MACMILLAN SPECIALIST CARE AT HOME

Findings from 2014–2016

WE ARE MACMILLAN. CANCER SUPPORT

With evidence from

The University of Nottingham

UNITED KINGDOM - CHINA - MALAYSIA
This report has been adapted from “University of Nottingham, Macmillan Specialist Care at Home: Independent Evaluation. November 2016.” This report has been designed as a condensed version of the original for accessibility. Should you wish to access the full report please email evaluation@macmillan.org.uk

With thanks to the evaluation team in Nottingham, to all the members of the project teams at the Innovation Centres and the additional health and social care professionals and volunteers who so generously gave their time. We would also like to thank the staff involved in maintaining databases and distributing the questionnaires, and the patients and families who took the time to share their experiences.
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1. About Macmillan Specialist Care at Home

Macmillan Specialist Care at Home is an innovative approach that supports more people to access high-quality specialist palliative care closer to home and to live and die in their preferred place. Conducted between April 2014 and August 2016, this evaluation focuses on the six innovation centres that have piloted Macmillan Specialist Care at Home: Birmingham and Solihull, Dudley, Hull, the Isle of Wight, North London and West Norfolk.

1.1 Background

An estimated 160,000 to 170,000 people in England receive specialist palliative care every year. Around 80% of these are people living with cancer.1

However, an estimated **350,000 of the 500,000 people who die each year would likely benefit from specialist palliative care**2 – pointing to a significant shortfall in meeting patient needs. What’s more, NHS expenditure on specialist palliative care varies significantly across regions, implying inequalities in access.3 This all suggests that, despite significant progress, end of life care services in England are still falling short of the targets4 laid out in the Government’s 2008 End of Life Care Strategy.5

At the time of writing, there is no national definition of what counts as a ‘specialist palliative care service’, and there are no standardised referral practices.6–8 But we do know that people with chronic non-cancer conditions and uncertain prognoses are less likely to access specialist palliative care because of the fluctuating nature of their illness. Instead, they are more likely to experience fragmented care over the course of their illness, and to receive care of sub-optimal quality as they approach end of life.9

In England, 56% of deaths occur in hospitals, while many people who die at home or in long-term care are often discharged from hospital close to death. Most people who die in hospitals have ‘non-traditional’ palliative care needs, i.e. they tend to have multiple morbidities, uncertain capacity and an unclear prognosis. Many have had a number of previous hospital admissions.10 Although 90% of all people with palliative care needs spend some time in hospital during the last year of life, the quality of end of life care in hospitals is rated significantly worse than any other place of death by relatives of people who have died in hospital.11
With the right support, 64% of people with cancer would prefer to die at home, but only 30% currently do. Just 1% would prefer to die in hospital, but 38% of people with cancer currently do. While dying at home is more challenging to achieve and is associated with a range of clinical and social complexities, most people would prefer to remain at home with appropriate support from community-based services.

1.2 Innovation centres

Macmillan Specialist Care at Home is an innovative service that supports more people to access high-quality specialist palliative care closer to home and to die in their preferred place.

The approach was first piloted in Midhurst in the south of England, with results showing that it reduced the need for emergency admissions to hospital in the last year of life by providing better planned and resourced care, and that it supported families and carers in caring for their loves ones. After the success of Midhurst, Macmillan partnered with six centres across England to try and replicate the outcomes in different contexts. This report provides a summary of the key learnings from these pilots.

Macmillan Specialist Care at Home brings together teams of professionals in a more integrated way to improve palliative and end of life care for people affected by cancer and other life-limiting conditions. By establishing sustainable, affordable specialist palliative care services in the community, it aims to maximise the delivery of treatment and support closer to home, and to reduce the need for acute hospital interventions and inpatient stays. The key features of the service include:

- Early referral: people are referred to the multidisciplinary team, often whilst still receiving treatment. This allows enough time to build strong relationships, plan ahead and provide practical and emotional support when needed.

- Close and proactive collaboration with primary care and other service providers: better coordination of care and joint working between service providers, often through co-location, are key to a better experience of care.

- Interventions at home where possible: a broad range of interventions (including blood transfusions, IV antibiotics or bisphosphonates, ultrasound, intrathecal analgesia) can be provided at home or in a community setting. This can be less stressful for patients and carers, and saves time and energy for other things.

- Flexible teamwork between specialists, generalists and trained volunteers: patients, carers and staff say that the flexibility of roles taken on by team members is critical. Research shows that caregivers value accessibility and support, whilst patients emphasize the psychosocial aspects of services.
Innovation centres, funding and goals (2014–2016)

Birmingham and Solihull (£250,000)
- Develop links and consistency in service delivery.
- Build a local primary care learning network to improve knowledge about palliative and end of life care.
- Create a volunteer service in the area to visit people in their own homes.
- Develop protocols and deliver interventions at home.

Dudley (£250,000)
- Create a single point of access to enable earlier referral, reduce unplanned hospital admissions and increase service integration.
- Fund additional personnel, including two part-time consultants and expand specialist palliative care.
- Work to integrate community teams and create a central hub based at the local hospice.
- Develop protocols and deliver interventions at home.

Hull (£220,278)
- Fund more consultant time to provide an additional palliative care clinic in the north of the city.
- Work with 4 selected local care homes to pilot education and support as a means to reduce their high hospital admissions at end of life.
- Develop an ongoing end of life education programme for all staff and specialist palliative care forum.
- Develop a volunteer service in the area to visit people in their own homes.
- Draw up protocols and deliver interventions at home.

Isle of Wight (£249,976)
- Fund additional personnel, including community support workers and an occupational therapist.
- Work to integrate community teams through a single point of access at the hospice.
- Improve early identification of people nearing the end of life.
- Increase rapid response in the community and 24/7 access to care.
- Develop protocols and deliver interventions at home.

North London (£251,000)
- Fund additional personnel, including a staff grade doctor, advanced nurse practitioner and two part-time healthcare assistants.
- Develop systems for increasing early referrals.
- Build a rapid response team of healthcare assistants to provide hands-on care.
- Create a volunteer service in the area to visit people in their own homes.
- Develop protocols and deliver interventions at home/in hospice.

West Norfolk (£251,349)
- Invest in a nurse consultant for palliative care and a Project Manager to coordinate the Macmillan Specialist Care at Home service.
- Promote integrated working by bringing together the Hospice at Home team, the Care and Support Team and the Macmillan Nurse team.
- Create a single point of access as a specialist referral point for all services.
- Develop the existing volunteer service to visit people in their own homes.

All centres also secured substantial local funding, in addition to Macmillan’s support, to enable the above service enhancements. Additional funds were also provided by Macmillan in 2015 to support set-up of the volunteering services: Birmingham and Solihull £26,362, Hull £42,201, Dudley £23,420. £88,883 was provided to North London in 2015 to increase the staff grade doctor role to a consultant level post.
2. About the evaluation

Carried out between April 2014 and August 2016, the evaluation of the Macmillan Specialist Care at Home centres aimed to:

• inform the service’s development on an ongoing basis and explore whether the new approach achieved better outcomes for people affected by cancer and a more efficient use of resources;

• provide an understanding of the impact on the experiences of patients, their families, staff providing care, and other staff within the health and social care community;

• to recommend how the approach could be replicated and developed in other areas in future, and how Macmillan can work with commissioners and service providers to understand and develop services in their local areas.

A mixed methods approach was adopted, with collection of both quantitative and qualitative information.

Qualitative data

• Project mapping: this took place at the start of each evaluation to gather background information about each centre and its current service status.

• National stakeholder interviews: five key national and strategic stakeholders were interviewed to identify their expectations for Macmillan Specialist Care at Home, and its place in addressing national policy goals to improve end of life care. Interviews were conducted with: National Clinical Director for End of Life Care – NHS England; Chief Executive Officer – National Council for Palliative Care; National Clinical Lead – Hospice UK; Director for England – Macmillan Cancer Support; Director of Midhurst Macmillan Specialist Palliative Care Service.

• Focus groups and interviews: carried out with innovation centre staff and volunteers.

• ‘Pictor’ interviews with staff, volunteers, patients and carers: the Pictor technique uses a simple participant-constructed visual layout to represent a patient case, which is then examined with the researcher.
Quantitative data

• Service assessment: a bespoke Service Data Tool (SDT) was created to record information on referrals, place of death, staff activity logs and interventions, including their location.

• Patient assessments: Palliative Prognostic Index (PPI) and Palliative Performance Scale (PPS) scores were used to give an indication of symptom burden, physical function and expected survival time upon referral to the service. Additionally, the Integrated Palliative Care Outcome Scale (IPOS) was completed by patients on each home visit (max. once a week).

• Carers assessments: the Carers Support Needs Assessment Tool (CSNAT) was used to capture change in carers’ needs over time, in this evaluation the questionnaire was sent once to carers to gain an overall picture of needs.

• VOICES questionnaire: the Views of Informal Carers – Evaluation of Services is a questionnaire used to gather the views of bereaved carers of people who had received services from the centres.
3. Key findings

The findings discussed here bring together service data with insight from staff, patients and carers across the six Macmillan Specialist Care at Home centres and are broken down by theme: referrals, service delivery, meeting the needs of patients and carers, and workforce and training.

3.1. Referrals

Summary of findings

• All centres had flexible referral criteria to allow them to capture the most appropriate referrals, and aimed to gain access to patients earlier so that they could put services in place to keep them in their own home and prevent crises. However, each centre approached this in a different way, and there was no universal definition of what ‘early’ referral meant.

• There is wide variation in symptom burden of patients at referral, and some centres were able to reach people earlier in their disease trajectory than others. This depended on the team’s referral criteria, its capacity and what processes are in place.

• In some cases, the push to early referral could result in episodic care and lead staff to feel the service was intrusive if patients and families are coping themselves.

• A single point of access seems to improve responsiveness and direct people to the right services at the right time.

• Inequalities in the system, such as location, language barriers and economic and educational status, may prevent some people from seeking out support.

3.1.1. Timing of referral

Whilst the vast majority of patients (94.2%) referred to a Macmillan Specialist Care at Home service went on to receive care from that service, 145 individuals (4.4%) died after being referred to the service but before any care could be delivered. This suggests that not all referrals were made early enough.

The PPI scores at referral suggest that referrals occurred either when patients had PPI scores that indicate a life expectancy of more than six weeks (1,278, 51.0%), or when they indicate a life expectancy of less than three weeks (939, 37.5%). Comparatively few referrals were made when PPI scores indicated a life expectancy of between three and six weeks (290, 11.6%). Individuals with a PPI score indicating more than six weeks life expectancy could be considered ‘early’ referrals because, at this point, they are likely to be relatively unburdened by symptoms. However, individuals with a score
indicating less than three weeks of life expectancy are likely to have a relatively high symptom burden and could be considered ‘referrals for end of life care’.

The PPI data also reveals the different referral criteria at each centre. West Norfolk has a higher rate of referrals at less than three weeks life expectancy than they do at more than six weeks life expectancy, due to only collecting data from the Hospice at Home team whose referral criteria is the last 6 weeks of life. By contrast, the Isle of Wight has a high number of referrals with an expected survival of more than six weeks, and a low number of referrals where expected survival is less than three weeks. This suggests that this centre was already capturing ‘early’ referrals. The Isle of Wight had a single point of access referral system in place beforehand, which facilitated liaison between the community and hospice staff. However, there is no evidence as to what impact timing of referral may have had on patient outcomes and place of death.

3.1.2. Achieving early referral

The findings show that defining ‘early referral’ was problematic; in turn, this made it difficult to evaluate how each service was progressing when it came to achieving this objective. This quote from a staff member summarises what an early referral might look like;

‘I guess an early referral would be before somebody is at the point of crisis. And you can get a measure of the person and their normal support structure, their normal coping skills, without a number of external influences that makes something a crisis. That, for me, would be an early referral – just evidence that someone was thinking ahead.’
– Staff focus group participant

While the VOICES questionnaire does not directly ask about appropriate timing of referrals, a small number of bereaved respondents suggested they would have appreciated an earlier referral:

‘I cannot complete much of this survey as we were only introduced to your organisation four days before he died – but we did appreciate your care during that time. Earlier support would have been helpful.’
– Carer and VOICES respondent

Pictor interviewees also highlighted the possibility that the push to early referral could result in episodic care in some cases. This might lead staff to feel the service is intrusive if patients and families are coping by themselves over a longer period of time.

‘The good side is that we’re building up relationships with the patient and family. The bad side is sometimes our remit is very wide … you might be monitoring them for a while, and then you phone them and everything’s all right and then it feels too intrusive … Sometimes we’re there a bit too early.’
– Nursing staff member
Overall, healthcare staff said that building relationships with patients and families early on facilitated planning of future care. However, services must be realistic about what they can deliver. At some centres, balancing supply and demand required strict criteria around who can be accepted into the service (particularly in terms of the length of time they remain in the service).

Additionally, staff found that services could not be offered indefinitely if the person’s care needs changed and they no longer required the support. Patients’ and families’ needs and wishes may also change throughout the course of an illness. Additionally some people do not wish to access healthcare services until unavoidable, which could lead to later diagnosis and potentially crisis situations.

This suggests flexibility is needed when it comes to entry criteria into the system and ‘holding’ people on registers – especially if their needs change whilst in the system.

However, staff did identify inequalities in the system – such as location, language barriers and economic and educational status – which may prevent some people from seeking out information and support.

3.1.3. Single point of access

At baseline it was identified that some referral systems and processes seemed to improve or exacerbate the challenges of receiving patients early. Where there were various referral points into services, there was also the potential that people might ‘fall through gaps’ or be assessed using differing standards and criteria.

‘I feel that there are huge gaps for patients. Once they are not in the system for curative care or curative treatment, they fall in a huge gap and the GP is not always really on the ball.’

– Staff focus group participant

A single point of access for referrals seems to be the best approach as it ensures people are known to services, even if they do not consistently use them. What’s more, the allocation process that accompanies a single point referral system can help to make sure a person is seen promptly, and by the right professional, for the first intervention. For staff, it ensures a fairer and more appropriate distribution of workload.

‘Patients are seen by the service that they need to be seen by first, in a more timely fashion, because the referrals all come in to one point. The team then sit round and allocate the referral to the most appropriate person, which isn’t necessarily who the referrer thought it was.’

– Staff member

Successful and appropriate referrals also rely on good information about a person’s condition and potential palliative care needs. If this was not provided, staff had to find other ways of getting hold of this information – such as an extra assessment to determine a person’s particular needs.
Case example

Dudley

Historically the hospital, hospice and community care sectors had worked separately with some tension between the sectors, particularly around the responsiveness of the community Macmillan nursing team. The single point of access element of Macmillan Specialist Care at Home was seen as enabling both greater integration and more effective use of resources.

As a result of setting up the single point of access, the Macmillan Specialist Care at Home service delivery team were also now co-located at the hospice. This supported more effective communication and greater ability to appropriately allocate patients, reducing duplication of work.

‘I think there’ve been referrals come in that might have asked for one of the specialist nurses to go first, whereas actually the team looked and thought they’re appropriate to come straight into hospice. So it cuts out a visit.’
– Project team focus group participant

This project team also engaged with ongoing feedback and made adjustments to the new single point of access accordingly:

‘We were getting feedback around difficulty with communications, and people were feeling that work was being duplicated ... so we changed the processes within the single point of access. Now, we communicate back to the GP as soon as the referral has been made ... GPs tell us the change has made a huge difference.’
– Project team focus group participant
3.2. Service delivery

Summary of findings

• In the first 15 months, the Macmillan Specialist Care at Home centres carried out 450 interventions; before the service was in place, it is likely that most of these interventions would have required a hospital outpatient appointment.

• 80% of interventions were carried out in patients’ usual place of residence; phlebotomy accounted for most of these. Whilst specialist intervention was expected to be the focus, considerably more staff time was spent delivering conventional support to patients.

• Helping patients and families to better understand services empowers them to know what it is they need and manage their expectations about what services they might receive and when.

3.2.1. Who received care from Macmillan Specialist Care at Home?

A total of 3,286 people were referred to the six Macmillan Specialist Care at Home centres during the evaluation period. Dudley received the most referrals, with the centre enabling existing services to come together in an integrated service across the hospital, hospice and community.

For some centres, the information collected during the evaluation represented their entire caseload, whereas for others it only captured those using the new parts of the services funded by Macmillan. At Birmingham and Solihull, the low patient numbers reflect the fact that their primary focus was on education and transfer of skills with a GP network. Interventions at home and in the day hospice were also tested as a small-scale pilot.

Each centre was based in a different area of the country, with different local influences and demographics. Whilst travelling to people’s homes in densely populated London or spread-out West Norfolk did present challenges for these teams, most were used to working in these environments. A more significant issue was the number of clinical commissioning groups each Macmillan Specialist Care at Home team must liaise with, as well as the number of GPs, GP practices and community teams.
Case example

Birmingham and Solihull

This project needed to work across three CCGs, a large number of service providers and two quite distinct areas with large and ethnically diverse populations. Project team members reported that in retrospect a narrower focus may have had more impact for patients:

‘I think if I were to do it again I would concentrate it on one patch. Because we’ve stretched the money so far over such a massively different area, you’re not comparing apples with apples.’

– (Project team focus group, final)
The demographic and clinical details of people cared for by the Macmillan Specialist Care at Home services are shown in Table 1 (Birmingham and Solihull are not included given their focus on education).

The mean age of patients across all centres was 75.7 years old, and just over 50% of the patients were men.

Approximately one-third (32.5%) of the patients had a non-cancer primary diagnosis, suggesting that centres were reaching a broader range of patients beyond the national average (Dudley in particular, 42.8%). In Hull, the centre seemed to have established links which resulted in higher levels of referrals for people with neurological conditions.

<table>
<thead>
<tr>
<th></th>
<th>Dudley</th>
<th>Hull</th>
<th>Isle of Wight</th>
<th>North London</th>
<th>West Norfolk</th>
<th>All sites</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (SD)</td>
<td>76.5 (12.5)</td>
<td>68.6 (15.2)</td>
<td>75.5 (11.7)</td>
<td>72.9 (13.4)</td>
<td>75.9 (10.2)</td>
<td>75.7 (12.5)</td>
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<td>Gender (%)</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Women</td>
<td>996 (49.8)</td>
<td>50 (49.5)</td>
<td>280 (43.3)</td>
<td>161 (56.9)</td>
<td>87 (44.4)</td>
<td>1574 (48.7)</td>
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<tr>
<td>Men</td>
<td>1006 (50.2)</td>
<td>51 (50.5)</td>
<td>367 (56.7)</td>
<td>122 (43.1)</td>
<td>109 (55.6)</td>
<td>1655 (51.30)</td>
</tr>
<tr>
<td>Diagnosis (%)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Cancer</td>
<td>1133 (57.2)</td>
<td>82 (81.2)</td>
<td>539 (84)</td>
<td>241 (86.1)</td>
<td>166 (84.7)</td>
<td>2161 (67.6)</td>
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<tr>
<td>Non-cancer</td>
<td>847 (42.8)</td>
<td>19 (18.8)</td>
<td>103 (16.1)</td>
<td>39 (13.9)</td>
<td>30 (15.3)</td>
<td>1038 (32.5)</td>
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<tr>
<td>Neurological conditions</td>
<td>162 (8.2)</td>
<td>11 (10.9)</td>
<td>17 (2.8)</td>
<td>9 (3.3)</td>
<td>3 (1.6)</td>
<td>202 (6.4)</td>
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<td>Dementia / Fraility</td>
<td>173 (8.7)</td>
<td>3 (3.0)</td>
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<td>5 (1.8)</td>
<td>1 (0.5)</td>
<td>201 (6.4)</td>
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<td>Cardiac conditions</td>
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<td>2 (2)</td>
<td>11 (1.8)</td>
<td>7 (2.6)</td>
<td>7 (3.7)</td>
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<tr>
<td>Respiratory conditions</td>
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<td>2 (2)</td>
<td>13 (2.1)</td>
<td>8 (2.9)</td>
<td>10 (5.3)</td>
<td>162 (5.1)</td>
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<tr>
<td>Multiple Co-morbidities</td>
<td>30 (1.5)</td>
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<td>1 (0.2)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>31 (1)</td>
</tr>
<tr>
<td>Other</td>
<td>206 (10.4)</td>
<td>1 (1)</td>
<td>10 (1.6)</td>
<td>2 (0.7)</td>
<td>2 (1.1)</td>
<td>221 (7)</td>
</tr>
</tbody>
</table>

Table 1 – Demographic and clinical details of patients referred to Macmillan Specialist Care at Home centres – PPI & PPS data
3.2.2. What types of care did people receive?

The findings reveal that specialist interventions only made up a small proportion of activities, with staff spending considerably more time on delivering conventional support. Across the six centres, 450 specialist procedures were provided during the evaluation period, with 80% of these delivered in the home environment, including in nursing homes. Before the service was launched, these interventions would likely have required a hospital outpatient appointment. These interventions required a high volume of medical and nursing input.

A total of 450 procedures were carried out during the evaluation period, with 80% of them in patients’ homes. 72% of them were categorised as ‘phlebotomy’. Putting processes in place to carry out more complicated interventions, such as blood transfusions and paracentesis, proved to be complex and time-consuming. And as the Isle of Wight team discovered, even when processes were put in place, there was little demand for these more complex interventions.
Case example

Isle of Wight

The Isle of Wight put a lot of time into setting up policies for interventions in the home environment. The project team anticipated providing blood transfusions and bisphosphonates in patients’ homes as part of their Macmillan Specialist Care at Home service. As it turns out, this centre carried out the highest number of phlebotomy and ultrasound procedures and were the only centre to provide subcutaneous fluids and paracentesis. However, there was limited demand for interventions such as blood transfusions and bisphosphonates. Throughout the course of the evaluation, the team had to balance the demand for interventions with the time and skill they required from the palliative care team.

“What we haven’t done much of is the blood transfusions and the bisphosphonates. With a clinical team of one nurse per shift, you’re struggling at the best of times. I think if I’d have found early on that there were lots of times when that would have been useful, we’d have pushed it. The time we did the bisphosphonates, the consultant went out with [the nurse] and they did it themselves. And that was really useful, because this chap couldn’t get up to the hospital or the hospice. I want to carry on with it, and I want to have it as part of the team, but I don’t see it as a huge necessity.’

– Project team focus group participant
3.2.3. Establishing the service

Successfully establishing the service requires centres to be clear about what the service is offering, who needs to be involved and who has responsibility for each part of the service.

When asked about early and appropriate referrals, project teams and staff highlighted the need to increase patient and professional awareness of the services they offered. In particular, they emphasised the importance of promoting the service amongst people with long-term conditions, where the disease trajectory may be particularly unpredictable.

“We’re seeing so many more patients with long-term conditions and neurological conditions. Specialist palliative care is complex symptom control management, and that’s where our expertise is. And we’re now seeing patients in their last years of life, who are often having really complex symptoms. So it’s where we should be going. We just need to be getting the word out, and that’s about education of primary care teams, really, and hospital teams.”

– Project team focus group participant

It was also recognised that reaching patients in need would require investments of both time and staffing resources:

“We have the in-reach, and the nurse goes in and trawls the wards and she is physically looking for patients who have got either long-term conditions or are frequently in and out of hospital, or regular users of the GP … So they do try and get them at an early stage.”

– Staff focus group participant

3.2.4. Building awareness of the service

In some instances, leaflets were used to raise awareness of the Macmillan Specialist Care at Home service. Staff also seized any opportunities that came up to generate publicity when working with partners. Education events offered an ideal forum to promote the service among staff and wider partners, e.g. GPs.

Based on visits to the centres during the evaluation, there was growing staff engagement with Macmillan Specialist Care at Home. Project teams suggested that the Macmillan branding helped them to attract more attention and made people more aware of their services.
‘If we didn’t have Macmillan acting as a vehicle for us all being able to do more, and the funding and the encouragement and the support, and sharing of policies and programmes, I think it would have been a challenge to do what we’ve done. With Macmillan’s support and badge, we’ve been able to achieve a lot more. And it’s given us some backing and kudos really.’

– Project team focus group participant

Responses to the VOICES and CSNAT questionnaires suggest that carers were not always aware they were accessing a specific service. Patients and carers often identified nurses visiting them at home as Macmillan nurses when they were possibly district nurses, whilst others used various other names for the service they received.

3.2.5. Impact of the local health economy

Some centres are located in local health economies that face great uncertainty. As well as being very unsettling, this also increases staff workload (for example, due to report preparation, extra meetings and presentations), at the cost of advancing and developing the service. Teams found that a strong local governance structure at their centre, with representatives from as many arms of the service as possible and champions in wider partner organisations, helped to provide a buffer against the impacts of significant changes.

The Hull centre, in particular, witnessed the impact of disruption in the local health economy when the service underwent a re-negotiation and tendering of its contract during the pilot. This created uncertainty for staff and prevented cross-sector working, putting collaboration with the local hospice on hold and restricting communication with the CCG. Once the process was complete and the centre had been re-awarded the tender, the project team was able to continue working with commissioners to develop the local end of life care strategy.

3.3. Meeting the needs of patients and carers

Summary of findings

• Carers generally felt well informed in all the areas covered by the CSNAT questionnaire. However, some would have liked more information on what to expect when their relative is very near to death, so that they can feel more prepared.

• Based on the service data and responses from carers, an average of 50% of people died in their own home. 88.3% of bereaved carers thought the patient had died in the right place.

• Common barriers to achieving preferred place of death included; complex symptoms that cannot be controlled at home, differences of opinion amongst professionals and death happening sooner than anticipated.

• The availability of a multidisciplinary team improves centres’ capacity to keep people at home.
• Project teams felt that Macmillan Specialist Care at Home provided added value by preventing readmission to hospital when social care packages did not dovetail with the discharge of the patient.

• Staff acknowledged that people often feel compelled to call the emergency services when difficult physical symptoms occur, and identified anticipatory prescribing and patient/carer education key to preventing this.

• Findings suggest that Macmillan Specialist Care at Home may reduce crises in the final year of life and avoid unscheduled hospital admissions.

3.3.1. Outcomes for service users and carers

Of the 238 people who completed the IPOS questionnaire more than once, almost one-third (78) were in the service for more than 100 days, and one-fifth were in the service for between 100–199 days. There was no consensus on the length of time a person should remain in the service.

While the findings from the IPOS questionnaires were not statistically significant, they did show a slight decrease in symptom burden over time. The fact that symptom burden was maintained or even reduced as people remained in the service is positive and suggests high-quality end of life care.

The CSNAT questionnaire was completed by 241 carers across five of the six centres. Findings show that carers generally felt they did not need more information. However, the question: ‘Do you need more support with knowing what to expect in the future when caring for your relative?’ received the most responses – suggesting that more support in this area would be appreciated.

The VOICES questionnaire asked bereaved carers to rate the care they had received from Macmillan Specialist Care at Home. Interestingly, a small number (10%) did not realise that they had received care from the service, highlighting the difficulty that people may have in differentiating between care providers.

For those who did know that they had received support from Macmillan Specialist Care at Home, the majority (68%) said they had received an ‘exceptional’ or ‘excellent’ quality of care; only 4% felt that the care had been ‘fair’ or ‘poor’. This was further reflected in the details of carers’ responses with 75% feeling they had been involved in decisions about treatment as much ‘as they would have liked’, and 65% said they had as ‘much help and support as they needed’.
Of the 102 bereaved carers who returned the VOICES questionnaire, 79% made comments in response to one or more questions. Most of the comments were positive and many praised the input of a range of services and professionals – including Macmillan nurses, district nurses, night sitters, home care support workers, GPs and hospice staff (not just Macmillan Specialist Care at Home). Some family carers reported more negative experiences, often due to poor communication between services, a lack of information or poor access to help and resources when needed – for example, due to out of hours or limited staffing.

‘I found the support from the doctor at the Macmillan Specialist Care at Home service and the district nursing service was excellent. They gave me the support that other members of the family couldn’t. I think the support empowered us and made very painful decisions much easier.’

– Carer and VOICES respondent
3.3.2. Potential to reduce unscheduled hospital admissions

Qualitative findings from the evaluation suggest that Macmillan Specialist Care at Home may reduce crises in the final year of life and avoid unscheduled hospital admissions. In particular, the availability of a multidisciplinary team improves centres’ capacity to keep people at home.

‘The whole team worked well together, were well informed and helpful. They attended promptly and brought everything we needed. A wonderful service. Their care enabled mum to die peacefully, painlessly and in her own home – just as she wanted.’

– Carer

Being able to respond rapidly to situations can also prevent unscheduled hospital admissions. Centres with a particular focus on rapid response created teams underpinned by the HCA role.

‘I had one patient a couple of weeks ago and a Clinical Nurse Specialist told me that what I’d done had stopped him calling an ambulance and going into the hospital. That was taking his blood and getting his observations that day, so they could actually treat it all.’

– Healthcare assistant

‘We’ve had some phone calls from the ambulance service who have been out there, known about our involvement in delivering a Macmillan Specialist Care at Home service and said, “We don’t want to admit them, is there anyone that can come out and support?”’

– Project team focus group participant

Staff acknowledged that people often feel compelled to call the emergency services when difficult physical symptoms occur. They identified two key ways of addressing this: anticipatory prescribing and patient/carer education. Anticipatory prescribing requires forward-thinking at the point of discharge, confidence in decision-making by Macmillan Specialist Care at Home and community nursing staff, and understanding and cooperation from GPs (staff have suggested this is not always forthcoming). Patient/carer education involved making service users aware of Macmillan Specialist Care at Home as an available resource in emergencies.

3.3.3. Place of death

Of the 3,054 people who received care from Macmillan Specialist Care at Home during the evaluation period, 2,127 died. 1,085 deaths (51%) occurred at home, 316 (14.8%) in a hospice, 627 (29.5%) in hospital and 74 (3.5%) in other locations, while place of death was recorded as unknown for 77 (3.6%) patients.

Comparing place of death across centres where services are based in different settings can be problematic, though all centres increased their number of home deaths. The focus of the Dudley centre...
was to create a single point of access for palliative care and integrate specialist level palliative care services across the community, hospital and hospice. A higher rate of hospital deaths is therefore to be expected and will have increased the proportion of hospital deaths across all centres. Despite having a lower proportion of ‘earlier’ referrals, West Norfolk achieved the highest number of home deaths. Integrating their healthcare assistants and Hospice at Home teams may have affected this outcome. Hull also achieved a high proportion of home deaths. Both the Isle of Wight and North London services were hospice-based, so it is unsurprising that their level of hospice deaths are higher than other centres.

**Place of death**

![Place of death chart](chart.png)

Figure 2 – Place of death (Place of death figures from Birmingham and Solihull are not included in this table as their primary focus was on education and transference of skills across the two areas.)
Of the 102 VOICES questionnaires returned by bereaved carers, 61.8% knew the preferred place of death for the person they were caring for. Where a preferred place of death was known, 79.4% of patients died there. Furthermore, 88.3% of respondents felt the person they cared for had died in the right place.

‘With the help of the Macmillan nurse and the Hospice at Home nurses, my wife was able to come home. That was her greatest wish – to be at home with her family.’
 – Carer and VOICES respondent

‘My father had been in the care home for nearly three years and looked upon it as his ‘home’.’
 – Carer and VOICES respondent

Whilst most carers of people who died at home felt that it was the right place, two reported that this was not the case.

Seventy-four (72.5%) respondents to the VOICES questionnaire felt that the person they cared for had enough choice about where they died. Of those who received support at the time of death, 77% felt they ‘had definitely’ or ‘to some extent’ received the help and support they needed. Only 5.9% (6) of respondents felt they did not receive enough help and support at the time of death.

3.3.4. Achieving preferred place of death

While the comments from bereaved carers in the VOICES survey showed how Macmillan Specialist Care at Home teams helped many people to die in their preferred place, they also highlighted a number of potential barriers. Some respondents said that it was not possible to control all the patient’s symptoms at home or to provide the 24-hour care that is often needed at end of life, whilst others said they encountered staff who did not feel the patient should remain at home. For some, the unpredictable nature of death simply meant that it happened sooner than expected.

The findings also showed that social care packages did not always dovetail seamlessly with hospital discharges.

For Macmillan Specialist Care at Home staff, many of the tasks which increased the likelihood of preferred place of care and death required covering these gaps in care, managing the expectations of patients and families and working around domestic circumstances.

‘There can be days or weeks sometimes from getting them home from hospital to getting a care package in place, and getting them actually home once it’s in place. So we bridge the gap.’
 – Staff member

It was also important to manage the expectations of patients and their families when they were able to return home – for example, they often needed to adjust to a high volume of home visits from professionals. Other issues that were highlighted included housing problems and health and safety concerns (such as having to resolve unsafe electrics at a patient’s home).
3.4. Workforce and training

Summary of findings

- Service integration requires time to build up trust and communication between services with a long culture of working separately. This can be a slow and steady process.

- Respondents across all six centres recognised that a multidisciplinary team was important in providing high-quality palliative and end of life care. Co-location of key staff also makes it easier to get people together to discuss and allocate cases promptly, share information and seek advice.

- Consultants were seen as having a key role – for both their influence and their clinical knowledge to support a multidisciplinary team.

- HCAs play a valuable role as rapid response personnel who enable joined-up care and offer support until further services can be put in place. This was particularly true at the North London centre, where they helped to avoid unplanned hospital admissions.

- Volunteers provide a valuable range of services and were an important resource when people required additional support that did not involve clinical input.

- Local ‘champions’ who are highly motivated and committed to Macmillan Specialist Care at Home are seen as being central to a service’s success – for example, a dedicated project manager.

- There was a different emphasis on learning and development programmes across the six centres, but all saw education and training as a crucial element in supporting their workforce and increasing palliative care knowledge in non-specialist services.

3.4.1. Workforce

Project team members and staff at each centre recognised that Macmillan Specialist Care at Home could improve delivery of care. Many reported additional learning opportunities and building new, better relationships with other professionals – which in turn boosted their enthusiasm and job satisfaction.

For some of the centres, a key aim was to integrate palliative care service provision across hospice, hospital and community services. While integration can help to streamline service delivery, it also brings a range of challenges for staff in existing services. And at the start, some staff expressed concerns about the impact of a new service on their role.

At some centres, there were also concerns about historical antagonism between teams, for example, where there was an overlap of roles. Here, integration had to take place more slowly and sensitively to build trust between teams. A key factor in addressing challenges like this was to bring together staff whose roles overlapped at an early stage.
‘Integration is proving easier because community and hospital are one trust, and the Macmillan nurse lead has a foot in both camps – that may not have happened five years ago. There are fewer barriers now so it’s the right moment.’
– Project team focus group participant

All staff highlighted the advantages of having team meetings to be able to talk about patients, reporting that they provided a real sense of teamwork and connection.

Having a central base for staff also speeds up communication and makes it easier to get people together to discuss and allocate cases promptly, share information and seek advice. For the Macmillan Specialist Care at Home teams who focused on developing a common space, it proved instrumental to building good working relationships, ensuring continuity of care and avoiding duplication of effort.
Case example

West Norfolk

Prior to the launch of Macmillan Specialist Care at Home, West Norfolk had started to bring together the acute, community and voluntary workforce in the area. On the back of initial success, they applied for Macmillan funding with the aim of continuing this work.

‘What was helpful was that we were all providing, in some ways, a similar service but, in other ways, very different services. So we were able to signpost patients that came through our doors into other people’s services that were more appropriate. And that’s worked really well, and we’ve kept the links up. We certainly get quite a lot of referrals from the cancer support team through that.’

– Staff focus group participant

Both face-to-face communication and meetings were seen as key in expediting change and generating understanding. Another central part of integrating the services was to reduce duplication of effort and make better use of resources by triaging patients to the right service or health professional. Of course, this work was not without its challenges, especially with contractual issues ongoing in the background. Consistent recordkeeping was especially difficult.

‘All the community staff are now mobile and working with tablets. So they’re completing their records in real time whilst in patients’ homes. But we’re using different templates at the moment. So whilst most of the information is probably the same, it’s not being recorded in the same way.’

– Project team focus group participant

The integration of services in West Norfolk was considered a success by participants in the evaluation, despite facing challenges such as staff absence and problems filling vacancies. Since the start of Macmillan Specialist Care at Home, referrals to the service have increased by 75%. This centre was also able to support the highest number of home deaths (95.3%, 184/193).
While respondents across all six sites recognised that a multidisciplinary team was important in providing quality palliative and end of life care, there was particular emphasis on the roles played by consultants, healthcare assistants and volunteers. Respondents all referred to local ‘champions’ who were both motivated, and dedicated to the project, as central to its success. These people helped to drive the project and could often provide critical links to partner organisations. A dedicated project manager was often reported to provide this initiative.

**Consultants**

Consultants serve as a catalyst for action. Their expertise builds confidence in decision-making and facilitates aspects of service delivery, such as prescribing. Overall, consultants were highly valued for their capacity to:

- make key clinical decisions quickly and at the point of need (including in the community);

- influence partners in different sectors (e.g. GPs) in offering effective patient care at end of life; and

- encourage and provide confidence for other clinical and health care staff to carry out their roles.

‘The big change is the response time to patients, and the feel and support for team members. It’s different when you’re no longer actually feeling that it’s your total responsibility, especially for the most senior experienced CNS. We’ve got more consultants around you can bounce ideas off. You can share ideas and implement some more complex ones.’

– Project team focus group participant

**Healthcare assistants (HCAs)**

HCAs are able to respond quickly to patients in need, often managing a situation until a specialist assessment can be carried out. Centres valued HCAs for providing:

- continuity for patients and joined-up care;

- feedback to other team members in their capacity as the eyes and ears of the team in patients’ homes; and

- rapid response and fending off potential crises, often out of hours, by maintaining situations until a solution could be found.
Case example

North London

Rapid response HCAs played an important role at the North London Macmillan Specialist Care at Home service, responding to patients at home when other services could not – for example, before a care package could be put in place.

And knowing that it was part of a specialist programme to help people avoid hospital admission, the area’s ambulance service started to request this support:

‘We’ve had some phone calls from the ambulance service who have been out there, known about our involvement in delivering a Macmillan Specialist Care at Home service and said, “We don’t want to admit them, is there anyone that can come out and support?”’
– Project team focus group participant

‘Because they’re on the ground, they’re with the patients, their understanding is there … it makes it a lot easier to pass on information to the right person (whether it’s social work or CNS), and then get the support that the patient needs.’
– Staff focus group participant
Volunteers working within the Macmillan Specialist Care at Home service feel their work is different from hospice-based work. They have a strong sense of what they can contribute, often due to personal experience of illness or end of life care issues. Many were motivated by the idea of giving something back for the help that they or their family members had received.

Volunteers performed a range of activities (see Table 2), including befriending, housework, shopping and transport. At the four centres where volunteers played a role (only three centres reported the specific activities), the following key themes emerged:

- Volunteers’ roles spanned a wide range of activities.
- Volunteers experienced some challenges in adapting to their roles within the service, especially when it came to balancing being patient-centred with the need to observe protocols.
- The training they received varied, but volunteers considered a focus on lone working and risk assessment to be especially important.
- ‘Buddying’ systems, where each volunteer was linked to a health professional or more experienced volunteer within end of life services, were seen as important.

<table>
<thead>
<tr>
<th>Type of volunteer activity</th>
<th>Birmingham &amp; Solihull</th>
<th>Dudley</th>
<th>Hull</th>
</tr>
</thead>
<tbody>
<tr>
<td>Light housework</td>
<td>1 (1.7%)</td>
<td>6 (7.1%)</td>
<td>15 (11.2%)</td>
</tr>
<tr>
<td>Gardening</td>
<td>0</td>
<td>0</td>
<td>3 (2.2%)</td>
</tr>
<tr>
<td>Shopping/errands</td>
<td>5 (8.5%)</td>
<td>2 (2.3%)</td>
<td>13 (9.7%)</td>
</tr>
<tr>
<td>Looking after pets</td>
<td>0</td>
<td>1 (1.2%)</td>
<td>0</td>
</tr>
<tr>
<td>Providing transport</td>
<td>0</td>
<td>9 (10.6%)</td>
<td>4 (3%)</td>
</tr>
<tr>
<td>Accompanying (to go out)</td>
<td>0</td>
<td>0</td>
<td>1 (0.7%)</td>
</tr>
<tr>
<td>Physical exercise/walking</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Befriending</td>
<td>53 (89.8%)</td>
<td>67 (78.8%)</td>
<td>98 (73.1%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>59 (100%)</strong></td>
<td><strong>85 (100%)</strong></td>
<td><strong>134 (100%)</strong></td>
</tr>
</tbody>
</table>

Table 2 – Type of volunteer support
### 3.4.2. Education and training

Educational activities at the centres varied, as did the types of training provided (see Table 3). Many teams highlighted the need for palliative care training and education around the Macmillan Specialist Care at Home service.

The most common benefits of the training/education activities were highlighted as:

- networking to enable early referral and increased service integration;
- greater awareness of palliative and end of life care issues across the workforce;
- better understanding of other professionals’ roles and responsibilities; and
- having a positive impact on patient experience.

<table>
<thead>
<tr>
<th>Birmingham &amp; Solihull</th>
<th>Dudley</th>
<th>Hull</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain and symptom management</td>
<td>Pain and symptom management</td>
<td>Pain and symptom management</td>
</tr>
<tr>
<td>Loss, grief &amp; bereavement</td>
<td>EoLC for patients with non-malignant disease</td>
<td>Loss, grief &amp; bereavement</td>
</tr>
<tr>
<td>EoLC for patients with non-malignant disease</td>
<td>Advance care planning</td>
<td>EoLC for patients with non-malignant disease</td>
</tr>
<tr>
<td>Advance care planning</td>
<td>Priorities of care training</td>
<td>Advance care planning</td>
</tr>
<tr>
<td>Clinical interventions at home</td>
<td>EoLC/palliative care updates</td>
<td>Clinical interventions at home</td>
</tr>
<tr>
<td>Shadowing opportunities</td>
<td>Sage and Thyme® training</td>
<td>Shadowing opportunities</td>
</tr>
<tr>
<td>Informal/formal clinical supervision</td>
<td></td>
<td>Informal/formal clinical supervision</td>
</tr>
</tbody>
</table>

Table 3 – Types of training/education
Case example

Hull

Before launching the Macmillan Specialist Care at Home service, Hull had developed an ‘End of Life Care Academy’ that provided end of life care training for registered nurses and allied health professionals. Macmillan Specialist Care at Home supported an expansion of this scheme and saw the secondment of a Macmillan Practice Development Nurse Specialist who acted as both an education and project lead.

Over a 7-month period, Hull delivered internal and external training programmes, alongside their End of Life Care Academy, to 1,045 health and social care professionals. The training sessions have been tailored to the level of need, to help people to engage, build skills and feel confident in asking for advice.

‘Obviously, as a HCA, you haven’t done your nursing, you haven’t got that experience. So for us to have the training to recognise a DNR and if somebody’s in pain or agitated, or if they don’t have just-in-case medication – we can chase that up and we can make a call. I think that’s quite good.’

– Staff focus group participant

The academy has also been linked to engagement with four local care homes. Each of the care homes was offered a free place on the academy course, and the centre also provided direct support to the care homes through monthly multidisciplinary palliative care meetings and a tailored training programme based on a needs assessment of the staff involved.

‘They’ve had some of their staff do that academy, and then return with such a passionate desire to learn more and to encourage their staff … We can see their confidence in some of the elements actually growing.’

– Project team member

The academy continues to run three times a year and there is a waiting list for places. Hull’s approach has been recognised as an exemplary programme for training, with their education lead winning ‘Educator of the Year’ at the 2015 Macmillan Excellence Awards.
3.4.3. Sharing information and expertise

In feedback from staff, key areas of focus were the community of practice meetings organised by Macmillan, and the lead-in time and exit strategies for the projects. The community of practice meetings aimed to provide a ‘learn and share’ environment for the six centres, providing information and training and allowing centres to compare successes and challenges.

‘The community of practice has been invaluable in terms of ... finding out that the challenges we’ve had are pretty similar to challenges that everybody else has faced.’

– Project team member
4. Recommendations

The report makes the following recommendations for future Macmillan Specialist Care at Home centres.

Referrals

- Create a single point of access for referrals to improve responsiveness and direct people to the right services at the right time.

- Encourage earlier referrals to help patients and carers get the support they need and avoid crisis.

Interventions at home

- Make sure you’re familiar with the approval process prior to starting, and assess the need for specific interventions before starting an approval process. Getting approval for interventions at home can take some time.

Workforce and training

- Recruit a dedicated project manager to co-ordinate and manage activities. They do not have to be from a clinical background, but should have an understanding of the service and the clinical needs and processes, or work alongside a clinical expert. The project manager should be in place as soon as possible.

- Recruit a consultant lead to serve as a catalyst for action. Their expertise builds confidence in decision-making and facilitates aspects of service delivery, such as prescribing.

- Ensure the team has the right mix of roles and skills, including HCAs to provide continuity of care and ‘hold’ situations where necessary.

- Where possible, ensure team members are in the same location – preferably with other palliative care service providers. This aids communication, supports team cohesion and reduces duplication of effort.

- Provide education and training in palliative and end of life care to ensure the upskilling of generalist professionals to be confident to manage or refer cases where appropriate.
Volunteers

- Befriending is a key aspect of care provided by volunteers. This category should be looked at separately in future evaluations.

- Provide clear guidance about health and safety issues when working in people’s homes. There should also be a focus on lone working and risk assessment.

- Provide training on any additional issues that may come up when supporting people at end of life.

- Offer volunteers support and dedicated contacts, with back-up cover when volunteer co-ordinators work part-time or when volunteers are working out of hours.

Working with partner organisations

- Identify a ‘champion’ within commissioning groups and any outside agencies, such as the local hospice, to enhance communication and help to create better working relationships. Having a senior clinician as a team member can help to engage other agencies and commissioning groups.

Branding

- In discussions with partner agencies, establish how and when the Macmillan brand will be used, potentially alongside any existing branding.

- Ensure there is clarity around what happens to the branding once the Macmillan-funded period is over.
References


3. Hughes-Hallett, T, Craft, A, and Davies, C, Palliative care funding review: Funding the right care and support for everyone. 2011, Secretary of State for Health: London.


16. Higginson, IJ, Sarmento, VP, Calanzani, N, Benalia, H, and Gomes, B, Dying at home – is it better: A narrative appraisal of the state of the science. Palliative Medicine, 2013. 27(10):918-924.


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