



Hospice at Home TOOLKIT

Optimising Hospice at Home Care Delivery: *Co-Design, Pilot-Implementation and Evaluation of an Interactive Online Toolkit*

DISCLAIMER

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

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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HOW DID THE IDEA COME ABOUT?

- For many people, dying at home is an important priority and services called Hospice at Home (HAH) or similar have been developed across England to support people to achieve this.
- 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



REALIST EVALUATION

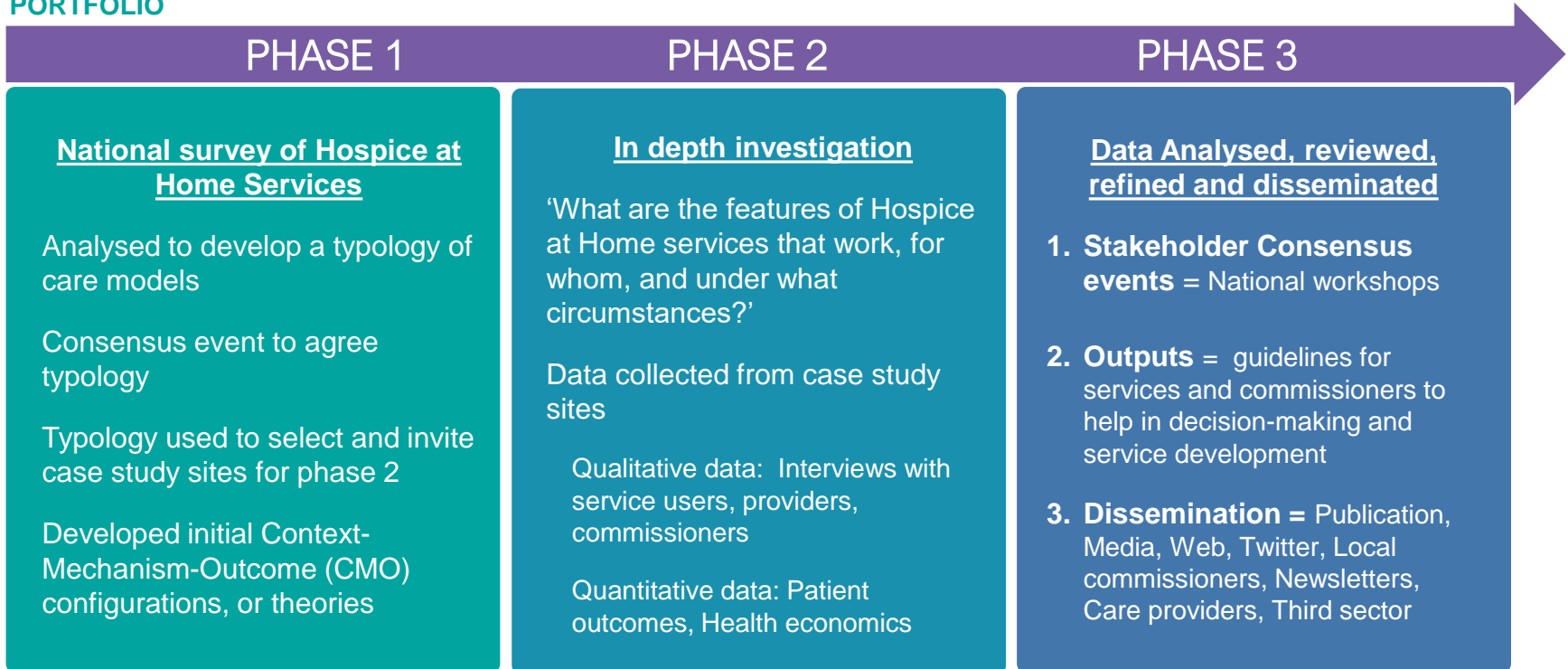
- Looks to answer the
How?
Why?
For whom?
In what circumstances?
- It is explanatory rather than judgemental



- It is theory driven – the phenomenon being evaluated has already been judged as worthwhile, the aim is therefore to understand under what conditions it works best

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 SURVEY

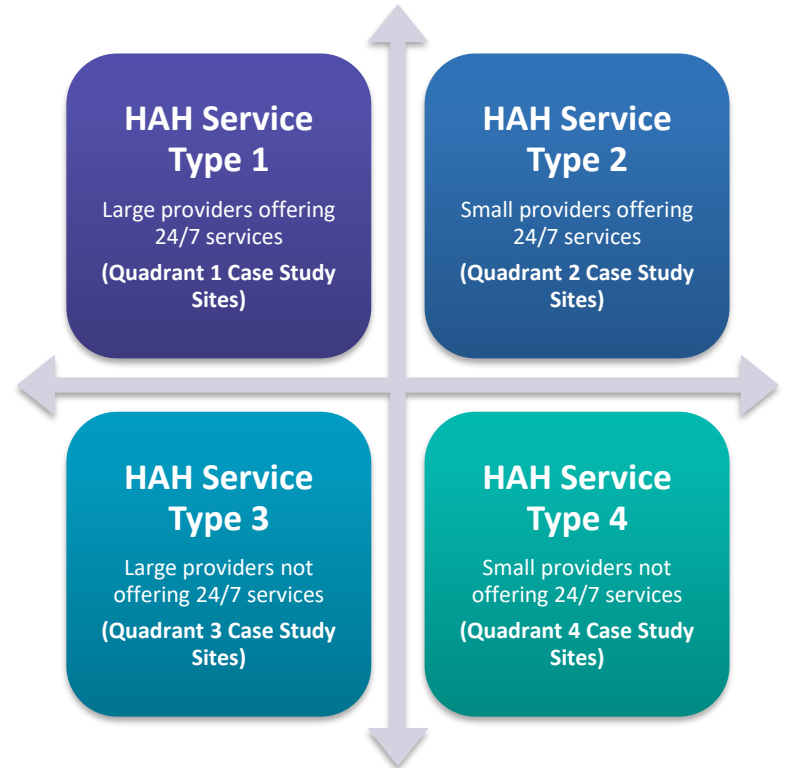


- 70 HAH services in England (55% response rate)
- **The services varied widely** in every dimension: size, geography, funding, staffing configurations and patient criteria.
- Almost all HAH services provided personal care, psychosocial support and symptom management; not all provided this 24/7.
- Most services provided care for between 1 week and 2 months from referral to death
- The majority of services reported using more healthcare assistants (HCA) than registered nurses (RN).
- Two thirds of services reported they were financed largely from charitable sources.

PHASE 1 → PHASE 2

Phase 2:

- 12 sites
- Geographically dispersed around England
- Also representing other features, e.g.:
 - Service admission criteria
 - Urban/rural
 - Deprived/affluent
 - Staffing mix (in particular registered nurse to healthcare assistant ratio)



PHASE 2 DATA COLLECTION

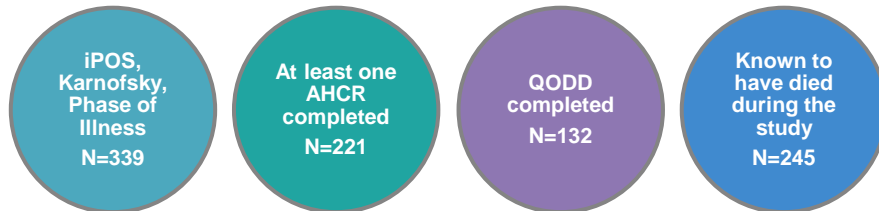
Quantitative data

- *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 4 months after death:* Quality of Dying and Death (QODD) 7-day recall (carers completed)

Qualitative data

- *Interviews with carers* 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*


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



143 interviews conducted.



PATIENT AND CARER DATA

- Most patients recruited to the study had a **diagnosis of cancer** (76.8%).
 - Most **informal/family carers** were female (70.2%) and the spouse/partner of the patient (60.4%).
 - **Patients** varied considerably in terms of performance status (i.e. how ill they were) on admission to HAH.
 - The duration of **time in the HAH** service varied from a few hours to over 1 year.
- 

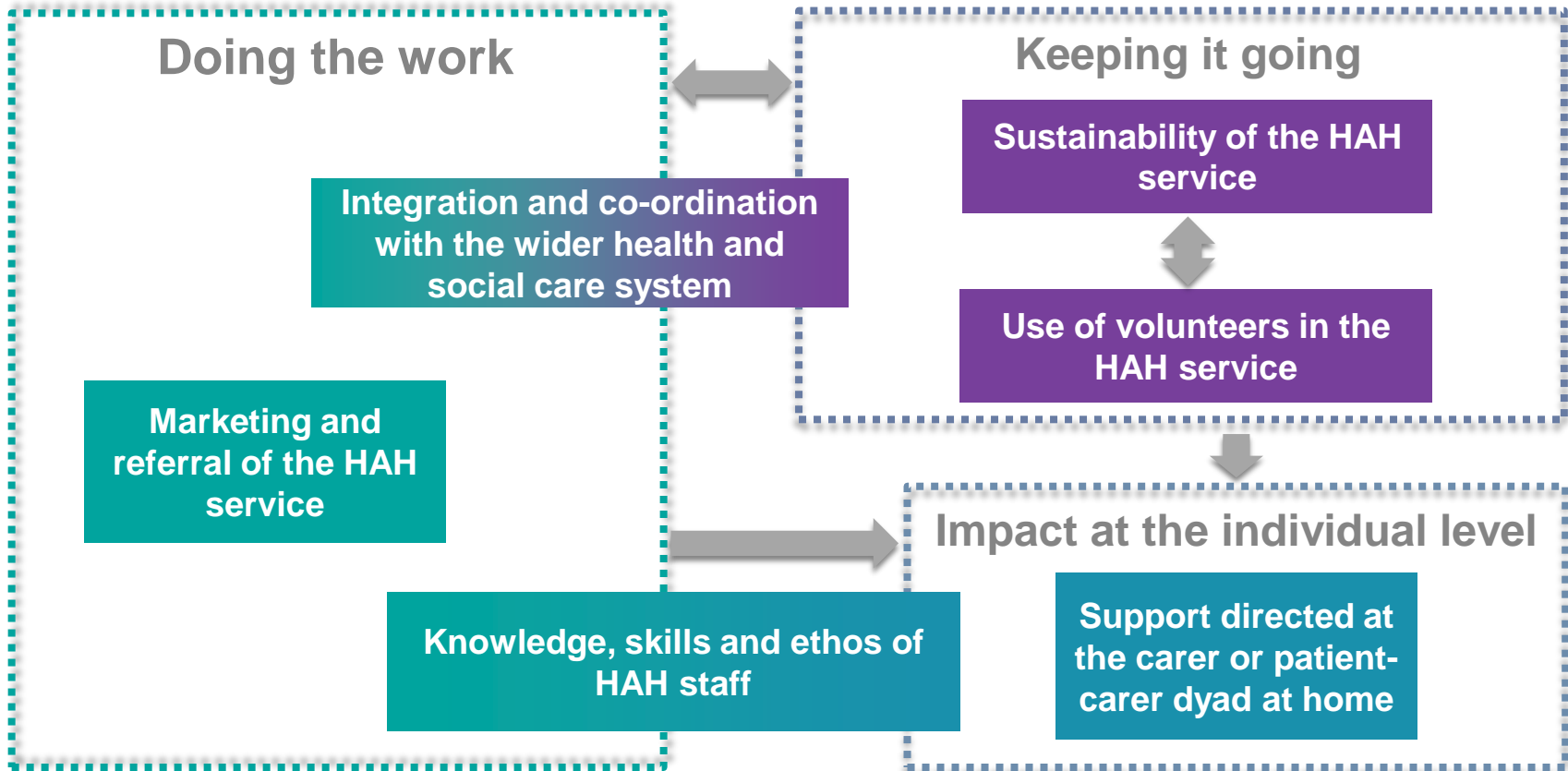
QUANTITATIVE FINDINGS

- The median **Quality of death and dying** score was 70.7 (range 0–100, with 70 indicating a good death).
- A total of 73% of patients achieved their **Preferred place of death**, with no statistically significant difference between the four service models
- Nine per cent of patients who had been admitted to HAH **died in hospital**.
- Most participants reported that they received as much **support** from health and social care services as they needed;
- Carers overall rated the help and support they received as excellent.

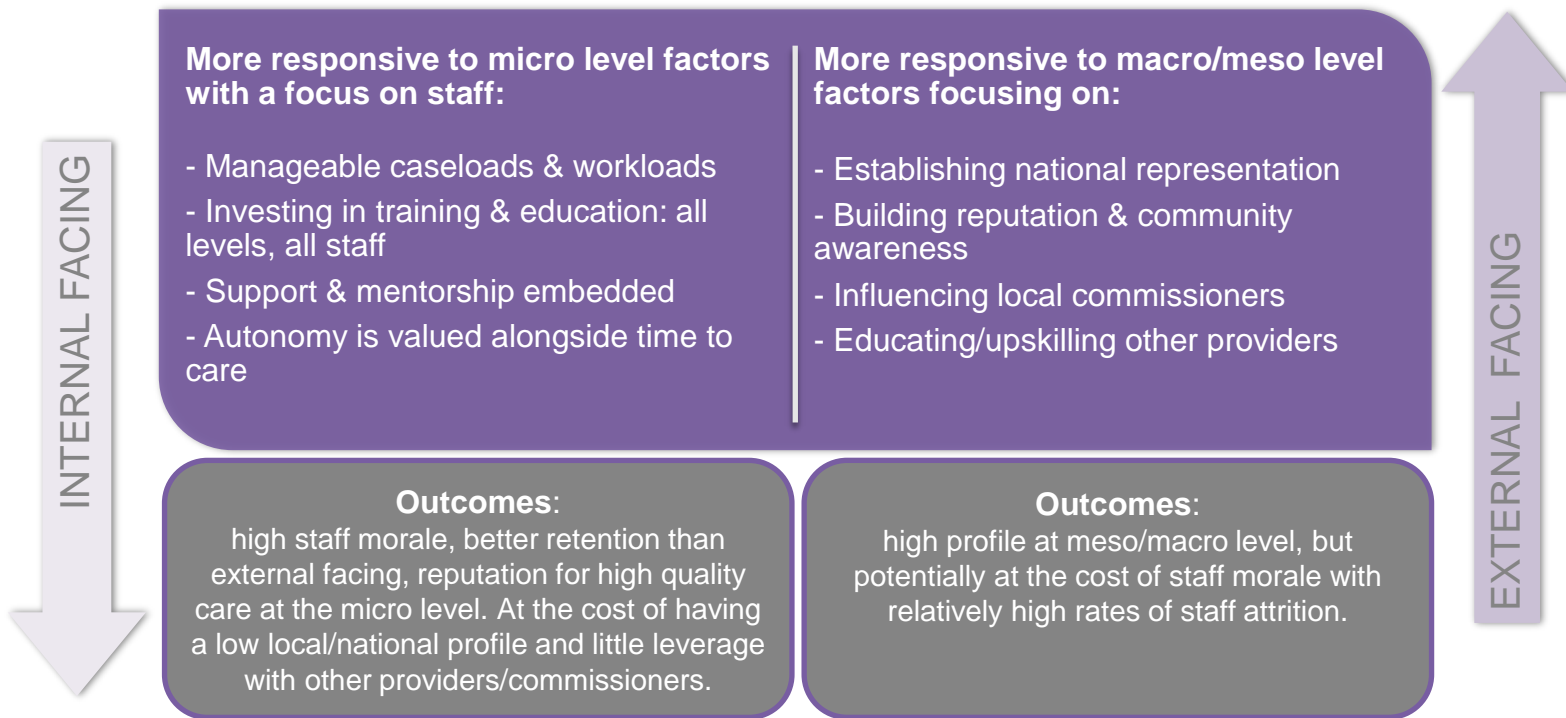
COSTS

- **Formal and informal caring** tended to be higher closer to death.
- **'In home' nursing and personal care** was the largest item of service use.
- **Service use in relation to outcomes:** carers reported higher QODD scores and higher levels of satisfaction in models receiving more “in home nursing and personal care” in the period closest to death (0-14 days) (and a higher proportion delivered by HAH staff).
- **Median daily costs** for all formal care for 0-14 days, 15-28 days, 29-92 days before death were £104.57, £80.08, £56.07.
- **Informal care costs**, valued at replacement costs (support worker) exceed formal care costs with daily medians of £580.00, £449.50 and £348.00 respectively.

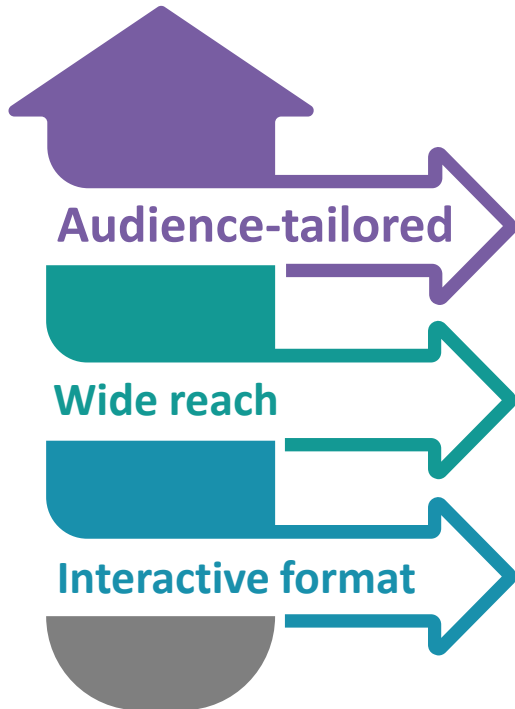
QUALITATIVE FINDINGS



EXAMPLE: SUSTAINABILITY

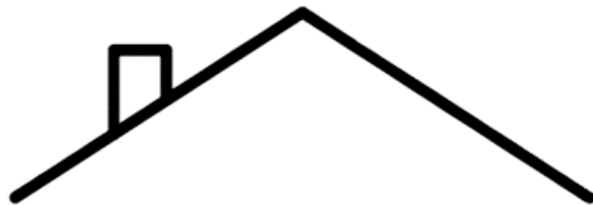


PHASE 3: HOW TO SHARE FINDINGS?



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



Hospice at Home **TOOLKIT**



AIMS & STAGES

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

The work has **6 stages**:

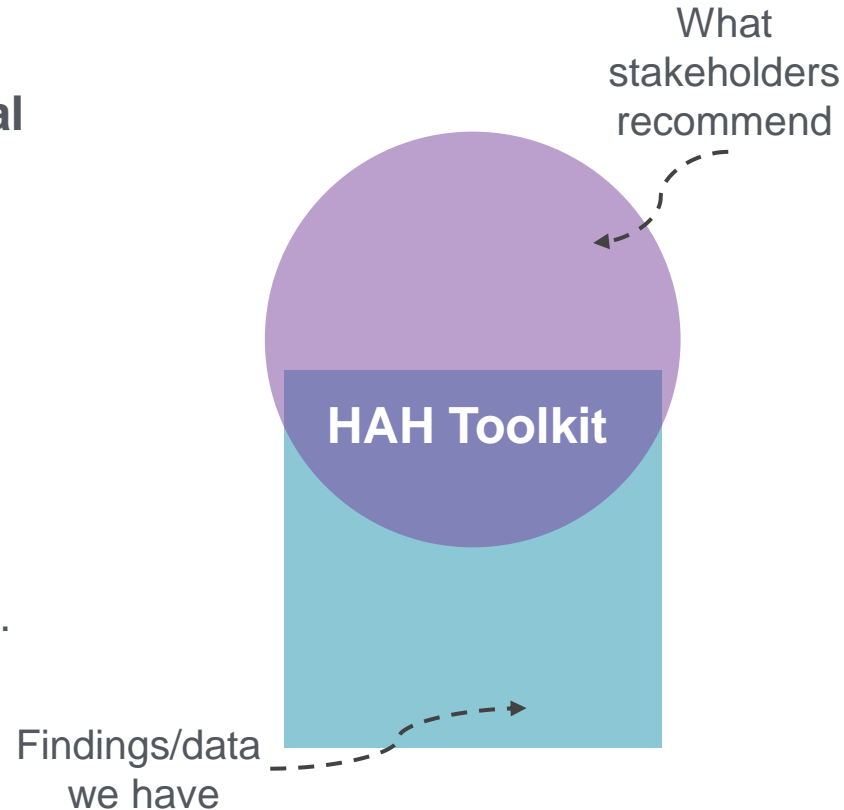
1. Co-Designing the toolkit with stakeholders
2. Consulting stakeholder on the demo version of the toolkit
3. Refining the toolkit (round 1)
4. Releasing the toolkit as a pilot and evaluating its usability, value and impact
5. Further refining the toolkit (round 2)
6. Promoting the toolkit



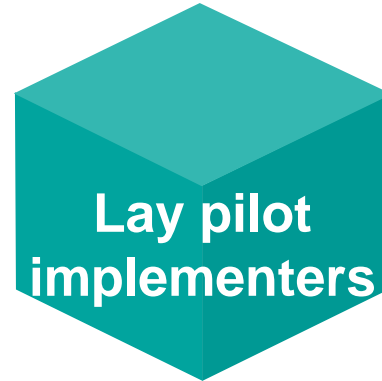
#HAHtoolkit

STAKEHOLDER ENGAGEMENT

- **Stakeholder engagement is both central to and extensive within this project**
- Stakeholders include:
 - HAH service providers
 - Members of the public (some with experience of palliative care delivery)
 - Professionals outside of HAH who enable/provide palliative care support (e.g. district nurses, GPs, physiotherapists)
 - Commissioners



EXPERT BY EXPERIENCE INVOLVEMENT



EVENT #1: CO-DESIGN

What would you like to know?

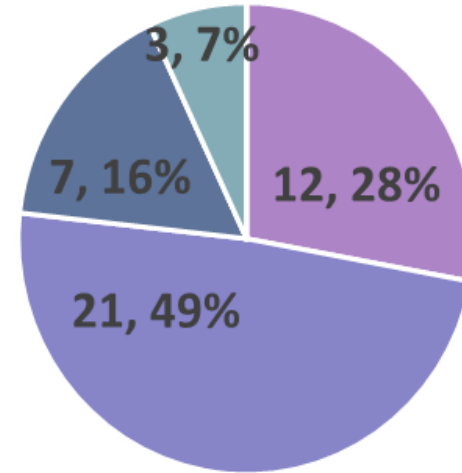
- Available services and how to access them
- Accessing person-centred care
- Available support for carers and families

Best ways to share OPEL findings?

- Support for carers and families
- Guidance on communicating properly with patients and families, particularly in hospitals
- Highlighting cultural shifts (i.e., celebrating life, talk about death)

Thoughts on the toolkit and its format?

- Accessible, snappy; has value to public
- Caution around language use, including the term 'toolkit'



- Member of the public / patient / informal carer
- Professional working in/managing a Hospice at Home service
- Professional working in palliative care (not a Hospice at Home service)
- Commissioner of palliative care services
- Researcher/academic
- Other

EVENT #2: CONSULTATION ON THE DEMO VERSION

Discussion 1:

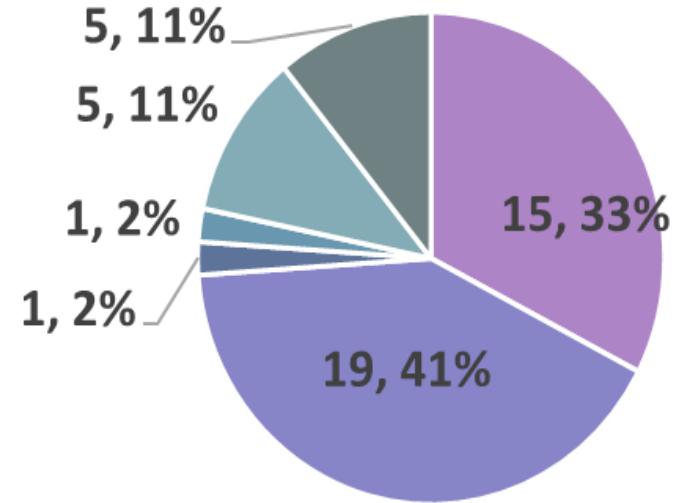
Did we get it right? [i.e. what the toolkit is about] Is there anything major missing?

Discussion 2:

Reflections on Service Assessment – usefulness of content, structure, interface, navigation, accessibility

Discussion 3:

Reflections on remaining elements – usefulness, structure, interface, etc

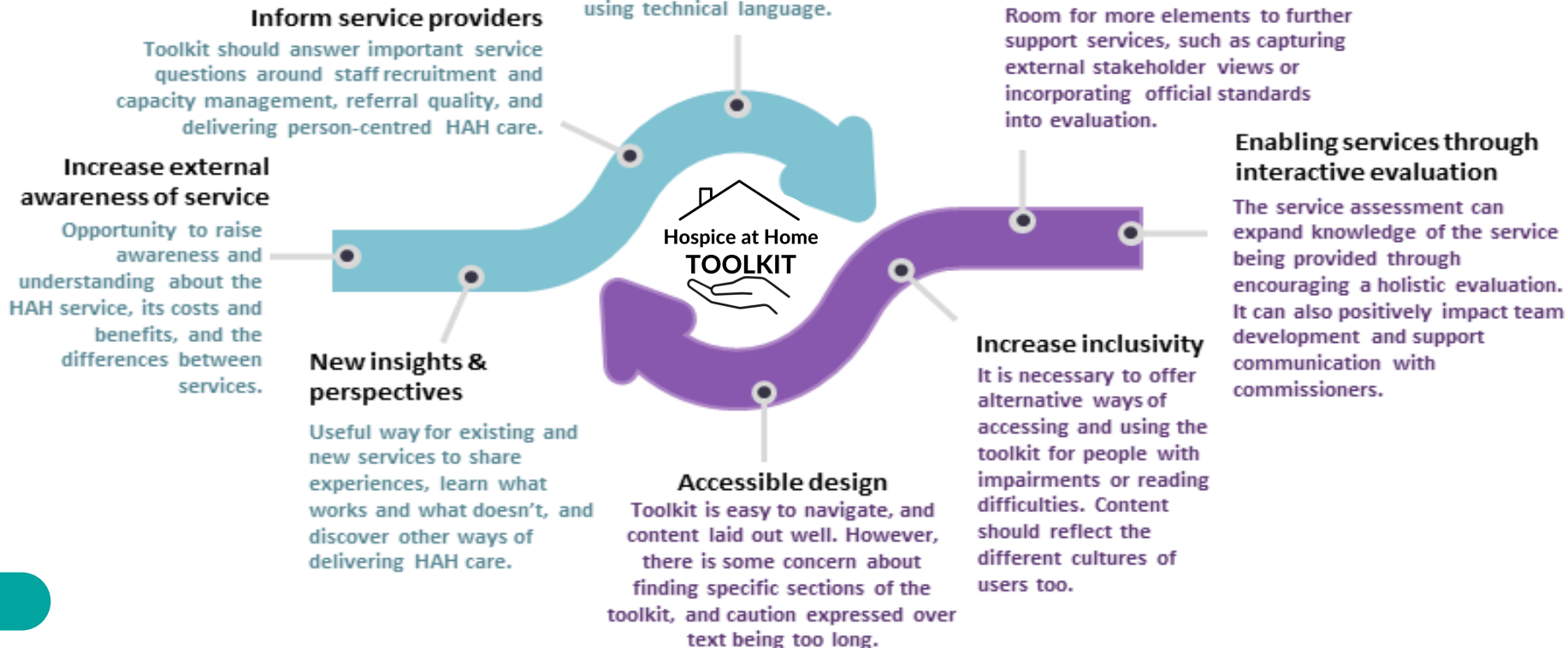


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**KEY FINDINGS
FROM CO-DESIGN EVENT**

RESULTS

**KEY FINDINGS
FROM CONSULTATION EVENT**

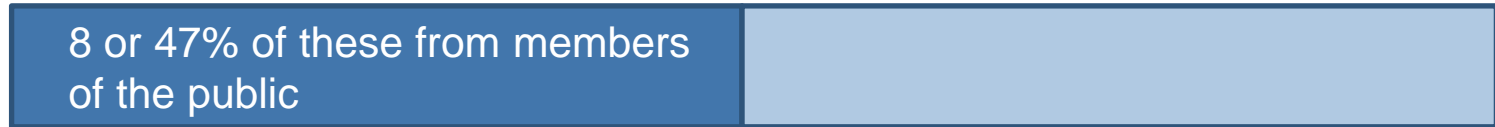


POST-EVENT REVIEW

250 stakeholder comments:



17 reviewers:



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](#).

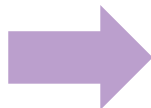
Understandably, you may end up focussing on the person nearing death more than yourself. It is crucial that you don't forget yourself and maintain your physical, mental and spiritual health. Find out if you can access respite services (eg from your local hospice).

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](#).

Hospice at Home

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Relationships

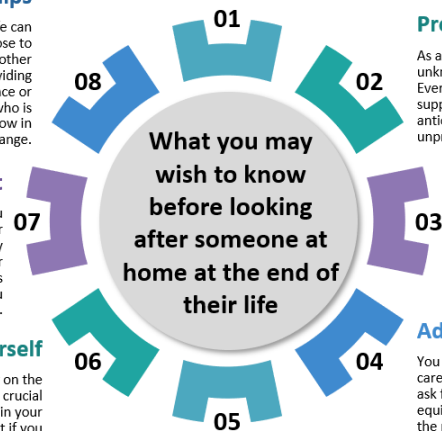
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Bereavement support

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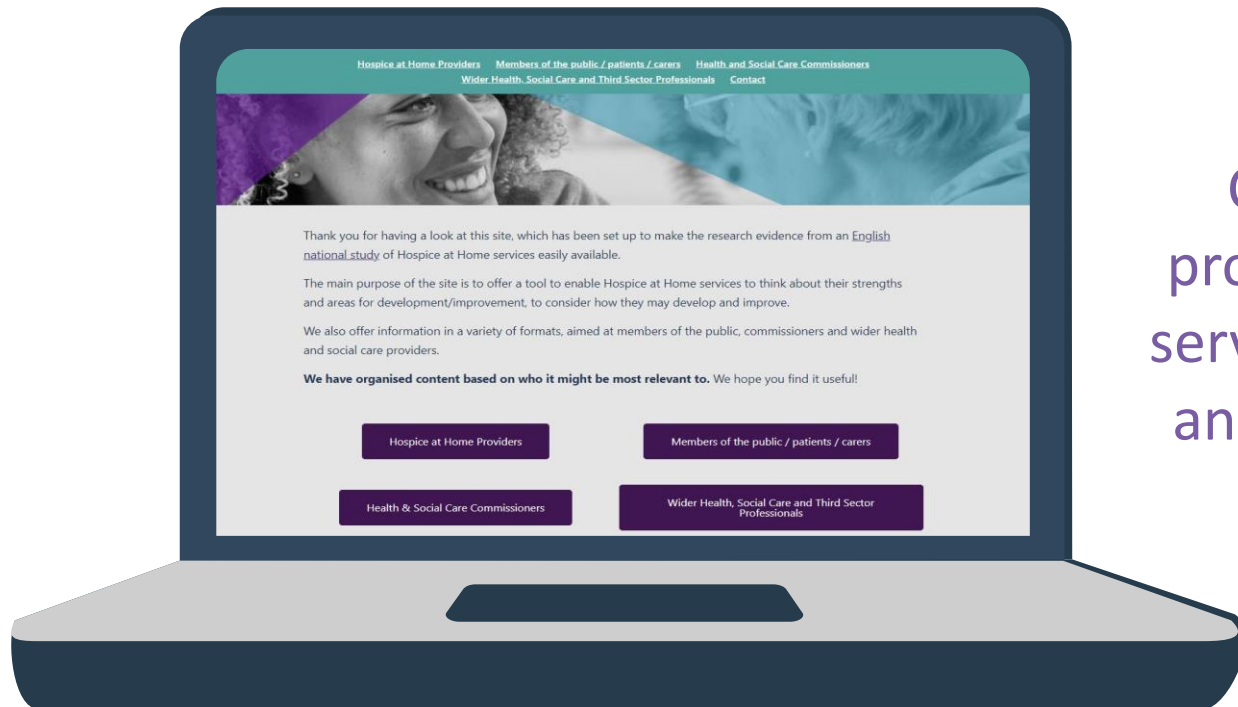
Not forgetting yourself

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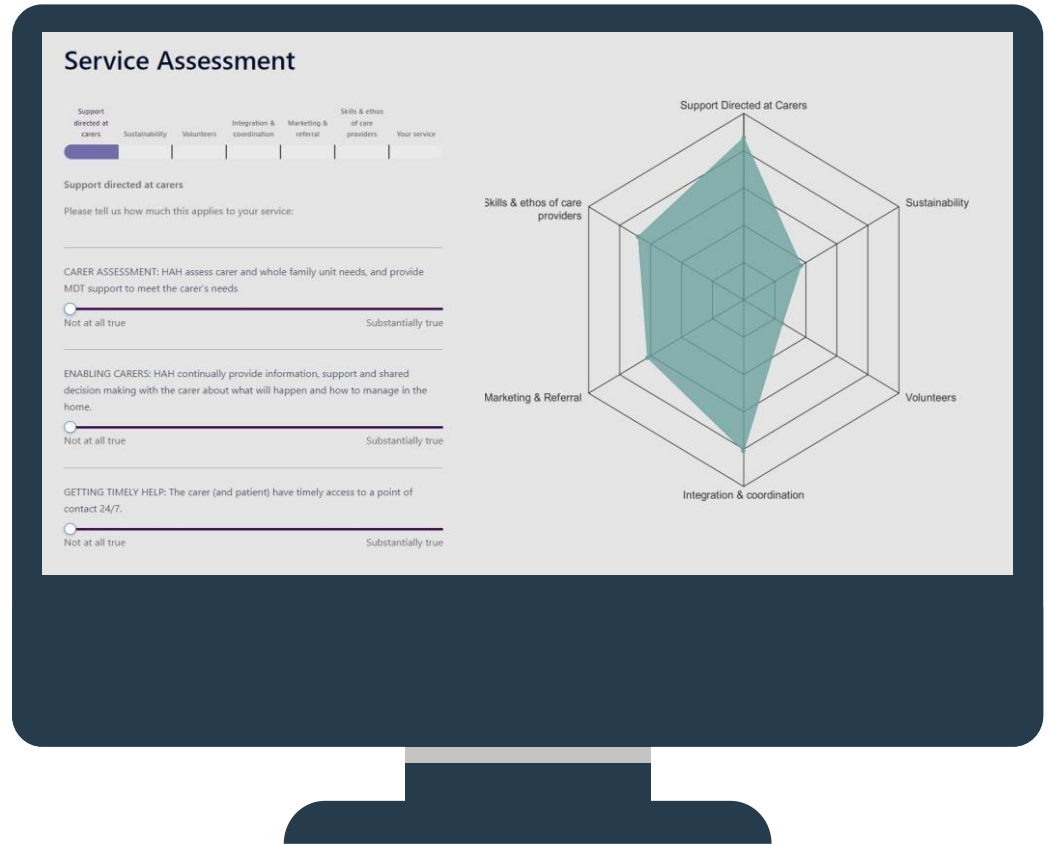
THE TOOLKIT



Content for HAH providers, the public, service commissioners and wider workforce

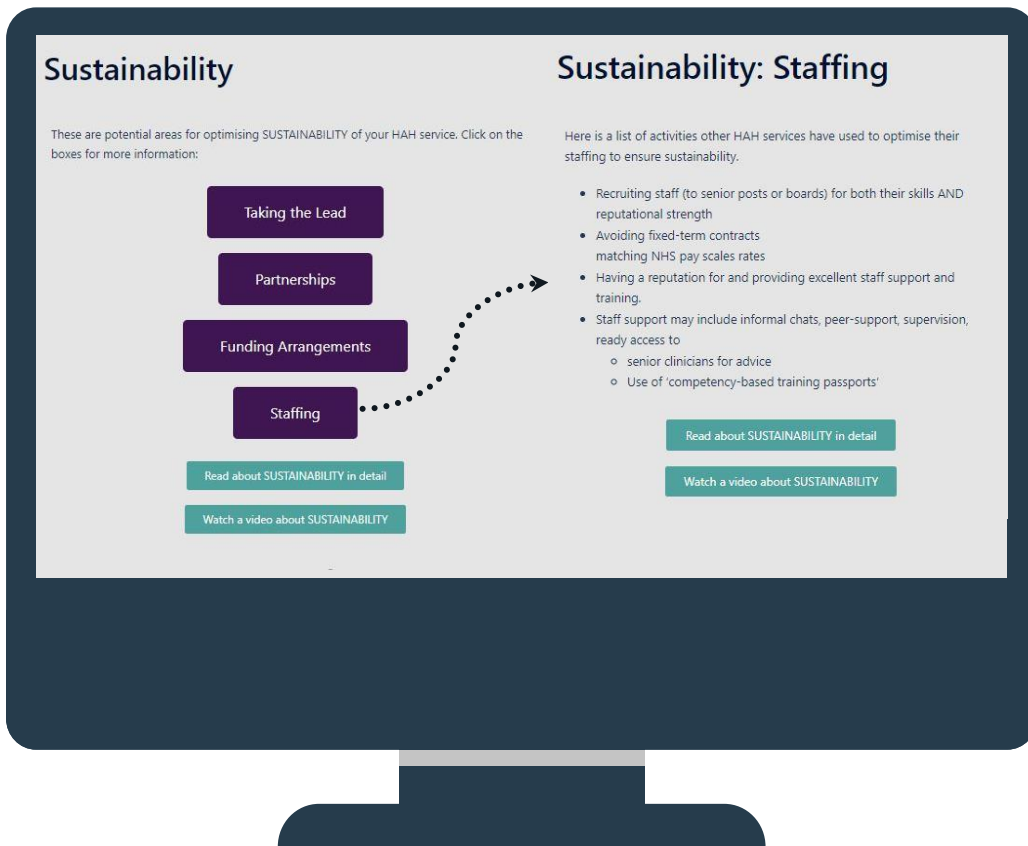
THE TOOLKIT

Interactive Service Assessment helping to map areas where further optimising is needed, with a list of ideas from other HAH services on how they optimised



THE TOOLKIT

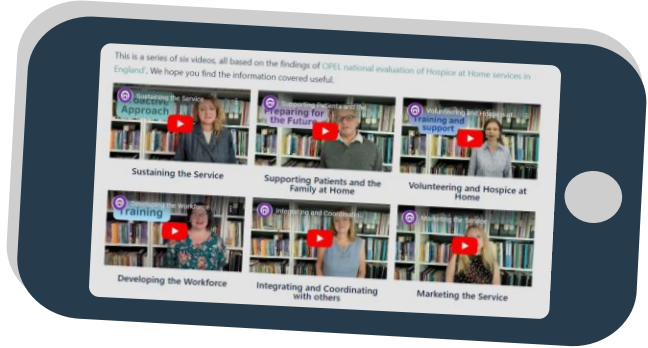
Interactive Service Assessment helping to map areas where further optimising is needed, with a list of ideas from other HAH services on how they optimised



THE TOOLKIT



Videos



1-page summaries for a variety of audiences

...and much more!!

One Page Summary for:
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 undertook a national survey and then looked into 32 services around the country in detail. We recruited 339 patients and their family/friend carers and interviewed 83 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]).
 • All Hospice at home services offered care which was highly rated by family/friend carers.

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

<p>Preparedness</p> <p>How the patient, family and carers feel about the care and what they need to be ready to respond to the care at home. This will be a mix of things that you can prepare for and things that you can't.</p> <p>1</p>	<p>Addressing the needs of the carer</p> <p>Staff from a range of disciplines need to be involved in responding to the carer's needs. This will be a mix of things that you can prepare for and things that you can't.</p> <p>2</p>	<p>Expectations</p> <p>The HAH staff fully informs what might happen in terms of the care and the increasing burden of care over time. Carers will then know what to expect and can rapidly respond to a change in care (usually from control to crisis).</p> <p>3</p>	<p>Support for caring</p> <p>The patient and carer are offered support and advice on how to manage the care and what to expect. This will be a mix of things that you can prepare for and things that you can't.</p> <p>4</p>
<p>Partnership</p> <p>Partnership is a mix of things that you can prepare for and things that you can't. This will be a mix of things that you can prepare for and things that you can't.</p> <p>5</p>	<p>Full assessment of care</p> <p>A full assessment of care is needed to understand the patient's needs and what the HAH service can offer. This will be a mix of things that you can prepare for and things that you can't.</p> <p>6</p>	<p>Responsiveness to changing needs</p> <p>Responsiveness to changing needs, including up-to-date information and 24/7 access to support and advice, gives confidence in the hospice.</p> <p>7</p>	<p>Marketing & referral</p> <p>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.</p> <p>8</p>

One Page Summary for:
Hospice at Home Frontline Staff
 Download Full Report

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 • 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:

<p>1 Time to care & expertise</p> <p>HAH staff make family/friend carers feel they have 'time to care' and are clearly experienced in and comfortable with dying and death.</p>	<p>2 Caring for the carer</p> <p>Successful carer 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 less valued.</p>	<p>3 Hands-on care</p> <p>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.</p>
<p>4 Agency</p> <p>Responsiveness to changing needs, including up-to-date information and 24/7 access to support and advice, gives confidence in the hospice.</p>	<p>5 Marketing & referral</p> <p>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.</p>	<p>6 Integration & coordination</p> <p>Formal arrangements for integration and coordination are important. In addition, much of this works on the ground, as colleagues on the front line work together for the patient.</p>

How will this information affect my practice?
 This research allows you to see what is going on across all hospice. Some of the factors identified in this research include ways to guide practice and to improve.

One Page Summary for:
Hospice at Home Managers and Leaders
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Key markers linked with the best outcomes for patients and families were:

<p>1 Sustainability</p> <p>HAH may be more sustainable if their service is proactively planned, with regular statutory funding, engaging with the organisation, local care environment and, if a charitable organisation, under the governance of a range of sources. To recruit and retain staff to deliver the care that patients need, the 'Compassionate Communities' reputation for care service and expertise in staff development.</p>	<p>2 Volunteers</p> <p>Volunteers who are effectively recruited, trained and managed, including the provision of support and lines of reporting, HAH services could have a significant impact. When HAH services use the same approach to some experienced volunteering, along the lines of the 'Compassionate Communities' model, in which volunteers act as role models.</p>	<p>3 Integration & coordination</p> <p>A full assessment of care needs including the whole family/care set-up is required. The HAH service negotiates a partnership with the carer, including clarity about what can and cannot be provided, and recognition of what the patient-carer dyad were.</p>
<p>4 Marketing and referral</p> <p>To increase referrals in general, and in particular of those who are poorly represented in hospice services, HAH needs to actively market its service to professionals and the public through clinical and public engagement. Referral is particularly important and needs support from a range of sources.</p>	<p>5 Skills & Ethos of Care Providers</p> <p>To add value to the whole system of care, HAH services need to invest in expert knowledge and skills in EOLC staff with a suitable ethos. This is a service to professionals and the public through clinical and public engagement. Referral is particularly important and needs support from a range of sources.</p>	<p>6 Support directed at the patient-carer dyad</p> <p>A full assessment of care needs including the whole family/care set-up is required. The HAH service negotiates a partnership with the carer, including clarity about what can and cannot be provided, and recognition of what the patient-carer dyad were.</p>

One Page Summary for:
Health and Social Care Commissioners and Integrated Care Boards
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 • All HAH services offered care which was highly rated by family/friend carers.
 • The majority of HAH services were being delivered to patients dying of cancer (77% of patients admitted to HAH services were being delivered to patients dying 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?

<p>1</p> <p>Commissioners should ensure that their service is proactively planned, with regular statutory funding, engaging with the organisation, local care environment and, if a charitable organisation, under the governance of a range of sources. To recruit and retain staff to deliver the care that patients need, the 'Compassionate Communities' reputation for care service and expertise in staff development.</p>	<p>2</p> <p>Volunteers who are effectively recruited, trained and managed, including the provision of support and lines of reporting, HAH services could have a significant impact. When HAH services use the same approach to some experienced volunteering, along the lines of the 'Compassionate Communities' model, in which volunteers act as role models.</p>	<p>3</p> <p>A full assessment of care needs including the whole family/care set-up is required. The HAH service negotiates a partnership with the carer, including clarity about what can and cannot be provided, and recognition of what the patient-carer dyad were.</p>
<p>4</p> <p>Commissioners should ensure that their service is proactively planned, with regular statutory funding, engaging with the organisation, local care environment and, if a charitable organisation, under the governance of a range of sources. To recruit and retain staff to deliver the care that patients need, the 'Compassionate Communities' reputation for care service and expertise in staff development.</p>	<p>5</p> <p>Volunteers who are effectively recruited, trained and managed, including the provision of support and lines of reporting, HAH services could have a significant impact. When HAH services use the same approach to some experienced volunteering, along the lines of the 'Compassionate Communities' model, in which volunteers act as role models.</p>	<p>6</p> <p>A full assessment of care needs including the whole family/care set-up is required. The HAH service negotiates a partnership with the carer, including clarity about what can and cannot be provided, and recognition of what the patient-carer dyad were.</p>

One Page Summary for:
Anyone Providing Hands-On Care 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 undertook a national survey and then looked into 32 services around the country in detail. We recruited 339 patients and their family/friend carers and interviewed 83 professionals (frontline staff, managers, senior decision makers in the hospice and commissioners).

What did the research show?
 • Hospice at home services provided personal care, psychosocial 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 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:

<p>1 Time to care & expertise</p> <p>HAH staff make family/friend carers feel they have 'time to care' and are clearly experienced in and comfortable with dying and death.</p>	<p>2 Caring for the carer</p> <p>Successful carer 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.</p>	<p>3 Hands-on care</p> <p>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.</p>
<p>4 Agency</p> <p>Responsiveness to changing needs, including up-to-date information and 24/7 access to support and advice, gives confidence in the hospice.</p>	<p>5 Marketing & referral</p> <p>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.</p>	<p>6 Integration & coordination</p> <p>Formal arrangements for integration and coordination are important. In addition, much of this works on the ground, as colleagues on the front line work together for the patient.</p>

How will this information affect my practice?
 This research allows you to see what is going on across all hospice. Some of the factors identified in this research include ways to guide practice and to improve.

TOP TIPS for optimising Hospice at Home services

- Get a seat at the table with commissioners and other service providers to work together and integrate care.
- 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 daily work with colleagues.
- 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?
- Consider how to respond rapidly to changing patient needs, including access to 24/7 advice and support by telephone, which gives families confidence that help will be forthcoming in crises.
- 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*?
- Train and support your HAH staff to give them confidence managing dying and death, and maintaining the quality of care and also to improve staff retention.

TOP TENSIONS in optimising Hospice at Home (HAH) services

- Challenge yourself and your colleagues about these difficult balancing acts and keep them under review
- Quality vs Reach**
 Finding the correct balance between the (highest) quality service and reaching more people in need. However, don't compromise on key elements of time, expertise and integration which achieve the best outcomes (and therefore add value).
 - 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 people. 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.
 - Strategic vs Operational**
 Organisations investing heavily in working with partners in wider 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 be out on having a seat at the table in planning and provision at a strategic level.
- Read our Top Tensions, too!

TOP TENSIONS in optimising Hospice at Home (HAH) services

- 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 range of roles for volunteers and/or relaxing the bureaucracy around some volunteer roles (see Top Tips).
- Medical vs Social Care Alignment**
 Some services were medically oriented, 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 risks. Medical 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.
- 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.

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

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 you are caring for. Sometimes it might be hard to know in advance how relationships will change.

Bereavement support
 After the person you care 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 focusing 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

- 01 **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.
- 02 **Influence on your life**
 You will need time to plan and consider options of caring for someone at home. Care will be likely to influence your life practically, logistically, financially and in a number of other ways (eg through family and social life). Discuss this with people around you, including health and social care staff who may be providing support.
- 03 **Advocacy**
 You will need to establish links with health and social care professionals for all aspects of care, and be ready to ask for advice (eg regarding provision and use of equipment). Carers are likely to involve advocating for the person nearing death, especially if they are no longer able to do so themselves. You may wish to consider *Dower of Attorneys and Advance Care Planning*.
- 04 **Hospice at Home**
 This document was written by a lay person with experience of providing palliative care. The authors presented their views to the first national study to look at a range of different hospice at home services. You can learn from them.

You may need palliative care support from services called 'Hospice at Home' or similar. You should know there are considerable differences from one hospice to the next in what support is offered and how you can access or refer to that support. Look up the website for *Hospice at Home* (Carer, HospiceUK.org). You may also visit *Maria Curie* website or call their helpline 0800 900 3309.

Wishes

Many people in the UK would prefer to be looked after and die at home, and this can often be achieved. But 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 complexity of the carer become adversely affected.

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



Developing the Workforce



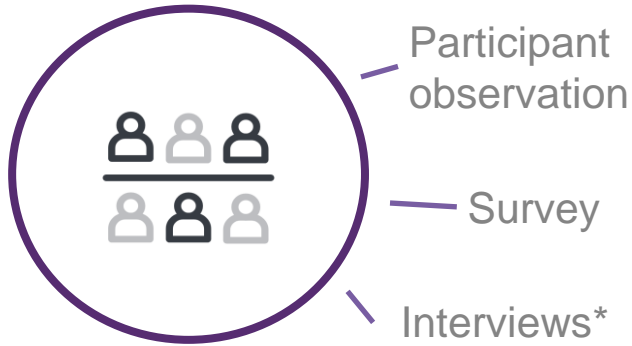
Integrating and Coordinating with others



Marketing the Service

EVALUATION: WHAT WE AIMED FOR

10 HAH teams
(3-5 in each)



(nurse/HCA, service lead,
senior decision maker,
commissioner, lay adviser)

2-5 Members
of the Public



1-2
Commissioners

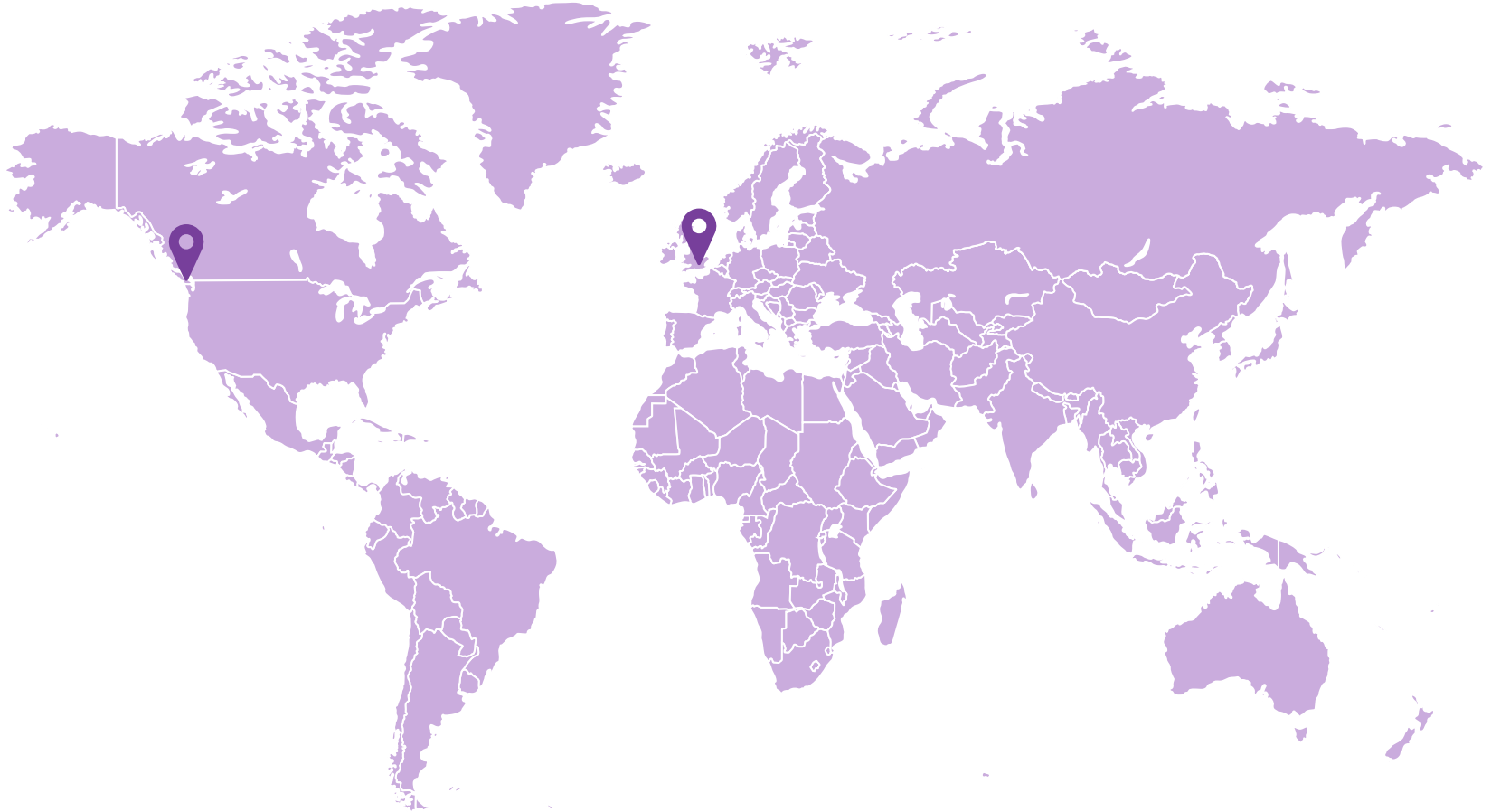


**after piloting and
3mth follow-up*

EVALUATION: WHAT WE ACHIEVED SO FAR



EVALUATION: WHAT WE ACHIEVED SO FAR



EVALUATION: WHAT WE HAVE ACHIEVED SO FAR

All recruitment targets met:

- **10 HAH services** (2-13 participants in each)
 - One additional pilot rescheduled for end of June
 - Interviews ongoing
- **4 members of the public/carers**
 - Recruiting 2 more; sampling for ethnic diversity
- **1 commissioner**
 - In conversations with another

Participant mix in piloting meetings:

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

PRELIMINARY HAH PILOTING 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)
- A number of **changes** proposed/observed on making the toolkit easier to navigate and use

“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)

PRELIMINARY PILOTING SURVEY RESULTS

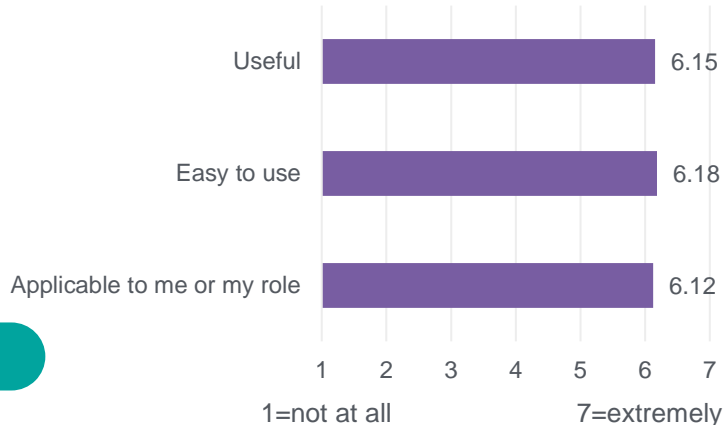
How would you rate your experience of using the HAH toolkit?



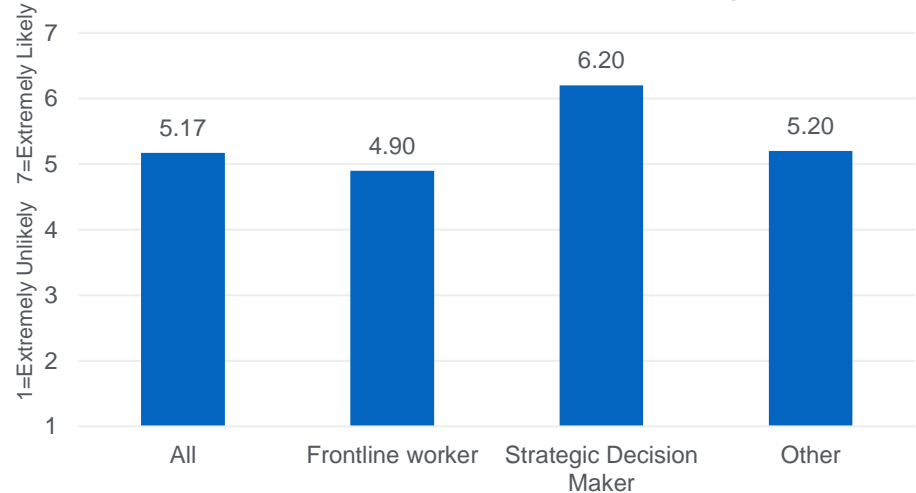
89% said the toolkit gave them ideas on how to further optimise their HAH; only 3% said it did not.

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?



PRELIMINARY MEMBER OF THE PUBLIC PILOTING 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 you 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)

WHAT'S NEXT?

Further refinement

- We will make final toolkit amendments based on evaluation findings
 - Based on participant feedback
 - Input from the steering group
 - Input from the whole team

Evaluation Report

- We will produce a final project report focusing on toolkit:
 - accessibility at lay, operational and strategic levels
 - relevance and applicability of the strategies generated by the toolkit
 - impact on piloting organisations, and
 - application as well as sustainability of any changes

WHAT'S NEXT? VIRTUAL ROADSHOW

- We shall contact **Hospice at Home services throughout the country** with the help of National Association of Hospices at Home
- We will send a brief **advert** introducing the toolkit

AND

- Offer to join HAH teams by **video call to tell them about the toolkit**, its uses and potential (based on piloting findings)





THANK YOU

Any questions?

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