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Evaluation of the Midhurst Real Choice Project: A joint report of findings and conclusions arising from studies by Monitor, the University of Sheffield and the University of Huddersfield.

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1. Background

The Midhurst Palliative Care Service was developed following the closure of the King Edward VII Hospital, West Sussex in 2006. Like the inpatient facility, the new service was funded by grants from the NHS and Macmillan Cancer Support. On its inception the local model of care was developed with the following aims:

- To put in place a sustainable and affordable specialist palliative care service for the population within the Midhurst and surrounding areas
- To ensure that patient choice is maximised by providing as much treatment and support in the home/community setting as possible and
- To reduce acute hospital interventions and inpatient hospice stays

Additional aims were

- To achieve close working between the NHS voluntary, charitable and private sectors.
- To increase compliance with NICE guidelines

The Specialist Palliative care service in Midhurst was staffed by members of the team previously employed on the King Edward VII inpatient and community service and based their service on the Swedish Motala Model for advanced home care.

The service is one of only two in the UK that involves a consultant led multi-disciplinary team that aims to provide round the clock 'hands on' care and advice at home, in community hospitals and in nursing/residential homes. The community team provides a range of palliative interventions, including blood/blood product transfusions, blood treatments, IV antibiotic, IV bisphosphates, fluids, paracentesis and intrathecal analgesia.

The comparable service is Hospice at Home, West Cumbria, which was established in 1987. Both services care for adults with any diagnosis, have education and training programmes for staff and utilise volunteers. The Cumbrian service utilises twice as many volunteers as Midhurst, sees more non-cancer patients than Midhurst and offers round the clock care, seven days a week. Midhurst offers seven day care until 20.30, after which callers are transferred to an answer phone that is monitored hourly during the night. Midhurst operates with approximately 28% more funding than Hospice At Home . The Midhurst service attends only 9% more deaths than the Cumbria service but receives 49% more referrals.

2. The Evaluation

Macmillan Cancer Support commissioned two evaluations of the Midhurst service which, together served three overall aims:

1. To assess whether the Midhurst service meets the original aims of the palliative care initiative
2. To gather robust evidence that commissioners and Macmillan can use to agree future commissioning /funding intentions
3. To assess the extent to which the Midhurst service can serve as a model of palliative care for other parts of the UK

This report combines the economic and clinical evaluations of the service. It incorporates data derived from NHS sources, surveys of GPs and bereaved carers as well as interviews with health care professionals, patients and their carers.

The study by Monitor of economic and clinical activity was largely quantitative, based on a retrospective analysis of HES data supplied by the three surrounding PCT's; West Sussex PCT, Surrey PCT and Hampshire PCT. Central to the analysis was the comparison of health care usage for patients using Midhurst, patients using local hospices and those not known to have used Midhurst or a local Hospice. Patients' use of healthcare services across inpatient, outpatient and A&E was contrasted across the three groups. This allowed a full economic overview of service use in the last year of life.

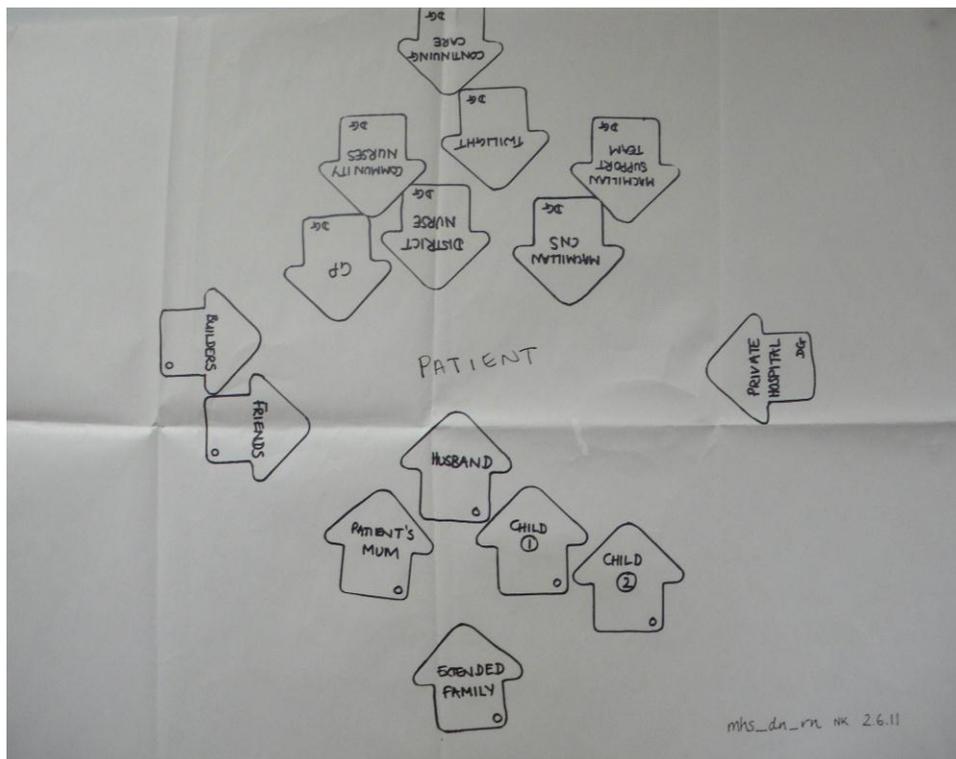
In comparing patients under the care of Midhurst, patients under the care of Hospices, and those patients using the acute sector only, the impact on when a patient was referred to the service was a very important factor. The point of referral was categorised as either: (Group A) before any inpatient stay, (Group B) after one inpatient stay, or (Group C) after two or more inpatient stays. These categories are a proxy of how early in an illness a patient is identified and referred for specialist palliative or supportive care as well as a proxy for the complexity of cases.

The University of Sheffield compared the characteristics of the Midhurst service with its only other UK equivalent in Cumbria by documentary analysis of annual reports and key informant interviews. A postal survey of GPs in the three Primary Care Trusts serving the Midhurst area collected data on reported clinical practice, views on palliative care services, participation in national initiatives and organisation of palliative care. Researchers also used the VOICES questionnaire in a further postal survey of bereaved carers of patients who died following referral to the Midhurst service over the period of one year.

The University of Huddersfield was focussed on the role of the Midhurst team and the nature of its relationship with patients, carers and other health and social care professionals. It examined practices from the perspective of all these groups through the use of semi-structured interviews employing the Pictor technique. The Pictor technique uses a simple

participant-constructed visual layout to represent a case to be examined with the researcher, allowing the exploration of collaborative working in specific cases, identified by the service.

Figure 1. EXAMPLE OF PICTOR CHART



The Pictor chart is illustrated by an example taken from an interview with a district nurse in figure 1.

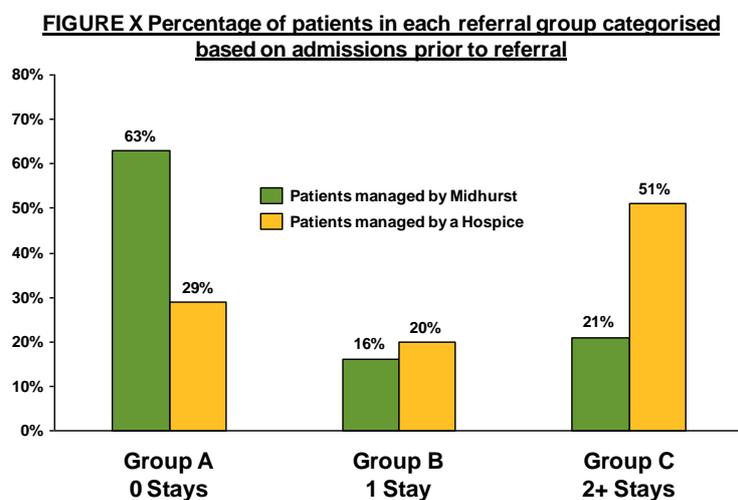
3. Findings

The most important findings arising from the various elements of the evaluation are set out below:

3.1 Volume and scope of the Midhurst service: The Midhurst Palliative Care Service receives referrals for patients in the population served by 19 general practices. The total size of the population is about 155,000 and 389 referrals were received last year, of which about 85% were patients with cancer. It is likely, given a current national death rate of 1%, that the Midhurst service sees about a quarter of all dying patients in the area it serves.

Last year, 283 patients died under the care of the service. The overall cost of the service is divided evenly between grants from Macmillan Cancer Support and the NHS. The mean cost of the service itself is about £3,000 per patient referred (based on a service budget of £1,200,000). Our analysis estimates the average cost of Midhurst service interventions in the last year of life at about £1,900. This figure was reached by creating an ‘activity based costing’ framework for all Midhurst activities associated with cancer patients in their last year of life. It also reflects the fact that some of the most complex patients, including those patients who do not have cancer, require costly treatment that may last for longer than one year.

3.2 Extends choice: The Midhurst service extends choice for patients, clinicians, families and carers and facilitates a higher percentage of patients to die at home or care home and facilitates 71% of patients to die at home or in a care home. Both the Midhurst and Hospice Care models reduce the number of deaths occurring in a hospital setting and should both be seen as part of an integrated set of services to meet the range of need of patients, their families and carers in the last year of life. Patients referred to the Midhurst service were more likely to have had no previous inpatient stays than patients referred to the Hospice model of Care (See figure X).



3.3 Reduction in Inpatient Care: Patients who use Midhurst spend less time in hospital than patients under hospice care. On average, they also have fewer A&E attendances than any other group of patients. Patients referred to Midhurst prior to any inpatient stay or after only one inpatient stay (Group A and Group B: 79% of Midhurst cohort) use less inpatient care than those in the hospice model. But patients referred after two or more inpatient stays (Group C: 21% of Midhurst cohort) use more inpatient care than the hospice model. The majority of Midhurst patients use less inpatient care than hospices or those patients who have cancer but were never referred to specialist palliative care

3.4 Outpatient Care: Patients who use the Midhurst service use more outpatient care than those in the hospice model. Patients referred to Midhurst prior to any inpatient stay or after only one inpatient stay (Group A and Group B) use more outpatient care than the hospice model. As a total group Midhurst patients use more outpatient care than those referred to a hospice. It should be noted that the Midhurst Service will accept patients who are undergoing anti cancer treatment. Therefore some Midhurst patients will be attending outpatient clinics for this care, this was particularly the case for Group A who attended outpatient appointments a mean of 9.4 times post-referral, of which a mean of 2.8 were for chemotherapy.

3.5 Substitution of NHS Costs: Both Midhurst and hospices reduce the use of NHS services for patients under their care. Hospices substitute more NHS costs, i.e. the use of secondary care services post-referral is lower than for patients referred to Midhurst. However, our analysis suggests that the provision of Midhurst services is less costly than our estimate for Hospice-led services. These relative costs balance out. Overall, for each referral group there is little difference in cost between the two care models (see Figure X). It should be noted that hospice patients attend outpatient care less often than Midhurst patients. In addition Midhurst patients are looked after for a longer period of time and this has a cost implication.

The costs of Group A, B and C for both the Midhurst and Hospice patients are also shown in Figure X. Patients referred before an in-patient stays, or after just one stay have mean total care costs in the range of £9,382 - £10,883 (Group A, B). The mean total care cost was approximately £16,000 for Group C. There is little difference in cost within groups for those patients referred to Midhurst or the Hospice model. However, there is a substantial increase in costs across groups.

Figure X. Comparison of total mean cost of care in the last year of life

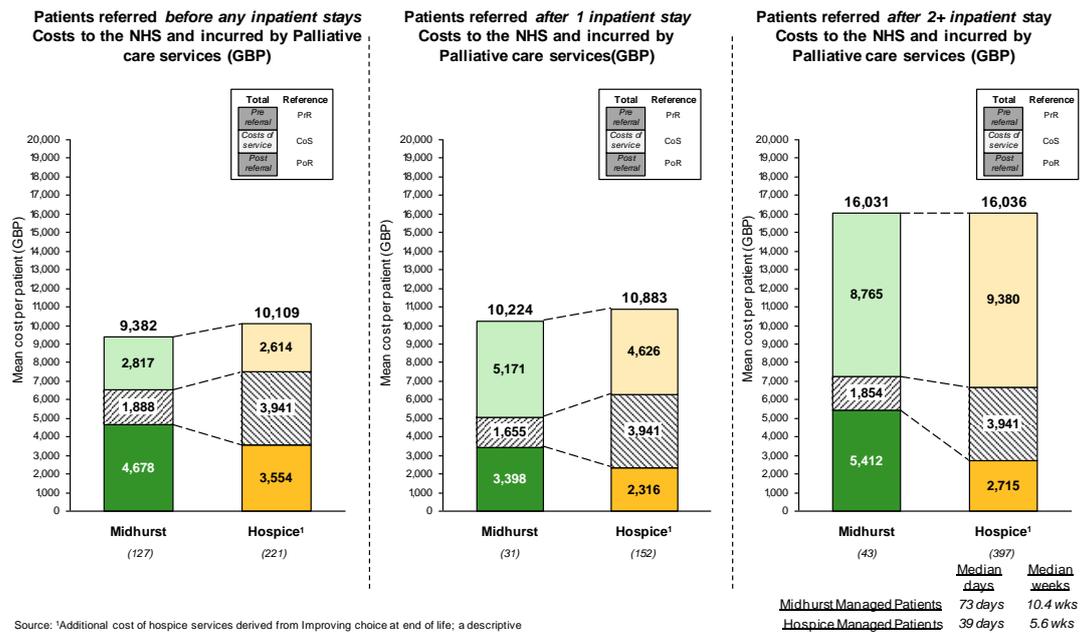


Figure 2. 3.6 Economic gains of integrated service provision: The presence of Midhurst created an additional referral choice. There was a substantially higher percentage of Midhurst patients (63%) in Group A (no inpatient admissions prior to referral) than Hospice patients (29%). Group A is the least costly patient group. In contrast, there were substantially more hospice patients in Group C (more than two stays category, 53%), which is the most expensive group (cf Figure X). It follows that more costs would be incurred for the health economy should only a hospice led model be available. This is because the costs to the health economy in the Hospice model are driven by a large number of patients falling into Group C, who have high mean costs of care. Much of these costs are accumulated prior to referral to specialist palliative care. In contrast, the cost to the health economy in the presence of the Midhurst service was reduced, as patients were referred earlier (Group A, Group B), leading to substantially lower costs. The availability of a service-model like Midhurst could lead overall to around 20% less cost being incurred, through this facilitation of earlier referral, which in turn leads to less cost to the healthcare system. In conclusion the total cost to the healthcare system for end of life care for cancer patients could be around 20% less than under the Hospice model. This could be due to the higher percentage of patients referred prior to an inpatient stay, reducing the overall cost of care in the last year of life, or it may indicate a great complexity of need in hospice patients.

3.7 Relationships with other services: Data from semi-structured interviews gave an account of good, functional relationships between the Midhurst professionals and community nursing services, general practitioners and NHS outpatient services. The geographic

organisation of nurse specialists within the Midhurst team appeared to facilitate this. The flexible way in which the Midhurst nurses worked (both the specialists and the Community Support Team) occasionally raised the danger that other services could feel Midhurst were "stepping on their toes". However, Midhurst staff showed awareness of this, and disputes and ill-feeling around role boundaries appeared to be uncommon. Professional working relationships with local hospices and community hospitals, when patients required admission were also good. Patients, on the whole appeared to regard their professional attendants as working together.

3.8 Quality of care in the Midhurst service: Observation and interviews confirmed the ability of Midhurst to give flexible and truly holistic care. The fact that Midhurst provides cancer treatment at home, for patients not in the terminal phase, appears to be one of the factors allowing GPs and hospital consultants to refer patients early in the course of illness and has avoided the stigma of a service principally concerned with the dying. The range of clinical interventions on offer, some of which avoid the need for travel or admission to hospital or hospice are instrumental in promoting confidence in home care as disease progresses. In the interviews, current patients and carers were very positive about the supportive and personal nature of the care they experienced from the Midhurst team. Often Midhurst staff were presented as playing a key role in enabling patients and carers to cope with the very difficult situation in which they found themselves.

3.9 The Midhurst team approach: Researchers with an extensive experience of evaluating palliative care services were impressed by the quality of working relationships within the Midhurst team. These were characterised by flexibility of role, so that tasks were performed by the professional close at hand and by those familiar to the patient. Medical staff were available for complex and detailed consultations at patients' homes when required. Volunteers fulfilled many important roles and were well employed within the service. The organisation had a clear sense of purpose and appeared to function well with little need of non-clinical management.

3.10 Bereaved carers' satisfaction with services provided at home

A substantial majority (83%) of bereaved carers who responded to our survey reported services at home to be excellent or good, and good experiences predominated in the comments on care quality. A majority reported that they received as much support as they wanted. Almost half of respondents reported the experience to be rewarding, with few saying it was a burden. However, 43% of respondents had given up or reduced their work in order to look after their relative; underlining the importance of informal caregivers in care at home. Personal care needs were less well met, except in the last three days of life. Most people were cared for at home (or in a care home at the end of life), and a majority of deaths took place there. Although there were a few admissions from home to hospital or hospice in the last few hours of life, a substantial majority of respondents felt that their relative had died in the right place. Bereavement care was reported to have been helpful, and had been received by nearly all of those who felt they wanted it.

3.11 Bereaved carers' satisfaction with other services: Respondents reported good care in hospices and nursing/care homes for the minority of people who were cared for there. Hospice doctors and nurses were unanimously rated excellent or good, as was care in all but one of the nursing/care homes. A majority (73.6%) reported GP care to be excellent or good, with understanding GPs and good access to visits. Pain control was similar across all settings. However, the quality of care from doctors and nurses in hospital had lower ratings: doctors were reported as excellent or good by slightly under half of respondents, and nurses by only just over a half.

3.12 Lessons to be learnt from bad experiences: Although factors that bereaved carers find crucial to a good experience of care are illuminated by the VOICES responses; nevertheless reports of bad experiences illustrate failures of service for some of those cared for at home. Not receiving services, or late referral to the services, was one important issue along with inadequate GP cover and poor continuity, particularly with out of hours services. Across all these settings, the issue of personal needs not being met as well as other aspects of care could indicate a deficiency in the resource available for basic nursing care.

3.13 Primary care services: The economic evaluation was unable to compare the cost of primary care provision between patients referred to Midhurst, hospice or only acute NHS services. We are unable to say whether Midhurst substitutes community NHS provision or tends to rely on it when maintaining care in the community.

When the three PCTs; West Sussex, Hampshire and Surrey are compared to the rest of England in our 2007 national survey, they appeared to be more advanced in their participation in national initiatives and scored significantly higher in quality indicators of palliative care provision. Figure 3. Illustrates the current survey, the observable differences in the reported quality of palliative care provision between PCTs, and although participation in national initiatives has increased, there is little change in reported quality of care since 2007.

Figure 4. Illustrates the finding that quality indicators of the GP palliative care provision in the Midhurst area provided a picture of care commensurate with provision throughout the three PCTs.

Figure 3. Number of palliative care initiatives in 3 PCTs

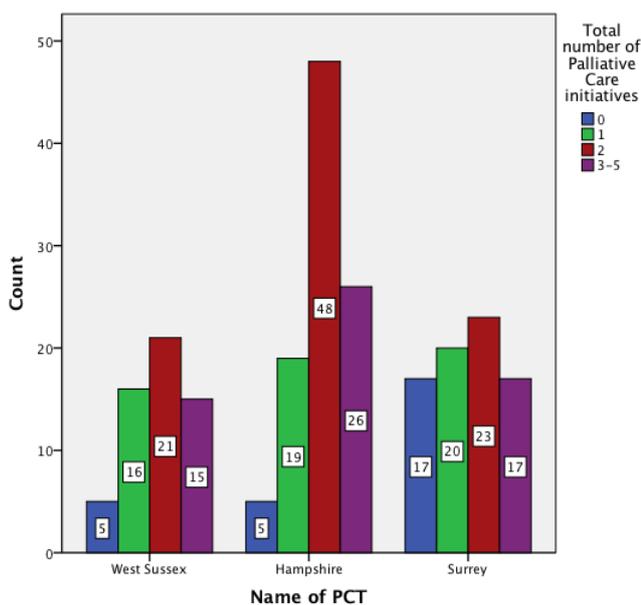
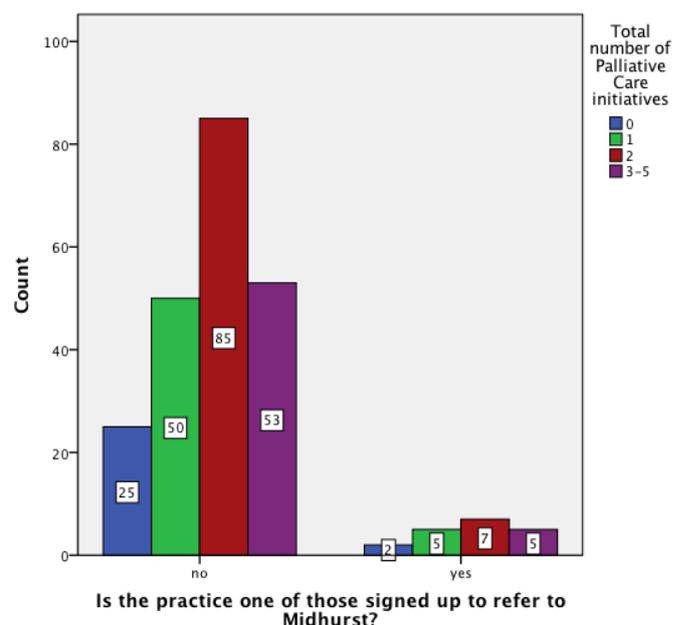


Figure 4. Number of palliative care initiatives in Midhurst area Practices



4. Summary themes for the integrated evaluation

The complete evaluation represents a comprehensive review of the Midhurst service. It has examined service provision, carer, patient and staff experience, referrer's commentary in addition to quantitative clinical and economic outcomes. Combining these results, we can draw six summary themes, which are supported by both qualitative and quantitative data.

Catchment Population

No part of the study has led us to understand that the patients using Midhurst are the result of referrer-level selectivity. Interviews with referrers suggest that Midhurst is the service they refer to systematically for their patients requiring specialist palliative care. The pattern of service use for patients under the care of Midhurst showed only very few patients dying in a Hospice environment. We have no data to suggest that Midhurst is not able to serve as a comprehensive model of care for all cancer patients requiring specialist palliative care.

Role Flexibility

Patients, carers and staff themselves report that a key aspect of Midhurst service provision is the flexibility of roles of the team members. It is the person with the patient, who will undertake all the necessary tasks, so long as they have the requisite skills. (Clearly some specialist tasks require the appropriate team member). This finding is supported from the activity based costing analysis. A broad range of different team members will undertake a span of different activities. This is also consistent with the quantitative analysis.

Early Referral

The quality, flexibility and holistic nature of the care provided by Midhurst appears to be a factor that allows GPs and hospital consultants to refer patients earlier in the course of illness. Midhurst is less associated with the stigma of services principally associated with the dying. Clinical data on patient characteristics, beyond referral acceptance based on eligibility criteria, was not collected by the evaluation team. Therefore, in order to better understand the timing of referral, a categorisation system based on in-patient stays prior to referral was constructed (Group A, B, C). The majority of patients referred to Midhurst (Group A, 63%) took place before an inpatient admission; this compares to only 29% for patients referred to hospices. Most patients referred to a Hospice will have had at least 2 admissions prior to referral (Group C, 53%).

Clinical Outcomes

The breadth of services delivered into the patient's home, and the earlier referral to Midhurst provides the opportunity to develop a relationship of trust between the patient, carers, family members and the team. The consequences of this are seen in the less frequent A&E attendances, decreased hospital stays and 71% patients dying in their own home or care home. The choice of home death appears to be in line with patient and family wishes, as indicated in our survey of bereaved carers. Conversely, the openness to accepting patients

with ongoing therapy (chemotherapy or radiotherapy) provides a reason for the higher number of outpatient attendances.

Economic Outcomes

Relationships with other services are sound, functional and supportive. The perception of patients was of their professional attendants working together. The challenge to the economic analysis, i.e. that the Midhurst service cost is underestimated because resources from primary and community/social care have not been considered, does not gain support from the qualitative research phase. None of the professionals from outside the Midhurst service suggested that the existence of Midhurst added to their workloads, while many reported that access to expert advice and sometimes hands-on support from the Midhurst team helped them in their work with palliative care patients. The overall findings from the economic analysis stand. In summary, for individual patients the overall cost to the health economy is similar for a patient referred to either Midhurst or to a hospice-model of care; economic savings could be made, however, through earlier access to community-based specialist palliative care, which may be facilitated via a Midhurst-type model.

Characteristics of an Effective Community Palliative Care Team

The qualitative analysis suggests a number of characteristics of the Midhurst team that enable it to function very effectively in the service it offers patients and their families. Flexibility is key. This includes being flexible about role definitions (as noted above), and about such things as working hours and geographical boundaries. A lack of emphasis on hierarchy in relationships within the team helps make people feel valued and fosters a willingness to work flexibly in the manner described. Leadership within the team is clear and effective. Structurally the combination of patch-based Community Nurse Specialists and a pool of nurses and nursing assistants in the Community Support Team works very well. Community Nurse Specialists are able to build relationships with other health and social care professionals local to their patch, facilitating collaboration, while the Community Support Team can be deployed flexibly to respond to fluctuating demands across the Midhurst area as a whole. Finally, the comprehensive nature of the team – with doctors, therapy professions, and counselling as well as nursing - means they can respond to a wide range of patient and carer needs in the community.

5 Conclusions

Conclusions are set out in relation to the three original aims of the evaluation:

5.1 Midhurst service meeting the original aims of the palliative care initiative:

1. To put in place a sustainable and affordable specialist palliative care service for the population within the Midhurst and surrounding areas
2. To ensure that patient choice is maximised by providing as much treatment and support in the home/community setting as possible and
3. To reduce acute hospital interventions and inpatient hospice stays

The Midhurst model allows the clinical team to function in a flexible fashion, accommodating and complementing various other services to share the care of the patients. Maintaining good relationships with other services and gaining the confidence of patients and carers facilitates a 71% rate of deaths at home or care home.

Reports by patients, carers and bereaved carers point to satisfaction with the Midhurst service where they have played a major role in end of life care. GPs reported satisfaction with access to advice and palliative care services.

It may be the case that an existing clinical team, unfettered by institutional constraints and presumptions, with the benefit of good clinical leadership were enabled to design a palliative care service that focussed on personalised care. The model appears to accommodate cancer patients, referred early, particularly well and these are most likely to benefit from the Midhurst service, as are their carers.

5.2 Evidence that commissioners and Macmillan can use to agree future commissioning and funding intentions:

When individual patients are compared, the overall costs associated with the Midhurst service are similar to hospice services in each of the referral categories. However, as physicians tend to refer to the Midhurst service earlier, this appears to allow it to contain costs over time and may have cost-saving implications.

Since the Midhurst service is providing palliative home care at a cost less than hospice, but with a similar overall level of NHS funding for comparable cases, there appears to be a justified role for voluntary sector funding. External voluntary sector funding appears to facilitate low administrative costs within the service and the clinical freedom to work flexibly with other local services.

GPs view good access and good relationships with palliative care services as an enabling factor for achieving good palliative care. Evidence from bereaved carers suggests that they receive good or excellent support from Midhurst, which can make the experience of care rewarding.

5.3 The Midhurst service as a model of palliative care for other parts of the UK:

There was no evidence that the Midhurst service was reliant on high quality primary care or that it deskilled local GPs or district nurses. In this sense, it was truly complementary, operating at a secondary care level and filling gaps in existing community service provision.

Other than good access to a volunteer workforce, there does not appear to be any special feature of the Midhurst area that is particularly advantageous to the service. It is likely that a similar model could be established in other areas and that it has the potential to serve 25% of a population at the end of life. Given the likely increased demand for specialist palliative care as a result of the Palliative Care Funding Review the Midhurst model may represent an efficient way of expanding capacity without incurring significant capital costs. This may be achieved through expanding the role of existing hospital-based palliative care consultants into the leadership of community-based, services delivering care in patients' own homes.

The service operates in an area that spans three PCTs with differing engagement with national end of life care policy, suggesting that the Midhurst model could apply to diverse areas. It is likely that flexibility of the individuals concerned in the Midhurst team is crucial and necessary for the model to work. Rigidity of institutional control or professional working styles would hamper the ability to supplement other community services.

Evidence from a comparable service in the UK suggests that this model is sustainable and capable of serving a greater proportion of patients with a diagnosis other than cancer. The ability to care for patients with diagnoses other than cancer would depend on referrals of patients with chronic conditions and Midhurst finding ways to substitute for hospital inpatient or outpatient or day-care.