

openheart Integrating palliative care and heart failure: a systematic realist synthesis (PalliatHeartSynthesis)

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ABSTRACT

Objectives (1) Develop a programme theory of why, for whom and in what contexts integrated palliative care (PC) and heart failure (HF) services work/do not work; (2) use the programme theory to co-produce with stakeholders, intervention strategies to inform best practice and future research.

Methods A systematic review of all published articles and grey literature using a realist logic of analysis. The search strategy combined terms significant to the review questions: HF, PC and end of life. Documents were included if they were in English and provided data relevant to integration of PC and HF services. Searches were conducted in November 2021 in EMBASE, MEDLINE, PsycINFO, AMED, HMC and CINAHL. Further relevant documents were identified via monthly alerts (up until April 2023) and the project stakeholder group (patient/carers, content experts and multidisciplinary practitioners).

Results 130 documents were included (86 research, 22 literature reviews, 22 grey literature). The programme theory identified intervention strategies most likely to support integration of PC and HF services. These included protected time for evidence-based PC and HF education from undergraduate/postgraduate level and continuing professional practice; choice of educational setting (eg, online, face-to-face or hybrid); increased awareness and seeing benefits of PC for HF management; conveying the emotive and intellectual need for integrating PC and HF via credible champions; and prioritising PC and HF guidelines in practice.

Conclusions The review findings outline the required steps to take to increase the likelihood that all key players have the capacity, opportunity and motivation to integrate PC into HF management.

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INTRODUCTION

Heart failure (HF) is now referred to as a modern-day epidemic across the world, with similar prevalence rates as the leading forms of cancer.^{1 2} The number of people living with HF will continue to increase with an ageing population,^{3 4} as HF mostly affects older people (those over the age of 65 years). In addition, due to advancements in drugs, device and surgical interventions,⁵ there has

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Despite over two decades of research and clinical guidelines calling for integration of palliative care (PC) into heart failure (HF) management, this is still difficult to achieve in practice.

WHAT THIS STUDY ADDS

⇒ This synthesis outlines strategies around what works, for whom and in what circumstances when integrating PC into HF management.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This synthesis provides practical implications for practice and recommendations for policy and future research. Integration of PC into HF management is more likely to work when service providers are motivated to integrate services and have the right opportunities and capabilities to support integration.

been a decline in the number of patients with HF experiencing a sudden death. This causes high levels of chronic physical, psychological and social burden on patients and their informal carers.⁶⁻⁹ The impact on healthcare service costs is also substantial.^{10 11}

Integrating palliative care (PC) and HF services offers a practical, effective solution to many of these issues, including the relief of physical, psychological and social burden via holistic care^{12 13} and reduced healthcare costs from avoiding unnecessary hospital visits and inpatient time.¹⁴⁻¹⁷ PC aims to 'improve the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.¹⁸ HF services focus on ameliorating HF symptoms such as breathlessness, oedema and fatigue through optimising medication and supporting people to self-manage their HF. PC and HF services work together towards a shared goal

of care to alleviate HF symptoms and address PC needs which impact on a patient's quality of life, including physical, spiritual and psychosocial issues, as part of an advanced care plan so that their needs and wishes are clearly documented by all those involved in their care.

Research on integration of PC and HF has been on the rise since the turn of the century, increasing from on average 10 publications in 2000 to over 100 publications per year in 2017, with calls for PC and HF integration also included in clinical guidelines.^{19 20} However, three systematic reviews published between 2017 and 2020^{21–23} have highlighted the urgent need for research on how best to embed integrated PC and HF care in practice given the cultural and environmental contexts in which PC and HF services are delivered.

Challenges to integration persist and can be partly explained by patient and practitioner misunderstanding of PC as only applicable at end of life^{7–9 24} and fragmentation of inpatient and outpatient services.²⁵ Promising examples of integrated PC and HF interventions exist,^{26 27} but differ vastly across countries and healthcare settings, employing different mixes of multidisciplinary teams, modes of delivery and intervention components. As a result, it is making it difficult to determine what works, for whom and in what circumstances for successful integration of PC and HF.²⁸

This systematic review of the literature employed a realist synthesis which is designed to answer these questions, thereby providing a way to understand and develop key intervention strategies to bridge the long-standing gap between evidence and implementation into practice. The added value of the realist approach includes the inclusion of a diverse range of international evidence, from trials and other studies, policy documents, clinical guidelines and expert opinion. Given the ever-increasing global incidence of HF and overwhelming benefits of integrating PC, this review is both important and timely to add the missing piece of the puzzle—identifying why it has been so difficult to integrate PC and HF services, and most importantly, to offer solutions.

METHODS

The purpose of programme theory is to understand what works for whom, in what circumstances, how and why when integrating PC and HF services. To do so, we used a realist synthesis approach.²⁹ While standard meta-analysis aims to determine statistical power through amalgamating small study effect sizes, realist synthesis is a theory-driven approach, commonly used in health sciences for understanding existing diverse sources of evidence relating to complex interventions.³⁰ The methodology followed Pawson's³¹ five iterative stages for realist synthesis: (1) locating existing theories, (2) searching for evidence, (3) selecting documents, (4) extracting and organising data, and (5) synthesising the evidence and drawing conclusions. The review ran for 22 months, from September 2021 to June 2023. The protocol was registered on PROSPERO

(registration number CRD42021240185), published in *BMJ Open*³² and follows the Realist And Meta-narrative Evidence Syntheses: Evolving Standards quality standards for realist synthesis.²⁹

Patient and public involvement

Our patient and public involvement (PPI) partners were involved throughout all stages of this review and coauthored this finding's publication (JB, BJ, BR). They helped shape the plain English summary and review questions for the project funding application. Once funded, PPI representatives contributed to stakeholder meetings, which involved 32 international participants including specialist HF nurses, cardiology and PC consultants, policymakers and researchers. PPI partners helped to develop and refine our programme theory based on their lived experience, reviewed and contributed to project outputs, to ensure they met the needs of patients and the wider public. They also provided input and support for our dissemination strategy, sharing core outputs (blogs and animation of review results—see <https://palliatheart.synthesis.co.uk/>) with relevant cardiovascular and HF patient groups.

Data sources

The first stage of the review included exploratory searches to locate key literature sources and any relevant existing theories. Exploratory searches were carried out on MEDLINE using key terms for PC and HF. Drawing on the literature identified in the informal searches and the project team's experiential and content knowledge, a 'preliminary' initial programme theory was developed to explain how integrated PC in HF management may work, and the core mechanisms which generate its outcomes. In November 2021, CD (information specialist) conducted formal database searches in: MEDLINE (via Ovid), EMBASE (via Ovid), PsycINFO (via Ovid), AMED (via Ovid), HMIC (via Ovid) and CINAHL (via EbscoHost), and results were exported to EndNote V.X9 (Clarivate Analytics, Philadelphia, Pennsylvania, USA). Grey literature was identified via simplified searches on Google, OpenGrey and the National Institute for Health and Care Excellence Evidence search website (see online supplemental file 1). Monthly alerts were set up using Google Scholar using the terms "heart failure", "palliative care" and "end of life". The only change to the protocol³² was the omission of forward citation searching, as the large volume of documents retrieved did not necessitate additional searching.

Study selection

The initial inclusion and exclusion criteria for the review were deliberately broad as we aimed to identify all relevant quantitative, qualitative, mixed-methods and non-empirical documents relating to HF and PC:

- ▶ Focus on PC for adult patients (18 years and over) with HF.

- ▶ Any combination of PC strategies for the management of patients with HF.
- ▶ Any healthcare setting (inpatient, outpatient, home-based).
- ▶ Any study design and non-empirical data (eg, from opinion/commentary pieces) which helped direct/shape theory development.
- ▶ English language.
- ▶ Documents from 2000 onward in line with early reports of integrated PC and HF.

Progressive focusing during the initial screening process resulted in additional inclusion criteria. For example, our initial programme theory and stakeholder feedback indicated that we should focus on healthcare professional (HCP) perspectives, as the key barriers to integrating care largely involve human behaviour in response to underlying processes (motivation, etc) shaped by the contexts in which HCPs operate. Returns from the searches were screened in three stages: by title and abstract; in full text; and finally, full texts were only included if they contained relevant data of sufficient rigour. Screening was conducted by CH, and a random 10% subsample was checked by TM for systematic errors.

Data extraction

Full-text documents were uploaded into NVivo (V.12, 2018), with initial coding undertaken by CH and CB, and a random 10% independently checked by TM and JR. Coding was inductive (codes emerging through data analysis) and deductive (codes determined prior to analysis through initial programme theory and stakeholder discussions). The coding framework was refined as the analysis progressed. We used deductive coding because we had an initial programme theory that contained our embryonic understanding of the important data that we would need to capture to test (confirm, refute or refine) our initial programme theory. We also used inductive coding as doing so would enable us to capture new concepts or themes that are derived from the data. This meant that we would not 'miss' anything new or different 'coming from' the data if we had only used deductive coding. We identified relevant contexts in which mechanisms were likely to be 'triggered', such as a shared understanding that PC in HF management positively contributes to optimised quality of life. Such contexts and mechanisms became 'codes'. Data extraction for each included document also included participant characteristics, study characteristics and implications (see online supplemental files 2–4). The same quality assurance process described above was replicated for data extraction.

Analysis and synthesis

The analysis was driven by a realist logic³³ using the data coded in NVivo to draw relationships between context, mechanism and outcome configurations (CMOCs),³⁴ and to further develop our initial programme theory. Using a realist logic of analysis provides a way to interrogate theory with data and to use theory to understand patterns

in the data to further refine the programme theory. A realist logic of analysis was also used as it informs the way that causal explanations are expressed in a realist review—namely when this context is present, it triggers this mechanism which in turn causes this outcome. Such causal explanations are called CMOCs and go to make up a programme theory.³⁰ The evidence synthesis process was achieved using the below analytical processes:

- ▶ Data reported in different documents were compared and contrasted.
- ▶ When outcomes differed in seemingly comparable circumstances, further investigation was undertaken to find explanations for why different outcomes happened.
- ▶ When findings from different documents had similarities, a judgement was made as to whether these similarities could adequately form patterns to inform the development of CMOCs and programme theory.

We used the Capability, Opportunity, Motivation, Behaviour (COM-B) model³⁵ to help identify interventional strategies needed to produce desired behaviours and avoid undesired behaviours. This behaviour change model was considered helpful for framing the review findings, as successful implementation of integrated PC and HF can be essentially explained by HCPs' capabilities, opportunities and motivation (or lack of) to integrate care.³⁶

RESULTS

In total, 1768 records were identified through database searching and screened, with 1076 documents meeting the initial inclusion criteria. Progressive focusing reduced the original 1076 to 140, with a further 48 removed based on exclusion criteria. A further 38 relevant documents were identified from alerts (n=27) and stakeholder documents (n=11). In total, 130 documents were included in the review (see figure 1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020 flow diagram for new systematic reviews, and online supplemental file 5 for CMOC per study).

The majority of documents were from the USA (36%; n=46 of 130) and a smaller number in the UK (26%; n=34 of 130). The majority focused on a combination of HCPs, patients and informal caregivers (37%; n=48 of 130), on physicians (of different specialties) (6%; n=8 of 130), nursing staff (6%; n=8 of 130) and a minority on general practitioners (1%; n=1 of 130). Publication date ranged from 2000 to 2022, with the majority published between 2011 and 2021 (69%; n=90 of 130). Most documents were research (66%; n=86 of 130), including qualitative work (29%; n=37 of 130), survey designs (15%; n=19 of 130), literature reviews (17%; n=22 of 130) and a small number of clinical trials (4%; n=5 of 130). Most documents focused on barriers and facilitators to PC in HF management (72%; n=94 of 130), but some focused on aspects of integrated service design or tools to assist PC needs assessment (10%; n=13 of 130).

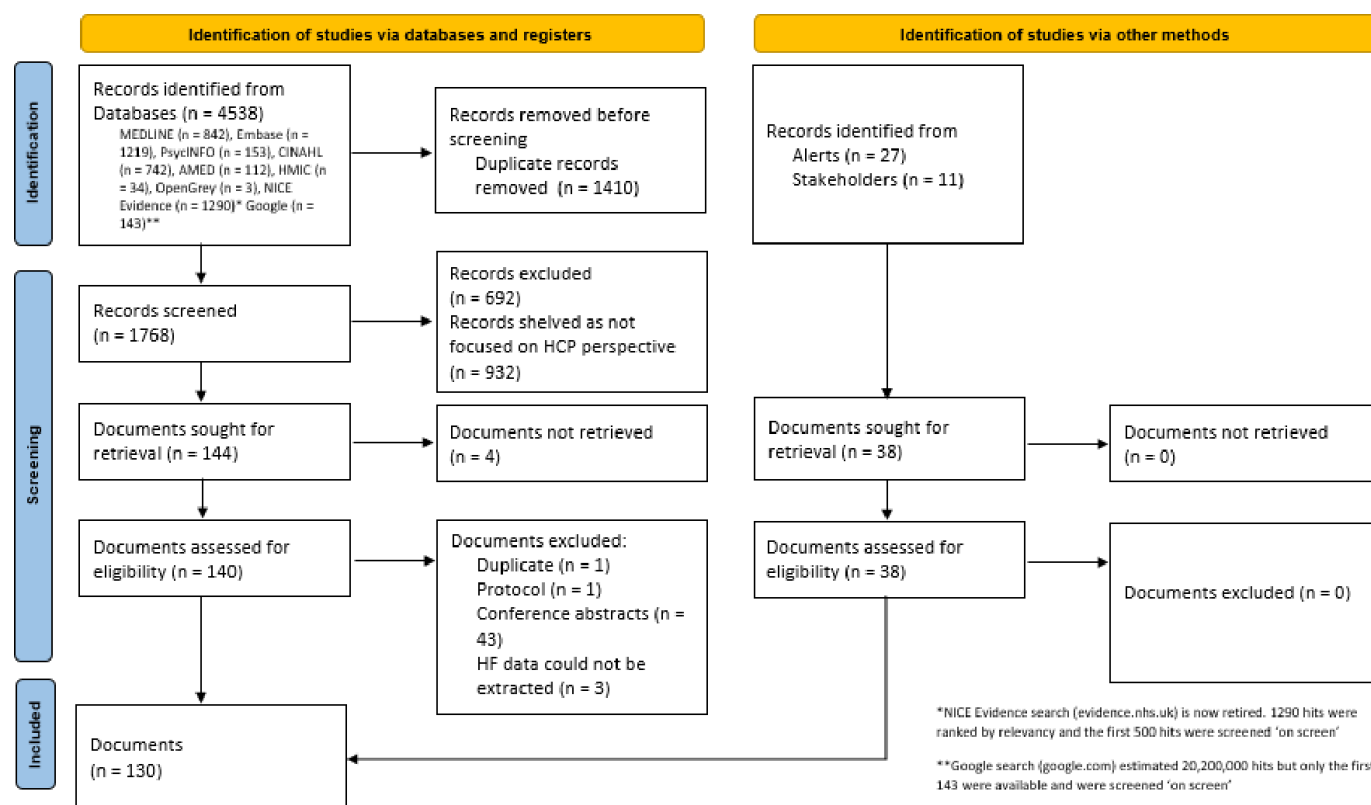


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020 flow diagram for new systematic reviews reproduced with permission from Page *et al.*³⁷ This is an open-access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited (see: <http://creativecommons.org/licenses/by/4.0/>). The figure includes minor additions and formatting changes to the original figure. *Nice Evidence search (evidence.nhs.uk) is now retired. One thousand two hundred ninety hits were ranked by relevancy and the first 500 hits were screened 'on screen'. **Google Search (google.com) estimated 20 200 000 hits, but only the first 143 were available and were screened 'on screen'. HCP, healthcare professional; HF, heart failure; NICE, National Institute for Health and Care Excellence.

The realist analysis yielded six overarching CMOcs with 30 sub-CMOcs grouped into three key clusters (see online supplemental file 5 for CMOcs and references to all 130 included documents). Illustrative data (eg, extracts from included documents) which show how we made our interpretations and inferences for each of the CMOcs can be shared upon request. As key barriers to integrating care largely involve human behaviour in response to underlying processes shaped by the contexts in which key players operate, the COM-B behaviour change model, which includes the core determinants of behaviour (capability, motivation and opportunity), provided a useful framework for presenting the review findings. See figure 2 for an overview of intervention strategies by COM-B component, and the relevant CMOc(s) which address each strategy. References for each CMOc can be found in online supplemental file 5.

Capacity

According to the 'capacity' component of the COM-B model,²⁸ individuals must believe they have the required knowledge and skills to carry out a behaviour. Unsurprisingly, education was a key intervention strategy for providing key individuals with the required knowledge and skills to

overcome many of the key blockages to integrated care identified in the literature. These challenges included a biomedical culture (CMOc 1–1.1), professional misunderstanding of terminology which equates PC with end-of-life care (CMOc 1.2–1.5), complexities of the HF illness trajectory (CMOc 1.6–1.7) and the inherent difficulties of managing patients with HF who have life-prolonging devices (CMOc 1.8–1.8b). The realist analysis and synthesis of the literature helped uncover what 'types' of educational strategies could support the integration of PC into HF management. These included shared education and experiential learning within and between disciplines across all care settings (CMOc 2.1), communication skills training (CMOc 2.8), a public health approach/messaging (CMOc 2.9), evidence-based examples of good practice when integrating PC and HF (CMOc 3), and integrated PC and HF guidelines embedded in undergraduate (UG) and postgraduate (PG) education (CMOc 6).

Opportunity

The opportunity component of the COM-B model proposes that individuals must have the required time and resources for any behaviour to occur. Providing evidence-based educational strategies is not enough to create behaviour change without due attention to the required opportunities. Both

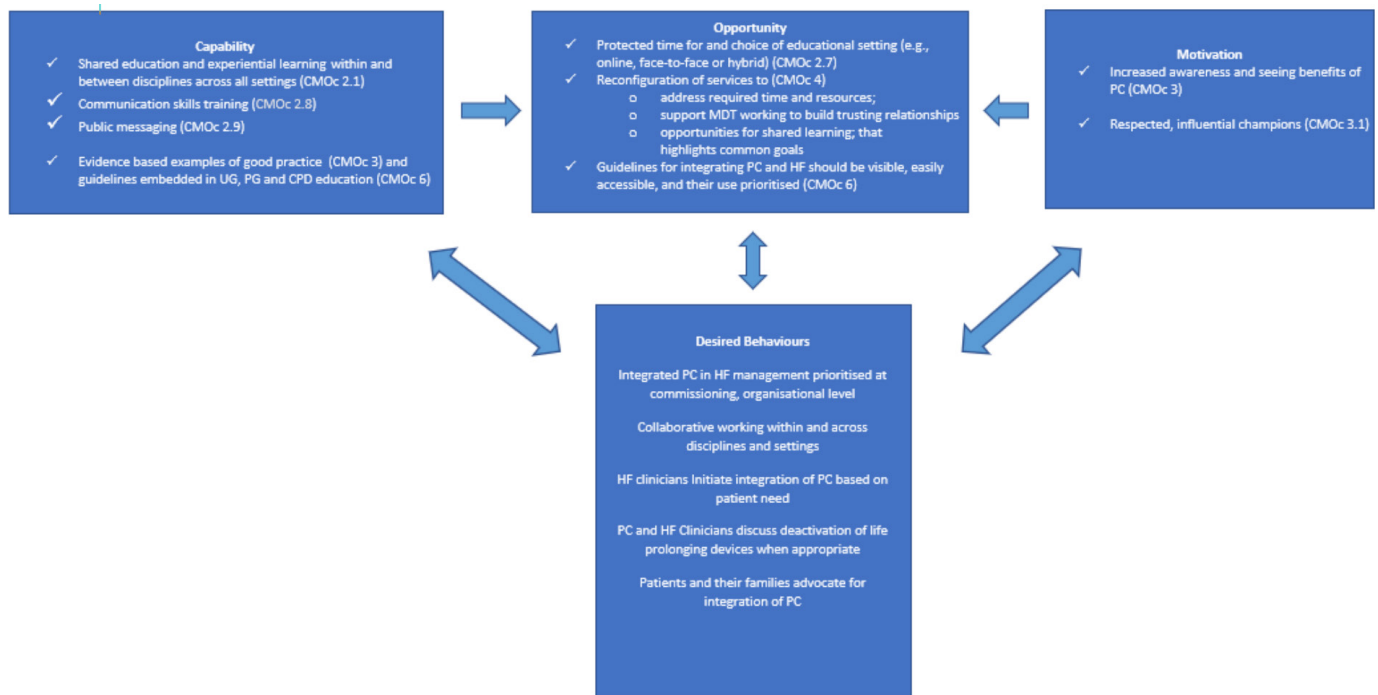


Figure 2 An overview of intervention strategies likely to produce desired behaviours and avoid undesired behaviours to facilitate the integration of PC into HF management structured around the COM-B model. CMOc, context, mechanism and outcome configuration; COM-B, Capability, Opportunity, Motivation, Behaviour; CPD, continuing professional development; HF, heart failure; MDT, multidisciplinary team; PC, palliative care; PG, postgraduate; UG, undergraduate.

the literature and stakeholders stressed the importance of protected time for education and choice of educational setting (eg, online, face-to-face or hybrid) (CMOc 2.7). The importance of having guidelines was also highlighted but, where guidelines exist, there is still a lack of clarity within HF management around who is responsible for initiating PC conversations, when this should happen and how often. Therefore, guidelines for integrating PC and HF should be visible, easily accessible and their use prioritised, with clarity on expectations and roles, so patients receive the right care, from the right people at the right time (CMOc 6).

Motivation

According to the COM-B model, motivation is a core component necessary for behaviour change, meaning that the behaviour must be more desirable and important than other competing priorities. CMOc 3 identified the importance of increased awareness and seeing benefits of PC in HF management (CMOc 3) as key intervention strategies. Stakeholders noted that evidence may win minds, but we also need to convince hearts. The synthesis of the evidence within this review also supported the importance of conveying the emotive and intellectual need for integrating PC and HF via credible champions, seeing direct patient benefit and evidence-based education (CMOc 3.1).

DISCUSSION

Given the global burden of HF,⁴ there is an urgent need to understand how best to integrate PC services in order to reduce human and health resource burden.³⁰ To our

knowledge, this is the first realist synthesis of the literature to develop key intervention strategies for integrating PC and HF services. Based on our findings, we developed intervention strategies (see figure 2) outlining the required steps to ensure the core components and determinants of behaviour are in place so that all key players have the capacity, opportunity and motivation to integrate PC into HF management. To enable change, it is important that each intervention strategy is not acted on in isolation. The factors that will aid integration are inter-related. We also acknowledge that providers and patients all start at different baselines and so not all intervention strategies will apply to all key stakeholders.

In summary, our key findings identified several challenges, but also multiple opportunities to support the early and ongoing integration of PC into HF management. Opportunities to change culture and address misconceptions included PC education for all health and social care (HSC) staff. Education should focus on helping clinicians to understand that PC for non-cancer illnesses should be based on need and not prognosis.^{26 27} Learning should be embedded throughout UG, PG and continuing professional development. Educational strategies that are likely to be effective include experiential learning among both disciplines of PC and cardiology. Communication skills training is important and needed so that all clinicians have the core skills and confidence to have meaningful PC conversations from the point of an HF diagnosis, if appropriate, or soon after a diagnosis.^{7-9 24} Such conversations would ensure that

PC runs in parallel with HF management and is introduced in a sensitive way as early as is appropriate, based on patient preferences. Setting up and running multidisciplinary team meetings for those involved in PC and HF is also key for the development of trusting relationships, collaborative working and creating opportunities for clinicians to learn from each other.²⁵ Wider public messaging can also help dispel myths and misunderstanding around PC. Finally, champions are important across all levels, from patients and informal carers, to clinicians, right up to senior decision-makers in the HSC system, in order to win the hearts and minds of those responsible for integrating PC and HF.^{26 27} Winning both is also a key opportunity to support integration and can be achieved through showing examples of good practice and improved patient, informal caregiver and health-care system outcomes.

In this review, limitations included lack of clarity over cardiac subspecialties (eg, interventional cardiology, electrophysiology and advanced HF and transplant cardiology), which were rarely reported in included documents. The majority of the included documents were focused on HF physicians and HF nurses and did not reflect the multidisciplinary of the HF team that would provide PC. The realist approach to analysis means that findings are based on the authors' interpretation of the data. A different team of researchers could have reached different interpretations. However, the close involvement of key stakeholders throughout the programme theory development increases our confidence that the findings are credible and have been developed through a robust, iterative realist synthesis process.

Further research is required to evaluate existing integrated PC and HF services to identify what works/does not work, for whom and in what circumstances. This would provide an opportunity to test (ie, confirm, refute, refine and expand on) the programme theory from this realist synthesis of the literature and develop detailed 'how to' guidance for setting up and sustaining integrated PC and HF services.

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Contributors The study was conceived by TM and JR. The search was coordinated by CD. Study screening and data extraction were undertaken by CH, CB, TM and JR. The analysis was led by CH and CB with comments provided by JB, CD, LH, BJ, BR, GW and JR. TM wrote the first and final manuscript drafts with all authors providing input. TM is responsible for the overall content as the guarantor and accepts full responsibility for the work and/or the conduct of the study, has access to the data, and controlled the decision to publish.

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