

Below we have compiled all information the OPEL toolkit provides.

Please use the results of your service assessment (the spiderweb diagram) to guide you in deciding which areas of optimising hospice at home you would like to know more about.

SUPPORT DIRECTED AT CARERS

These are potential areas for optimising SUPPORT DIRECTED AT CARERS in your HAH service.

Carer assessment

Provision of information,
training and support for
the carer

Personalised care for the
carer

Bereavement support

Carer assessment

Here is a list of activities other HAH services have used to optimise the way they carry out carer assessments.

- Assessing and regularly reviewing carer needs (including the whole family) both individually and as a care unit/patient-carer dyad
- Negotiating which care tasks will be delivered by the carer and how much they are willing and able to do
- Assessing what equipment and training the carer may need to provide care

Provision of information and emotional support for the carer

Here is a list of activities other HAH services have used to optimise the way they provide information and emotional support for the carer

- Providing support, reassurance and encouragement to the carer in their role
- Informing carers as early as appropriate about what HAH can/cannot offer and how it fits in with other services
- Informing carers what to expect in terms of illness trajectory and increasing burden of care

- Ensuring carer is informed about and signposted to other services and community support (including services specifically directed at carers) and advocating for the patient and carer if they are unable
- Informing carers about funding options and available financial support; assisting where needed
- Enabling (quick) access to an appropriate point of contact 24/7 (e.g., advice line); clarity of who to contact and when is paramount (e.g. via single point of access)

Provision of training and practical support for the carer

Here is a list of activities other HAH services have used to optimise the way they provide training and practical support for the carer

- Offering carers training/information on practical aspects of care (moving and repositioning, medication administration, mouth care, preventing pressure sores)
- There is carer-centred guidance available on practical tasks **after** death (e.g. death certification, funerals, legal advice and dealing with leftover equipment/medication/records)

Read about support directed at cares in detail

Unpaid care provided by family and friends is critical to enable patients to remain at home. How the patient and their informal carer, as a unit in the home, feel about dying at home and respond to the challenge of this situation will be key to achieving death at home. The carer may require confidence and new skills to enable them to provide care up to and including the point of death at home. In bereavement, there may be short or long-term consequences of caring to the carer's mental and physical health. However, there is a concern about medicalising bereavement which is a normal process.

A full assessment of care needs including the whole family/care unit is required. The HAH service fully informs the carer about what might happen in terms of the trajectory of illness and the increasing burden of caring over time. Carers will then know what to expect and can rapidly recognise a change in caring situation from control to crisis. If carer and patient choices are affirmed and supported wherever possible, the carer and patient have an increased sense of control. The HAH service should negotiate a partnership with the carer, including clarity about what can and cannot be provided, and recognition of what the patient-carer dyad wants. Pre-and post-bereavement support is based on relationship and understanding of the situation, and a shared story of caring for the patient. In addition, those not experiencing normal

bereavement need to be recognised and additional help made available. This should not rely on self-referral and the timing may be many months post bereavement.

-

The impact of all the HAH services, with their various approaches to sustainability, volunteering, integration and coordination, marketing and referral, knowledge, skills and ethos, was ultimately felt in the patient's home.

During end-of-life care

Hospice at home staff recognised the need to extensively support carers, and some of our case study sites offered specific carer interventions such as support groups and sitting services. Practical carer courses were also found to be useful:

I thought the mobility one was very good, which was teaching us how to use the slidey sheet and how to get people out of a chair ... all that sort of stuff...There's one about nutrition, interesting,... and then there's another one ... about the actual dying process and the symptoms and what to look for and you know, how the process proceeds.

EC06

Communicating with carers was key:

...massive part of our job yeah talking to families because they feel the responsibility ...if the agreement has been made that they wish to die at home most people haven't done it before ...we're there preparing for it so they're not quite so frightened when it does actually happen. I would do extra visits for that reason, not for symptom management but just to support the family...

XSP01 (CNS)

While wishing to support the choice of their loved one, some carers were anxious about whether a "good death" would be possible in their own home. For these and many other carers, the arrival of the HAH brought a huge reduction in their sense of physical and emotional burden:

I felt a great sense of relief from the very first time they came here...They're just so compassionate and they were so wonderful with me as well, it was as if I was a patient as well really as far as they were concerned...she explained to me that he was going downhill...And then on the morning that he died, coincidentally, she was meant to come that morning and she just took charge, ...she just did everything for me...

MC36

When asked what was unique about the care from HAH, many carers spoke of the professional, competent, caring, and calming nature of the HAH team in which the family could fully trust, providing the space for them to prepare themselves, and spend quality time with their loved one:

...just caring for my dad and I know that's putting it simply, but because they were, as you might say, experienced, qualified, they could spot any signs, ...it's sort of gave us the peace of mind and confidence that whilst we were there they were more than caring for me dad...

DC11

While for many carers, the “handing over” of care to HAH felt almost like a rescue, for others this was tinged with a sense of sadness that they were unable to continue caring for their loved one without help:

I felt rather sadder than when I had been able to do something like help. I felt I was more of a spectator, and hopefully a comfort, but was unable to physically do anything, but I felt sad that this was the case she needed and I was pretty happy that they had come and were exceptional...

PC58

Nevertheless, for carers wanting a more proactive role in the hands-on care, the HAH often enhanced their sense of confidence and backed up decisions the carer made. Positive experiences of carers also included being able to “double up” with the HAH and undertake care as a partnership with some HAH describing how they would teach carers to undertake care activities. Compared to the other services they may have been receiving, HAH was often characterised by a relationship underpinned by continuity, and in most cases being easy to contact.

For many carers, this relationship was strengthened when extended to the whole family. Indeed, the use of “family” as a metaphor was frequently used by both carers and HAH staff to describe the relationship, particularly in the smaller providers:

...I felt comfortable, almost like a family...you feel cocooned in this world of they're there to help you and I felt comfortable...

GC18

While seeing the HAH as a temporary extension to the family unit, it was also important to tailor the relationship to the patient/carer dyad, with some couples wanting more marked boundaries to maintain a sense of the home as private.

Most carers highly valued HAH. However, for some the HAH did not meet expectations. For a few carers, this was influenced by home not being the preferred place of death for their loved one, but feeling that there was an inherent pressure in seeing dying at home as the preferred option:

The main thing that I came away from all of this was the concept of, you know, encourage people to do it have this happen in their home and service results you get asked quite frequently, you know, are you happy to die at home and we get asked are you happy for your mother to die or your wife to die at home? And, you know, the natural instinct that question is yes because you feel, you know, you want to be in the body of the family and it's a nice way for anything to happen...It's very seductive to say to somebody do you want to die at home...

XC01

This perceived pressure was extended in the view of another carer, by expectations that the HAH would be providing the same level and intensity of care provided in an in-patient hospice, including physiotherapy and 24/7 attention.

Expectations of HAH service delivery were also recognised as a potential issue by HAH providers:

...we have had a couple of comments from families, who said, "we want more". But, You know, when you've had a good service for a couple of days and you suddenly realised, actually, this is wonderful, but actually the patient stabilises and we have to sort of re-evaluate how much care with putting in because this other patients who also need, then they'll say, "oh, please don't take it away from us"...

DSP02 (Director of Care)

The majority of the carers we interviewed were realistic about HAH capacity. However, the following quote also demonstrates that earlier support would have been welcomed, whereas many of the smaller providers only provided input in the last few days of life:

...if we could've had that similar service right from the start, I know that sounds a bit selfish in a way, ...just that unfortunately a lot of organisations just don't have the capacity to provide, if you like, the service we got at the very end, or towards the end...

DC11

Nevertheless, there was evidence that information about HAH was lacking. This fell into two categories. First, some carers commented that they had little awareness in the early days of how to contact palliative care

support staff, and what HAH offered, with detail on the latter being seen as important in reducing anxiety when deciding to care for a loved one at home. This was less likely to occur when carers were already well-networked and knowledgeable about the whole system of care:

...we were very lucky in that our GP is a friend who's known us for 20 years so, you know, we were very good friends so we did have a lot of support there and also [name]'s oncologist, our daughters went to school together so, again, we had a good solid...

GC04

However, for some even when in the HAH service, they were still not clear on who to contact:

...who the hell am I going to turn to? Have I got to phone the ambulance because I can't get you out of the chair, do I phone the (HAH), the community lifeline? I didn't know, in that situation (patient stuck in chair), who I was supposed to call...

EC14

Overall, most carers felt that the HAH had more than exceeded their expectation of care and support. In contrast, only a very few carers received the support they wanted post-bereavement.

After death

One carer described how she felt supported by the HAH after bereavement:

...the lady that came was here for a couple of hours talking it's always nice, when something happens, it's not just that's the end, they've gone, there is someone following it up to make sure that things were okay and things are okay.

WC69

Nevertheless, many of the carers we interviewed found it very difficult to move from a relationship with the HAH team as being part of an extended family, to a sudden halt in their visits, almost creating a second sense of loss:

...the one thing I found hard is (husband) passed away, the girls (HAH) left and that was it. Now, you're very busy at first...we had the funeral we did all the form filling and then suddenly, I'm on my own...

LC29

Carers appeared reluctant to proactively seek bereavement support from the HAH, recognising that the service was already very busy, or not knowing who to contact. Some HAH staff also recognised that while bereavement support tended to be delivered by a different part of the hospice organisation, there may be times when follow up by the HAH team may be beneficial:

I think there are certain patients and families that we could probably go in and see once or twice after the patient has died, and I think they would benefit greatly from that, because obviously they have built up a relationship with us... it's kind of cut off from that moment that the patient has died.

ESP04 (HCA)

For those who had proactively sought support from the Hospice, there was evidence that the format was not matched to the carer:

I tried last week to go to a bereavement group because they send me mail outs and things, for walking, in [name of] Park. So I tried to do that, but I took my dog, because I wouldn't want to go walking in a park without the dog, and nobody- I mean ...I ended up walking the dog by myself, like... [pauses], ... I dunno, I'm not a joiner-in of groups with people.

PC12

The importance of being supported in bereavement by someone who had shared the end of life care journey was summed up by this carer:

[HAH nurse] came after [husband] died. She came the next day or two days later and I think she came once after that but following that they were telephone calls, yeahit was a huge difference because I think that makes you feel more comfortable,... you know, they're aware of what you've been through so it's easier to talk to somebody that you've already... that you know that's empathetic towards the situation that you're in and that you've been through than it is to a complete stranger who you've never seen before so, yeah...I think it made me aware or feel that, you know, if I did run into a brick wall at any point, you know, that I could pick the phone up and talk to somebody.

VC09

SUSTAINABILITY

These are potential areas for optimising SUSTAINABILITY of your HAH service.

Taking the lead

Partnerships

Funding arrangements

Staffing

Taking the lead

Here is a list of activities other HAH services have used to optimise taking the lead to ensure sustainability.

- Proposing a business plan and “selling it” to commissioners;
- Taking the lead and providing services (sometimes without a great deal of scrutiny from commissioners)
- Having (or recruiting) a trustee or executive leader with a reputation for excellence, meaning they are trusted to use funding well
- securing NHS Continuing Healthcare (NHS CHC) funding to provide or part-fund services

Partnerships

Here is a list of activities other HAH services have used to optimise their partnerships to ensure sustainability.

- Working with other providers to provide joint services (provider partnerships may enable small organisations to maintain their responsiveness and alacrity and to provide care 24/7)
- Taking on a lead provider role and subcontracting with other providers in the area

Funding arrangements

Here is a list of activities other HAH services have used to optimise their funding arrangements to ensure sustainability.

- Having (or recruiting) a trustee or executive leader with a reputation for excellence, meaning they are trusted to use funding well
- Accepting a block contract from commissioners to enable predictability to the funding available
- Securing continuing healthcare funding to provide or part-fund services

- Accepting NHS funding which will support the HAH service and requires it to deliver other (“non-palliative care”) roles, such as OOH catheter replacement, general rapid response for example.
- Accepting funding for elements of service from Personal health budgets
- matching NHS pay scales rates can be key in ensuring adequate staff recruitment and retention

Staffing

Here is a list of activities other HAH services have used to optimise their staffing to ensure sustainability.

- Recruiting staff (to senior posts or boards) for both their skills AND reputational strength
- Avoiding fixed-term contracts
- matching NHS pay scales rates
- Having a reputation for and providing excellent staff support and training.
 - Staff support may include informal chats, peer-support, supervision, ready access to senior clinicians for advice
 - Use of ‘competency-based training passports’

Read about sustainability in detail

HAH services exist in an environment where there are constantly changing funding arrangements and commissioners, and an increasing requirement for data to provide evidence to support commissioning. There are also local and national shortages of health and social care staff, alongside a national drive towards care at home. For sustainable, longer-term funding within this context, the HAH needs to proactively seek control over available statutory funding, engage with the wider health and social care environment, and if a charitable organisation, to undertake fundraising and income generation from a range of sources. To recruit and retain staff to deliver the care that patients need, the HAH requires a reputation for excellence and investing in staff development and will alter skill mix profiles in response to local workforce shortages.

Funding

Ensuring sustainable funding to enable the long-term viability of the service was a major concern for all our case studies. This challenge was further complicated by frequent changes of commissioners, with very few

in post long enough to develop a good understanding of palliative and EOLC services, including national initiatives. In contrast, having an established relationship with the commissioner was beneficial:

...we've been quite open and honest with each other and from my point of view I think it's helped having me consistently be involved with them. I think if you had a number of commissioners over a number of years which other CCGs have had to contend with, you've just got to rebuild relationships every time ...

EComm01 (Commissioner)

One commissioner also highlighted that the relationship was easier with smaller HAHs:

It feels like a particularly open relationship... they're not a big provider for us, ... so I guess that the risk perhaps isn't there so that that relationship can develop in that way for that reason.

VCom01 (LA commissioner)

For commissioners, the challenge was keeping up with the constant pace of change:

...commissioners are permanently chasing their tail doing 100 brand new projects that NHS England have imposed and there's much less time to actually think about, you know, the next one / three / five years of local services because there's just, you know, there's so much change all the time...

XComm01 (Commissioner)

In addition, the landscape of change did not have EOLC as a priority:

...it's just not a priority at the moment with everything else that's going on, the transitions that's happening around CCGs merging and things like that...

EComm01 (Commissioner)

Many of our sites also expressed a concern that commissioners may not recognise the full cost of what they are commissioning, not recognising that charitable funds were significantly supporting the service. Paradoxically, there was also the perception that fundraising was compromised by a public perception that HAH was substantially supported by statutory funding.

Case studies had taken different approaches to ensure sustainable funding. Many proactively presented a business plan, continually selling it to commissioners or the HAH simply took the lead and provided services. In all examples this was facilitated by a board of trustees or executive leader with a known reputation for excellence, resulting in being trusted by commissioners to use the funding well. Having a trustee who was closely linked with NHS commissioning was particularly beneficial:

...hopefully through my influence as Clinical Chair of the Commissioning Group, is to increase the amount of funding we have provided for Hospice at Home...

CSP01 (Trustee)

This sense of trust was often matched by light touch scrutiny. However, feedback from our consensus workshops highlighted that while light touch scrutiny may be welcomed, reputation and trust was also enhanced if commissioners had a greater understanding through scrutiny of the quality of care the service was delivering.

In the early months of fieldwork, one case study site had taken on a lead provider role, subcontracting work to other providers in the area:

...we subcontract some bits to (another charity). ... I think there's certainly efficiencies to be made...

GSP06 (Business Manager)

Other case studies were also considering this model. The disadvantage this approach brought was that there were variations in quality and access from different providers. This in turn became a new context whereby the HAH service was forced to set standards and manage contracts, similar to taking on a commissioner role. Feedback from our consensus workshops suggested that there was a possible negative reputational impact of this. In later phases of fieldwork, this approach had been rejected by case studies previously contemplating it because of the possible negative impact on collaborative partnerships with other local providers. While a shared caseload may allow the most appropriate staff and services to be deployed, and create economies of scale and efficiencies, corporate identity may be diluted impacting negatively when competing for funding (CW).

Accepting a block contract from commissioners to enable predictability of the funding available was another approach used by services. These were seen by commissioners as representing very good value for money:

...it was quite clear from all of the information we got back that [Hospice name] were by far the best provider, they offered us the best value for money, they had all of the schemes and initiatives already established, they had staff working in the area... so on that basis we awarded them a contract...

EComm01 (Commissioner)

However, these contracts often only lasted one year at a time which was not long enough to adequately sustain services and did not encourage innovation. Capacity, demand, and community priorities often

outpaced the length of the contract cycle. An alternative approach used by several case studies was to secure continuing healthcare (CHC) funding to provide or part-fund services. However, this may result in inequities particularly if some CHC packages are topped up, or conversely rigidity of service when providing only what is CHC funded in terms of amount of service and duration of service.

The difficulty we have with our HAH service and we've had twice recently is where people need HAH but they're not at the stage of their illness where they're eligible for continuing fast track funding. Then we have a dilemma because the size of our services versus the need, ... we would be showing inequality if we were taking on people who were not funded through continuing health care in place of people who were.

LSP04 (Director Clinical Services)

It was uncommon to find services accepting funding for elements of service from personal health budgets. Overall, patients and families towards the end of life struggled to manage this process. There was some concern at our consensus workshops that the use of personal health budgets may result in actual or perceived inequities, where preferential treatment may drift towards those who pay.

There were a few examples where HAH services accepted other NHS funding to support HAH, but this came with a requirement to deliver other non-palliative care roles, such as for example out of hours urinary catheter replacements. While case studies using this approach justified positive outcomes as building professional credibility and relationships, feedback from our consensus workshops identified concerns around maintaining competencies, the loss of specialist palliative care skills and the potential to squeeze out available resources for EOLC.

One case study had developed income generating care services which subsidised elements of HAH service provision:

...the care agency is a separate organisation to the hospice but it's a sister organisation so it's very close working in the sense that it's a social enterprise so any profits that the agency make completely come 100% back into the hospice...

HSP01F (Lead Nurse)

This element of privatisation of care could lead to availability being only for those who could afford to pay and may cause dissonance with the charitable ethos (CW).

Finally, to manage public assumptions that HAH is significantly funded by the NHS and hence does not require charitable donations, there was some evidence that hospice charities may not be fully transparent

about their access to statutory funding, in order to make their fundraising activities more effective. While this may simplify information about complex funding and charitable arrangements as a public message, there was the potential risk of harming reputation if transparency was not maintained (CW).

One of the things that we are hoping is that our providers and hospices will get to a point where they're willing to be more financially transparent with each other about the level of funding that they're receiving from commissioners and the level that's coming from charitable donations or other income.

XComm01 (Commissioner)

Overall, being a smaller provider necessitated working with other local services, although how this linked to sustainability varied. Strategic direction for sustainability was exemplified in one smaller provider by a focus on its relationship with other providers, and in particular the local NHS Trust. This had resulted in a meshing of NHS community nursing services with the HAH service in providing a rapid response team.

We are fortunate that our rapid response service actually is a combined service with the community health team who also provide the district nurses so therefore we forged a really strong relationship with the district nursing teams...

VSP03 (Chief Executive)

HAH staff held honorary NHS contracts, and were able to deliver some elements of care outside of EOL, such as catheterisation. Perceived benefits of this blended model included the up-skilling of community nurses (through working with experienced HAH staff) and earlier identification of patients who would need EOLC in due course. In addition, for this HAH, one of the main anticipated benefits was increased visibility and having a presence on the strategic agenda for local care provision. However, this investment in the outward facing focus, on external relationships, may have resulted in losing inward focus and investment in the service. For example, staff motivation to strive for self-development was questioned. In contrast, another site worked closely with community nurses at the care level, but there were more concerns about sustainability at this site because of their difficulties in having a "seat" at local provider strategic meetings. Nevertheless, this small provider exhibited several positive benefits of being an inward facing organisation, including high staff morale and fewer issues in recruitment and retention. This need to have both effective outward *and* inward facing investment and relationships for sustainability is explored further in Chapter 8.

Staffing

The need to recruit and retain staff was set against a backdrop of local and national health and social care staff shortages. As mentioned earlier, inward facing organisations often had a focus on investing in staff

through CPD. They also tended to be organisations that deployed staff in preferred areas of work with the necessary skills training. In contrast, some services needed to adapt their skill mix profiles in response to local shortages, particularly RNs. In some cases, this led to RNs being solely office-based, or non-registered staff taking on roles previously held by RNs:

... there's such a lot of training available now and opportunities for non-registered general nurses, I think we need to think more about that. Not just to be able to give our non-registered nurses the opportunity to develop, but also because the pool of registered general nurses has become so difficult to recruit.

WSP02 (Clinical Director)

However, this was not without its problems:

...I think it's a bit embarrassing when you've got to, you know, wait for a district nurse to come and give medication. But a lot of hospice at home staff are not qualified nurses so I get that.

LSP06 (Medical Director)

The reputation of a HAH proved a strong magnet for attracting staff. This pull was created by either the reputation for staff investment, or the HAH (or its leader) having a reputation for excellence:

I think it's a popular service to work in and ...so certainly in my experience it's never been a problem with patients accessing the service because of difficulties with recruitment or retention or whatever.

CSP01 (Trustee)

While this success in recruitment and retention was welcomed by the HAH, there was the potential to have a negative knock-on effect through depleting the workforce on other parts of the local health and social care system.

National Policy

There is a national drive towards care at home which is clearly linked to the discourse of enabling patient choice. However, it was also recognised that care at home offers a potential cost saving, and the argument for commissioning HAH was underpinned by both rationales.

...by far the best value for money because there's no overheads... often the family are the carers as well which means that you don't necessarily need to staff them like you would an inpatient bed ... Hospice at Home is probably by far the most effective model....

EComm01 (Commissioner)

The reality in all our case study sites was that hospice beds were a relatively scarce resource and the provision of HAH was one way of meeting that gap. Commissioning decisions were inevitably influenced by economic factors alongside a desire to reduce inequalities in EOLC:

...there are big gaps all over the place for people who are dying at home... you know, when you look at the landscape, there are a lot of incredible Rolls Royce services being delivered in hospices and then there are a lot of very patchy, very much less good services being delivered for people that choose to be at home

XComm01 (Commissioner)

For most of our patient and carer participants, HAH brought high quality care to the place where patients and carers wanted to spend their last days together. However, for some patients and carers, this drive towards care at home led to a sense of obligation to manage dying at home which they found difficult. Preferences can change and there was a need for HAH services to explore and revisit the wishes of patients and carers over time.

Data and evidence

To support decisions about sustained funding, NHS commissioners and charity boards required data to be collected.

... it was a matter of persuading the Board that it would be cost effective... then it was quite a hard sell at commissioner level because the perception was, well we've got a service already, we've got district nursing, we've got Primary Care, you know, we've got a Hospice if need be for patients to go in, why would we need Hospice at Home ..., what's the added value of it for the money we're going to have to put in?

CSP01 (Trustee)

This resulted in enormous volumes of activity data being harvested, but with very little outcome or cost benefit data (such as avoided hospital admissions). Hence, the usefulness was questioned of activity data and our consensus workshop also confirmed the sense of frustration felt by staff, with a consequent resistance to collecting the data. However, larger, 24/7 services (model 1) were more orientated to a data collection culture, and had sought to address data utility:

We've done a piece of work with the commissioners where ...we can give NHS numbers to them, so all through the proper data sharing agreements. They can then do analysis on the admissions to hospital... so we can say, yes, we've avoided hospital admissions...

VOLUNTEERS

These are potential areas for optimising VOLUNTEER involvement in your HAH service.

Innovative volunteer roles at HAH

Clinical volunteer roles in HAH

Strengthening traditional volunteering

A radically different approach

Innovative volunteer roles at HAH

Here is a list of activities other HAH services have used to optimise innovative volunteer roles in HAH.

- Involving volunteers in non-clinical activities of HAH (e.g. shopping, befriending, 'sitting in' to relieve the carer)
- Recruit young volunteers with a view to have 'work experience' in a care setting, which may then inform future career choices
- Seeking out advanced clinical practitioners as volunteers (e.g. trained counsellors acting as volunteers)

Clinical volunteer roles in HAH

Here is a list of activities other HAH services have used to optimise clinical volunteer roles at HAH.

- Involving volunteers in clinical tasks and/or personal care as part of HAH delivery (this will require considerable resources to train and manage)
- Active recruitment of 'expert' volunteers with particular skills (e.g. retired nurses and trained therapists) enhances specialist services available

Strengthening traditional volunteering

Here is a list of activities other HAH services have used to strengthen traditional volunteering.

- Investing in effectively recruiting, training, and managing volunteer roles in hospices or HAH; this reassures the employing organisation about the risks of working with a volunteer workforce
- Volunteers are given clear responsibilities, expectations, and have lines of support, monitoring and reporting

A radically different approach

Here are activities other HAH services have used to adopt a radically different approach to volunteer involvement.

- Reframing HAH/provider approach to volunteering within the paradigm of “compassionate communities” by:
 - 1) Either tolerating a different level of “risk” and a less tightly controlled volunteer workforce within the hospice, allowing volunteers to act more like neighbours without a great deal of bureaucracy and procedure (and maintaining a triad relationship between the volunteer, the family and the hospice).
 - 2) Or working with “compassionate communities” existing schemes, possibly sharing volunteers, but much more like neighbours (maintaining a dyad between family and volunteer, with the hospice relinquishing tighter control of volunteers)

Read about volunteers in detail

Workforce shortages and the willingness of many people in the local community to volunteer makes the volunteer workforce attractive to hospice and palliative care organisations. Changing societal norms around family and community structure have impacted on the social networks of many patients and carers, with demand on carers compounded by HAH’s limitations in providing longer periods of input. Whilst a volunteer workforce could result in extending this period of care, HAH need to effectively recruit, train, and manage volunteers including providing clear responsibilities, support and lines of reporting. However, to reduce the bureaucratic burden, the HAH may take a different approach to some aspects of volunteering, along the lines of the Compassionate Communities model with volunteers acting as good neighbours.

While many carers had friends and family to support them, we found evidence of increased carer burden when little social network support was available. Some carers would have greatly valued more support from someone to provide longer breaks:

...the length of time that they said they (HAH paid staff) could do it for, was not helpful at all...there’s not a lot you can do in two hours...if I’d had to catch the bus, I would have literally have had enough time to run into the chemist, get the prescription and come home...

WC48 (carer)

However, because HAH services were predominantly focused on the patient rather than the carer, the rapidly escalating healthcare needs of the patient, and the requirement for skilled hands-on care to meet these needs, resulted in many HAH services not seeing a potential role for volunteers to support the patient in their own home. One volunteer organiser was aghast at a potential volunteer role in providing physical care:

...I was a bit, um, instantly gut reaction adverse to that idea that they would have healthcare assistant roles as well ... it would be "oh somebody might need to be fed or got up in the morning" and that's not what the volunteers want to do...

XSP02 (Volunteer Manager)

For volunteers, the length of time to develop a relationship with the patient and family was important, which was unlikely to be available in some of the HAH services where contact was only in the last few weeks of life:

...the longer that relationship goes on, then the more that person relies on you...it would seem that the patient gets a great deal of benefit out of my visiting.

WSP06 (Volunteer)

Nevertheless, while some carer interviews suggested that it was more befriending or "errand running" that would have helped, one of our case study sites did have volunteers providing hands on physical care. This site ran an adult care certificate programme for volunteers. Training included personal care and symptoms to look out for, and initial experience was gained in the inpatient unit. A volunteer interviewee described how they were asked to consider providing respite care in the patient's own home. With no previous experience in health or social care, the volunteer describes how they

...have been trained on how to, if they've had a bowel accident or something, I know what I need to do. I've also been trained on suction because a couple of patients can't swallow, can't do anything, so they're at risk of choking, so I've been trained on how to clear the throat.

ESP05 (Volunteer)

The volunteer provided two hours of respite care every other week. They described their role as taking a referral with minimal information, preparing for the visit, which included trying to glean knowledge about the patient's interests, and doing basic care if necessary. The volunteer was also able to double up with a HCA for HAH visits. The volunteer described their remit as being a friend to the patient and carer, giving the carer a break, and freeing up skilled staff.

When interviewing the commissioner for this case study site they felt that the volunteers were an essential part of the service as it made “*the money stretch*”. However, as the service was contracted by the Clinical Commissioning Group (CCG) they needed to be sure that volunteers were adequately trained and appraised, which led to a cost for the service. Added to this were concerns from the site on the challenges of managing a workforce which was not in an official contract with the organisation:

...you are beholden to volunteers that have you know, they're not contracted to us, they can go on holiday whenever they please and they can go away for 6 months if they want to...

ESP06 (Head of Wellbeing)

However, this hands-on volunteering role was often a very positive experience for volunteers and had led some to a career change as described by an HCA who, from an unrelated work background, had started volunteering in the hospice after experiencing hospice care for a relative, completed the care certificate, and eventually became a full-time HCA.

Volunteers who had previously been health or social care professionals were particularly valued. Examples of this role included advance care planning with patients, and being used in bereavement support services:

Fifty odd volunteers offering bereavement support ...we have quite a few that have been nurses in the past and things like that... you are obviously retired from that role but then come back as volunteers...

VSP03 (Chief Executive)

While volunteers were used extensively in bereavement services, we found little evidence that carers found this particularly helpful. What they desired most was to keep some contact with HAH care staff with whom they had developed a close relationship during difficult times (discussed further later in this chapter).

One case study site was notable for the range of community-based volunteer roles provided; these included:

- Hospice neighbours: social support provided early on during palliative phase.
- Carer companion: later on during EOLC with the relationship extending up to 3 months post bereavement.
- Bereavement support volunteers: 10 day training provided and volunteers delivered:
 - One to one bereavement support for up to 6 weeks, each volunteer has a maximum caseload of 3 bereaved carers,
 - Facilitating monthly support groups,
 - Participating in “walk and talk”,

- Attending early bereavement cafes.
- Discharge buddies: supporting patients discharged from the in-patient hospice.
- CCG/Hospice hub volunteer: particular remit to draw up Advance Care Plans with patients not in the EOLC phase.
- Compassionate neighbours: facilitating a more natural friendship when compared to the more purposeful Hospice neighbours:

...compassionate neighbours... the expectation is that you visit someone for about an hour a week, that you would spend time with them that way. But the idea of a compassionate neighbour... it's like generating genuine friendships and connections ...

PSP05 (Volunteers Manager)

At this site volunteering was perceived as innovative, was embedded within policies, and facilitated by a volunteer manager. However, there were challenges. In addition to the resource implications of managing and training the volunteer workforce, one of the biggest issues was ensuring volunteers kept within boundaries:

...I think sometimes people feel for themselves as a volunteer that it's different to a member of staff, which of course it is, but it doesn't mean that boundaries are different. But I think people think well it's ok for me to because I'm a volunteer, well it's not actually... you're a representative of an organisation...

PSP05 (Volunteers Manager)

The potential benefits and challenges of volunteers were also expressed by sites considering developing their volunteer workforce. One respondent from a site felt:

...there's an untapped resource we could use there and so many of our volunteers have the skills that could be developed into the clinical development...clinical volunteer role...so it is something we would like to develop...

VSP03 (Chief Executive)

In contrast, another respondent from the same site expressed:

...there's a risk to our reputation that if we put volunteers in doing respite in someone's house and that patient became soiled, that actually that volunteer can't deal with that, and then that we're kind of leaving a patient suffering... the boundaries would need to be very, very clear before we introduced volunteers...

VSP04 (Director of Operations)

This tension between recognising a potential volunteer role in the last days of life, versus seeing any benefit of this role outweighed by potential risks, was amplified in our consensus workshops. While there was acknowledgement that the volunteer workforce has “huge potential”, the risks to the reputation of the employing organisation were frequently mentioned. Concerns centred on governance and health and safety, and maintaining the fine balance in ensuring boundaries are clear and adhered to, versus allowing natural responses to compassion and empathy that underpin much of the motivation to volunteer. These issues were prevalent in the case studies, illustrated by this caveat on using volunteers to assist physiotherapists:

We've already assessed the person at home and they say I would like a zimmer frame so then the volunteer would go out and give them a zimmer frame and just check that they're all right with the height etc...we're looking into that but obviously we've got to look at the insurance side of it...

GSP02 (Physiotherapist)

Commissioners appeared aware of the potential benefit of volunteers, but cognisant of less formalised approaches to quality monitoring:

...we would expect to see certain training needs met, appraisals being done, that sort of thing and that's not always the case with volunteers so I think our Safety and Quality team are working with them to try and come up like with a meet halfway type scenario...

EComm01 (Commissioner)

INTEGRATION & COORDINATION

These are potential areas for optimizing **INTEGRATION AND COORDINATION** of your HAH service:

Integration across provider organisations

Anticipatory care planning

Division of labour... with coordination

Flexibility at the clinical interface

Integration across provider organisations

Here is a list of activities other HAH services have used to optimise their integration across provider organisations.

- Elements of budgets, workforce and organisational structure are managed in an integrated way across provider organisations.
- Clinical records are shared with other organisations.
- The HAH service has direct access to shared equipment stores or have their own stores

Anticipatory care planning

Here is a list of activities other HAH services have used to optimise their anticipatory care planning.

- The provision of anticipatory (advance) care plans and information. (This becomes even more critical if elements (e.g. night-time cover) are not provided directly by the HAH service)
- The HAH service may have medical or non-medical prescribers available within their service.
- There are local systems to ensure that medications and equipment needs are anticipated and provided on time (The HAH service may direct access to shared equipment stores or have their own stores).

Division of labour... with coordination

Here is a list of activities other HAH services have used to optimise their coordination using clear division of labour.

- Coordinating care (e.g. via a 24/7 helpline which may be a joint venture), particularly at night and if HAH is not a 24/7 service
- District nurses provide and administer all anticipatory medications (agreed division of labour)
- Other providers trust the HAH staff to make assessments and will act on their recommendations

Flexibility at the clinical interface

Here is a list of activities other HAH services have used to optimise their flexibility at the clinical interface.

- A blended service is provided whereby different services can provide what is needed by the patient without hard boundaries around particular roles; honorary contracts with NHS may facilitate this.
- Regardless of 'formal' arrangements for integration and co-ordination, HAH enables its staff to get on to work for the patient with colleagues who are co-dependent
- Other providers trust the HAH to make assessments and will act on their recommendations.
- An element of flexible workforce is employed (by the HAH service or others) or staff are flexibly deployed from other areas (e.g. inpatient unit)
- A secondment into a different setting (e.g. a healthcare worker into social care) may facilitate integration by the "learning of another language".

Read about integration and coordination in detail

Services across the whole system commonly act in silos, resulting in both duplication and gaps in services received by patients. This is compounded by a limit to services, funding, and workforce. In addition, issues of professional ownership of end-of-life care are at play, and organisations seek their own branding and distinctiveness for sustainability purposes. Patients in the last phase of life often have unpredictable needs at times which are difficult to anticipate. Some patients and carers will not know when to ask for help or who to contact. The HAH service needs to work in a coordinated and effective way with other service providers. This may be through a blended service without hard boundaries around roles or services, a secondment into a different setting which facilitates integration, or an agreed division of labour between services. If patients and carers are provided and updated with information, including who and how to contact professionals, then the chances of them receiving a seamless service and continuity of care with consistent information increase.

National perspective

National policy and strategic direction impacted on integration and coordination, particularly through their influence on commissioners and commissioning practices. One commissioner expressed a view at the consensus meeting that HAH organisations in general were not in a state of readiness to participate fully in collaborative commissioning.

HAH organisations that kept a close eye on national policy could capitalise on or anticipate the impact of this and plan their local strategies and plans for integration, coordination and thereby sustainability accordingly.

Some case studies invested substantial effort in this (see above under Sustainability and the Discussion chapter exploring outward versus inward facing organisational focus).

Service perspective

HAH services commonly formed part of a hospice organisation, often a charity, which was providing other palliative and end of life care services. Even the largest hospice organisations were relatively small players in local health and social care economies, but many were small or very small provider organisations, which often triggered a focus on developing partnerships with other providers. Some of these smaller services had worked hard to become involved in commissioning decisions:

... we make sure we always inform them what's going on, we make sure that we write in the notes, we communicate, if we've been out to see a patient we would phone the District Nursing Team and talk to them if we've got any concerns...then we have the quarterly meetings where we all get together and talk about if we've got any issues. And then either, as the Lead within the service, would go to the End of Life Community Meetings within the Trust, so that we've got that strategic level conversation that's ongoing.

MSP005 (Community Team Leader)

Good quality integration and coordination at the service level were not automatically straightforward and required a considerable investment of time and effort. We found examples of a range of strategies employed by HAH services to enhance integration and coordination:

A “blending” approach between services

Different services can provide what is needed by the patient without hard boundaries between services via several strategies, e.g.:

- Joint posts e.g. consultants working across settings/organisations, honorary contracts with the NHS were emblematic and may facilitate this.
- Shared clinical records/IT systems (this was not common).
- A whole range of collaborative hub, coordinator, single point of access arrangements.
- Systems to facilitate communication and reduce bureaucracy between services.

Building relationships

- Joint clinical visits, regular meetings between clinical colleagues from different services (e.g. primary care End of Life meetings)
- A secondment into a different setting (e.g. a healthcare worker into social care) may facilitate integration by the “learning of another language” (dependent on workforce availability).

Agreed "division of labour"

- Community nurses provide and administer all anticipatory medications.
- The HAH service is trusted to make assessments which other professionals will act upon; this trust is based on individuals and/or on the reputation of the HAH service.
- The HAH service has direct access to shared equipment stores or have their own stores.

A number of the smaller HAH services worked alongside other providers, for example through Palliative Care Hub working:

...we just refer to each other and talk to each other. You know, there's no having to refer to a specialist nurse with a particular form, I would actually just speak to them and discuss it and they'll pick up the referral...

XSP04 (Community Matron EoL and Supportive care)

Secondments into a different setting also helped integration, for example XSP04, a community matron, had worked in various settings in the area and had strong links with her palliative colleagues:

I've turned to (HAH) for support in complex situations like that, you know. I've used their social worker, I've used, you know, I know their therapists and I know their senior nurse, I could phone and discuss anything.

XSP04 (NHS Community matron)

Good working relations often stemmed from the bottom up, based on pragmatic decisions of '*finding the best person to do the job at the time*' (XSP04, community matron) and for the smaller HAH services agreeing how tasks were divided up, keeping patient need at the forefront:

...when the Hospice at Home service started with the registered nurse part of that service, that involved quite a lot of negotiation with the district nurse about who should actually do what and it's definitely an ongoing discussion about how things are divided up.

XSP01 (CNS)

Where there was less evidence of effective joint working was with social services:

...if you're talking Social Services, they talk a different language, don't they, you know, urgent to them means completely something different than urgent to me...

XSP04 (Community matron)

There were also examples of silo working, even within the wider hospice organisation, e.g. between the inpatient unit, day service and HAH, which partly related to capacity but impacted on integrated working between staff:

...we are trying to break down any barriers between the departments. I'd like to have, for example, the rota-ing...is done by each department on their own at the moment and looking at whether or not that should be blended together as one. So that actually staff are much more used to working across departments rather than I'm a ward HCA, or I'm a HAH HCA.

HSP02 (Chief executive)

Professional perspective

There were many examples where HAH staff worked closely with colleagues in partner organisations, particularly community nursing, to enhance integration and co-ordination, regardless of organisational arrangements or constraints:

... he was discharged without a hospital bed without a care package...the wife was feeling very anxious, they felt very on their own and so... I phoned my colleague at the hospital first of all to find out what was going on. She referred to the district nurses; the district nurses were able to order a hospital bed that actually arrived by that evening. I then came and fast tracked the patient and care was initiated... the carer started the next morning, then they attended regularly... so that is a really good example of how myself, the hospital clinical nurse specialist; the district nurses; the team, the carers team here were all able to work together to make sure that he actually did die at home ...

GSP003 (Clinical Nurse Specialist)

Nevertheless, there were times when HAH staff felt over-burdened with attempts to coordinate services on behalf of the patient:

...different services that are involved, families find it difficult to get their head round sometimes, you've got Marie Curie, you've got us going in and then sometimes you've got community carers going in 4 times a day, they go in just to do the personal care, sometimes they'll say who are you, where are you from...so I do think they find it difficult...

DSP003 (Healthcare Support Worker)

And in some cases, there were "ruffled feathers" as services, individuals or roles came into conflict.

...the district nurses get to know the patients... and build up relationships with them... and then we suddenly go in and they are sort of pushed to the side. I think that's what they feel, and we can tend to look... over zealous...

Patient and family perspective

Patients and their carers in the home were not overly concerned about which organisation, funding stream or system was providing the care, provided their needs were met as and when they arose. Examples of arrangements which improved access to people receiving “right care, right place and right time” included a single point of access and 24hr access to advice and support from a readily accessible telephone number or locality rapid response service:

And we'd been looking after mum all those years and struggling to get appropriate help and advice about the dementia, and it had been extremely frustrating at times but at the end of that phone call, the nurse at the end of that phone said to me “now you do realise we have a 24 hour helpline at the hospice, if you have any queries, any problems whatsoever just pick up the phone and someone is here”... And I put the phone down and I burst into tears because it was the first time I felt we were being truly supported to care for mum.

DC21

There were many examples where the hospice telephone service was the gateway to solving problems; in this example the carer was talking about his mother’s poor inpatient experience:

...when [hospice] became involved, nothing went amiss... I'd ring 'em up and say 'I've got this problem' and within hours the problem was solved... people would be forced to react after the [hospice] had spoken to them

EC03

The role of individual professionals on the ground was pivotal to the patient/carers experience, particularly ‘just to have a name and know that there was support if we needed it’ (PC12) and if they called, a response would be forthcoming.

I'd always said right from the start I wanted him at home and he'd said, you know, it's too much and what if we don't get the support... one Sunday night he said I feel really awful... can you call the nurses and suddenly, it's sort of 9 / 10 o'clock and I said Why? Why are we calling them? And he said I just need them to come here... they literally come, they reassured him and then they went away and I think it was his sort of test that if we called someone, they would come.

GC04

Regardless of what services or organisational arrangements for integration and coordination were in place, carers did not always know who to contact, when or how, and sometimes found themselves in unhappy situations as a result. In this example, the husband explained how they received monthly monitoring calls from HAH. However, when his wife deteriorated unexpectedly, they did not know who to call:

During the day, she was in pain a couple of times and wasn't- I suppose being naïve and never being involved in this- wasn't quite sure who we should call so we phoned the hospice and uh, they said "well, I think you better call the doctor or ring" was it, 111 or something like that? ... and eventually the ambulance took her to the hospital, and the final time she never came out, so we never used the hospice. Although, she did want to go to the hospice but things didn't turn out that way.

EC05

Despite many examples and evidence of good ideas and areas of good practice, the overall impression from public attendees at the consensus workshops was of a whole health and social care system in chaos. People frequently experienced multiple assessments, conflicting advice and information, delays to their care and treatment and often found that they (or their carer) were the only source of up-to-date information, in a sense acting as their own care coordinator. This was compounded for several carers by scant knowledge of local services, and for some a lack of prior awareness of their local HAH. In response to this and other contextual factors, HAHs focused some salient actions around marketing and referral.

MARKETING & REFERRAL

These are potential areas for optimising **MARKETING AND REFERRAL** your HAH service:



Referral mechanisms

Here is a list of activities other HAH services have used to optimise their referral mechanisms.

- HAH enables self-referrals or referrals by family/informal carer
- HAH includes a pro-active element to draw in suitable patients (e.g. directing marketing to those under-represented groups,)
- Referral process into HAH is easy and quick
 - Does not require lengthy forms, but enough information is collected so HAH do not have to routinely seek additional details
 - Forms are readily available and can be sent to HAH in a variety of ways (email, website form)
 - Shared IT systems / patient records

Referral and Discharge Criteria

Here is a list of activities other HAH services have used to optimise their referral criteria.

- HAH has robust criteria for identifying which referrals are suitable (may include trained triage staff to manage service admission)
- Clearly boundaried funding arrangements (e.g. CHC funding) enabled more robust management of accepting or discharging patients from the HAH service, including possibility of reduced care when HAH resources are stretched
- Discharging or transferring patients from HAH was a consistent difficulty ("we'd never leave anyone in the lurch"), commonly managed by reprioritisation of HAH visits.

Marketing

Here is a list of activities other HAH services have used to optimise their marketing.

- HAH service is actively marketed to the public (e.g. through website and fundraising activities); communities are aware that HAH is one of the services offered

- Potential referrers (GPs, community nurses, hospital services) are actively made aware of HAH, what the service offers and how to refer
- Clinical/frontline HAH staff encourage referrals through day-to-day interactions with colleagues and the public.
- External education and skills training offered to support recognition of end of life and encourage referral.

Expectations

Here is a list of activities other HAH services have used to optimise managing expectations.

Criteria, explanation of the service and treatment are clearly communicated to patients, families and health and social care professionals through a range of approaches:

- skilled day to day information giving and negotiation with patient and carer in the home
- written information to refer to outside of visits, containing contact information for 24/7 advice
- relationship-based communication with colleagues, based on trust and respect

Read about marketing and referral in detail

There is a complex system of health and social care providing end of life care for patients in the community. Furthermore, hospice services are often thought of as a building and there is less understanding of HAH services. HAH functions in a society where there is a fear and stigma around death and dying, (particularly in some communities), with potential referrers reticent to have conversations with the patient regarding prognosis. To increase referrals in general, and in particular of those that are poorly represented in hospice services, HAH needs to actively market its service to professionals and the public through clinical and public engagement. Referral systems need to be as simple as possible and not require complex transfer of information.

Raising awareness

Organisations employed a range of strategies to achieve knowledge and understanding of the HAH service and its role, e.g.:

- Allowing self-referral and raising awareness to the public directly (via phone number, website, GP, previous experience of hospice services). At times people who became aware of the service were able to “get a foot in the door”, even if they were not able to self-refer directly.
- The fundraising element of the organisation used events to market the service and educate the public about its role.
- Clinical staff had an important role in encouraging referral to the service through their day-to-day work and interactions with colleagues and the public.

One site reviewed the demographics of patients coming through the service and acted:

...we knew that there were patients in the local community, the Chinese community, not far from us that weren't accessing any of the services.... So, a couple of the HAH nurses went there and spoke to the residence ... we talked specifically to them about HAH and the sorts of things we could offer... to try and break down some of the barriers.

MSP04 (Head of Service Improvement and Quality)

Fear of death and dying

This context was well recognised as a backdrop in which all the HAH services operated.

...you'd be surprised how many local people just don't know we're there because people go around quite blinkered you don't want to be involved with a hospice unless you need it. And we're trying to dispel those kinds of myths and get people aware of what we do.

GSP07 (Fundraiser)

The provision of training for staff outside the HAH service was one response to this, explored further in the “Knowledge, Skills and Ethos” section, but also relevant here.

Getting to the right patients and equity

To continue to function effectively and equitably, services had referral criteria and strategies to discharge or transfer care out of the HAH service. Several services, particularly the larger, 24/7 services (model 1) in this study, had patients under their care for longer periods of time (> 6 months) and had patients with varying levels of need over time. While carers appreciated early support, paradoxically this left carers if needed to proactively contact the HAH between visits and many of our carer respondents from these services had less contact with the service:

...when they made their appointments said oh we'll come and see you in such-and-such a... you know, in a few weeks' time and in-between we didn't really need to ring them for anything.

PC30

A range of strategies were employed to manage demand for HAH, including:

- admission criteria, which varied between HAH services, in terms duration of service, patient factors, and the funding source;
- having trained triage staff to manage service admission;
- the provision of clear information about referral on to other services when the HAH service was not, or no longer, deemed suitable;
- categorising patients' levels of need and adjusting the service level accordingly and/or
- the utilisation of other hospice services (e.g. day care).

One site triaged patients into six categories, according to their level of need, from 'actively dying' to 'three monthly monitoring':

...we have our 'Blues' who don't need a face-to-face but you need to keep in contact with them because they're the type that will hit crisis and won't think about phoning in, so they have like a monthly phone call...

ESP01 (Deputy Director of Care)

Another site employed strict criteria in terms of the duration of their input:

We have a four-week End of Life criteria, ... so we will review at two weeks and look to see whether or not people have had onward referral to CHC or Social Services and we will pull out at four weeks if appropriate. Now if it's four weeks and somebody's clearly dying then we would stay, but generally we would, we don't provide ongoing care ...We've got limited resource.

MSP05 (Integrated Community Team Leader)

Another site described criteria as follows:

...one is somebody that's on the End of Life, maybe the last week of life, few days, and we will go in as a team and do whatever that patient needs to keep them at home... the other one is if somebody's in their last 12 months of life but has got an acute episode, and that may be uncontrolled pain ... most of the time it's carer fatigue, where the carer just can't do it anymore

CSP02 (Team leader, HAH)

Overall, we found services reticent to discharge patients “we’d never leave someone in the lurch” was a common refrain. Mostly, it seemed preferable for HAH services to control their caseload by managing access at the point of referral. One site *only* took CHC referrals, but the conflicts remained:

The difficulty we have with our HAH service and we’ve had twice recently is where people need HAH but they’re not at the stage of their illness where they’re eligible for continuing fast track funding. Then we have a dilemma because the size of our services versus the need, you know, we would be showing inequality if we were taking on people who were not funded through continuing health care in place of people who were. We wouldn’t really be fulfilling our contractual agreement... (however) ... we would never leave anybody in a true crisis.

LSP04 (Hospice Director)

It seemed that none of the services had waiting lists as such, but some (re-)prioritised in times of high demand, according to unofficial criteria, for example:

...if it does peak then we’ll look at our bank ... see if anybody else can do any extra hours... If it becomes...you know, over a long period of time or a sickness or whatever we’re not able to meet demand then we have to prioritize... although our primary remit is for patients who are in their last days or weeks of life ... and you know we can’t see those patients if they have low complexity and low need we go back to the district nurses and say we’re really struggling today. We can’t go.

MSP04 (Head of Service Improvement and Quality)

Managing expectations

Managing patient and family expectations was a process of continuous work over time, involving information provision and negotiation between HAH and those in the home (see also “Support Directed at the Carer” section). Where this worked well, patients and their carers could make informed decisions and choices at each stage of their pathway, even adapting their requirements to the availability of the HAH service.

Qu: did you feel there was quite a lot of expectation from you in terms of care provision for your husband?

A: No. No, I did a lot more than what was expected, you know, because they would always say, ‘oh well we usually do this’ you know, they joked with me because they got to know me, because I liked to do it, you know, that was something I could do for my husband. But no, it wasn’t expected of me to have done any of it.

LC01

Some family carers did not feel prepared for the complexity of need and challenges:

...the process of encouraging people to die at home I'm sure is absolutely fine... But I'm quite sure there are going to be many, many, many cases... where it places an enormous strain on the family we had no preparation...

XC01

When expectations were not well managed, disappointment and frustration could result.

I called every day to that last week saying "Any beds, any beds?" and [nurse] saying "Nope, nope, sorry, sorry, sorry" and on Friday she said "we'll talk on Monday" and I said, "it's not... he's not going to last that long" ... and I was right, he died on the Sunday morning, on his birthday. And at that point I would've thought "is it worth moving him?" because he's not, you know, he's so unwell and it's that mad- "you have to be sick enough to get in, but not so sick that you're about to die any second" so, it's like the goldilocks of terminal illness, ... that makes me sad

PC12

The need for marketing to increase visibility and referral numbers for sustainability purposes, together with a genuine desire to encourage the identification and referral of the whole range of suitable patients who could benefit from HAH, seemed to conflict with elements of the "hospice ethos" of services: preferring not to discharge patients, not trusting other services to provide adequately, not wanting to abandon patients and families. As a result, caseload management became a significant challenge (overlapping with the "Knowledge, Skills and Ethos" section).

SKILLS & ETHOS OF SERVICE PROVIDERS

These are potential areas for optimising **MARKETING AND REFERRAL** your HAH service:

Training and support

Time

Personalised care

Expertise

Training and support

Here is a list of activities other HAH services have used to optimise their training and support for staff.

- Investment in training of staff at all levels, including communication skills, so that they can create an environment in which patients and carers feel they are in expert hands
- Offering accredited training that is transferable across providers
- Train(ing) staff in culturally competent/appropriate care for the population they serve
- Providing HAH staff with support to manage the stress of their work and to develop the necessary emotional resilience
- HAH staff can call for advice and support with their work from expert colleagues who are part of the HAH (or wider) organisation.

Time

Here is a list of activities other HAH services have used to optimise the way they offer their time.

- HAH staff have time to offer patient-led, personalised care, and in addition,
- HAH staff have expertise which enables them to give the feeling that they have time to work at the pace of the patient
- Time pressures were well managed by HAH organisations through consistent communication with patients and carers (e.g. if they are going to be delayed or if work needs to be reprioritised on the day)

Personalised care

Here is a list of activities other HAH services have used to optimise the way they personalize care.

- Prioritising having time to offer patient-led care
- Negotiating with the informal carer on what care is offered and by whom, ensuring the carer is sufficiently supported to provide the care they wish to provide

- Communicating and negotiating HAH availability with patients and carers sensitively when the service is under pressure
- Working at the pace of the patient and carer (even when time is limited)

Expertise

Here is a list of activities other HAH services have used to optimise the way they use expertise within and outside the HAH teams.

- HAH employ experienced staff, who spend a significant proportion of their time in palliative care and EOLC and are capable and competent in these settings, so patients, families and other HCPs trust them
- HAH staff can quickly and effectively seek advice from expert colleagues, e.g. advice line to senior clinical staff both within HAH and the wider organisation

Read about skills and ethos of care providers in detail

Whilst all health and social care workers should have basic knowledge and skills in end-of-life care, sometimes these are lacking, including a lack of confidence in communicating at end of life. For some patients, basic skills may not be adequate to meet their difficult or complex needs. Palliative and end of life care has developed into a specialty area of knowledge, skills and ethos, and this distinctiveness is prized by HAH organisations. However much of this expertise still resides in cancer care and patients with other illnesses, such as dementia, may present challenges to staff and organisations. Some services (HAH and non-HAH) may also lack time to offer personalised and patient led care, while commissioners may prioritise equity of access across the population rather than time and expertise. To add value to the whole system of care, HAH services need to provide expert knowledge and skills in end-of-life care with a suitable ethos to support this care. This is enabled by experienced staff who have spent a significant proportion of their time in EOLC so that patients and families trust them. Staff at all levels, including volunteers, are suitably trained including appropriate communication skills so that they can create an environment where patients and carers have confidence and feel they are in expert hands. HAH services value the time to offer personalised patient led care, leading to better patient and carer experience and sense of agency.

Know-how, experience, and expertise

HAH services identified and prized their specialist status:

...we are the only specialist provider and so HAH is the only specialist palliative/end of life care service in the area....

HSP02 (Chief Executive)

And the patient and their carer or family were the ultimate beneficiaries of the know-how, experience, and expertise of HAH staff.

It's a skill level isn't it, to be able to detect, because I hadn't detected it and I'm his wife. [HAH staff] had. She said no his breathing's changed, and she knew. So I was very grateful that she was there because [...] she had had quite a deep nursing background so she had the skill, so I'm very grateful for that.

PC48

Time

The resource of "time" was a context which all HAH services prioritized but was a particularly strong theme in the smaller providers. It was also a mechanism which achieved high quality care and confidence in the support that patients and carers received.

I keep coming back to time. I just feel time is such a massive, massive factor. And that just allows people to open up more when we're there each day. They can see that there's no rush. ...It's priceless isn't it - time.

MSP001 (Registered nurse)

It was very good, very professional. They took me and my husband at our pace.

LC01

This was such a valued resource that patients and carers were prepared to compromise in some respects (e.g. not knowing what HAH care they will receive that day until the morning of the day or accepting a reduced service when they knew the HAH service was under pressure, provided it was clearly communicated).

[T]hey always let me know what was happening ...and if they might say 'oh we've got to go to [another area] first, would you like us early or later, I said oh can you come later now that settles him down for the night. They said 'no that's fine with us' and we sort of worked it all between us it was brilliant...

LC29

Again, time pressures were well managed by HAH organisations through consistent communication with patients and carers (e.g., if they are going to be delayed).

[I]f there was going to be a change [HAH] ring you up and say "look we're running about twenty minutes late, we'll be with you at such and such a time". And that even went for the weekend, absolutely brilliant...

MC10

Training

Both the experience in end-of-life care and the training of HAH staff contributed to making patients and carers feel they were in expert hands which inspired trust and confidence.

Even you know doctoring dad's pyjama trousers so they could pass tubes through...and things like that it was...again without that knowledge you...without their support we wouldn't have even thought of things like that...

MC10

Providing training to up-skill staff outside the HAH service was also seen as important.

Supported staff

Policies and processes in some HAH services supported and allowed for extended roles (flexibility of roles) as necessary to meet patient needs. This feature characterised services that prioritised responsiveness to patient need rather than a more rigid service structure and functioning, and may also be a feature of smaller, potentially nimbler organisations. For example, one smaller service had set up a new urgent care service.

...the Urgent Response has changed the culture of the HAH Team because they recognise that they've got the skills to be able to go out and deal with things urgently, so they don't need to refer onto a CNS to do that, but actually we trust and respect them to go out and do that. It's changed the culture of the wider team because it's bridged how they work together and improved the working relationships and it's changed our culture of care...we know that within the total service that we can respond much, much more quickly.

MSP005 (Community Team Leader)