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Title Page

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Understanding what works, why and in what circumstances in Hospice at Home Services for End of Life Care: applying a realist logic of analysis to a systematically searched literature review.

Abstract

Background:

We have undertaken a systematically searched literature review using a realist logic of analysis to help synthesise the diverse range of literature available on hospice at home services.

Aim:

To find out in the existing literature what features of hospice at home models work best, for whom and under what circumstances.

Design:

A realist logic of analysis was applied to synthesise the evidence focusing on mechanisms by which an intervention worked (or did not work). An initial programme theory was developed using the National Association for Hospice at Home standards, Normalisation Process Theory and through refinement using stakeholder engagement.

Data sources:

PubMed, Science Direct, AMED, BNI, CINAHL, EMBASE, Health Business Elite, HMIC, Medline, PsychINFO, SCOPUS, Web of Science, DARE, Google Scholar, NHS Evidence, NIHR CRN portfolio database, NIHR journal library of funded studies, including searches on websites of relevant professional bodies [August 2014, June 2017, June 2019].

Results:

Forty-nine papers were reviewed, of which 34 wereincluded contributing evidence to at least one of eight theory areas: marketing and referral, sustainable funding model, service responsiveness and availability, criteria for service admission, knowledge and skills of care providers, integration and co-ordination, anticipatory care, support directed at carers.

Conclusions:

Our literature review showed how it was possible to develop a coherent framework and test it against 34 published papers and abstracts. Central to this review was theory building, and as further evidence emerges, our programme theories can be refined and tested against any new empirical evidence.

Key statements:

Hospice at home services comprise of a diverse range of services based on local needs and contextual factors but little is known about which models work best, for whom and under what circumstances.

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Key areas to be taken into account in optimal hospice at home provision include the importance of the sustainability of the hospice at home service, supporting carer needs and having anticipatory care in place. There are gaps in the evidence in understanding how referral categories, training for non-specialist staff and better care co-ordination influences optimal hospice at home service provision.

This paper contributes to understanding what needs to be in place for optimal hospice at home service provision.

Understanding what works, why and in what circumstances in Hospice at Home Services for End of Life Care: applying a realist logic of analysis to a systematically searched literature review

1. Introduction

The World Health Organisation has recognised that people in need of palliative care prefer to remain at home, and in order to respect this preference, palliative care programmes should be incorporated into existing health care systems to enable end of life care to be accessible in patients' homes.[12] While the majority of people would wish to die at home and the evidence indicates that the number of people expressing this wish is increasing,[3–6] health and social care services are ill-equipped to meet this demand.[7] Evaluations often demonstrate positive benefits for patients, such as increased choice and death at home.[8–10] However, it is unclear what elements of these services deliver which outcomes and to what extent such outcomes are delivered in conjunction with other primary care and community services.

In 2012, a multi-service survey of hospices by the National Association for Hospice at Home and Help the Hospices (now Hospice UK) undertaken across 76 hospice at home services in England, confirmed that there was a need to increase understanding of hospice at home due to the lack of clarity about what was the best model of care. [11] The National Association for Hospice at Home have since identified national standards developed through stakeholder engagement (Table 1), which were underpinned by structural, procedural and outcomes criteria to facilitate a clearer definition of hospice at home .[12]

<<INSERT TABLE 1 HERE>>

Despite the standards, the current evidence continues to demonstrate a diverse range of services based on local needs and contextual factors. Published studies are predominantly descriptive making it challenging to identify any emerging concepts or theories. In response to this gap in the evidence, this paper presents findings from a systematically searched literature review, which applied a realist logic of analysis to explore which models of hospice at home work best, for whom, and under what circumstances. It was undertaken as separate piece of preparatory work for a nationally funded evaluation study of hospice at home services currently being conducted across England ('Optimum

'Hospice at Home' Services for End of Life care or OPEL-H@H study') and was not part of the main study.[13]

2. Applying a Realist Logic of Analysis to a Literature Review

The realist approach is a theory-driven methodology used to evaluate complex interventions.[14] At the core of realism is the notion of 'generative mechanisms'; a causal link between a triggering context and mechanism which creates an 'effect'.[15] Realist approaches attempt to theorise what the mechanisms are, even though they are not necessarily 'measureable' in an empirical sense though it seeks to find evidence of their existence. The relationship between mechanisms, their contextual triggers, and the effects they produce are represented through propositions, which take on a basic formula of: context + mechanism = outcome configuration. As a first step when undertaking realist methodology, initial programme theories are constructed using stakeholder consultation, expertise and the literature including the search for middle range theories. These are formal theories that may provide a guide to causal links, whereas programme theories are a set of assumptions that explain how and why a specific intervention will reach its objectives.[16] Propositions are heuristic and give more detail of the causal links within programme theories and are tested out within a realist synthesis, or an empirical realist evaluation.

We have drawn from approaches used in realist reviews to include all types of literature to identify and retrieve materials to purposively answer particular questions, as often there are many potentially useful sources of information that can help to explain sometimes complex social interventions.[17] Conducting a systematically searched literature review also involved following sequential steps for searching and reviewing the literature, and meets the need for transparency or 'auditability' in the review processes. The aim was to provide an explicit account and justification of the decisions made in the literature search and review, so that others can follow how the review was conducted from the opening questions to the results.[17] We used Wong et al's reporting checklist developed realist review publication standards known as RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) to guide this review.[18] Realist reviews supports the need for quality and rigour, but takes a different position on how research quality is judged in comparison to traditional systematic reviews. As described by Pawson, "*Relevance…*in realist review is not about whether the study covered a particular *topic*, but whether it *addressed the theory* under test; *Rigour…*whether a particular inference drawn by the original researcher has sufficient weight to make a methodologically credible contribution to the test of a particular intervention theory". Both relevance and rigour are therefore not the dominant criteria on the reasons why a study is included or not included, but whether the components of a study are fit for purpose for a particular review.[17]

We used a realist logic of analysis to synthesise the evidence, which meant following a process of constantly moving from evidence to theory (abductive analysis justifying our propositions within empirical evidence) to refine explanations about why certain patterns were occurring, and then to try to frame an explanation that could cover a range of types of services or patterns in different settings.[19] In the process of configuring propositions, we used an analysis method described by Jagosh. He reported in his own realist review on participatory research (PR), that it involved extracting pieces of evidence and placing this element into the context, mechanism and outcome categories, even if the extracted evidence did not necessarily fall neatly into each. He describes a process where there were instances in which evidence could be simultaneously a contextual factor, a mechanism or an outcome, and reasonably placed in one or more of the categories. Rather than labouring over the question of which category the evidence would be best placed, he argues it is better to approach the proposition with the intention of making sure no outcomes were missed, regardless of where the evidence was placed.[19]

The findings from this review provide the first tentative steps in developing the components of an overarching programme theory to determine what features of hospice at home models work best, for who and under what circumstances. It offers a platform for further theory refinement, testing and building for future studies on hospice at home services.

3. Method

Findings from an evaluation of a hospice at home service caring for adults in East Kent indicated that there is value in *hospice at home* as a concept, but led to the question whether there is a more effective alternative model of hospice at home care, which could improve the outcomes for an even higher proportion of patients whose preference was to die at home.[20]

This prompted a systematic literature review to understand what hospice at home models exist in comparable settings (such as the UK) and their value. This review therefore aims to answer the research question: In the existing literature what features of hospice at home models work best, for whom and under what circumstances?

3.1. Search strategy

We took an inclusive approach when searching all literature describing and evaluating hospice at home models regardless of rigour or method[19,21] The search was performed to identify any type of literature or study which aimed to describe or evaluate a hospice at home model in the UK providing care to adults with a life limiting illness who wish to die at home. This service could be described as a hospice at home service by name, or could potentially be a community service under a different name. Therefore our search strategy had to include concepts that could identify these services in the literature.

These search concepts were chosen based upon a previous literature review by Stosz,[22] which identified four characteristics as recommendations to establish future hospice at home services. These characteristics were:

Rapid response
Crisis management
24 hour coverage
Staff in service are palliative care specialists who are hospice trained

A set of searches were carried out on a number of databases of academic publications, grey literature, and current research including: PubMed, Science Direct, AMED, BNI, CINAHL, EMBASE, Health Business Elite, HMIC, Medline, PsychINFO, , SCOPUS, Web of Science. Additional searches were also carried out in DARE (search database for systematic and Cochrane reviews), Google Scholar, NHS Evidence, NIHR CRN portfolio database, and NIHR journal library of funded studies (Figure 1). Searches on websites of relevant professional bodies (e.g. Hospice UK, National Association for Hospice at Home were also conducted (see supplementary document for further detail of these searches and search terms used).

<<INSERT FIGURE 1 HERE >>

3.2. Inclusion and exclusion criteria

Articles were excluded if they were not a UK based model of care, if they provided care for children only, were not describing or evaluating a hospice at home service model or if a service by another name, did not fit within the hospice at home broad characteristics. The majority of articles included were evaluations or descriptions of one service model within one locality. Only one of the studies in articles identified looked at a number of models of care, [23,24] a small number looked at a variation of the same model. [25–27]

3.3. Developing an initial programme theory

An initial programme theory (IPT) was developed using the National Association for Hospice at Home standards and Normalisation Process Theory;[12] a middle range theory that explains how new services or practices become embedded as part of normal service delivery. Normalisation Process Theory characterises implementation processes as the product of four social mechanisms (see Table 2). Advocates of realist reviews suggest initiating a review with a middle range theory ,[19] and we found Normalisation Process Theory a useful tool to unpick our programme theory. Using this framework focused our analysis on the characteristics of implementation processes, and in doing so facilitated an understanding of contexts, social structures and processes within which hospice at home services operate in, thereby helping to understand the relationships between the mechanisms, their triggers and the effects they produce. We employed a similar method, as used by Johnson and May to code relevant parts of the evidence which provided rich descriptions of the context and background of hospice at home services.[28] The coding framework was used to determine which Normalisation Process Theory constructs were covered in each of the hospice at home interventions as described in the literature.[28]

<<INSERT TABLE 2 HERE>>

As in other Normalisation Process Theory informed studies (for example, Wilson et al),[29] we assumed that individual and collective work would need to be undertaken by a broad range of stakeholders including commissioners, managers, services providers, plus the recipients (i.e. the carers and patients). Table 3 maps both the 16 Normalisation Process Theory statements and the National Association for Hospice at Home's core standards (Table 1) to illustrate how hospice at home services may be embedded within the EOLC pathway. This mapping helped identify key areas to develop our initial programme theory (see Table 2 column four) in discussion with our stakeholder group (see Table 4).

<<INSERT TABLE 3 HERE >>

<<INSERT TABLE 4 HERE>>

Our initial programme theory was refined through stakeholder involvement in an iterative process throughout the review (please refer to Table 4) and supplemented by the emerging findings of Phase 1 of the OPEL-H@H study [13] (please visit the project's website to view the results of the survey: poster presentation https://www.kent.ac.uk/chss/docs/OPEL%20HAH/Phase%201%20poster.pdf; supplementary handout visit: https://www.kent.ac.uk/chss/docs/OPEL%20HAH/Phase%201%20findings%20-%20A4%20summary.pdf. .The purpose of the survey was to gain an understanding of the range and characteristics of hospice at home services. A newly proposed programme theory was co-produced by the clinical, public and service user stakeholder representatives (Table 4). It was also used as a basis for a data extraction form, which acted as a template to interrogate the papers (Table 3).

Each paper was scrutinised to identify studies which related to programme theory areas.[14] From each paper, we looked for a diverse array of information salient to the synthesis, which could provide an explanation of the programme in terms of describing the relationships between the programme theory areas and the context in which they occur to produce a certain outcome.[30]

3.4. Data extraction and analysis

Multiple reviewers were used to extract the evidence.[14,31] Each paper was reviewed independently by two researchers, then discussed between three reviewers (CBr, FH, CBu) to reach a consensus on whether papers should be accepted for the review. We applied a realist logic of analysis, which involved analysing sections of texts that related to contexts, mechanisms and / or outcomes. Analysis required interpretation and judgement of evidence and was subsequently confirmed with the rest of the team. Evidence was coded deductively (to help evaluate potential propositions, and draw logical conclusions from emerging patterns in the literature), inductively (enabling new ideas and propositions to emerge from the evidence) and retroductively (identifying and exploring new patterns using theory to offer causal explanation).[32]

Forty-nine papers were reviewed in total, of which 29 were accepted for inclusion, 13 papers were rejected as they did not go beyond superficial description or did not introduce any new theory areas that had already been developed and refined in the existing configurations. Where papers reported one study, these were grouped together into one set .[23,24,33,34 35,36]

Seven papers where consensus could not be reached were reviewed by a fourth researcher (PWi), independent of the reviewing team to act as an adjudicator, who made the final decision. Of these, two were rejected as they were lacking contextual detail. Thirty-four papers were accepted in the final review at the end of the reviewing process (Figure 2 and Table 5).

<<INSERT FIGURE 2 HERE >>

<<INSERT TABLE 5 HERE >>

Following completion of the evidence extraction, we mapped the entire set of evidence onto our context, mechanism and outcome framework, using Normalisation Process Theory as a lens to draw out how our programme theory areas could lead to hospice at home services being embedded as part of EOLC service provision.

4. Findings

Included papers reported findings from a range of research study designs. There were studies reporting on the evaluation of the Marie Curie Delivering Choice programme,[8,25–27,37,38] with one of these using a realist evaluation approach.[27] Relevant evidence from the review was extracted and added into a table under the four Normalisation Process Theory constructs, within the eight programme theories. Table 6 provides a summary of each of the eight programme theory areas.

"Marketing and Referral"

There was evidence of awareness raising events in some hospice at home services with local healthcare professionals. [39–41] One study by Wye et al 2012 recommended that the hospice at home's Out of Hours (OOH) advice and response lines needed to be marketed to distinguish them from other OOH services.[26] Another hospice at home service noted that it was working effectively with local stakeholders to agree a clear referral criteria for targeted marketing. [33,34] Some hospice at home services had low referral rates from deprived areas, and non-cancer patients.[36,38,42,43] Awareness raising activity was still required in other hospice at home services with carers, patients, families and healthcare professionals based in hospital settings.[8,10,25,44,45] There was evidence that healthcare professionals were actively referring into the hospice at home service.[25,39,46] On the other hand, it was also reported that GPs were incorrectly referring into one hospice at home service.[47] In addition, without the availability of GPs and DNs to enable access to the hospice at home service, referrals would be limited.[43] Some hospice at home services were being actively introduced to suitable patients by 'in-reach' nurses in particular helping to identify non-cancer patients, and resulted in reducing hospital readmissions.[26,27,38] Although direct evidence on the monitoring of marketing and referral strategies of hospice at home services was far from explicit, it was recommended by Gage et al that commissioners would benefit from knowing about service under-utilisation.[48] In addition, Wilson et al noted that carers required more awareness raising about the availability of bereavement support.[49]

"Sustainable Funding Model"

We found evidence of hospice at home services undertaking local consultation activity to identify need prior to introduction of a service, widespread consultation before implementation, health service management identification of service need according to local setting, and providers and commissioners being involved in designing 'individualised support'.[9,33,34,40,50] There was evidence that managers and commissioners were uncertain at identifying what type of services would be provided by the hospice at home services and what the costing implications were.[23,24] The evidence also showed that one hospice at home service was exploring categorising different hospice at home models to help identify whether an area would benefit from a given hospice at home model type. [10] Hospice at home services were working at a comparatively lower cost by linking services with community nurses and rapid response teams, and securing sufficient funding with the collaboration of local partners.[26,37] It was reported in one hospice at home service that to provide successful holistic community based care, it needed to be co-ordinated and supported by an experienced hospice team.[51] Other hospice at home services had more difficulty in getting other providers to pick up care after a crisis.[51] It was reported in one hospice at home service that it was flexible to be able to adapt to local and national policy changes.[47] Evidence by Gage et al suggests that having an integrated co-ordinating service between providers did not impact upon whole systems costs.[48]

"Service Responsiveness and Availability"

If patients and carers had regular contact with a hospice at home service that had adequate rapid response capacity,[23,24] the evidence showed that patients and carers would continue with the hospice at home service,[9,51] as increased availability would be responsive to patient choice, would adapt to changes in preferences supported by adequate staff resources, and underpinned by access to equipment to meet demand.[37,44,45,47,48] The availability of a co-ordinating centre for identifying access to care packages and equipment was important for providing fast and efficient care,[25,27,33,34] and having access to palliative medicine and specialist nursing staff for symptom management and psychosocial support.[26,36,37,39–41,44] The problems with access to medications and issues around organising visits from trained staff were reported as common barriers encountered,[10,47,49,51–53] with rural areas reporting particular problems with access to trained staff.[10] Although one service was resourced adequately, there was a common perception that the hospice at home service was unable to meet demand.[45] Having a dedicated telephone line resulted in high carer satisfaction and supported the work of the hospice at home service.[27,49] In terms of monitoring the hospice at home's responsiveness and availability, it was noted that not all patients received care in their preferred choice due the high demand,[10,36] in one instance the rapid response service did not impact on the patient's documented preferred place of death,[20] with a recognition that the hospice at home service needed to consider the complexities of providing 'individualised support' to deal with the changing journeys of carers and patients when dying.[9]

“Criteria for Service Admission”

Primary and community healthcare professionals were using a diverse range of criteria to refer patients for admission to hospice at home services, which demonstrated that referral categories differed across services, resulting in considerable uncertainty from healthcare professionals around which patients to refer.[10,41,46] Carers were keen to be kept informed about referrals, assistance with navigating different healthcare service providers and on-going emotional support for older carers.[41] It was recommended by Purdy et al that GPs needed further training to identify patients early and place them on the End-of-Life Care Register.[25] GPs were important in enabling access to the service, if they deemed that a patient could be cared for at home,[39] and if a family required psychological support and needed practical help for symptom control.[35,36] Referrals were also being appropriately triaged by the senior nurse at the hospice at home service using a RAG rating on the severity of clinical need of the patient and family. In terms of monitoring the criteria for service admission, the main tool used for reporting was whether patients died in their preferred place.[35]

“Knowledge and Skills of Care Providers”

We found evidence on training to support extended roles to enable specialist hospice at home nurses to provide care, and carers trained to administer medications.[44,45,53,54] Hospice at home staff were valued for their knowledge of navigating complex health systems.[41] GPs were reported to have a patchy understanding of the skills and knowledge of hospice at home staff,[47] preferring to work with fellow GPs.[26] There was substantial evidence that staff were actively undertaking training including specialised palliative care in order to ensure optimal delivery,[9,36,47] additional clinical training for nursing staff,[39] training on navigating palliative care services and the health systems,[27] offering psychological support to help engage patients and carers, communication skills for having a holistic understanding of patient and carer needs, and respecting choice in EOLC.[36,41] We found evidence that the skills of the hospice at home staff had a significant impact on satisfaction and care received.[44,55] Some patients and carers still misunderstood what advance care planning involved, and elderly patients had difficulties in understanding what would be involved in using the hospice at home service.[44,49] It was reported that GPs lacked the skills in assessing palliative care needs, with community nurses finding it difficult to discuss advance care planning,[49] and rapid response nurses facing difficulties in the administration of drugs therefore requiring further training.[10]

“Integration and Co-ordination”

We found evidence of successful multiagency collaboration to support the hospice at home service.[39,40,54] While teams of people recognised the importance of sharing information systems on patient records,[23,24,54] in practice not all staff registered to access shared electronic records.[26,27] Strong communication between DNs and hospice at home teams was required to avoid duplication of work and alleviate concerns around the blurring of roles.[8,39,40] Yet, there was also evidence of poor communication by hospice at home services to carers and patients on how hospice at home services worked alongside local services, with patients and carers not knowing what to expect from their hospice at home service, heightening feelings of uncertainty and turbulence at such difficult times.[44] The vast body of evidence showed that hospice at home services were well coordinated with local EOLC services and was demonstrated by the following activities: having a named co-ordinator to assist patients,[38] a link to the service via a GP or DN team,[8,10,41] good communication and co-ordination between DNs and hospice at home teams to deliver cheaper care packages, a shared approach to care planning and communication,[36,47,49] successful delivery of care packages organised by co-ordination centres,[25–27] hospice at home services liaising with local community pharmacies for immediate access to drugs,[39,40] and regular visits to patients and carers by the same hospice at home staff to build trust.[55] However there was also evidence of less successful coordination, which included the lack of face-to-face communication from the hospice at home service with patients and carers to avoid hospital admission. [25,26,45]

“Anticipatory Care”

We found evidence in one hospice at home service of an expert panel making recommendations for an anticipatory medications system to be in place, and in another hospice at home service ensuring that there was immediate access to medicines and equipment in particular out of hours.[23,24,39,40] There was evidence of uneven access to availability of drugs with one hospice at home service reporting being fully resourced for their “in-hours” service by careful planning, yet another having a lack of availability.[23,24,47] Some hospice at home services were able to provide anticipatory care through having palliative care pharmacists providing immediate access to medications, and good communication between the hospital and community teams to ensure carers were provided with up-to-date information about providing anticipatory care.[39,49] Although there was evidence that healthcare professionals could access the End of Life Care Register through IT systems, sometimes this did not take place.[26,27]

“Support Directed at Carer”

Hospice at home services were providing holistic support and reassurance to the carer by giving regular updates on referral information and the communication taking place between professionals and across agencies to ensure responsiveness and continuity of care.[10,49] There was widespread agreement in one hospice at home service that supporting carers was part of their work. Family carers were supported following a crisis intervention via follow-up telephone calls, and through the provision of both day and night respite care including practical care supporting family carers’ to lead a day-to-day normal life. [27,46,47] There was substantial evidence that carers were being supported based on a co-production model with reciprocal trust between care providers and carers. Carer support from hospice at home services included activities such as: reducing carer burden and providing carer respite which was achieved by hospice at home services providing physical, emotional and social support such as providing a night sitting services, reassurance and peace of mind that patients were being looked after, and staff building up a relationship with a carer to build their confidence; [9,41,44,45,47,51,52] providing emotional support especially to elderly carers;[8,40,44,46,55] providing reassurance about using equipment and carrying out key tasks, and knowledge about what to do in a crisis intervention.[10,41,56] Drawing from the evidence reporting on hospice at home models providing carer support, there was a lack of detail on how hospice at homes supported carers practically and emotionally. [48,55]. There was further evidence reported from the carers’ perspective that they valued the hospice at home’s presence,[10,46] felt supported to lead a normal life, had access to a 24/7 palliative care advice line,[27] and were provided with a bereavement service.[39,44,55] There was limited evidence on carer reported outcomes to find out if carers were receiving adequate support.[20,57]

<< Insert Table 6 here >>

Discussion

The evidence reviewed from each of our context, mechanism and outcome configurations addressed our research question: ‘In the existing literature what features of hospice at home models work best, for whom and under what circumstances?’. This review has sought to identify mechanisms that are triggered across a variety of contexts operating at different levels (both individual and collective) within hospice at home services, to achieve specific outcomes. We have started to develop the components of the overarching programme theory (Table 6) to help determine what features of hospice at home models work best, for whom and under what circumstances.

Awareness raising was a key theme that emerged from the literature (“Marketing and Referral”). The paucity of public knowledge about hospice at home services is not isolated to the services alone, but is a wider issue concerning public perceptions about end of life care. Although it is recognised that public attitudes to palliative care are complex, there are nonetheless insufficient conversations about death and dying. The majority of the public would welcome discussions with clinicians in advance about end of life care issues, with an expectation that healthcare professionals will offer insight into addressing the psychological, spiritual, emotional and practical needs of the patient.[58] Support for families caring for the dying at home was perceived by healthcare professionals as not always possible, as budgetary constraints meant that commissioners were uncertain with what the delivery and cost implication were of providing specialist palliative care. This resulted in some patients not being offered a home death, even though it was acknowledged that offering care in a patient’s own environment was assumed as where most people would like to be cared for (Sustainable Funding Model”).[58]

Holistic care was a repeated theme in the literature, but little attempt was made in discussing how this is interpreted in end of life care (“Support Directed at Carer”). Often thought of as ‘patient-centred’, ‘whole-person’ and ‘whole situation’, the holistic model recognises that changes or disturbances to either the mind, body or spirit can have an overall effect on the health and quality of life of an individual (patient) and the family (usually carers). However, there was little engagement in how it can be universally standardised to help hospice at home services be responsive in providing supportive palliative care.[59] Care-coordination is also recognised as an important part of end of life care services (“Service Responsiveness and Availability”). A recent UK national policy framework addresses what building blocks should be in place for care to be coordinated.[60] These include: shared records, clear roles and responsibilities, a system-wide response, with local systems of care putting the widest range of people at the centre, as well as continuity in partnership. The extent to which services are able to identify and put these elements in place is yet to be evaluated (“Integration and Co-ordination”).

Non-hospice at home healthcare professionals such as GPs and district nurses were potentially central in determining location of care and preferred place of death (PPD) (“Knowledge and Skills of Care Providers), yet GPs and district nurses often regard other healthcare professionals as having greater responsibility in initiating such discussions, frequently leaving hospice staff as the bearers of bad news in situations where other healthcare professionals have neglected to give patients any warning.[61] This points to the need for more palliative care training in general medical settings, including the importance of discussing PPD with patients where possible as it increases their sense of control, enhances trust and rapport between patients and clinicians contributing to holistic care.[61]

An underlying theme that emerged from the evidence was that of inter-professional collaboration to provide integrated clinical care (“Integration and Co-ordination”). Hospice at home services are dependent upon partnerships across health and social care agencies. Yet, it is precisely the structural and organisational factors that are a catalyst and a barrier to seamless care being delivered by hospice at home services. Bliss et al have noted that given the level and number of multiple organisations involved, the broad types of service availability and differing lines of accountability, has meant providing seamless care is challenging. Further research is required to explore the barriers and facilitators to inter-professional working across organisations (“Service Responsiveness and Availability”).[62]

The value of advance care planning (ACP) was also a repeating theme found in our review. ACP allows patients to express their wishes for care prior to sudden deterioration, providing them with supported care options and inclusion in the decision-making process (“Anticipatory Care”). A co-ordinated team-based approach with a clearly identified population at risk of hospitalisation, can reduce admission rates leading to an increased likelihood of patients being allowed to die at home (“Criteria for Service Admission”).[63] Discussions around ACP are a valuable aid, yet, patients’ ACPs need to be recorded electronically so that the information is available to emergency services, primary care and hospitals. Electronic records provide an ideal system for sharing key information about future care plans, but need to be accessed and used by professionals in primary and secondary care and regularly updated. We did not find evidence of ACPs being recorded electronically or having a shared electronic database of patient records (“Anticipatory Care”).[64]

Strengths and Limitations of the review

We have presented a broad picture of hospice at home models that work, for whom and in what circumstances. However, we were only able to use the evidence that was available in the published and grey literature. The published evidence included in our review was only as good as the evidence available, and may be limited in terms of its value in contributing into further understanding the key contextual and background issues.

Implications for policy, future practice and research

A systematic literature search and review of hospice at home services has been presented focusing upon which models work best, for who and under what circumstances. A realist logic of analysis was applied to help analyse and interpret a diverse body of literature, which was coded deductively, inductively and retroductively. Key areas to be taken into account for policy considerations include promoting the sustainability of a service supported through local and national cross-collaboration partnerships, with local policy activity aimed at increasing the hospice at home service's profile with patients and healthcare professionals.

For future clinical practice, commissioners and healthcare professionals require further exposure to understanding the value hospice at home services undertake in providing specialist palliative care skills and knowledge, appreciating the complexities around navigating local health systems, and ensuring that suitable and timely referrals are made to services. The importance of supporting carers and patients with appropriate service arrangements, available staff as well as having anticipatory care in place was highlighted.

Gaps for future research include the need for a clearer understanding of the referral categories, training for GPs and community nurses in assessing palliative care needs, better care co-ordination, and lastly, meaningful engagement activity with stakeholders involved in EOLC service delivery to ensure partnership working and sustainability. The latter of which will be addressed through our ongoing national realist evaluation of hospice at home services.[13]

Conclusion

Our literature review showed how it was possible to develop a coherent framework and test it against 34 published papers and abstracts. Unlike systematic reviews which focus primarily on methodological design and research outcomes, central to this review was theory building, and our programme theories provide a framework that can be built upon as further evidence emerges. Future work should include exploration and refinement of these eight programme theories through consideration with other theories, and tested against new data from empirical studies.[32]

Authorship

With respect to the authorship of this article: FH, CBr, CB undertook the review, CBr conducted the search, PW provided methodological guidance, FH, CBr, CB analysed / interpreted the evidence, FH and CBr wrote the first draft, PW provided feedback on the first draft; all authors contributed to drafts and approved the final version.

Declaration of conflicts of interest

The Authors declare that there is no conflict of interest.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

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Figure 1: Search method

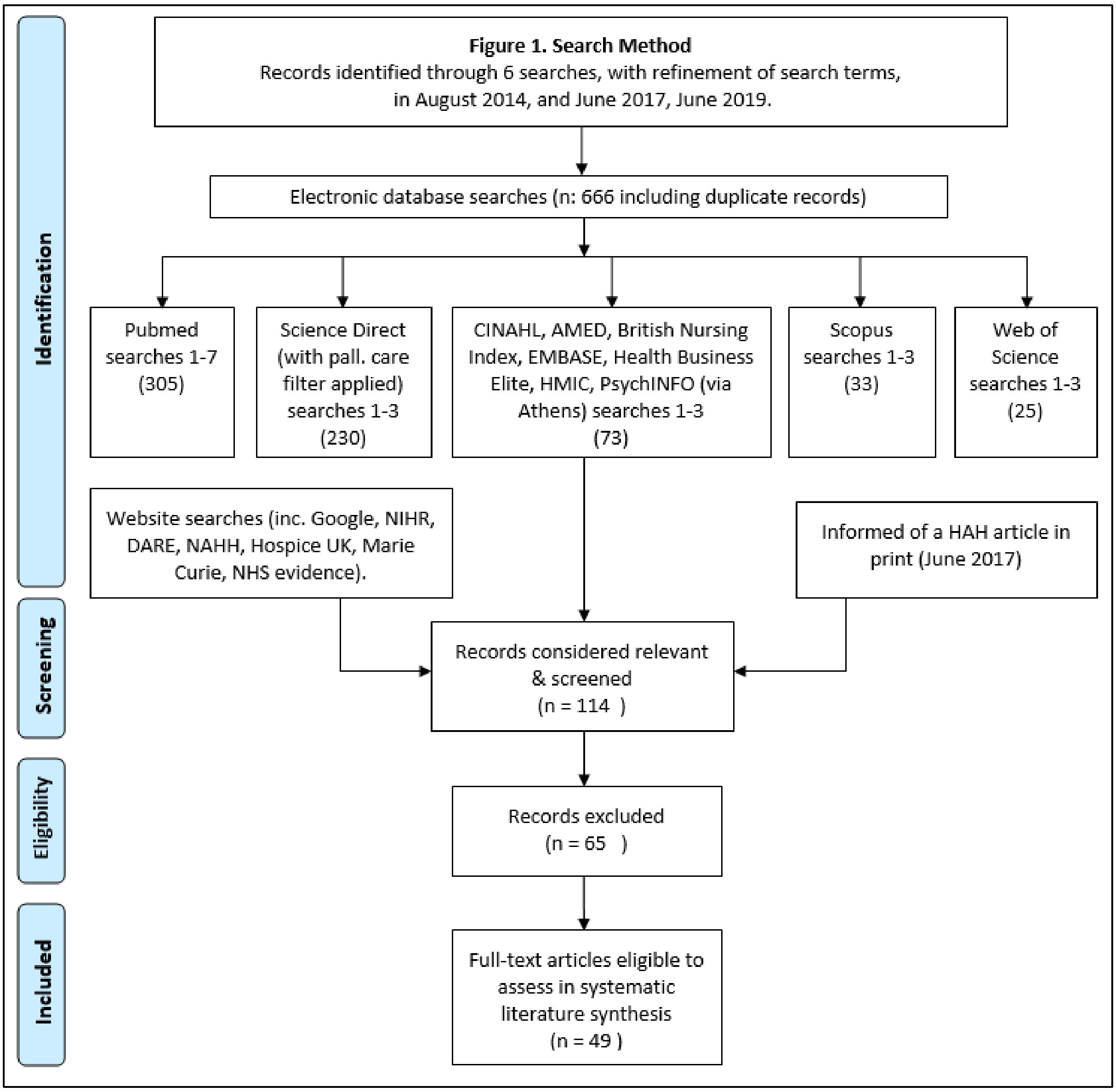

Figure 2: Assessment of the literature following data extraction

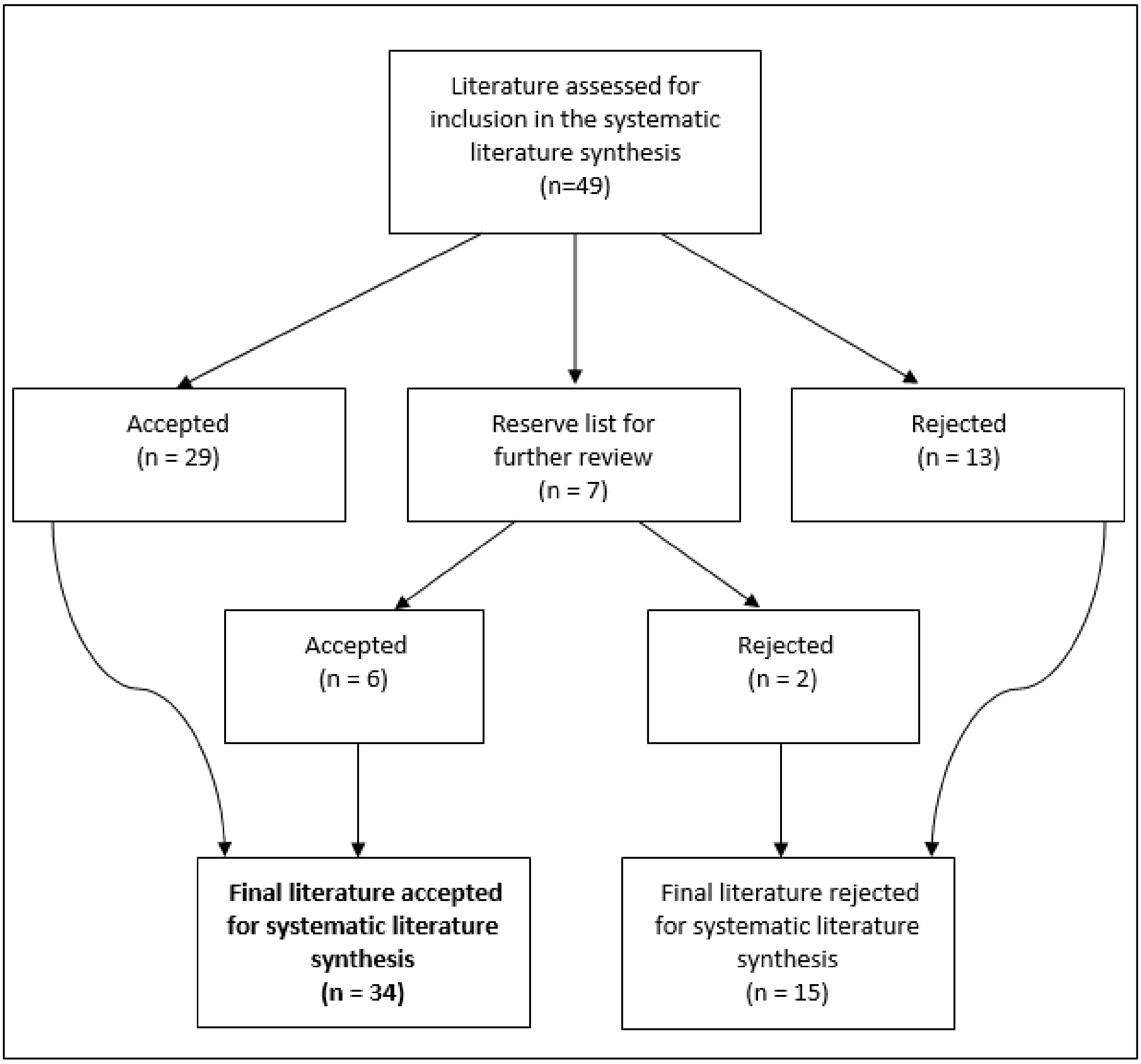

Table 1 NAHH core standards (Bell et al 2013)

Standard Number	Statement
1	The hospice-at-home service has a workforce management, education and development strategy that ensures the competence and confidence in practice of its employees to deliver and support high-quality clinical services
2	The hospice-at-home service is integrated into the local end-of-life care service provision and involved in providing coordinated care for patients and families
3	The hospice-at-home service clearly defines and communicates referral criteria and pathways to all referrers, key stakeholders and other partners
4	The hospice-at-home service ensures that any patient, and their families and carers, receive the service information required to enable them to make informed choices in relation to their preferred place of care and support, including at the end of life
5	The hospice-at-home team's care and support service, in partnership with other agencies, meets the assessed needs of patients, carers and families
6	The hospice-at-home service has systems and processes to ensure pre-and post-bereavement support for patients (where appropriate), carers and families

Table 2: Developing Initial Programme Theories: Normalisation Process Theory (NPT)[a] & National Association for Hospice at Home (NAHH) Core Standards

NPT Construct 1: Sense-making (coherence)		**NAHH Core Standards (Outcomes)**	**Initial Programme Theories**
'*Sense-making'* is the work that people do individually and collectively when they are faced with the problem of operationalising some set of practices	1. Distinguish H@H as discrete from other EOLC delivery services	3	Commercial commodity (funding to sustain service, clear communicated access, criteria for referral to service)
	2. All agree about the purpose of the H@H model or service	2, 5	Support directed at the career as well as the patient, e.g. training, assessment by staff, and support from family and volunteers
	3. Individually understand what the H@H service requires of them	3	Integration & co-ordination (single point of access),Communication Commercial commodity (funding to sustain service, clear communicated access, criteria for referral to service)
	4. Construct potential value of the H@H service of their work	3, 5	Commercial commodity (funding to sustain service, clear communicated access, criteria for referral to service) Support directed at the career as well as the patient, e.g. training, assessment by staff, and support from family and volunteers
NPT Construct 2: Buy-in (cognitive participation)			
'Buy-in' is the relational work that people do to build and sustain a community of practice around a new technology or complex intervention	5. Key individuals drive the H@H service forward	3	Integration & co-ordination (single point of access) Communication
	6. Agree that the H@H service should be part of their work	2	Integration & co-ordination (single point of access) Communication
	7. Buy into the H@H service	1, 2	Extended roles and skills (communication), marketing Integration & co-ordination (single point of access) Communication
	8. Continue to support the H@H service	1, 2	Extended roles and skills (communication), marketing

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[a] May et al 2011, 'Evaluating complex interventions and health technologies using normalization process theory: development of a simplified approach and web-enabled tool kit'. *BMC Health Services Research*, 2011.

			Integration & co-ordination (single point of access) Communication
NPT Construct 3: Doing (collective action)			
'Doing' is the operational work that people do to enact a set of practices, whether these represent a new technology or complex healthcare intervention	9. Perform tasks required by the H@H model or service	1, 5	Extended roles & skills, training & support of clinical staff & other support (e.g. volunteers) Responsiveness (access and availability). Anticipatory care in place, integration & co-ordination of services
	10. Maintain trust in each other's work and expertise through the H@H	1, 5	Extended roles & skills, training & support of clinical staff & other support (e.g. volunteers) Support directed at the career as well as the patient, e.g. training, assessment by staff, and support from family and volunteers
	11. Work of the H@H model or service is allocated appropriately	1, 2	Extended roles & skills, training & support of clinical staff & other support (e.g. volunteers) Integration & co-ordination (single point of access) Communication
	12. The H@H service is adequately supported by host organisation	5	Responsiveness (access and availability). Anticipatory care in place, integration & co-ordination of services
NPT Construct 4: Appraisal (reflexive monitoring)			
'Appraisal' is the monitoring work that people do to assess and understand the ways that a new set of practices affect them and others around them	13. Access information about the impact of the H@H service	6	Commercial commodity (funding to sustain service, clear communicated access, criteria for referral to service)
	14. Collectively assess H@H service as worthwhile	6	Commercial commodity (funding to sustain service, clear communicated access, criteria for referral to service)
	15. Individually assess the H@H service as worthwhile	6	Commercial commodity (funding to sustain service, clear communicated access, criteria for referral to service)
	16. Modify their work in response to appraisal of the H@H service	6	Commercial commodity (funding to sustain service, clear communicated access, criteria for referral to service)

Table 3 Mapping of emerging programme theories

Theory area	Initial Programme Theory	Components from IPT adapted for data extraction form	Proposed Programme Theory*
1	Integration & coordination (single point of access). Communication	Integration and coordination of all services providing care for the patient	CMO 1: “Sustainable Funding” CMO 6: Integration and co-ordination
2	Extended roles and skills, training & support of clinical staff and other support (e.g. volunteers)	Knowledge and skills of clinical staff	CMO 5: Knowledge and skills of care providers
3	Extended roles and skills (communication) , marketing	Patient information and choice	CMO 2: Marketing and referral CMO 4: Criteria for service admission
4	Responsiveness (access and availability). Anticipatory care in place, integration & coordination of services.	Access and availability of staff, equipment and resources	CMO 3: Service responsiveness and availability CMO 7: “Anticipatory care”
5	Support directed at the carer as well as the patient, e.g. training, assessment by staff, and support from family and volunteers	Carer assessment and support	CMO 5: Knowledge and skills of care providers CMO 8: Support directed at the carer
6	Commercial commodity (funding to sustain service, clear communicated access criteria for referral to service)	Marketing and access to the service	CMO 1: “Sustainable Funding” CMO 2: Marketing and referral

* Eight CMOs were finalised as of 14th August 2017 following a stakeholder meeting where evidence from NAHH standards and phase 1 survey was discussed on 10th August 2017.

Table 4 Stakeholder Involvement in Refining CMOs

Stakeholder Activity	Date	Stakeholders involved	Theory Refinement Focus
Stakeholder workshop, London	30/3/2017	NHS England Clinical Lead in Palliative Care General Practitioner Hospice CEO Patient and Public Involvement Representatives Academics / researchers	NPT & realist evaluation & NAHH standards
		From feedback of stakeholders	CMO version 1 (8/6/2017) created following meeting of 30/3/2017
Stakeholder workshop, Canterbury	10/6/2016	Researcher & former palliative care nurse Clinical Lead in Palliative Care General Practitioner Hospice CEO Patient and Public Involvement Representatives Academics / researchers	Discussion of NPT, NAHH standards & CMO version 1
		From feedback of stakeholders From feedback of stakeholders	CMO version 2 (updated following meeting of 10/6/2016) CMO version 3 (3/8/2017)
Stakeholder workshop, London	10/8/2017	NHS England Clinical Lead in Palliative Care Hospice CEO Patient and Public Involvement Representatives Academics / researchers	Discussion of NPT, NAHH standards & CMO version 3
		From feedback of stakeholders From feedback of stakeholders	CMO version 4 (updated following meeting of 10/8/2017) CMO version 5 (17/8/2017)
Stakeholder workshop, London	15/1/2018	Clinical Lead in Palliative Care General Practitioner Patient and Public Involvement Representatives Academics / researchers	Discussion of CMO version 5

		From feedback of stakeholders	CMO version 6 (updated following meeting of 15/1/2018)
Stakeholder workshop, London	25/6/2018	NHS England Clinical Lead in Palliative Care General Practitioner Hospice CEO Patient and Public Involvement Representatives Academics / researchers	CMO version 7 (updated following meeting of 25/6/2018)

Table 5 Author, topic and research focus of papers included in the review

	Author	Locality & country of origin	Topic	Research focus
1	Addicott and Dewar (2008)	Lincolnshire, England	Impact and costs of Marie Curie delivering choice programme	Report of descriptive analysis of the impact and costs of new services, focusing on the Marie Curie Delivering Choice programme.
2,3	Addington-Hall et al (2012abstract & 2013report)	England and Scotland	Out of hours end of life care provision	Mixed methods study with senior managers and key informants involved in commissioning, providing or responsible for end of life care or out of hours care. 50% of Primary Care Organisations were sampled.
4,5	Baldry et al (2011abstract & 2011paper)	North West England	Evaluation of a pilot hospice at home service	Retrospective cohort study and stakeholder evaluation during a one year pilot study of a bespoke hospice at home service.
6,7	Buck et al (2014abstract & 2018paper)	Cambridgeshire, England	Nature, scope and identification of equality in provision	A mixed methods study (case review and qualitative interviews) on the nature and scope of a new hospice at home service; later paper has a focus on persistent inequality in provision.
8	Butler et al (2012)	East Kent, England	Evaluation of a hospice rapid response community service	A pragmatic quasi-experimental controlled trial using postal questionnaires sent at patient intake to the hospice service and eight months later. Carers' perceptions of care received and patients' death assessed in one-to-one interviews. Service utilization costs collected compared to usual care.
9	Butler and Holdsworth (2013)	East Kent, England	Set up of new evidence-based hospice at home service	This paper summarises the results of a literature review and then describes the new service that was established including setting and context.
10	Campbell et al (2010)	North West England	Socio-economic status and other key demographic indicators associated with referral and access	This paper provides descriptive analysis of profiled electoral ward characteristics using simple correlations and regression modeling

				estimated associations with referral rates.
11	Exley and Tyrer (2005)	East Midlands, England	Bereaved carers' views	A qualitative study using semi-structured interviews to explore bereaved carers' views and experience of a hospice at home service.
12	Gage et al (2015)	East Kent, England	Impact of a hospice rapid response service	This paper reports on data (demographic, preferences for place of death, service use data) comparing the characteristics of a rapid response service (RRS), dying in the place of choice and monitoring service utilization and costs of users and non-users.
13	Grady and Travers (2003)	Glasgow, Scotland	Evaluation of a crisis intervention (second of a linked paper with Travers and Grady 2002)	The article presents the evaluation of the service for patients with advanced cancer. Use of mixed methodology to measure and evaluate process and outcomes.
14	Grande et al (1999)	Cambridge, England	Evaluation of impact on place of death	This article presents an evaluation of the impact of place of death on a hospital at home service in a pragmatic randomized controlled trial.
15	Grande et al (2002)	Cambridge, England	Referrals to hospice provided 'hospital at home' service	A study comparing cancer patients referred to hospital at home service for palliative care with cancer patients not referred who died within the same period.
16	Grande et al (2004)	Cambridge, England	Caregiver bereavement outcomes	A randomized controlled trial designed to investigate the impact of a hospice at home service on caregiver bereavement outcomes.
17	Holdsworth et al (2015)a	East Kent, England	Impact of rapid response service	A quasi-experimental controlled evaluation of the impact of a hospice rapid response community service for end-of-life care on achievement of preferred place of death
18	Holdsworth et al (2015)b	East Kent, England	End-of-life experiences from bereaved carers' perspective	A qualitative study with bereaved family carers who received care from a new rapid response hospice at home service.

19	Jack et al (2010)	West Lancashire /Southport & Fornby, England	Evaluation of Marie Curie Delivering Choice programme	A report of a mixed methods evaluation involving documentary analysis, focus groups & interviews and a descriptive survey of health care professionals.
20	Jack et al (2013)	North West England	Healthcare professionals' perspectives of individually tailored hospice at home service	This qualitative evaluation study used a variety of tools including interviews, focus groups and an open-ended electronic survey of healthcare professionals.
21	Jack et al (2014)	North West England	Bereaved family carers' experiences	A qualitative study to explore family carers' perceptions and experiences of the hospice at home care service.
22	Jack et al (2016)	North West England	Patient and family caregiver experiences	A qualitative study to explore patients' and family caregiver experiences and perceptions of the hospice at home care.
23	King et al (2000)	Highlands, Scotland	Evaluation of a rapid response service.	Descriptive evaluation analysing documentary and activity data, hospital records. Case by case questionnaires & focus group with service providers. Interviews with carers.
24	Lucas et al (2008)	Bradford, England	Evaluation of the service from the perspective of carers, nurses and GPs	An evaluation using postal questionnaires sent to carers, district nurses and GPs using the hospice at home service.
25	McLaughlin et al (2007)	Northern Ireland	Explored bereaved carergivers' experiences	A postal survey sent to bereaved caregivers to explore their experiences of a hospice at home service, undertaken as part of an audit in 2002.
26	Payne et al (2008)	Lincolnshire, England	Evaluation of Marie Curie Delivering Choice programme	A report of a mixed methods formative evaluation drawing data from multiple perspectives.
27	Purdy et al (2014)	Somerset & North Somerset, England	Impact of Marie Curie Delivering Choice programme	A retrospective cohort study of eligible palliative care patients who died over 6 months. Quantitative data was collected on the use of the Delivering Choice services.
28	Sullivan et al (2005)	Northern Ireland	District nurses' experiences of the service	A survey of DNs with previous experience of the hospice at home service. The evaluation focused on satisfaction levels of DNs gathering both

				quantitative and qualitative data.
29	Todd et al (2002)	Cambridge, England	GPs and DNs' views of the service	A postal survey of GPs and DNs, whose patients were potential users of the hospice at home service. Topics covered: referrals, benefits, access to and quality of care.
30	Travers and Grady (2002)	Glasgow, England	Development of a crisis intervention (first of a linked report with Grady and Travers 2003)	The paper provides an overview of relevant literature and describes the development of the 'hospice at home' service.
31	Waight and Noble (2018)	Surrey, West Sussex and Hampshire, England	Consultant-led palliative care community team providing care at home	The evaluation was undertaken to determine whether the service had met its original aims in the provision of palliative care.
32	Wilson et al (2015)	South Yorkshire, England	Evaluation of palliative care and hospice at home service	A qualitative study using focus groups to explore the views of stakeholders including healthcare staff and service users, of an expanded hospice at home service.
33	Wye at al (2012)	Somerset and North Somerset, England	Evaluation of Marie Curie Delivering Choice programme	The evaluation collected and analysed quantitative data from routine sources (on deaths and hospital service usage) and 'realistic evaluation' methodology.
34	Wye et al (2014)	Somerset and North Somerset, England	Results of a realist evaluation of palliative care services	An evaluation of end of life care services including coordination centres and telephone advice line using realist evaluation collecting quantitative routine data, documentation, observations of services and interviews with family carers and professionals.

Table 6 Summary Findings for each CMO from the Reviewed Evidence

Research Question: In the existing literature what features of HAH models work best, for whom and under what circumstances?

CMO	Summary proposition
Marketing and Referral	Evidence from the literature indicated that if HAH services actively marketed its service to healthcare professionals and the public through clinical and public engagement through improved marketing and referral strategies (Context), this would trigger increased awareness and visibility of the HAH service (Mechanism). This would lead to patients equitably receiving a more timely HAH service (Outcome).
Sustainable Funding Model	The synergy created through collaboration and partnership working between commissioners and stakeholders (Context) promoted an integrated and agile service offering clinical expertise and enabling sustainability in the operation of the HAH service (Mechanism). HAH services were able to provide a sustainable service in order to continue its operation despite changes in local and national policy (Outcome).
Service Responsiveness and Availability	We found that if there are suitable arrangements in place for accessing medications and trained staff, underpinned by a whole package of continuous care that included rapid response, with ongoing availability of support from staff and access to equipment and medications (Context), the HAH service would be responsive to patient choice (Mechanism), leading to an increased likelihood of carers and patients continuing with using the HAH service (Outcome).
Criteria for Service Admission	We found that if HAH services had robust referral criteria for identifying suitable patients, and were able to communicate to carers and patients the length of time it would take a referral to be dealt with (Context), then carers and patients would know what to expect in terms of the care input (Mechanism), which would lead to less patients requiring emergency admissions, and enhanced discharge from hospital (Outcome).
Knowledge and Skills of Care Providers	We found that if palliative care training was available for all HAH and non-HAH staff, including further training for supporting extended role activities (Context), then GPs would recognise the value of HAH staff having specialist palliative care knowledge and skills to navigate the complex health system (Mechanism). The outcome would be that carers and patients would receive the quality of care and respect to uphold patient choice (Outcome).
Integration and Co-ordination	Within a context of substantial multiagency collaboration between different NHS partners and the HAH services (Context), greater service co-ordination between HAH services and relevant agencies would help to overcome issues around access and administration of medicines underpinned by use of shared electronic records (Mechanism). The resultant outcome would be continuity of care, timely and appropriate HAH service provision, and less emergency hospital admissions (Outcomes).
Anticipatory Care	We hypothesised that if there are arrangements in place for anticipatory prescribing, equipment and care planning (Context), underpinned by good 24 hour communication between healthcare professional (shared IT

	systems) (Mechanisms), the outcome would be that patients would receive the care they needed in their preferred place of care, with a reduction in unplanned admissions (Outcome).
Support Directed at Carer	With a holistic understanding of carer needs, including an assessment by a multidisciplinary team involving the carer and HAH staff (Context), then carers will receive the practical and emotional support to be mentored to use equipment, undertake key tasks, and receive support through a crisis (Mechanism). The outcome would lead to carers being able to continue to provide sustainable care at home to patients, and enabling services to understand what carers may need in terms of an additional assessment or support (Outcomes).