The aim of hospice care is to improve the quality of life of people who have an incurable illness up to the point of death. This includes medical, emotional, social, practical, psychological, and spiritual care, as well as addressing the needs of the person’s family and carers. Currently a range of different Hospice at Home services exist in England, aiming to provide hospice-type care to support people who prefer to be cared for and to die at home. Professor Claire Butler is leading a national study to understand what features of Hospice at Home services work best for patients and their family carers at home.

Phase 3 of the project involved holding two Consensus Events, in January 2020, to gather stakeholder feedback on the emerging results. The events were well-attended, with hospice service providers, members of the public, commissioners and researchers present.

Table 1. Event attendance by location and participant group

<table>
<thead>
<tr>
<th>Service Provider</th>
<th>London</th>
<th>Leeds</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Hospice) Service Provider</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(other) Commissioner</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Member of Public</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (e.g. researcher)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>49</td>
<td>39</td>
<td>88</td>
</tr>
</tbody>
</table>

The purpose of the consensus events was to refine and confirm the findings from phases 1 and 2 of the study, which had involved a survey of Hospice at Home services in England and in-depth investigation of 12 case study sites across England. We have collated and analysed the contributions from the event attendees and fed these into the overall findings from the study.

**Preliminary findings: a summary of what features of Hospice at Home (HAH) services worked best for patients and their family carers at home**

The staffing and operations of a HAH service were optimum where it was integrated and embedded in its particular local setting with other relevant services, and had a seat at the table with commissioners and other providers. HAH providers benefited from taking a pro-active approach to securing the available statutory funding and were trusted to do this on the basis of their reputation. On the ground, HAH and other staff often worked well together regardless of organisational arrangements, with a focus on the patient’s needs, and this as assisted when HAH organisations allowed their staff flexibility and autonomy.

Other key features of HAH which promoted good outcomes for patients and their families were:

- Having sufficient time and taking the time to provide seemingly unhurried, person-centred care.
- There was a trend for HAH services providing more practical care versus more “clinical/medical” care to provide better outcomes for patients, suggesting the prime importance of hands on care and relational support.
- Developing a supportive relationship with the patient, carer and family (even being perceived as becoming part of the family), which would ideally continue on into bereavement (see below).
- HAH staff who demonstrated knowledge, skills and experience in dealing with death and dying and thereby gave reassurance and confidence in the home.
- Internal investment in the training and support of HAH staff.
• Agility to respond rapidly to changing patient needs, including access to 24/7 advice and support by telephone and confidence that help would be forthcoming in crises.
• Support from the service directed at assessing and meeting the informal carers’ needs as well as the patient. Expectations, planning, information and points of contact were particularly important to carers.
• Smaller sized services tended to work better with other local services.
• However, while the above points had impact on the very last days of life, earlier contact (and this was primarily found in the larger services) also positively impacted on outcomes.

The study also highlighted areas where most HAH services could look to improve their impact:
• On the whole, carers were not being offered the bereavement support they would have preferred. Shortly after bereavement, the clear preference 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.
• HAH services could capitalise more on the volunteer workforce by considering a wider range of roles for volunteers and/or by relaxing the bureaucracy around some volunteer roles.

Figure 1. Feedback on Dissemination and implementation

We also collected information on where and how best to support organisations to implement the findings from the study. People who attended the events emphasised the need to adapt dissemination materials to different audiences, including commissioners and policy makers, lay audience and a wide range of services providing end of life care (even if they are not called Hospice at Home).

Interactive format for online/electronic materials was also emphasised, potentially in the form of a context-specific toolkit with ability to choose which information is relevant to a specific service or area. Short videos and ‘bite-size’ podcasts were also mentioned alongside 1-page infographic summaries.

What’s next?

We will be submitting the OPEL draft project report to the National Institute for Health Research in March 2021 and it is likely to be published in early 2022.

Want to know more about the study?

Please visit the study link at: https://www.kent.ac.uk/chss/research/docs/current/2016_11_21_HAH.html

Would you like to be notified with the project report is published?

If so, you can use the ‘alerts & updates’ on right hand side of the following page: https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1419744/#/