



Hospice at Home
TOOLKIT

Optimising Hospice at Home Care and Delivery:

The Hospice at Home Toolkit

DISCLAIMER

This research was funded by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration Kent, Surrey, Sussex and Medway Community Healthcare.

The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.



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WHAT IS THE HAH TOOLKIT?

The Hospice at Home toolkit is a **free-to-use research-informed** online resource for:

- hospice at home providers
- members of the public (including patients and carers)
- health and social care commissioners
- wider palliative care workers

The toolkit website provides **a range of tools and resources** including:

- a service assessment
 - one-page summaries of research evidence for different audiences
 - videos on a variety of topics
- 

OVERVIEW

1

Setting the Scene

2

Toolkit Demo

3

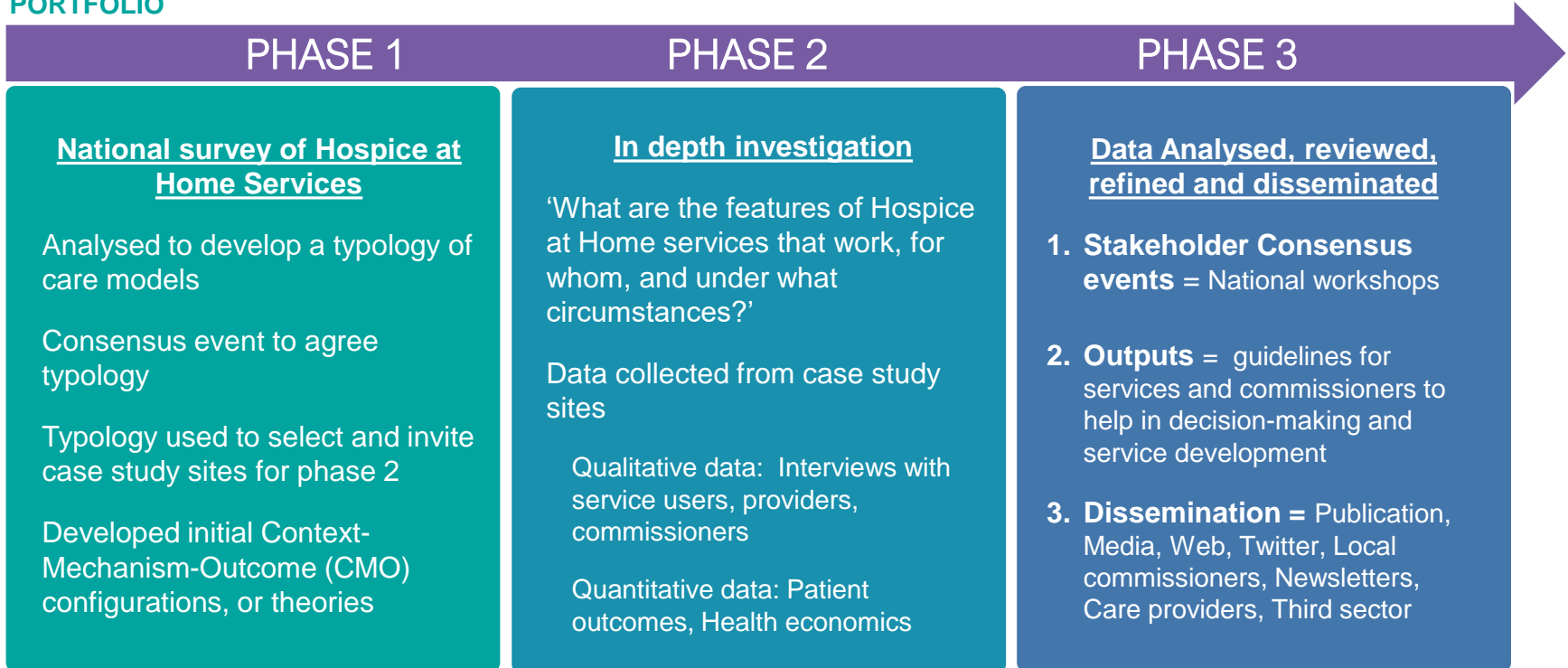
Pilot & Evaluation

4

Supported Use

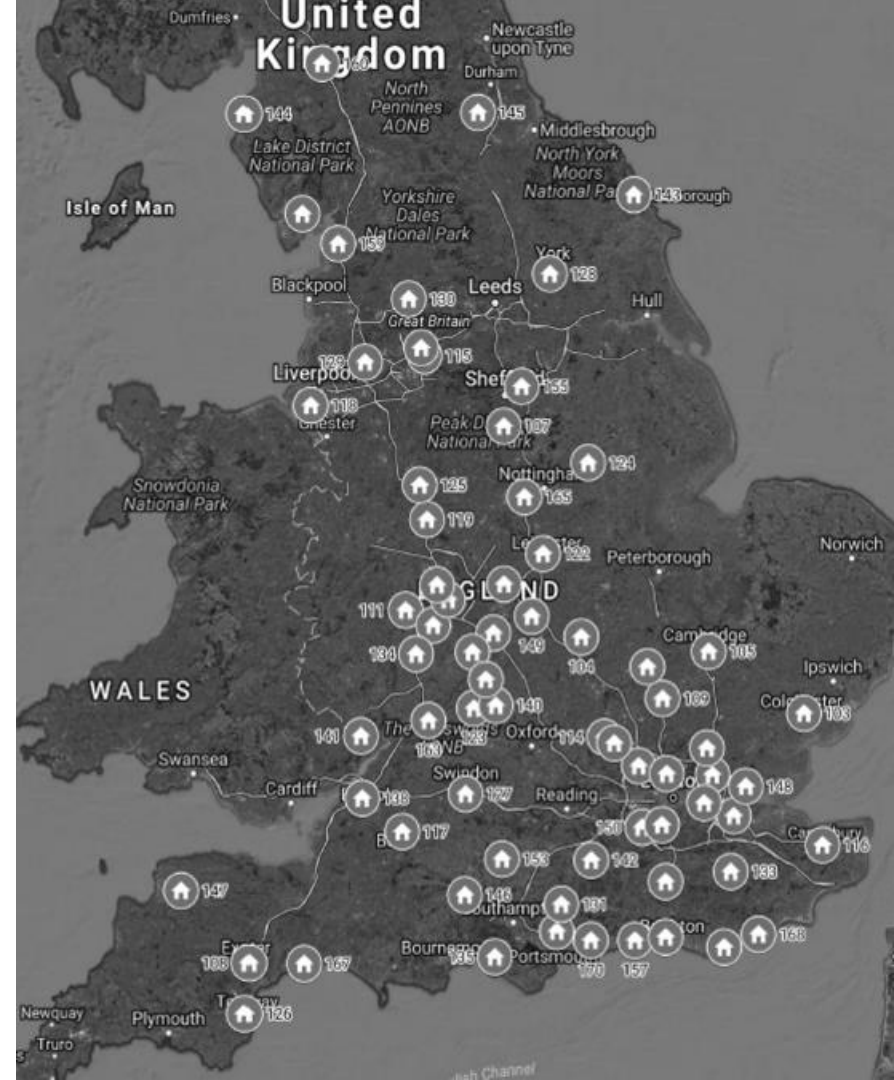
OPEL STUDY OVERVIEW

STUDY DESIGN: A mixed methods study (qualitative and quantitative methods) with an over-arching Realist Evaluation approach
NIHR HEALTH SERVICES AND DELIVERY RESEARCH PROJECT GRANT – STUDY ADOPTED ONTO NIHR CRN PORTFOLIO



PHASE 1 – NATIONAL EVALUATION

- Used National Association for Hospice at Home (NAHH) and Hospice UK databases to identify Hospice at Home services in England
- 128 Hospice at Home Service Managers contacted
- Feb 2017 – July 2017: conducted 70 interviews
- 22 services opted out and 36 were not contactable
- Looked at the data to see if there were any common features amongst services

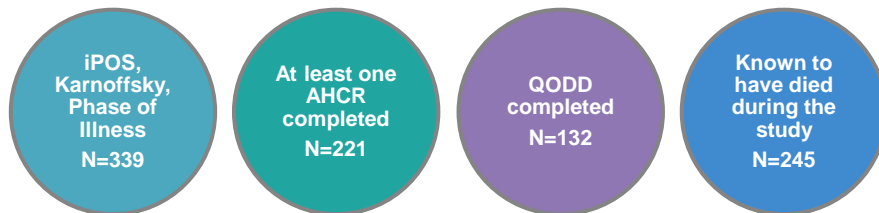


PHASE 2 – 12 CASE STUDY SITES

Quantitative data

- *At admission to HAH: iPOS, Karnofsky, Phase of Illness* (HAH staff completed)
- *Every 2 weeks until bereavement: Ambulatory and Home Care Record* (carers completed)
- *Soon after death: Date and place of death* (HAH staff completed)
- *Around 6 months after death: Quality of Dying and Death (QODD) 7-day recall* (carers completed)

Of **341 dyads recruited**, 339 could be included in the quantitative data analysis.



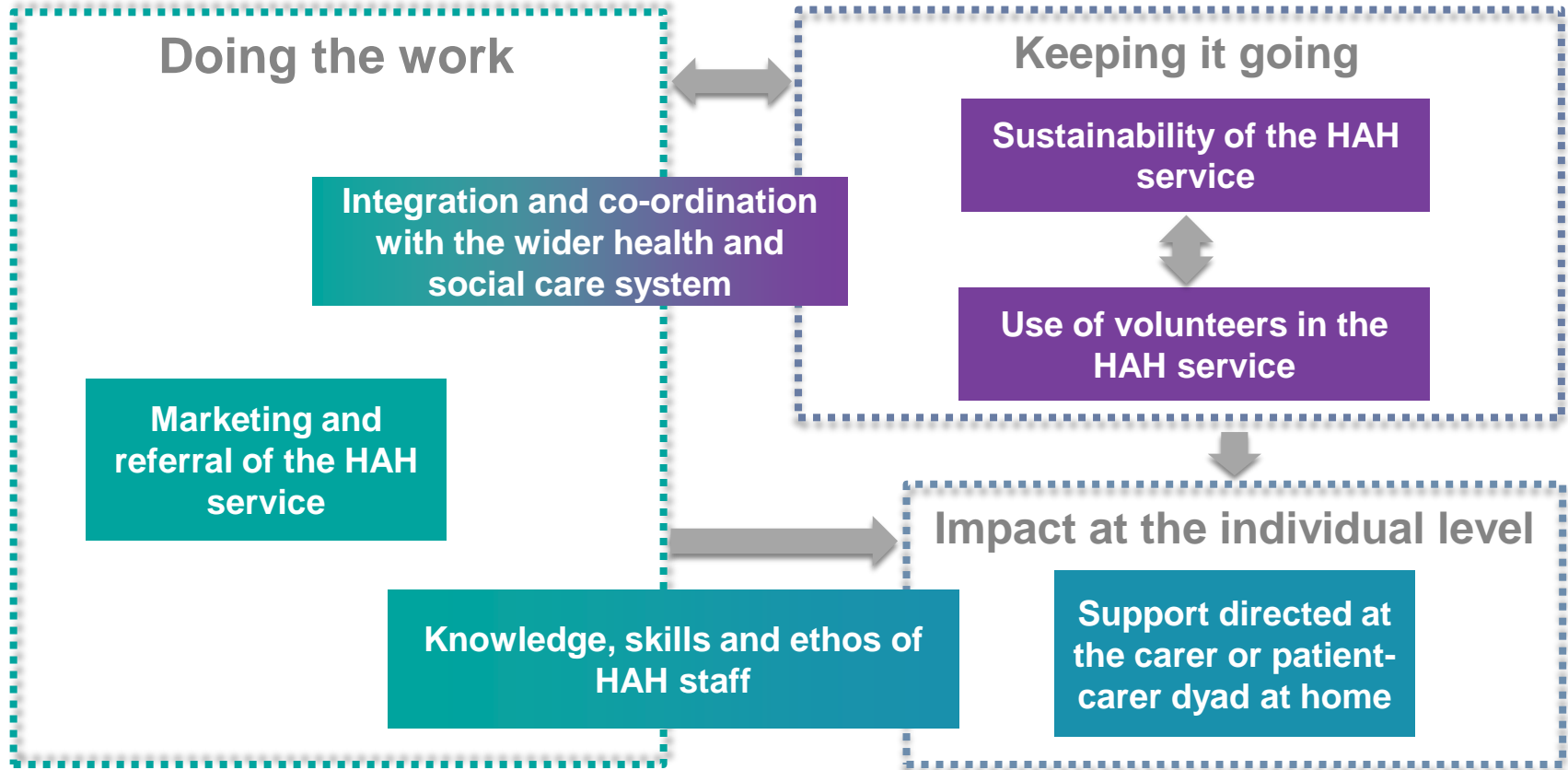
Qualitative data

- *Interviews with carers* around 6 months after bereavement
- *Interviews with service providers* (operational and managerial; follow-up interviews to see how the service changed)
- *Interviews with commissioners of palliative care services*

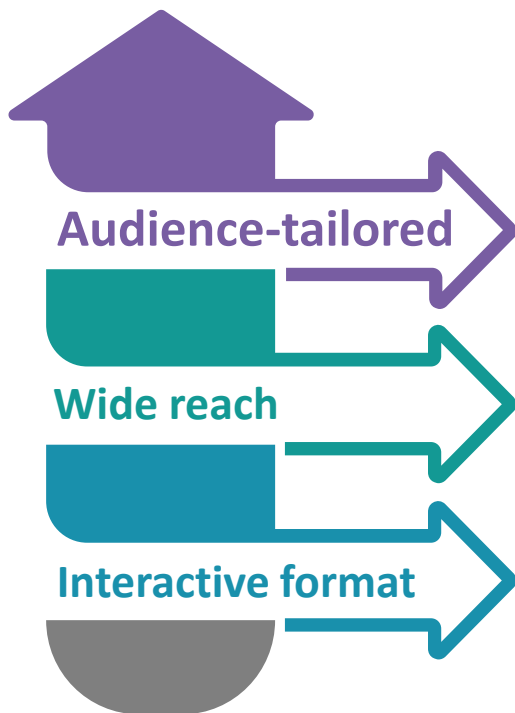
143 interviews conducted.



KEY AREAS OF OPTIMISING HAH



PHASE 3 – 2 CONSENSUS EVENTS (88 ATTENDEES)



London and Leeds OPEL Consensus Events 2020 with service providers, commissioners and member of the public

- Different language for different audiences, ensuring a wide reach
- Events coinciding with carers/volunteers/dying matters weeks
- Electronic and printable resources
- Pick-and-choose/‘click to dip in’ structure
- 1-page infographic summaries
- Bite-size podcasts/shot videos
- Top tips
- Examples on operationalising recommendations
- Demonstrating added value of putting recommendations in place

How do we turn a ~400p research report into something that is suitable to diverse audiences?

- The results from a national evaluation of HAH (Butler et al, 2022) provide evidence on the key factors which need to come together in each HAH to provide the best possible care.



Optimum models of hospice at home services for end-of-life care in England: a realist-informed mixed-methods evaluation

*Claire Butler, Patricia Wilson, Vanessa Abrahamson, Rasa Mikelyte, Heather Gage,
Peter Williams, Charlotte Brigden, Brooke Swash, Melanie Rees-Roberts,
Graham Silsbury, Mary Goodwin, Kay Greene, Bee Wee and Stephen Barclay*



WHAT IS THE PROJECT ABOUT?

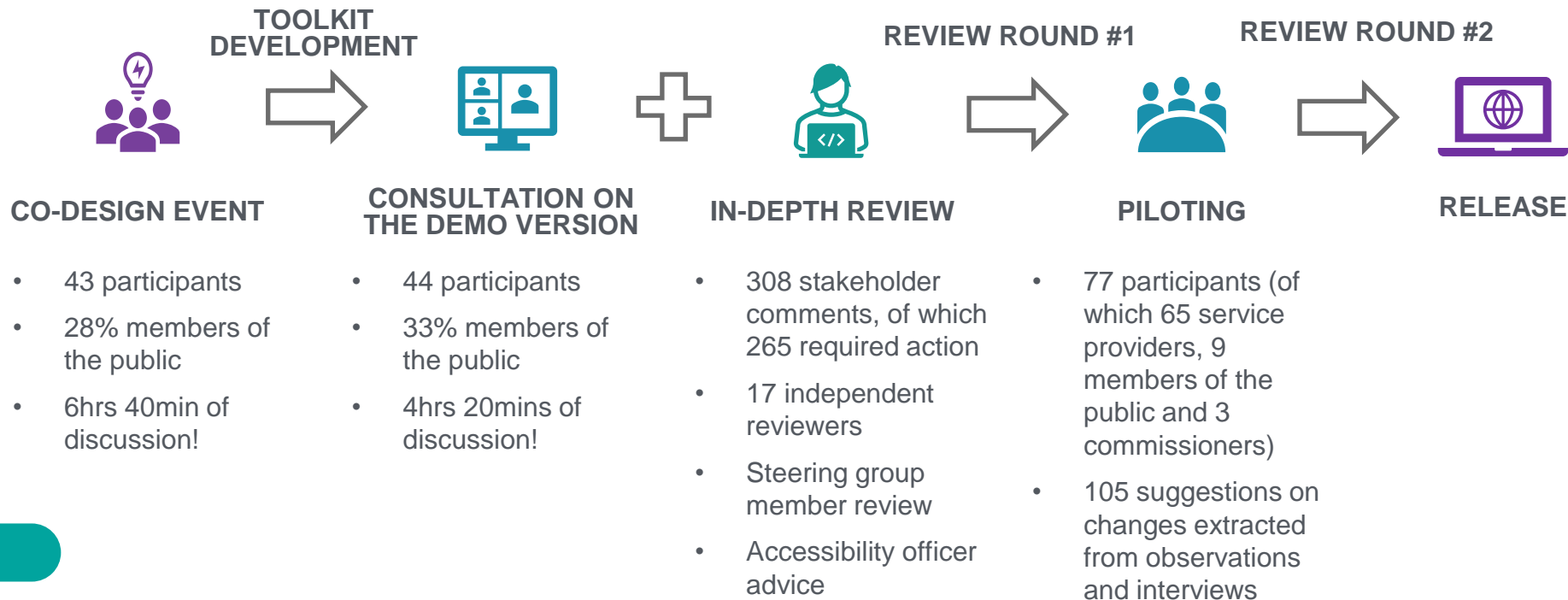
The project aimed to **design, pilot and evaluate the implementation of an interactive online toolkit** for optimising hospice at home care delivery.


Based on research evidence from the 'Optimum Hospice at Home Services for End-of-Life care (OPEL)' study:

- National, realist-informed evaluation
- NIHR, Health Services and Delivery Research funded 2017-2021



DEVELOPING THE TOOLKIT



- 
- Setting the Scene
 - 2 Toolkit Demo**
 - Pilot & Evaluation
 - Supported Use



Thank you for having a look at this site, which has been set up to make the research evidence from an [English national study](#) of Hospice at Home services easily available.

The main purpose of the site is to offer a tool to enable Hospice at Home services to think about their strengths and areas for development/improvement, to consider how they may develop and improve.

We also offer resources in a variety of formats, aimed at members of the public, commissioners and wider health and social care providers.

We have organised content based on who it might be most relevant to. We hope you find it useful!

A purple rounded rectangular button with the text 'Hospice at Home Providers'. The button is highlighted with a pink oval border.

Hospice at Home
Providers

A purple rounded rectangular button with the text 'Members of the public / patients / carers'.

Members of the public /
patients / carers

A purple rounded rectangular button with the text 'Health & Social Care Commissioners'.

Health & Social Care
Commissioners

A purple rounded rectangular button with the text 'Other Health, Social Care and Third Sector Workers'.

Other Health, Social Care
and Third Sector Workers



[Hospice at Home Providers](#) [Members of the public / patients / carers](#) [Health and Social Care Commissioners](#)
[Other Health, Social Care and Third Sector Workers](#) [Contact](#)



Hospice at Home Providers

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We offer a tailored tool called '**Service Assessment**' to enable services to think about their strengths and weaknesses and to consider how they may develop and improve.

We also provide information in a variety of formats, e.g. videos, one-page documents, top tips.

[Service Assessment](#)

[Videos](#)

[One page summaries](#)

[Top tips](#)

[Top tensions](#)

[Screen reader version](#)

[Screen reader version](#)

Support directed
at carers

Sustainability

Volunteers

Integration &
coordination

Marketing &
referral

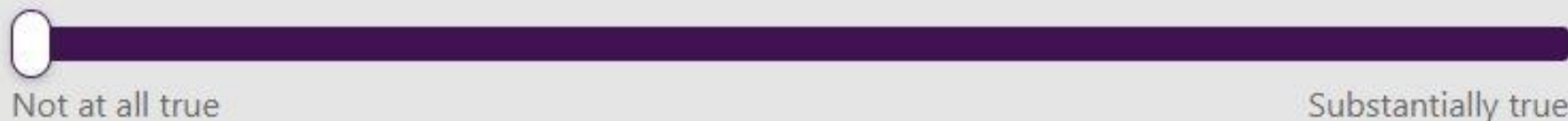
Skills & ethos of
care providers

Your service
(optional section)

Sustainability

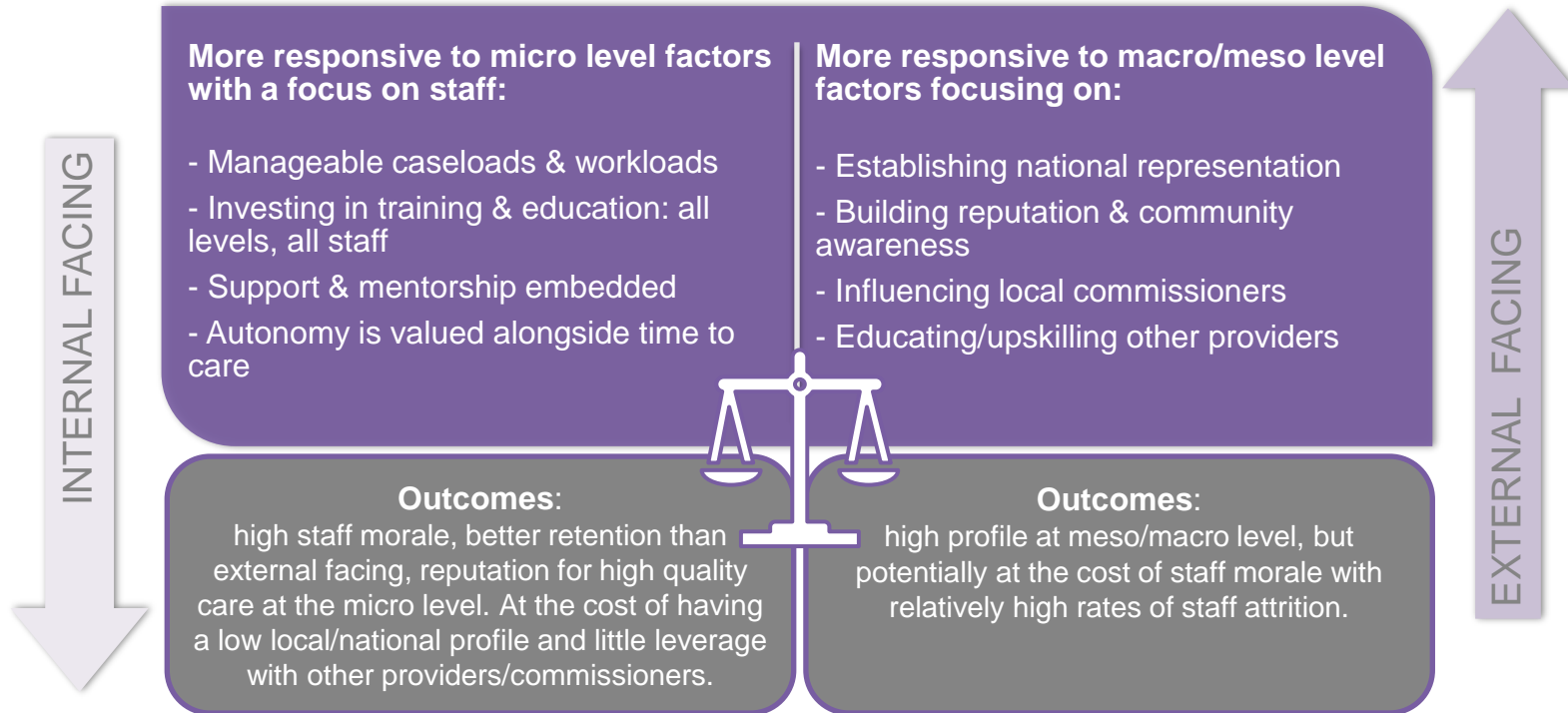
Please tell us how much this applies to your service:

FUNDING: HAH service is able to obtain sufficient and secure (longer-term) funding



STAFFING: HAH is able to recruit and retain the staff it needs to deliver care

EXAMPLE 1: SUSTAINABILITY



SUSTAINABILITY

CONTEXT

MECHANISM

OUTCOME

FUNDING

Statutory funding conditions and arrangements change over time.

There is often difficulty establishing consistent relationships with commissioners.

Commissioners may not be knowledgeable about palliative and end of life care.

Commissioners may not recognise the full "cost" of what they are commissioning as significant charitable funds are supporting the H@H service.

The H@H service needs to "be on the front foot", i.e. if the H@H service proactively seeks control over the available statutory funding by one or more approaches

AND/OR

If the H@H service is run by an independent organisation which undertakes charitable fundraising

AND/OR

The H@H organisation actively seeks external engagement with the wider health and social care environment.

MECHANISM RESPONSE

In each case, the H@H service is trusted and respected to know what services are needed, to raise funds and then to deliver them.

Sustainable, longer-term funding is enabled and patients will continue to receive the H@H service.

Access to statutory funds may be compromised as an assumption is made that they are not needed by charitably funded organisations.

STAFFING

There is a shortage of staff in health and social care nationally.

If the H@H has a reputation for investing in staff through CPD

AND/OR

If the H@H or leader has a reputation for excellence meaning it is an organisation people want to work for

AND/OR

Skill mix profiles may be altered in response to shortages of registered professionals and some staff deployed differently.

The H@H service is able to recruit the staff they need to deliver the care that patients need.

The H@H service may attract and retain staff from other services, depleting the workforce in other parts of the system - negative outcome triggered.

Staff take on roles they are not able to manage (in terms of skills and training).

Staff may not be doing their preferred work.

NATIONAL POLICY

There is a national drive towards care at home, ostensibly in response to patient "choice", but also with a view to cost savings.

AND

Hospice inpatient beds are a relatively scarce commodity.

Home based care is supported by local health and social care commissioning and funding.

If patients and families are already receiving H@H services and their wishes and preferences are not fully explored or revisited over time.

Home-based care is resourced and available.

Patients and/or carers may feel under an obligation to manage dying at home.

DATA

NHS commissioners and charity boards require the collection of data to provide "evidence" to support continuing service provision and development.

Enormous volumes of activity data are collected. Very little outcome data or cost benefit data is collected or derived (e.g. about avoided hospital admissions).

Activity data may satisfy some stakeholders.

Time is wasted in data collection which cannot inform funding and service decisions.

Support directed
at carers

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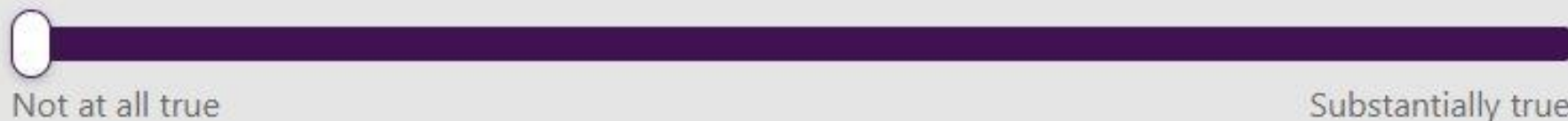
Skills & ethos of
care providers

Your service
(optional section)

Sustainability

Please tell us how much this applies to your service:

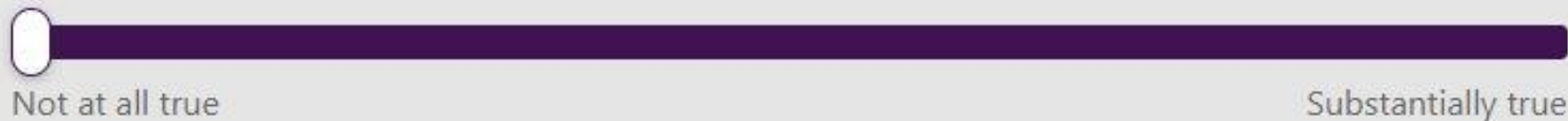
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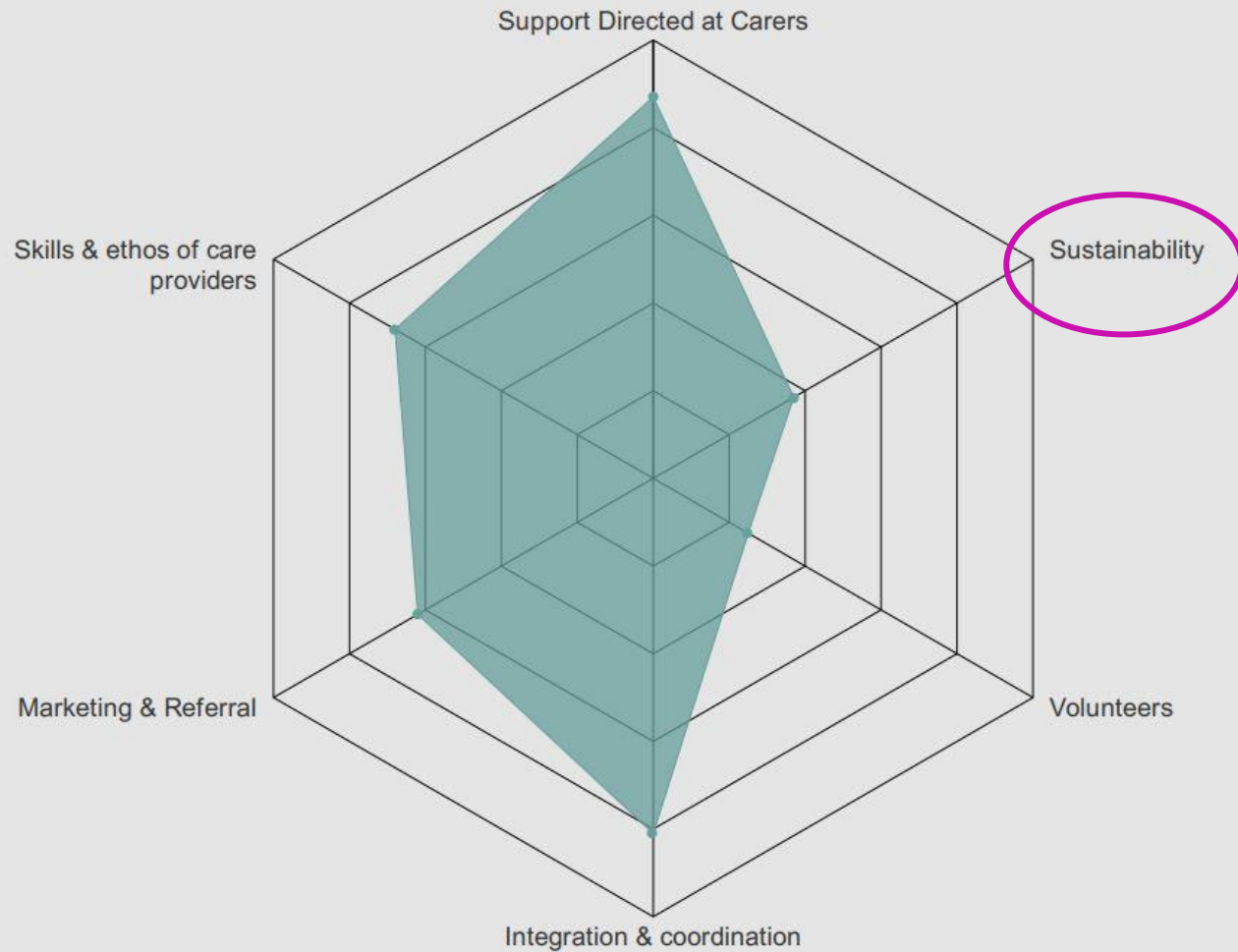
DATA COLLECTION: HAH is able to demonstrate its effectiveness by collecting patient outcome data



You can add any comments about your answers here. This is optional and will not influence the results.

PREVIOUS

NEXT



Sustainability

These are potential areas for optimising SUSTAINABILITY of your HAH service. Click on the boxes for more information:

Taking the Lead

Partnerships

Funding Arrangements

Staffing

[Read about SUSTAINABILITY in detail](#)

[Watch a video about SUSTAINABILITY](#)



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Sustainability → 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

[Read about SUSTAINABILITY in detail](#)

[Watch a video about SUSTAINABILITY](#)

Sustainability: full 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:

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...

Videos

This is a series of six videos, all based on the findings of **OPEL national evaluation of Hospice at Home services in England**. We hope you find the information covered useful.



Sustaining the Service



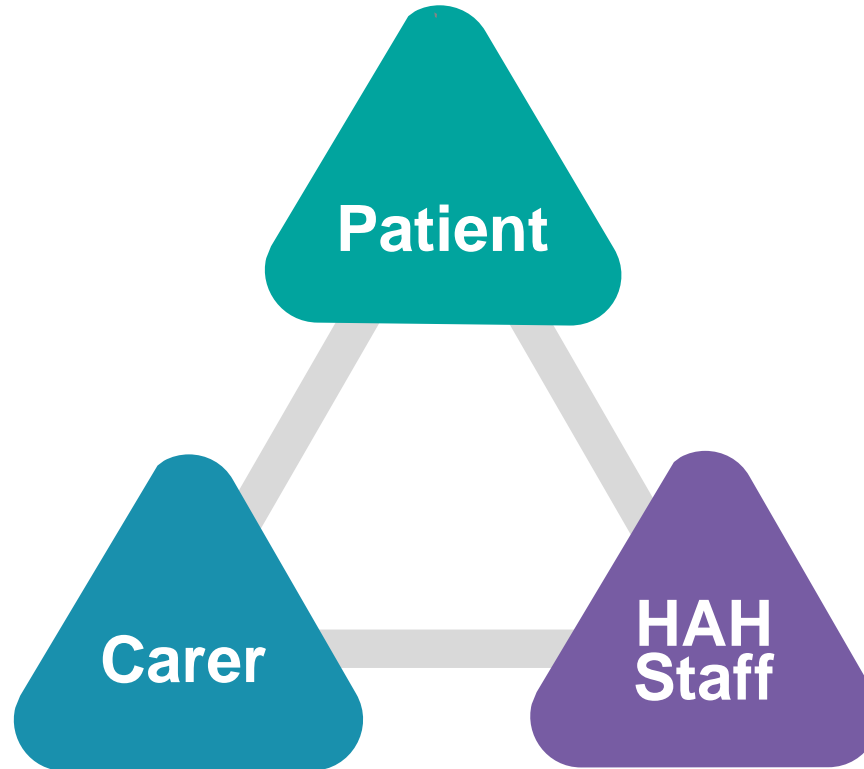
Supporting Patients and the Family at Home



Volunteering and Hospice at Home



EXAMPLE 2: SUPPORTING CARERS



SUPPORT DIRECTED AT THE CARER

CONTEXT

Unpaid care provided by family and/or friends is critical to enabling patients to remain at home.

How the patient and their informal carers - as a unit - feel about dying at home and how they respond to challenge.

The carer may require confidence and new skills to enable them to provide care up to and including the point of death at home.

AFTER DEATH

There may be short or long term consequences for carer's mental and physical health.

There is a concern about "medicalising" bereavement which is a normal process.

H@H services come to a sudden halt when the patient dies.

MECHANISM

If there is an assessment of carer needs and there is a multidisciplinary team available to meet their needs.

If carer and patient choices are affirmed and supported wherever possible.

If there is a continuously negotiated partnership between the carer and staff.

If the carer has (quick) access to an appropriate point of contact 24/7.

MECHANISM RESPONSES:

- Carers trust and have confidence in the advice and backup provided by the service
- Carers have an increased sense of control.

If there is support pre- and post-bereavement which is based on relationship and understanding of the situation and also a shared story of caring for the patient.

If there is a process to identify those who are experiencing "extreme" grief and may need additional/expert help.

OUTCOME

Carers will be able to continue to care, enabling more sustainable patient care at home.

Occasionally, carer needs may become the main focus at the expense of the patient.

If too much is expected of the carer, there are some tasks they may not be able to manage or they may not be able to continue caring.

The carer will have the best chance of a positive outcome following bereavement and recovery from the caring role.

Carers may have a negative experience of care and the burdens and difficulties.

NEVERTHELESS

Some carers may accept this negative experience as a price they wish to pay to allow their loved one to die where they want to.

Support directed
at carers

Sustainability

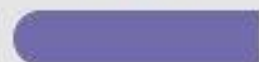
Volunteers

Integration &
coordination

Marketing &
referral

Skills & ethos of
care providers

Your service
(optional section)



Support directed at carers

Please tell us how much this applies to your service:

CARER ASSESSMENT: HAH assess carer and whole family unit needs, and provide MDT support to meet the carer's needs



Not at all true

Substantially true

ENABLING CARERS: HAH continually provide information, support and shared decision making with the

Carers are assessed and regularly provide information, support and shared decision making with the carer about what will happen and how to manage in the home.



Not at all true

Substantially true

GETTING TIMELY HELP: The carer (and patient) have timely access to a point of contact 24/7.



Not at all true

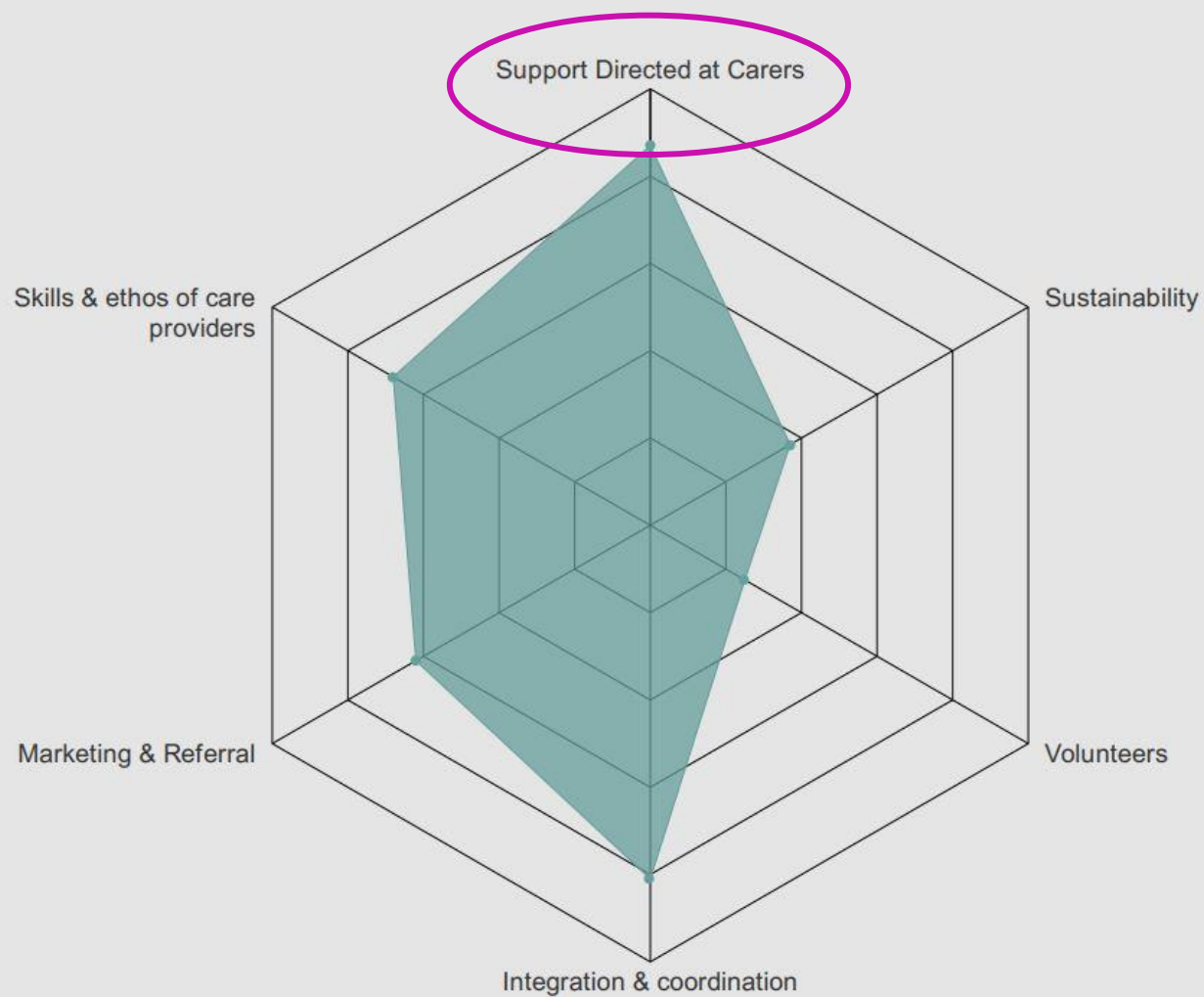
Substantially true

BEREAVEMENT: Carers are assessed after bereavement by HAH staff they already know in order to identify those carers who need additional help



Not at all true

Substantially true



Support directed at carers

These are potential areas for optimising your HAH service. Click on the boxes for more information:

Carer Assessment

Provision of information and
emotional support for the carer

Provision of training and practical
support for the carer

Bereavement support

[Read about SUPPORT DIRECTED AT CARERS in detail](#)

[Watch a video about SUPPORT DIRECTED AT CARERS](#)



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Support directed at carers → Bereavement support

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

- 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)
- Most carers prefer to have initial post-bereavement contact from HAH staff with whom they have an existing relationship, who knew the deceased, and shared the experience of care
- There are mechanisms to identify those who are not experiencing "normal" bereavement and may need additional/expert help. These may include keeping in touch with the hospice (e.g. memorial events)
- Provider/hospice offers flexible and varied post-bereavement support (e.g. support groups and one-to-one support) at the hospice and wider community, tailored to specific needs (e.g. needs of younger carers).

[Read about SUPPORT DIRECTED AT CARERS in detail](#)

[Watch a video about SUPPORT DIRECTED AT CARERS](#)



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Support directed at carers: full 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.

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...

Videos

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Sustaining the Service



Supporting Patients and the Family at Home



Volunteering and Hospice at Home





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[Videos](#)

[One page summaries](#)

[Top tips](#)

[Top tensions](#)

[Screen reader version](#)

[Screen reader version](#)

TOP TIPS

for optimising
Hospice at
Home services

Hospice at Home works! HAH services deliver high-quality care and a 'good death', with the majority of patients dying in their stated preferred place. Read our research-based Top Tips on how HAH can further-optimize their service provision.



1

Get a **seat at the table** with commissioners and other service providers and work together proactively to secure funding and to integrate care.

2

Consider **equity of access** to HAH; are all your local communities and patients of different ages and diagnoses getting support, how could you improve this?

3

Utilise volunteers to the full to support HAH:

- could they undertake non-clinical roles in the home (shopping, laundry etc)
- could retired clinicians have a role
- could there be a less bureaucratic approach to some volunteer roles as in the model of [Compassionate Communities](#)?

4

Market the HAH service so people in your area know about it:

- through fundraising and educational activities.
- by your clinical staff promoting the service through their day work with colleagues.

5

Consider how to **respond rapidly** to changing patient needs, including access to 24/7 advice and support by telephone which give families confidence help will be forthcoming in crisis

6

Train and support your HAH staff to give them confidence managing dying and death, to maintain the quality of care and to improve staff retention.

7

HAH staff need sufficient **time** and use it to provide seemingly unhurried,

TOP TENSIONS

in optimising Hospice at Home (HAH) services



Challenge yourself and your colleagues about these difficult balancing acts and keep them under review

1

Quality vs Reach

Finding the correct balance between the high(est) quality service and reaching more people in need. However, don't compromise on key elements of time, expertise and relationship that achieve the best outcomes (and therefore add value).

2

Integration vs Independence

Integration with other health and social care providers (e.g. providing joint services with statutory sector colleagues) can help the service increase capacity and reach more patients. However, extensive integration may lead to loss of independence in how the service is run, as well as loss of branding and "specialism", which organisations worry will negatively impact charitable fundraising.

3

Strategic vs Operational

Organisations investing heavily in working with partners in wider service planning and provision at a strategic level may under-invest internally in structure, training and support of HAH staff. Equally, organisations providing excellent internal management and support may miss out on having a seat at the table in planning and provision at a strategic level.

4

Risks vs Benefits of Volunteers in HAH

Volunteers are an essential part of the hospice workforce. We found that it was very rare for volunteers to be involved directly in Hospice at Home (HAH); there were concerns about boundaries, patients very close to death and reputation. Consider a wider range of roles for volunteers and/or relaxing the bureaucracy around some volunteer roles (see Top Tips).

5

Medical vs Social Care Alignment

Some services were medically orientated, others used a social model of care, but many were somewhere in the middle. HAH alignment along the medical-social care continuum offers both advantages and drawbacks. Medically aligned services have a higher proportion of advanced nurses, are able to prescribe and administer medication, but may offer limited personal care. Conversely, social model services provided significantly more hands-on care, employ more (or only) health care assistants, but are reliant on community nursing for medical/pain management.

6

Bereavement care

Shortly after bereavement, the clear preference expressed by carers was for support from the HAH staff who had been part of the story of caring, and not for referral to other elements of service. This impacts, however, on HAH staff time available for patient care.

Supporting Family and Friends Caring at Home

[Download Full Report](#)

Research into hospice at home services

Hospice at Home services support people towards the end of their life, to live at home for as long as possible and to die at home if that is their preference. We undertook a research project (2017-2020) to understand how to get the best performance from hospice at home (HAH) services in England, to optimise patient care and outcomes. We carried out a national survey and then looked into 12 services around the country in detail. We recruited 339 patients and their family/friend carers and interviewed 85 professionals (frontline staff, managers, senior decision makers in the hospice and commissioners).

What did the research show?

- Almost all Hospice at home services provided personal care, psychological and social support and symptom management (not all provided this 24/7); on average for 1 week – 2 months from referral.
- Hospice at home services overall provided care that was likely to deliver 'a good death' and 73% of patients died in their preferred place. Patients supported by hospice at home services were much less likely to die in hospital than the general population (9% vs 46% [2017 data]).

Key elements of Hospice at Home support linked with the best outcomes for carers were:

Preparedness

How the patient and their friend/family 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.

1

Addressing the needs of the carer

Staff from a range of disciplines need to assess and respond to the wellbeing and needs of the carer as well as the patient.

2

Expectations

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.

3

Support for caring

The patient and carer choices are affirmed and supported whenever possible, giving the carer and the patient an increased sense of control.

Bereavement

In bereavement, there may be short- or long-term consequences of caring on the carer's mental and physical health. Many carers would prefer bereavement follow up from HAH staff they already know. Some carers may need more bereavement support from experts.

5

Partnership

A full assessment of care needs including the whole family/care unit is required. 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 over time.

4

Negotiations take place with the carer about how much they are happy to take on and the carer receives skills training.

The carer is given permission to do caring tasks that are traditionally seen as 'professional' tasks. Their confidence will also depend on knowing how to get help or advice when needed 24/7.



Thank you for having a look at this site, which has been set up to make the research evidence from an [English national study](#) of Hospice at Home services easily available.

The main purpose of the site is to offer a tool to enable Hospice at Home services to think about their strengths and areas for development/improvement, to consider how they may develop and improve.

We also offer resources in a variety of formats, aimed at members of the public, commissioners and wider health and social care providers.

We have organised content based on who it might be most relevant to. We hope you find it useful!

Hospice at Home
Providers

Members of the public /
patients / carers

Health & Social Care
Commissioners

Other Health, Social Care
and Third Sector Workers



Part 1: How do you know that someone's life is coming to an end? What may you wish to consider next?



Part 2: How can you plan ahead for end of lifecare?



Part 3: What are you taking on, when looking after someone who wishes to die at home?



Part 4: What services are available to people wishing to die at home and their family/friend carers?



Part 5: What to do when the person you are looking after dies at home? What support may be available?



Or watch it in full. What to expect if you, or someone close to you, wish to die at home?

Pre-review

Are you considering looking after a relative or friend who wishes to die at home?



This document was written by a lay person with experience of providing informal care.

What may you wish to know before looking after someone at home at the end of their life?

Many people in the UK would prefer to be looked after and die at home, and this can often be achieved. Both the preferences of the dying person and the ability of the informal carers to continue caring may change, especially when health, care needs or confidence of the carer become adversely affected.

You may receive palliative care support from services called 'Hospice at Home' or similar. You should know there are considerable differences from one service to the next in what support they offer and how to you can be referred to them. It is important to find out about your local service; look up [Hospice Care Finder](#), [Hospice UK](#). You may also wish to visit [Marie Curie](#) website or call their helpline 0800 090 2309.

As a carer, you will need to be well prepared for the unknown journey that you will be embarking on. Every situation is different, but professionals supporting you may be able to help you prepare and anticipate some of the changes. Accepting unpredictability will be equally important.

Caring for someone nearing the end of their life can be very rewarding... or not! You may choose to provide care out of a sense of duty, or for any other reason. You should also consider that providing care, especially intimate care, might enhance or harm your relationship with the person who is dying. Sometimes it might be hard to know in advance how relationships will change.

You will need time to plan and consider options of caring for someone at home. Caring is likely to influence your life practically, logistically, financially and in a number of other ways (eg disrupt family and social life). Discuss this with people around you, including health and social care staff who may be providing support.

You will need to establish links with health and social care providers for all aspects of care, and be ready to ask for advice (eg regarding provision and use of equipment). Caring is likely to involve advocating for the person nearing death, especially if they are no longer able to do so for themselves. You may wish to consider [Power of Attorney](#) and [Advance Care Planning](#).

Understandably, you may end up focussing on the person nearing death more than yourself. It is crucial that you don't forget yourself and maintain your physical, mental and spiritual health. Find out if you can access respite services (eg from your local hospice).

After the person you cared for has died, you may need bereavement support and/or advice with practical arrangements. It is okay to need support for yourself. Consider reaching out to your local hospice. It is important to look after yourself while you grieve and reflect on your caring role.

What is this information based on?

We undertook a research project in England to find out what models of Hospice at Home (HAH) services work best, for whom and in what circumstances (2017-2020). This was the first national study to look at a range of different HAH services to learn from them all.

We found that almost all HAH services provided personal care, psychosocial support and symptom management (not all provided this 24/7). HAH services overall provided care that was likely to deliver 'a good death' and 73% of patients died in their preferred place. Patients admitted to HAH services were much less likely to die in hospital than the general population (9% vs 46%; 2017 data).

Post-review

Are you considering looking after a relative or friend who wishes to die at home?

Wishes

Many people in the UK would prefer to be looked after and die at home, and this can often be achieved. Both the preferences of the dying person and the ability of the family/friend carers to continue caring may change, especially when health, care needs or confidence of the carer become adversely affected.

Preparing for the unknown

As a carer, you will need to be well prepared for the unknown journey that you will be embarking on. Every situation is different, but professionals supporting you may be able to help you prepare and anticipate some of the changes. Accepting unpredictability will be equally important.

Influence on your life

You will need time to plan and consider options of caring for someone at home. Caring is likely to influence your life practically, logistically, financially and in a number of other ways (eg disrupt family and social life). Discuss this with people around you, including health and social care staff who may be providing support.

Advocacy

You will need to establish links with health and social care providers for all aspects of care, and be ready to ask for advice (eg regarding provision and use of equipment). Caring is likely to involve advocating for the person nearing death, especially if they are no longer able to do so for themselves. You may wish to consider [Power of Attorney](#) and [Advance Care Planning](#).

This document was written by a lay person with experience of providing informal care.

The information presented is based on the first national study to look at a range of different Hospice at Home services to learn from them all.

Relationships

Caring for someone nearing the end of their life can be very rewarding... or not! You may choose to provide care out of a sense of duty, or for any other reason. You should also consider that providing care, especially intimate care, might enhance or harm your relationship with the person who is dying. Sometimes it might be hard to know in advance how relationships will change.

Bereavement support

After the person you cared for has died, you may need bereavement support and/or advice with practical arrangements. It is okay to need support for yourself. Consider reaching out to your local hospice. It is important to look after yourself while you grieve and reflect on your caring role.

Not forgetting yourself

Understandably, you may end up focussing on the person nearing death more than yourself. It is crucial that you don't forget yourself and maintain your physical, mental and spiritual health. Find out if you can access respite services (eg from your local hospice).

What you may wish to know before looking after someone at home at the end of their life

Hospice at Home

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and Third Sector Workers

Health and Social Care Commissioners and Integrated Care Boards

Download Full Report

Research into hospice at home services

Hospice at Home services support people towards the end of their life, to live at home for as long as possible and to die at home if that is their preference. We undertook a research project (2017-2020) to understand how to get the best performance from hospice at home (HAH) services in England, to optimise patient care and outcomes. We carried out a national survey and then looked into 12 services around the country in detail. We recruited 339 patients and their family/informal carers and interviewed 85 professionals.

What did the research show?

- Hospice at home (HAH) services overall provided care that was likely to deliver 'a good death' and 73% of patients died in their preferred place.
- Patients admitted to HAH services were much less likely to die in hospital than the general population (9% vs 46% [2017 data]).
- All HAH services offered care which was highly rated by family/informal carers.
- The majority of HAH services were being delivered to patients dying of cancer (77% of patients admitted to HAH had main diagnosis of cancer).
- Two-thirds of HAH services reported charity donations as the main source of funds.

What does this mean for you when commissioning Palliative and End of Life Care services?

N.B. There were considerable variations in the detailed operations of hospice at home services from one locality to the next, so it is important to find out about your local service ([Hospice Care Finder](#), [Hospice UK](#)).

2 As significant funding for HAH across the country comes from charitable sources, commissioners who spend NHS funds on HAH are likely to get good added value, however →

3 As many HAH providers are small charities, there is a tension for them in terms of integration with other providers, which they fear may impact on their specialism and charitable fundraising.

5 Commissioners have important responsibilities for the equity of service availability. With the pressure to provide equitable services, some of the key features of HAH that drive better outcomes cannot be compromised, in particular: the elements of time, expertise and relational care which engender trust and confidence; agility of the service to respond to changing needs; identifying and addressing the needs of family carers as well as the patient at home.

1 Commissioners could utilise some of their budget effectively by funding HAH and achieving objectives enabling choice about place of care and reducing acute hospital pressures.

4 Commissioners should consider the sustainability of HAH when determining the amount of funding and the duration of contracts (which are often too short to provide adequate stability).

6 Commissioners may also want to consider how to work with HAH providers to extend their services to more people, and particularly to address the inequalities of provision for those with diagnoses other than cancer.

Commissioners

Health, Social Care and Voluntary sector workers

Anyone Providing Hands-On Care at Home

Download Full Report

Research into hospice at home services

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What did the research show?

- Hospice at home services provided personal care, psychosocial support and symptom management (not all provided this 24/7).
- Hospice at home services overall provided care that was likely to deliver 'a good death' and 73% of patients died in their preferred place. Patients admitted to hospice at home services were much less likely to die in hospital than the general population (9% vs 46% [2017 data]).
- All hospice at home services offered care which was highly rated by family/friend carers.

Key markers linked with the best outcomes for patients and families were:

1 Time to care & expertise

HAH staff make family/friend carers feel they have 'time to care' and are clearly experienced in and comfortable with dying and death.

2 Caring for the carer

Successful care at home depends heavily on the family/friend care set-up. Services providing assessment, care and support directed at the family carer and taking into account the needs of both patient and carer are highly valued.

3 Hands-on care

Hands-on, person-centred care, developing a relationship with the patient and carer in the home, is particularly valued by carers in the period close to death.

4 Agility

Responsiveness to changing needs, including updated information and 24/7 access to support and advice, gives confidence in the home

5 Marketing & referral

To increase referrals in general, and in particular of those who are underserved in hospice services, hospice at home needs to actively market its service to professionals and the public through clinical and public engagement.

6 Integration & coordination

Formal arrangements for integration and coordination are important, but in addition, much of this works on the ground, as colleagues on the front line work together for the patient.

How will this information affect my practice?

Consider how to improve my care for patients who are dying patients at home. Some of the factors identified in this research (above) may help to guide my practice and training.



1

Setting the Scene

2

Toolkit Demo

3

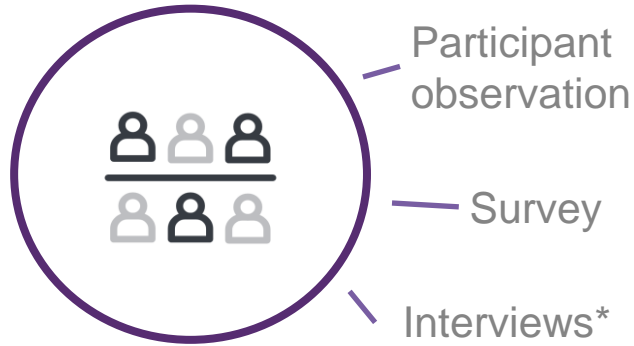
Pilot & Evaluation

4

Supported Use

PILOT & EVALUATION

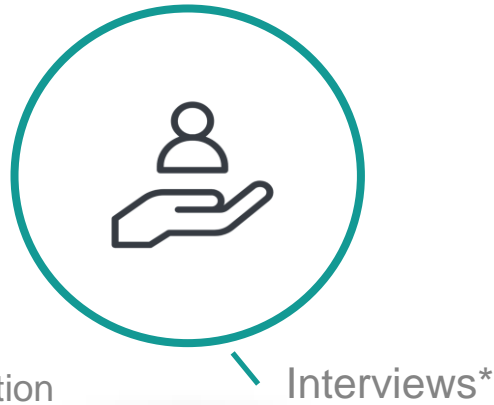
11 HAH teams
(N=72; 2-13 in each)



Participant mix in piloting meetings:

- Frontline HAH staff
- HAH leads
- Strategic decision-makers in the organisation
- Commissioners (if possible)
- Lay representatives (if possible)

7 Members of
the Public

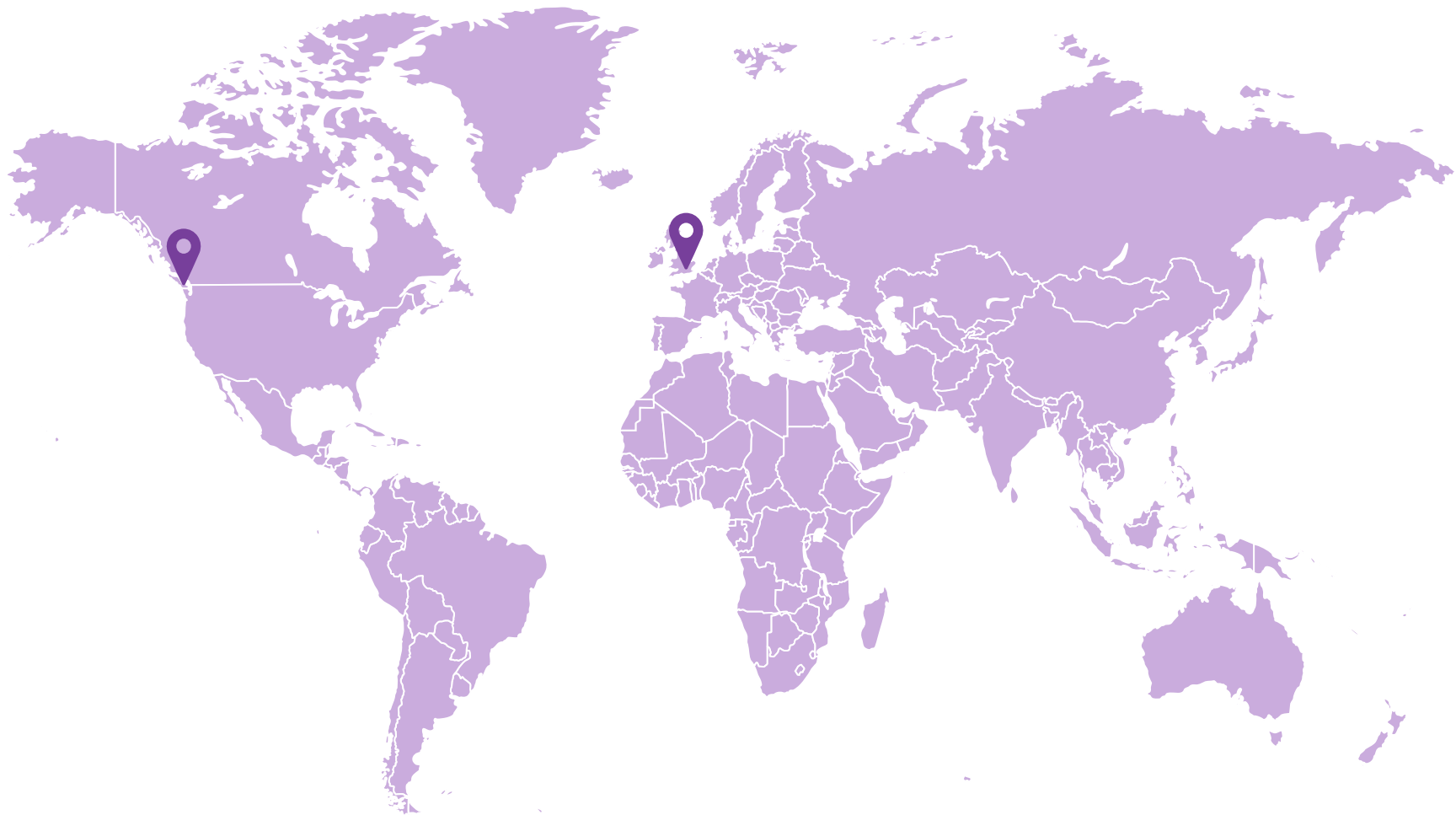


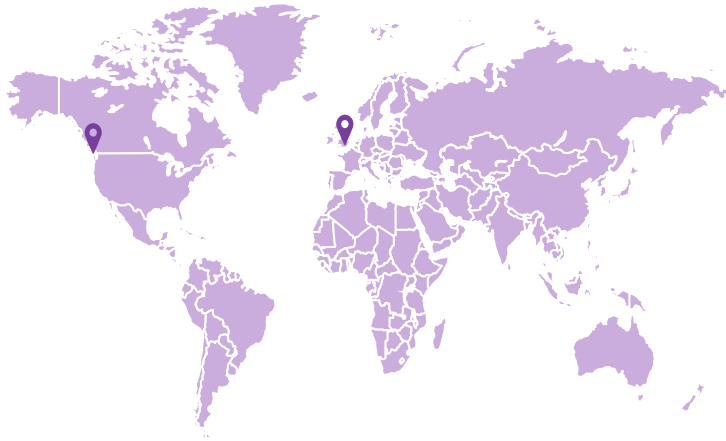
1 Commissioner



**after piloting and
3mth follow-up*







All recruitment targets met:

- **11 HAH services** (2-13 participants in each)
 - Follow-up interviews (n=5)

Participant mix in piloting meetings:

- 72 participants in total; 2-13 in each team
 - 67 service providers
 - 2 commissioners
 - 3 members of the public
- In-person or hybrid
- Two piloting meetings involved a commissioner
- Two piloting meetings involved experts by experience

HAH TEAM PILOT RESULTS

- Toolkit-facilitated **team discussion** is the most valued aspect
- Team get **involved equitably** overall, with some content more suitable to frontline and other content to decision-makers
- **Assessment generated ideas** in some teams, even before seeing what other teams had done
- Suggestions on optimising presented by the toolkit seen as **helpful**
 - As expected, not all suggestions on optimising were relevant to specific local contexts
- **Other resources valued** (saved; printed during some piloting meetings)

“It is a powerful and useful tool, thank you for letting me part of the whole process”
(S1P03, Head of Nursing)

“This was an unbelievable opportunity to participate and learn of such an involved project”
(S9P07)

“Looks much better than previous version, will be beneficial to improve and expand HAH services”
(S4P08, HAH team leader)

“I found a lot of the questions a bit ambiguous. Also a number of the questions are not within my knowledge so unable to answer.”
(S5P01, Nurse)

“We spent quite a lot of time answering questions which generated discussion + almost no time looking at resources” (S4P02)

Extending services to carers:

“I find it really useful for ideas for service development in the future. [...] So that's what [the toolkit] identified for me [...] that we informally support carers, but [...] **how do we formally assess carers and their role and what that looks like**. So that's a piece of work we're starting to work on now with our Patient and Family Support Team”. (S5P1)

(Re)considering inclusivity and under-served groups:

“**We believe we are an inclusive service, but we can't demonstrate this** [...] that's made me think about [another hospice service, not part of HAH]; we've not gone out to underrepresented groups” (S10)

“**Populations we don't even know we are not reaching**” (S8)

Using the toolkit to advocate for change:

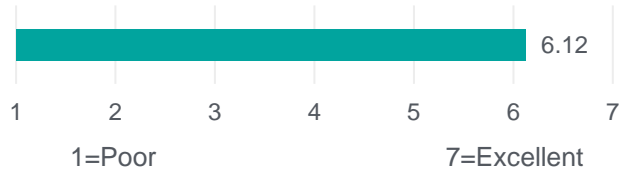
“I really like this... if I was selling this [a new HAH] to my CEO, he is very visual. **If this [the spider diagram] came up, it would give me a much better chance of getting what we need**” (S2)

Showing staff at all levels their impact:

“[...] I think you could use it in many ways, as almost an evaluation of what they do, and **having a more meaningful contribution into the service and the structure of the service**. Because when spider graphs come out, and you can see the strengths of the service... [...] but actually to just consolidate that, and put that in a very quantifiable way, could be quite powerful for people.”

PILOTING SURVEY RESULTS

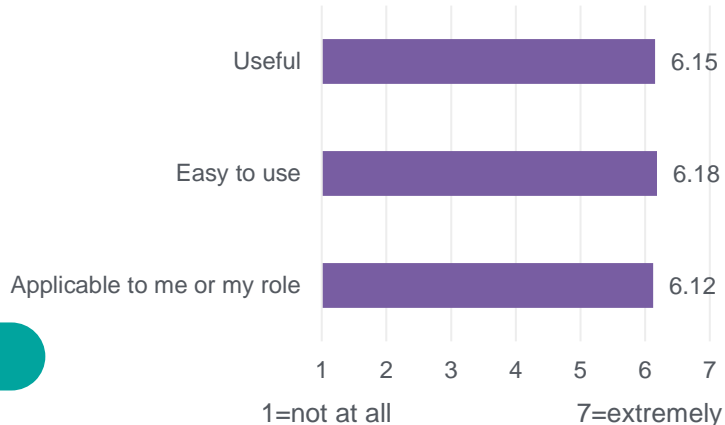
How would you rate your experience of using the HAH toolkit?



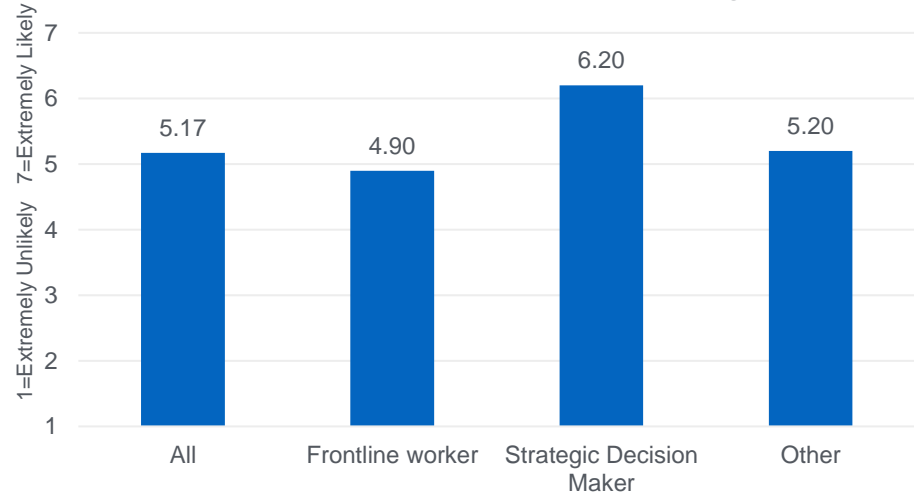
89% said the toolkit gave them ideas on how to further optimise their HAH; only 3% said it did not.

82% said they would recommend the toolkit to others; 9% said they would not.

How would you rate the toolkit on the following aspects?



How likely are you to use the toolkit again?



MEMBER OF THE PUBLIC PILOT RESULTS

- Members of the public found the information provided **appropriate and meaningful**
 - Both 'Member of the Public' area and the toolkit as a whole
- Appreciated a **variety of formats**
- Wondered how easy the toolkit was to find and navigate at a **time of crisis**
 - Suggested a separate website for patients/carers/members of the public

"It's concise, succinct and covers it [what to expect when caring for someone who wishes to die at home] on a high level and signposts you to other areas so you can pick what is relevant to you if want to know more" (PPI02)

"You're so [...] involved in the moment, every moment of every day of being with [husband who was dying...] My brain would not have coped" (PPI03)

"As a comment... I understand now what a good death means. But if I was in the throes of grief and heading towards [wife's] death, there's no way I would consider any death 'good'. Just... just that language" (PPI01)

"[Referring to 'Volunteers' video] I thought that was very insightful. Yeah... because I think it's something that... if only we could say something like that. " (PPI04)

OVERVIEW

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Setting the Scene

2

Toolkit Demo

3

Pilot & Evaluation

4

Supported Use



www.hospiceathometoolkit.co.uk

COMPLETING THE SERVICE ASSESSMENT

How?

The toolkit is best completed as a team activity.

Who?

We recommend that the team piloting the toolkit is diverse. Consider involving the following:

- Someone directly delivering care (e.g. a nurse or HCA)
- Someone who has responsibility over Hospice at Home (e.g. HAH manager)
- A senior decision maker
- (Ideally) a commissioner of palliative care services in your area
- (Ideally) a patient, carer or member of the public from your organisation's Patient and Carer Involvement group

How long?

We suggest that you set aside 2 hours for toolkit piloting. If your team is large, or there is lots to discuss, it may take longer.

Is it a one off?

Like the rest, this is up to you! However, we suggest you consider repeating the service assessment at regular intervals to track change/impact

USING THE TOOLKIT

- We offer to join HAH teams and other organisations/groups by **video call to guide through the service assessment.** This would be free
- We can also visit you in person, but that would have a cost implication.





THANK YOU

Any questions?