes, reinforce the view that people are not aware of the full range of services available<sup>36</sup>."*

*"I'm still not sure of all the services provided by Hospiscare particularly for patients who are dying and want to die at home but are previously unknown to the service – these arrangements have to be made quickly and often decisions are made out of hours."*

*"In general I think you provide a good service. I feel that I may not be aware of all the services that you provide. I have relatively little idea about the care that you provide in the community. Most communication takes place via written entries in medical notes."*

Not surprisingly then, the provision of education and information were survey respondent's highest priority for service development; supported by 89% and 85% of respondents respectively. Patients and carers wanted professionals to be more aware of what Hospiscare does and its ethos – they particularly mentioned training others to impart bad news sensitively.

Hospiscare has a growing reputation for education; it has been involved in training district nurses, staff at the RD&E and in nursing homes to use the Liverpool Care Pathway; it trains hospital staff in 'breaking bad news'; it has cascaded an influential programme on breathlessness throughout primary care; it teaches medical and nursing students. A number of respondents recognised Hospiscare's expertise and requested more educational opportunities; comments under the heading of most beneficial single action for patients included:

*"Dissemination of your expert knowledge to medical teams within the hospital. Possible production of guidelines for dealing with end of life problems and symptom control (other than Liverpool Pathway!)"*

*"More educational opportunities for all grades of staff working in community hospitals"*

*"Training and skilling-up for me and my team and responsive advice and opinions when requested"*

*"Education and sharing of information to Nursing Homes"*

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<sup>36</sup> Hospiscare Report on Consultation with Stakeholders 2006

*“Early advice and development of care plans”*

*“More education to ward staff caring for palliative patients to achieve 'a good death'”*

*“More interaction with Nursing Homes regarding palliative care training”*

The Review Group identified that developing education and information will be critical to support the government’s proposed ‘End of Life Strategy’, particularly elements of the Gold Standards Framework in primary care and skilling-up staff in nursing and residential homes.

The Group acknowledged the emphasis stakeholders put on education and information and also its strategic importance in the improving end of life care. It supported reviewing and enhancing information and education for professionals in association with local partners.

### **Partnership working**

Hospiscare is integrated well into the local health community and seen as a partner in providing care. It has effective partnerships with the RD&E, primary care and with the Peninsula Medical School. Positive expressions of partnership included:

*“We have an excellent relationship with the hospice nurses who go out of their way to liaise with us DNs and share information which is invaluable”*

*I invite Hospiscare Homecare team to attend our meetings with the GP when we have patients in common. When this is not possible due to time commitments myself and the GPs welcome being kept in contact by phone as much as possible”*

There were some concerns expressed about information sharing and ideas for improvement including observations that GSF will provide opportunities for closer working and earlier referral;

*“Sometimes information seems to be one-sided e.g. we give a lot of info to the Hospiscare team about patients but there is not always good communication in return” (6 similar remarks)*

*“It (communication) tends to be ad-hoc and drop-in according to immediate patient need. Would benefit from some planned meetings to discuss patient care pro-actively rather than reactively”*

*“The sharing of information could be improved; for example shared notes in patients homes”*

*“Hospiscare nurse to attend monthly GSF meeting at practice to discuss patients on GSF register”*

*“Attendance at core group meetings (adult services) to gain multidisciplinary approach to care”*

The Review Group recommends that Hospiscare reviews its methods of communication and liaison with local health and social care professionals.

The survey indicated that many stakeholders support Hospiscare's role in leading the development of palliative care in Exeter, mid and east Devon. This was supported by 79% of respondents and raised by the original inter-agency group that met prior to the development of the survey. Unsurprisingly it was not specifically identified by patients and carers but "a number of individuals identified the need for agencies to work more closely together, share information more effectively and learn from the approach of Hospiscare staff<sup>37</sup>."

The Review Group discussed Hospiscare's role in relation to the government's proposed end of life strategy. It recognised that a key feature of the strategy will be the co-ordination and integration of palliative care services.

The Group recommended that Hospiscare should be fully engaged as a partner in the development and implementation of the End of Life Strategy in this locality.

The Review Group identified that working relationships with the PCT and social services are less well established than with the local healthcare community. It recognised that it will be important for Hospiscare to engage with the new PCT and social services about the location, provision and commissioning of services in the future for end of life care.

The Review Group recommends that Hospiscare strengthens its relationships with the new PCT and Social Services in both their commissioner and provider roles.

The Review Group noted that the survey highlighted the support needs of nursing homes;

"The level of awareness of the group 'Nurses in Management' (*these were primarily Nursing Home Managers*) about the Gold Standards Framework and the Liverpool Care Pathway was low, particularly considering that the LCP is to be rolled out to Nursing Homes this year. If Managers are not fully aware of the standards, this has major implications for the training needs of Nursing Home staff, who are often less qualified than other health care workers, and increasingly likely to have English as a second language. Some Nurses in Management commented on the need for accessible and affordable training for a workforce with a high turnover<sup>38</sup>."

A number of comments indicated a strong desire from nursing homes for closer partnership with Hospiscare:

*"More support for nursing homes is vital. They struggle sometimes to get a GP to visit. They have major problems with the recruitment and retention of nurses. Introduce Gold Standards Framework with support. A dedicated GP for nursing homes who has an interest in palliative care happens in some parts of the country and could be ideal"*

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<sup>37</sup> Hospiscare Report on Consultation with Stakeholders 2006

<sup>38</sup> Hospiscare Report on Consultation with Stakeholders 2006

*“Education and sharing of information to Nursing Homes”* (single most beneficial action for patients)

The Review Group recommends that Hospiscare explores with nursing homes how it can support them better, including investigating different models of hospices working with nursing homes.

## **Theme 3: Resourcing and sustainability**

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The Review Group recognises that its recommendations have implications for the way in which Hospiscare applies its resources and configures its workforce of staff and volunteers. It is aware that the pressure on Hospiscare's resources was a major concern for both survey respondents and patients and carers:

“Whilst it can be seen that there is potential for development of services, it should also be remembered that all groups expressed their awareness of the existing workload and their concern about asking Hospiscare to deliver more on current resources – two of the three most common answers for ‘one thing that would most benefit patients’ were ‘more Nurse Specialists’ and ‘more resources’<sup>39</sup>.”

Developing a model that is sustainable; both in terms of applying current resources most effectively and identifying where new resources are required will be key to achieving these recommendations.

### **Workforce**

Successful implementation of the recommendations will require a workforce that is flexible and open to change. For example; responding and intervening flexibly depending on need which may be more variable for patients with a non-cancer diagnosis; providing more flexible, local ‘drop in’ opportunities for patients; supporting out of hours services, supporting hospice at home etc. There is also a need to provide sufficient secretarial/administrative support to front-line staff.

There may be opportunities for staff and volunteers to learn new skills, e.g. nurse prescribing; to introduce new roles for volunteers and organise teams differently in terms of skill mix and location.

The Review Group proposes that Hospiscare prepares a workforce development plan to implement its recommendations for service enhancement.

### **Physical Resources**

Ensuring easier local access to services has implications for accommodation where staff can be based and patients can visit. It will be essential that best use is made of Information and Communication Technology (ICT) to ensure effective and swift transfer of patient information and to facilitate internal communications. Hospiscare's planned implementation of the ‘Crosscare’ clinical database should support this.

The Review Group recommends that accommodation and ICT needs are factored into service development planning.

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<sup>39</sup> Hospiscare Report on Consultation with Stakeholders 2006

## **Funding**

Some of the recommendations for new or enhanced levels of service will require additional funding. A 'hospice at home' service, for example, would be a new level of service and would require new funding. Increasing referrals of non-cancer patients must be planned carefully so as not to overstretch current staff and volunteer resources. It will be important to monitor the impact of the roll-out of GSF on referral levels.

The Review Group recommends that funding issues should be part of any discussions about implementing an End of Life Strategy locally.

## **Evaluation**

The Review Group identified that it will be essential for Hospiscare to be able to demonstrate progress towards achieving seamless care and therefore determine indicators that will enable it to track how it is doing. The Group agreed that it would be useful to continue and extend the patient and carer focus groups. It was recognised that there were a number of areas that would benefit from greater scrutiny and understanding, such as the relationships between care for chronic and palliative patients, and that it may be appropriate to commission, with partners, additional research and/audit into these areas. The Group also agreed to continue to meet to monitor the implementation of its recommendations.

The Review Group recommends that Hospiscare discusses with commissioners and other partners appropriate measures and puts in place mechanisms to collect the required quantitative and qualitative data.

## **Appendix I**

### **Hospiscare Service Review Group**

#### **Chair**

Hugh Savill                      GP & Hospiscare Trustee

#### **Members**

Penny Andrewes	Independent Researcher
Glynis Atherton	Chief Executive, Hospiscare
Sandra Clark	Professional Lead, Community Nursing Services, Devon PCT
Peter Day	Hospiscare Trustee
Sarah Folland	Director of Patient Services, Hospiscare
Jim Gilbert	Medical Director, Hospiscare
Philip Jewell	Chief Executive, North Devon Hospice
Richard Kane	Director of Patient Services, North Devon Hospice
Jenny McNeil	Assistant Director of Strategic Development (Planning), Devon PCT
Julie Mitchell	Matron for Community Services, COPD & Diabetes Lead, East Devon Area, Devon PCT
Di White	Joint Agency Cluster Manager, Health and Social Care
Sarah Whitfield	Chief Executive, Dorothy House

## Appendix 2

Map of Area



## Appendix 3

### Overview of Hospiscare services

Hospiscare provides a comprehensive specialist palliative and supportive care service to the communities of Exeter, mid and east Devon thus serving a population of approximately 350,000. Through its multi-professional care team it aims to provide integrated and seamless services to patients and their carers in the following settings.

#### 1. Hospice-based services

##### In-Patient Unit

A 12 bedded ward facility provides in-patient care for patients requiring assessment and management of complex symptoms, and intensive nursing and supportive care. A skilled multi-professional specialist team work together to ensure that the physical, emotional and spiritual needs of patients are met through a holistic approach and to provide continuous 24 hour support. Accommodation for relatives enables relatives and friends to be alongside patients especially those in the terminal stages of their illness.

##### Daycare

Hospiscare provides 45 day-care places per week. The principal function is to be able to offer opportunities for assessment and review of patients' palliative care needs and to provide a range of nursing, psychological and social care interventions within a context of interaction, mutual support and friendship. The day care facility also allows respite for carers on a regular weekly basis.

#### 2. Community Palliative Care Team

A team of specialist palliative care nurses (23.0 WTE) provide assessment, advice and care for patients in community settings. Based locally the Hospiscare nurses work in conjunction with primary health care teams to provide specialist palliative care to patients at home, in community hospitals, or in nursing or residential care homes. The level of intervention will vary according to the assessed needs of each patient but the team will respond to those with physical symptoms or complex psychosocial issues and those requiring terminal care in the community setting. The team provide a 7 day home visiting service and 24 hour advice to patients, carers and other professionals. The team also provide education and support to other health professionals providing end of life care.

#### 3. Hospital Palliative Care Team

Hospiscare's hospital team, consisting of 2.8 WTE specialist nurses and supported by consultants in palliative medicine, provide assessment advice and care to patients in the acute hospital setting. The team will provide interventions to respond to unresolved symptoms and complex psychosocial issues for patients and their families; to those requiring help in making decisions and arrangements for terminal care. The team also provide advice, support and education to professional colleagues in all departments and wards at the RD&E hospital.

### **Supportive Care Team**

The supportive care team helps the patient and their family to cope with their illness and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, through the continuing illness and death, and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.

The members of the team include a chaplain and two care managers who are based in the in-patient unit and have responsibility for discharges. One of the care managers specialises in psycho-social needs, financial benefits and coordinating the bereavement service; the other specialises in rehabilitation and advice on practical aids. In addition there is a complementary therapies co-ordinator who manages a team of 30 trained volunteers which provides therapies to patients, carers and the bereaved. Carers are further supported with access to relevant information and monthly groups.

## **Appendix 4**

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