Exploring the impact of the Care and Support System for Patients and Carers, a remote monitoring and support system for palliative and end-of-life care: a mixed methods feasibility study

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Abstract

Background: The final 6 months of life is associated with increased healthcare utilisation, including avoidable A&E Department visits or hospital admission, with out-of-hours services often ill-equipped to provide proactive support to patients and their families, putting a strain on the NHS. The acute setting can be a highly pressured and busy environment that may not be best suited to these patients in the final weeks of life. Developing alternative models of care that support patients and their carers at home, provide palliative care tailored to individuals, enhance quality of life, provide more compassionate and cost-effective care while depressurising overburdened health and social care is imperative.

Objective: To explore the usability, user experiences and impact of a digital dyadic remote monitoring and supportive care system (CARE-PAC) for patients receiving palliative care and end-of-life care, their informal carers and health professionals involved in their care.

Methods: A mixed method approach was used. Quantitative methods used were quality of life scales, the System Usability Scale and NASSS-Cat (short) questionnaire. Qualitative methods used were short catch-up calls, in-depth interviews and focus groups with topic guides informed by the domains of the NASSS framework. The Wilcoxon ("Pratt") Signed-rank test statistical test of differences was used to analyse paired quality of life and usability data while the Wilcoxon rank sum test was used to analyse unpaired usability data. Descriptive quantitative analysis of the NASSS-Cat (short) questionnaire was performed. Thematic analysis was used to analyse the qualitative data, with patient/carer and clinician data analysed separately.

Results: CARE-PAC was used in 5 UK clinical settings. Twenty-six participants (13 patient/care dyads) used CARE-PAC for up to 12 weeks. No significant improvements were noted in patients' total QoL scores however significant improvements in 'overall' QoL and 'social' domains, and significant decline in 'physical' domains were seen. No differences were noted in carers' QoL scores or domains. Mean (standard deviation) total usability scores were 87.9 (12.4) for patients and 94.7 (3.8) for carers indicating an excellent user experience. Usability scores for clinicians were below average at 63.6 (15.6) but above 50 (which indicates a poor experience). Clinicians identified the illness/condition, the adopters and the organisations as complexities that could influence the adoption of CARE-PAC. Themes identified from catch-up calls (at least one from all patients and carers), in-depth interviews (2 patients, 2 carers) and 4 focus groups/1 interview (12 clinicians) were: Impact on care experiences; Reflections and Satisfaction; Challenges in project implementation and Future directions.

Conclusions: CARE-PAC is a usable, effective and reassuring remote monitoring and support digital system for patients nearing the end of life, their carers and healthcare teams that effectively identified patients' and carers' needs in real-time and made positive impacts on their well-being. Clinical Trial: None

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CARE-PAC is a usable, effective and reassuring remote monitoring and support digital system for patients nearing the end of life, their carers and healthcare teams that effectively identified patients' and carers' needs in real-time and made positive impacts on their well-being.

Keywords: palliative care, end-of-life care, ASyMS, CARE-PAC, remote monitoring, usability

Introduction

Palliative and end-of-life care

Palliative care improves the quality of life of patients and their families who are facing life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual [1]. The need for palliative care has never been greater and is increasing at a rapid pace due to ageing of the world's population and increases in cancer and other noncommunicable diseases [2]. Palliative care is explicitly recognised under the human right to health: provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals [3].

Current access to and provision of palliative care services in the UK

In England in 2021, nearly three-quarters (395,438) of people who died spent time in hospital during their final six months, accumulating a total of 7.7 million days [4]. Almost two-thirds (63.5%) experienced at least one emergency admission in their last three months of life, with 7.1% experiencing three or more emergency admissions [4]. This puts significant strains on NHS resources, with end-of-life care costs exceeding £1.2 billion in 2018-19 alone [5]. Access to essential out-of-hours care remains a significant challenge, especially for those living in deprived areas, leaving many without support during crises [6]. This further exacerbates healthcare costs and denies patients/families the compassionate, dignified end-of-life experience they deserve.

Despite the growths in drivers of palliative care needs, an estimated 100,000 people in the UK who could benefit from palliative and end-of-life care die each year without receiving it [7] and by 2040 in England and Wales, demand for palliative and end-of-life care is expected to increase by a further 25% [8]. The variation in access to palliative and end-of-life care means that many individuals are not receiving timely support or symptom management required at end of life [9] with informal carers, often family members, providing 75-90% of home-based care to people at the end of life, with caregiving demands broadly categorised as physical, emotional and financial [10]. These are particularly challenging for those facing poverty [11,12], and the cost-of-living crisis is causing even greater strain [13]. Despite home being the preferred place of death [14], in 2022 in the UK, 43.4% of deaths occurred in hospitals, while 28.7% of deaths occurred at home [15]. Issues such as symptom management and distress are frequently identified as responsible for the common out-of-hours hospital admissions of people receiving end of life care [14,16]. However, in addition, carer distress and burden, when caregivers experience high levels of stress, emotional burden and lack of support to the extent they feel overwhelmed and unable to manage the patient's needs at home, have been shown to lead to unnecessary patient hospitalisations near the end of life, even when it might not be medically necessary [16,17].

The key aim of palliative care is to enable patients to spend quality time at home through the provision of coordinated, continuous, and specialised palliative care at home [18]. Although the UK ranked top of 40 countries in a 'quality of death' index, based on palliative service provision and national strategic approach, it is estimated that 1 in 4 people are not able to access palliative and end of life care services [19]. Patients with a diagnosis other than terminal cancer are less likely to be offered or to access palliative care services, palliative care services are not yet available to all patients with serious chronic illness and there are challenges in finding reliable data on who is affected due to under-reporting, under-diagnosis or late diagnosis [20,21]. This results in patients experiencing challenges in relation to financial, health care and information, psychological and physical issues while carers experience unmet needs in relation to psychological and patient care and support, all of which are associated with high levels of distress, depression and anxiety [22].

Staffing shortage have been identified by nursing staff in a variety of settings as the main barrier to providing good care to dying patients, while also reporting that they do not feel sufficiently supported at work to manage grief and emotional stress [23]. The demand for services continues to outstrip the recruitment and retention of staff, with a shortage of palliative care expertise and training a barrier to provision [24].

Integrating technology into palliative care services

Implementing palliative care tailored to individuals is crucial to enhance quality of life, while depressurising overburdened health and social care systems, ultimately providing more compassionate and cost-effective care. Digital technologies can support the strengthening and scaling up of palliative care worldwide [25]. A meta-review identified the most common digital health interventions implemented in palliative care as videoconferencing, electronic health records and phone with the most typical usage of technologies being education, symptom management, decision making, information provision or management and communication [26]. A systematic review exploring patients' experiences of eHealth applications in palliative care has shown they have promise in promoting equal, individualised care, and may be a tool to endorse accessibility and patient participation in palliative care settings promoting feelings of safety and security while contributing to a more sustainable and efficient use of healthcare resources [27]. However, although an effective addition to the provision of care, the use of digital technologies should complement rather than replace face-to-face interactions [28] ensuring the provision of humanistic care for those receiving palliative care and their informal carers [29].

Development of a remote monitoring and support system for palliative and end-of-life care (CARE-PAC)

The Advanced Symptom Management System (ASyMS) is a remote monitoring and support system for people with cancer and chronic diseases [30-32]. Through the real-time monitoring of patient reported outcome measures, evidence based predictive risk algorithms and electronic decision support included within ASyMS, significant improvements in in QoL, self-efficacy, reduced symptom burden, anxiety and supportive care needs have been shown [32].

ASyMS provided the basis for the development of the Care and Support System for Patients and Carers (CARE-PAC), which was co-designed and developed with patients, carers and health professionals following a 2-stage process (Figure 1).

The final version of CARE-PAC developed (Figure 2) has 3 complementary components:

1. A patient/carer facing app that can be downloaded to a smartphone or tablet containing:
   a. a daily questionnaire set
   b. a 3-weekly set of outcome questionnaire
   c. an electronic library of information:
      i. links to reputable websites about topics within the questionnaire
      ii. local contact details for useful services e.g. triage helplines, local support groups, equipment, transport
2. A clinician website that can be accessed through any smartphone, tablet, laptop, PC to:
   a. Register patients and carers participating in the study
   b. Provide an overview of all participants' daily reports
   c. View and manage patient/carer alerts
3. A clinical algorithm that identifies clinically concerning symptoms/issues and flags these to health professionals through real-time alerts within the clinician website

Aim of this study

To explore the usability, user experiences and impact of a digital dyadic remote monitoring and supportive care system (CARE-PAC) for patients receiving palliative care and end-of-life care, their informal carers and health professionals involved in their care.

Methods

Participants and settings

Patient, informal carer and health professional eligibility criteria for the project were set (Textbox 1-3). The study was conducted in 5 clinical sites: 3 hospices, 1 hospital and 1 community setting across Scotland and England.

Textbox 1. Patient eligibility.

- Diagnosed with one or more of the following illnesses:
  a. advanced cancer (any diagnosis)
  b. advanced chronic respiratory diseases – such as chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, bronchiectasis
- Aware of their advanced diagnosis
- Registering 1 or more indicators on the Supportive Palliative Care Indicators Tool (SPICT) (including both general indicators as well as disease specific) as completed by a member of the multi-disciplinary team
- Receiving palliative care services
- Aged 18 years or over
- Have an informal carer who is also willing to participate in the study
- Able to give informed consent
- Deemed to be physically, psychologically and cognitively fit to participate in the study as confirmed by a member of the multidisciplinary clinical team
- Able to read, write and understand English and have a basic understanding of computer and audio-visual software (for data and outcome data collection purposes)
- If possible, have access to a PC, laptop, tablet, smartphone or other equipment that can

run the CARE-PAC system and support audio-visual communication software

Textbox 2. Informal carer eligibility.

- Identified by the patient (who meets the eligibility criteria above) as their key carer
- Aged 18 years or over
- Able to give informed consent
- Able to read, write and understand English and have a basic understanding of computer and audio-visual software (for data and outcome data collection purposes)
- If possible, have access to a PC, laptop, tablet or smartphone or other equipment that can run the CARE-PAC system and support audio-visual communication software

Textbox 3. Health professional eligibility.

- A member of the multi-disciplinary team caring for patients in any of the diagnostic groups identified in patient eligibility above
- Working in or across any clinical setting that provides care to patients in any of the diagnostic groups identified in patient eligibility above
- Have access to a PC, laptop or other equipment that can support audio-visual communication software and a basic understanding of computer and audio-visual software

Ethical considerations

The study was approved by North-West Preston Research Ethics Committee (reference 21/NW/0060) and sponsored by the University of Strathclyde. R&D approval was granted by each clinical site. All participants provided written informed consent.

In response to the digital divide, such as inequalities in access to the Internet and ICT, loan smartphones with SIMs were made available to anyone who wanted to participate in the study but who lacked the required technologies.

Use of CARE-PAC

During this study, patients and their carers were invited to use CARE-PAC for up to 12 weeks while health professionals in each of the clinical sites participated for the duration of the study.

Patients and carers

Using the app, patients and carers each completed a daily questionnaire. Patients completed the Integrated Palliative Care Outcome Scale (IPOS) (ref) and carers completed the Digital Carer Daily Assessment (DiCDA), which was co-created during Stage 1 of CARE-PAC's development. Patients' and carers' responses were automatically uploaded in real-time to the secure clinical database for clinicians. The daily questionnaire could only be completed once per day. The 3-weekly outcome questionnaires (QoL questionnaire and SUS) were also completed through the app. These automatically followed the daily questionnaire every 3 weeks and were available for completion for 2 consecutive days, after which they were unavailable until a further 3 weeks had passed. Patients and carers could access the electronic library of information at any time, and as many times as they wished. Patients and carers were instructed to delete the app from their device at the end of their participation in the project.

Health professionals

The team of health professionals at each clinical site developed their own local arrangements for checking the website daily in keeping with their daily workflow and routines. Through the daily checks they could:

1. access all participants' daily data reports to remotely review patients/carers, identify symptom trends and prioritise workload
2. view any alerts, initiate an appropriate clinical intervention and record actions within the clinician website.

Data collection and synthesis

Given that the study patient population had advanced disease, an attrition rates of around 30% was expected [33]. Consequently, a regular and frequent 3 weekly schedule of outcome data collection was chosen to mitigate this potential loss of data through withdrawal from the study due to disease progression/death. This ensured that all participants would have the opportunity to contribute their outcomes and experiences irrespective of their duration of participation. The study used mixed data collection methods across the study population (Table 1).

Table 1. Mixed data collection methods across the study population.

		Patient	**Carer**	**Health professional**
Quantitative data collection	Symptom questionnaire	Daily	Daily	
	Quality of life questionnaire	3-weekly	3-weekly	
	System Usability Scale	3-weekly	3-weekly	start & end
	NASSS-cat survey			end of study
Qualitative data collection	Catch-up calls	3-weekly	3-weekly	
	In-depth interviews	end of participation	end of participation	
	Focus groups			end of study

Quantitative data collection and synthesis

Quality of life measurements

The quality of life questionnaires used in this study (McGill Quality of Life-Expanded [34] and Quality of Life in Life Threatening Illness - Family Carer Version [35]) were specific to the study population (patients with life threatening illness throughout the illness trajectory and carers of people with advanced disease), extensively used in both research and clinical practice previously and designed to be used together. Previous users have reported these tools reflect relevant and important areas of their quality of life, are easy to understand and that their completion was valuable and meaningful, giving them the opportunity to express their feelings [36]. Completion time for both is between 10-20 minutes and this likely decreased as participants became familiar with the questionnaires. Local PIs agreed to the use of these QoL questionnaires within the study.

The McGill QoL Questionnaire Expanded (MQoL-E) builds on the original McGill QoL Questionnaire (1996), designed to assess quality of life (QoL) in individuals with life-threatening illnesses. The original version measured four domains: physical, psychological, social support, and existential/spiritual and was widely used because of its high validity and acceptability for end-of-life patients [37,38]. Following further research, including a qualitative study on end-of-life priorities, the MQoL-E was developed [34]. With 21 items, it provides a more comprehensive assessment of QoL by incorporating less commonly assessed domains such as cognition, healthcare, environment, and the feeling of being a burden, alongside the original domains, to better understand treatment impacts.

The Quality of Life in Life Threatening Illness - Family Carer Version (QOLLTI-F v3) is a validated 17-item tool used to assess the quality of life (QoL) of carers of patients with cancer. Unique in its inclusion of the carer's perception of the patient's condition, it highlights the close relationship between carer and patient. Developed from qualitative studies, it focuses on factors important to carers' own QoL rather than caregiving burdens. The tool measures seven domains: Environment, Patient Condition, Caregiver's Own Condition, Caregiver's Outlook, Quality of Care, Relationships, and Financial Worries. QOLLTI-F v3 is reliable, responsive to changes in QoL, and serves as a companion to the MQOL-E [35,36].

System usability assessment

CARE-PAC's usability was assessed using the System Usability Scale (SUS), a widely-used, quick, 10-item tool designed to measure users' subjective perceptions of a system's usability. Originally published in 1996 [39], the SUS is applicable to various technologies and has been extensively evaluated, proving to be both reliable and valid in assessing system learnability and usability [40].

A SUS score of 68 or higher is considered above average, while a score below 68 is below average. A score below 50 indicates a poor user experience, and a score above 85 indicates an excellent user experience (Sauro 2016). An adjective rating scale has been shown to correlate extremely well with total SUS scores and can be used to help understand how a total score translates into a judgement of overall usability [41].

Evaluating CARE-PAC implementation

The NASSS framework [42] helps explore the successes and challenges of technology implementation in healthcare and social care. Practical tools based on the NASSS framework, such as the NASSS-CAT (short) survey, are used to assess and address the complexities of implementing technologies. The survey offers a structured approach by covering key areas: the illness/condition, the technology, value proposition, intended adopters, implementing organizations, and the external context. The NASSS-CAT survey was emailed to all participating healthcare professionals at the end of the study to assess the adoption and sustainability challenges of the technology.

Qualitative data collection and synthesis

Catch- up calls during participation

Every three weeks, all patients and carers received a brief catch-up phone call from a research team member (MM), lasting 5-10 minutes. During these calls, participants were asked a series of questions, and the conversations were recorded using an encrypted digital device. Responses were extracted from the recordings, and participants' views or verbatim quotes were documented in an anonymised Word document for each call. These files were securely stored on the researcher's OneDrive.

Interviews and Focus Groups after participation

At the end of their participation, longer interviews were conducted with willing patients and carers, while all healthcare professionals were invited to participate in focus groups at the end of the study. These interactions followed a topic guide based on the NASSS framework [42], addressing topics such as perceptions of the technology, advantages and disadvantages of the system, and its impact/benefit. Both interviews and focus groups were recorded using encrypted devices, transcribed verbatim, and reviewed for accuracy by a research team member.

Data Analysis

Data from all 5 study sites was collated and unknown participant IDs or duplicate entries were removed. If a question was answered multiple times on the same day, the most up to date response was taken and the other(s) removed.

Quantitative data analysis

QoL questionnaires and System Usability Scale

For all questions the Wilcoxon (“Pratt”) Signed-rank test was used as the statistical test of differences. This test was used as the differences analysed were paired as the responses at first and last completion related to the same participant. The “Pratt” specification of the Wilcoxon test was used as there were some differences of zero that were of importance. In a standard Wilcoxon Signed-rank test these zero difference responses would be discarded. For the health professionals SUS analysis, the Wilcoxon rank sum test was used as the baseline and endline responses were not paired.

Quality of Life

To examine differences in response between QoL first and last completion, participants were included if they had at least two fully completed responses recorded on separate days. The difference in response from first to last completion were examined at an individual question level, at a domain level using a domain score, and an overall quality of life score. To ensure a consistent quality of life scale by domain, responses to some of the questions within each QoL questionnaire had to be transposed such that the new response was 10 minus the original response which ensures that a response of 10 is the best quality of life for each question. Within the patient QoL questionnaire, this related to two questions from ‘physical’ domain, five questions from ‘thoughts and feelings’ domain, and one question from ‘social’ domain and within the carer QoL questionnaire, this related to the question in the ‘patient condition’ domain, one in ‘your own condition’ domain, two in the ‘relationships’ domain, and the question in ‘financial worries’ domain.

System Usability Scale

Total SUS scores were calculated by firstly converting the individual question responses to a consistent point system. This was done by subtracting one from the original score for odd numbered questions and taking 5 minus the original score for even numbered questions. Then, for each individual, their new responses to the 10 questions were summated and the summed value was multiplied by 2.5. This gave a single Total SUS score for each individual, that could take the value 0-100.

Mean and standard deviation of overall and first and last SUS were calculated (Lewis and Sauro 2024) and to examine differences in response between Total SUS first and last completion, participants were included if they had at least two fully completed responses recorded on separate days.

NASSS-cat (short)

Descriptive quantitative analysis provided an overview of participants’ responses to each of the component of the NASSS-cat (short).

Qualitative data analysis

Data from the catch-up calls, in-depth interviews and focus groups were analysed using thematic analysis, a method of identifying, analysing, organising, describing and reporting themes found within a dataset [43]. NVivo software was used to analyse the data from in-depth interviews and focus groups. The initial coding framework was based on the interview/focus group topic guides and data from the two groups (patients/carers and health professionals) was analysed separately. Common over-arching themes were identified in both the patient/carer and health professional data. However, there were instances where patients did not comment on specific sub-themes highlighted by health professionals, as these often related to the practicalities of conducting the research within clinical practice—an area outside the patients' experiences.

Data analysis, coding, and thematic findings from the catch-up calls, interviews, and focus groups were conducted by one of the research team (MM) using a systematic thematic analysis approach. To ensure the rigor and validity of the findings, the emerging themes and sub-themes were regularly presented to the wider research team during collaborative meetings. These discussions provided an opportunity to reflect on the data, challenge interpretations, and ensure that the analysis remained grounded in the participants' accounts. This collaborative review process facilitated a shared understanding of the data and supported the refinement of themes to ensure they accurately represented the findings. Through this iterative process, the research team concluded that thematic saturation had been reached, enhancing confidence in the robustness and credibility of the analysis.

Results

Overview

Thirteen patient/carer dyads participated across the five clinical sites. Two participants, one patient and one carer (unrelated) borrowed a study smartphone for the duration of their participation in the project.

Participants

Table 2 provides details of the CARE-PAC population.

Table 2. Description of CARE-PAC population.

Patient population									
Gender		Age		Diagnosis				Relationship to carer	
Male	10	50-54	1	Cancer	12	Non-cancer	1	Spouse	10
Female	3	55-59	2	Lung	6			Sibling	2
		60-64	-	Prostate	3			Parent	1
		65-69	8	Pancreatic	1				
		70-74	2	Gastric	1				
				Sarcoma	1				
Carer population					**Health professional population**				
Gender		Age			Role				
Male	2	30-34	1		Palliative care consultant			4	
Female	11	44-49	2		Research nurse/co-ordinator			3	
		50-54	-		Specialist palliative care nurse			10	
		55-59	4						
		60-64	2						
		65-69	2						
		70-74	2						

Quantitative results

Quality of life

The QoL questionnaire was completed at least once by 11/13 patients and 9/13 carers. Two carers and three patients completed it only once, while the highest number of completions was five times, completed by one carer and two patients. On all attempts, for all participants, all the QoL questions were answered- no questions were skipped.

To examine differences in response between QoL first and last completion, participants were included if they had at least two fully completed responses recorded on separate days. This reduced the sample size of patients to 8/13 and carers to 7/13. The difference in response from first to last completion were examined at an individual question level, at a domain level using a domain score, and an overall quality of life score.

At an individual question level, there were significant differences in patients' and carers' responses to some questions within their QoL questionnaires (Table 3).

Table 3. Questions from the QoL questionnaires with significantly different responses.

Domain	**Question**	**Sig (%)**	**Direction of change**
McGill QoL-E (patient) questionnaire			
Overall QoL	Considering all parts of my life (for example, physical, emotional, social, spiritual, and financial) over the past two days (48 hours) the quality of my life was: very bad 0 – 10 excellent	5%	Improved
Physical	Over the past two days (48 hours), being physically unable to do the things I wanted was: not a problem 0 – 10 a huge problem	5%	Declined
Thoughts and feelings	Over the past two days (48 hours), I felt that the amount of control I had over my life was: not a problem 0 – 10 a huge problem	10%	Declined
Social	Over the past two days (48 hours) communication with the people I care about was: difficult 0 – 10 very easy	5%	Improved
Social	Over the past two days (48 hours) I felt my relationships with the people I care about were: more distant than I would like 0 – 10 very close	5%	Improved
Social	Over the past two days (48 hours), I felt supported: not at all 0 – 10 completely	5%	Improved
QOLLTI-F v3 (carer) questionnaire			
Your outlook	Presently I feel that my life has meaning: very little meaning 0 – 10 very much	10%	Declined

With regards to domains within each of the QoL questionnaires, a domain score was calculated for each participant as the mean of responses to questions in the domain. The patient group had significantly different domain scores from first to last completion for the domains: improved 'overall quality of life', improved 'social' and decreased 'physical'. The carers had no significant differences in domain scores.

The total quality of life score was calculated as the mean of the of the domain scores for each participant. Neither the patients nor carers had significantly different overall quality of life from first to last response.

System Usability Scale

The SUS questionnaire was completed at least once by 9/13 patients and 10/13 carers. Two carers and three patients completed it only once, while the most completions were five times, completed by two carers and two patients. On all attempts, for all participants, all the SUS questions were answered- no questions were skipped.

SUS scores of 68 or above are considered above average with a score above 85 indicating an excellent user experience [44]. Mean Total SUS scores of 85.5 are associated with the adjective 'excellent' and 90.9 with 'best imaginable' [41]. Combining first and last responses, the mean (standard deviation) Total SUS score for patients was 87.9 (12.4) and for carers was 94.7 (3.8) meaning that participants found the CARE-PAC patient/carer facing app extremely usable.

To examine differences in response between SUS first and last completion, participants were included if they had at least two fully completed responses recorded on separate days which reduced the sample size of patients to 6/13 and carers to 8/13. The patient data showed an increase in Total SUS score from first to last questionnaire completion that was significant at the 10% significance level. The carer data found no significant difference in Total SUS between first and last completion.

SUS was also completed by health professionals at baseline and endline. Twenty-three health professionals completed the baseline questionnaire and 18 completed the endline questionnaire. One of the health professionals skipped questions 3, 5, 6, 8 and 9 in the baseline questionnaire. The endline questionnaire was completed fully by all 18 clinicians.

Combining first and last responses, the mean (standard deviation) Total SUS score for health professionals was 63.6 (15.6), slightly below the average total SUS score of 68 [44] and between the adjectives of 'OK' and 'good' [41]. However, it was not below 50 which indicates a poor user experience [44]. Comparison of baseline and endline total SUS scores using an independent (non-paired) Welch's t-test gave a p-value of 0.7661 meaning there was no significant difference in mean Total SUS scores between the first and last completion.

NASSS-cat (short)

Fifteen health professionals completed the NASSS-cat (short) survey. While responses were relatively evenly split across each of the complexities (Table 4), there were more 'yes' than 'no' responses for the complexities in relation to the illness/condition, the adopters and the organisations.

Table 4. NASSS-cat (short) responses.

Complexity	Summary statement	Yes	No	Missing
The illness or condition	The condition has significant complexity which is likely to affect the project's success	8	6	1
The technology	The CARE-PAC system has significant complexity which is likely to affect the project's success	2	9	4

The value proposition	The value proposition has significant complexity which is likely to affect the CARE-PAC system's success	4	9	2
The intended adopters	There is significant complexity relating to intended adopters which is likely to affect the CARE-PAC system's success	8	5	2
The organisation(s) implementing the technology	There is significant complexity relating to participating organisations which is likely to affect the CARE-PAC system's success	7	6	2
The external context for innovation	There is significant complexity relating to the external context which is likely to affect the project's success	2	7	6

Qualitative outcomes

Themes identified

Overarching themes and sub-themes from patient, carer and health professional qualitative data (catch up calls and longer interviews/focus groups) were identified (Table 5).

Table 5. Themes and sub-themes from patient, carer and health professional qualitative data.

Theme	Impact on care experiences	Reflections and satisfaction	Challenges in project implementation	Future directions
Sub-themes	Proactive monitoring and early detection	Personal reflections	Technical issues	Sustainability
	QoL, empowerment and sense of worth	Perceived added value	Project population	Suggestions for improvement
	Increased sense of reassurance and security		Recruitment	
	Usefulness of reputable information		Resources, workload and staffing	

The overarching themes (i.e. impact on care, satisfaction and reflections, challenges in project implementation and future directions) were common across both groups with a few exceptions when sub-themes were only identified by health professionals. Therefore, the themes from all participants (patients, carers and health professionals) are reported together and identifiers are used to denote the group to which the participant belonged. Quotes for each sub-theme should be referred to when reading the thematic analysis section (Table 6).

CARE-PAC paper – qualitative analysis – presentation of quotes for each theme/sub-theme

Table 6. Quotes for themes and sub-themes from patients, carers and clinicians.

Theme/sub-theme	Relates Quotes
Impact on care experiences	
Proactive monitoring and early detection	‘It’s good in as much as things can be flagged up almost immediately…my pain and shortness of breath has been flagged up, my palliative care nurse got notified and I’m getting treated for that better now than before.’ (patient 1, site 1) ‘I was using it to almost monitor myself against a range. So for instance, tiredness, I've been struggling with tiredness. So when I put a three in, in my mind it means ‘OK, I've done this and that's why I'm tired’.’ (patient 3, site 4) ‘If you can actually have a fairly large percentage of the population that can benefit from CARE-PAC, yeah, that strikes me as a very cost effective way of actually being able to do wide scale sort of monitoring of them.’ (carer 1, site 4) ‘I think it's got potential. I think it might need a bit of tweaking to make it more useful but I think the early monitoring and picking up symptoms is helpful.’ (health professional 2, site 3)
QoL, empowerment and sense of worth	‘The app is great, it does force you to stop and think about the situation, about how I’m feeling, which is a good thing, because it’s making me stop and actually think about what’s going on rather than ploughing through every day and not really taking a step back and breathing a little bit.’ (carer 3, site 4) ‘I think she liked the control, it gave her that bit of control, didn't it? I think they enjoyed the process of being involved in research as well as using the tool. They felt that feeling of doing something to give back and that they were useful. For them to do something that felt important was really useful. And so the process of being involved in the trial was as valuable for them as the trial itself.’ (health professional 1, site 3)
Increased sense of reassurance and security	‘It’s almost as if you have another port of call, if something does go wrong and you can’t get in touch with the nurses, and he is going downhill now, and there’s been a couple of times that I’ve said ‘put it on your app’ and they (the nurses) have picked it up the following day and been on the phone and then come out.’ (carer 1, site 1) ‘I think the patients appreciated the support, that extra bit of support that the app gave them, this expression that there was an extra layer of care in a way that they wouldn't get missed. That was the positive feedback that I had from them.’ (health professional 2, site 4)
Usefulness of reputable information	‘the times that I did look up the information I thought it was spot on. It did seem to be able to direct you to the places that you needed to go to.’ (patient 1, site 4) ‘She (the carer) actually found great support from the links. She said ‘just that I can press a button and I don’t have to go into google and open up a can of

	worms. I can get into a good website here and get a wee look at things to help me'. She found that really reassuring.' (health professional 2, site 1)
Reflections and satisfaction	
Personal reflections	'We [the carer and her husband] carried on using it at first when we should have stopped. It became a habit. It's only been this last week we stopped using it.' (carer 1, site 3) 'Everybody knows that the NHS can't continue the way it is at the moment because it it's just overwhelmed, and we also know there isn't, unlimited money to throw at it. So I think it would be a general perception that technology has got to play a bigger part. And therefore apps like this will come into their own as that perception is gaining common ground across the whole population.' (patient 1, site 4) 'As a principle, I think it's (technology) the future. You know, I think patients taking control of their, their wellbeing and being able report things in real time and be monitored by a healthcare professional is the future. You can see how things can be improved just by doing this project.' (health professional 2, site 5) 'And there were a few patients that I felt they had the technical literacy, but no, when we explored it further, they said 'that's just beyond me'. … It was surprising how many people actually said IT was the issue. You know, they just didn't want to use another bit of technology and maybe they were sick of it. But you know, there was a few who just felt it wasn't for them.' (health professional 2, site 2) 'She just decided it wasn't for her. She liked the thought of it but the reality of it just made her think of all the things that were wrong with her.' (health professional 3, site 1) 'My overall emotion really is one of gratitude for being able to participate in the project.' (health professional 1, site 4)
Perceived added value	'For instance, the clot in my leg…now if that hadn't been picked up, I could have carried on for however long and by the time I went for a scan it would have been 10 times worse. And instead of just being on medication, I might have needed more intrusive treatment… so stopping that was a good thing.' [patient 3, site 4] 'One of the real benefits, I think of the app is the fact that it's looking at it from 2 perspectives. You know it's looking at it from the patient's point of view as well as the carer's. And often it's the carer who suffers, you know, probably as much if not more than the patient. But I think to be able to triangulate between the two that, you know, is really important… And that's a real value because too often, if I go into see a consultant or specialist nurse or any anybody else, they tend to very much focus on the patient… so having

	that way of, you know, being able to support the carer as well as the patient, I think is a real bonus of the app.’ (patient 1, site 4) ‘It definitely has benefits for both of us, it means he say what he wants on his (app) and I can say what I want on mine…so you’re not thinking, ‘oh I can’t say that because he might not want me to say that’, so it’s confidential, which is good as well.’ (carer 1, site 1) ‘And the mother said that it helped their relationship much more because they were asking each other what they were putting and how they might answer questions. And the mother said it's really opened up communication with her daughter, which is a nice thing and unexpected perhaps, but a nice thing for them so that was good.’ (health professional 3, site 5) ‘I used it to sort of track them, you know, because we were so busy. And I was having to look at my time and think about who were the people that I needed to see the most. And I could look at their responses and think, well, for him things are pretty steady at the moment. So that was quite useful because I could use it as a tool for checking.’ (health professional 1, site 3)
Challenges in project implementation	
Technical issues	‘it would be good if you could click on multiple alerts. So what I was doing is writing some text and copying and pasting that into each alert. But if I'd spoken to that patient that day and we came up with a plan that would be nice to just be able to knock out all those 10 alerts with the one sentence.’ (health professional 1, site 2) ‘Some bits (of the app) are slightly repetitive…the bit where you do your 3 more symptoms, you have to put ‘not applicable’ three times, that’s a bit annoying.’ (patient 4, site 4)
Project population	‘There were patients that I'd think ‘oh they'd be really good for this and be really engaged’. One lady who springs to mind in particular would have been perfect for it. And I spoke to her, and she was really positive, and she went home with the information. And then she came back and just said, ‘No, it's not my thing’. And you know she couldn't express why it wasn’t for her. And I think for her it was an extra thing that she didn't need at that time, which was a shame, because she would have been really good for it (the project).’ (health professional 1, site 3) ‘Probably years ago we would have had more appropriate patients because we saw people for a longer period of time. That's been a definite change…We take people when they're much more symptomatic and much nearer end of life now than ever.’ (health professional 3, site 1) ‘I don't know whether that (recruiting a dyad) put the CNSs off by making it more complicated. I think if it had just been a solo offer to the patients, maybe the perception would have been ‘it's less work’. I’m sure if we’d said to the specialist nurses ‘any one patient, send them to us’, we'd have got loads whereas it's when they're scratching their heads about whether they've got a

	carer or not. It just closed it off a bit, didn't it?' (health professional 1, site 5) 'One thing I didn't like was being called a 'carer', I see myself as her husband, I always have and I always will. I don't like being referred to as a 'carer' or to be answering questions as a 'carer'.' (carer 1, site 2)
Recruitment	'Once you'd decided that you'd have the chat with them, that took quite a chunk out your day. You know the discussions, the consent, the setting it up and all that. That was quite a lot of time.' (health professional 2, site 1) 'At the start, at the very start, there were lots of them [CNSs] saying, 'I can think of a patient now' or 'I've got someone in mind now' and then when it actually came to doing it, it didn't come off.' (health professional 2, site 5) 'We're protecting the patient. I think that's probably what happened with me with definitely one of my patients because if I pushed it a wee bit further, I probably could have got them to do it (participate in the project). But things changed and they were hospitalised. And it was too much, I felt it was too much for them to participate and for me to push it.' (health professional 2, site 2)
Resources, workload and staffing	'Ideally we'd also have worked with the Community Specialist Palliative Care Nurses. But I think the feeling was in our setting that they were just so stretched that that they wouldn't be able to take this on.' (health professional 1, site 4) 'I think that additional help for checking the alerts, so a dedicated person who was checking the alerts, would help. But that doesn't help with the actual time taken for the nurses actually following up on the alerts which I would say is the more time-consuming part of it.' (health professional 1, site 1)
Future directions	
Sustainability	'I think there's two things isn't there. Whether you need people specifically to train the patients and families or whether you are talking about digital team on the receiving end of the of these things. It should be possible to have it part of the healthcare professional's job to have this and it should really make them more efficient. But I don't know whether you're going to need extra staff to training up patients and families to use it.' (health professional 2, site 4) 'I think it's a culture, a cultural thing. If we were all using something it becomes part of the culture, and we get to the stage that people would be more open to it.' (health professional 1, site 5) 'I think it could quite easily be transferred to other long term illnesses quite easily but I think you would have to be fairly clear to people that, you know, this was aimed at people with cancer or people with MS or ME. But that's easy to do I think with the technology.' (patient 1, site 4) 'If you established it either at the very start of someone being involved in community services or before they get to that end stage. So then people who

	are in clinic and used to that process being there and then, you're quite right, when things are changing, moving towards end of life, it's already an established process.' (health professional 1, site 2) And as our services are increasingly stretched, looking at different ways that we can manage people is really important. So I absolutely think that there is a place for it. I just think we just need to find a way of integrating that into the normal workload to make it just part of day-to-day work. So I think if it wasn't part of a trial, that would probably be a bit more straightforward because you wouldn't need to have all of that extra paperwork, you'd just say this is what it is, do you want to use it? And so I think that would be a bit more straightforward, but I think all that information (related to the research aspect) was a bit much for some people.' (health professional 1, site 3)
Suggestions for improvement	'How about that you could individualise it for patients? So there are some patients where you know that they're going to be scoring high and actually that you don't need to do anything about that because they don't want to change anything. Or maybe there's nothing you can do and that's just how they are. Then you wouldn't want alerts from that patient, but maybe you would want alerts from someone where you know they're doing pretty well and things might change, or you worry that they might change suddenly.' (health professional 1, site 4) 'If I could go back and see the information that I'd already entered into it, but because I can't see that I had to manually track that and that becomes that becomes a bit of a mission…I would like the app to change, to be bit more pertinent to, to give me information more than me just feed it …because if you could put context to it and a rating system, and you can actually show individual trends, I think you would get a huge difference in your adoption population and rate, especially if you can show them the value of their own analysis.' (patient 3, site 4) 'If only the app was available to the GP and the oncologist and CNS at the hospital as well as my palliative care nurses, that would be really helpful.' (patient 4, site 1) 'I think it needs to be linked in, completed integrated. You shouldn't even have to put any details in at all because it's just there. And this would be just plug in.' (health professional 1, site 5)

Impact on care experiences

This theme related to the added value that the CARE-PAC system had on experiences of care delivery and receipt. Sub-themes identified were proactive monitoring and early intervention, impact on QoL and sense of worth, increased sense of reassurance and security and usefulness of reputable information.

Proactive monitoring and early intervention

Patients, carers and health professionals identified that using CARE-PAC provided a quicker, more enhanced way of sharing symptom information and providing appropriate intervention as early as possible. Patients felt that using the app to proactively track their symptom patterns increased their sense of responsibility in identifying and understanding their symptoms while health professionals identified that noting changes in a patient's symptom patterns would be helpful in their proactive management and intervention. The proactive nature of early detection was seen to be of benefit, not just to patients, but also to the healthcare system in that it was seen to be more cost-effective to prevent conditions from worsening rather than deal with them at a more advanced stage.

Impact on QoL and sense of worth

Participating in the project was felt by all participants to have impacted positively on patients and carers and increased their sense of worth. Patients and carers felt that using the CARE-PAC app helped them monitor their condition, put things in context and encouraged them to reflect on how they were feeling as well as contributing positively to the care of future patients and carers. Health professionals recognised that patients and carers valued the opportunity to participate in the project and that participating gave them a sense of worth and purpose.

Increased sense of reassurance and security

Patients, carers and health professionals believed that using the app gave patients and carers an increased sense of security, a peace of mind and level of confidence that someone was keeping an eye on them virtually, promoting feelings of additional support.

Usefulness of reputable information

The CARE-PAC e-library of links to websites for all the symptoms and issues mentioned within the daily questionnaires as well as a list of local services and their contact details was seen to be a valuable resource of trusted information in one easy to access place. Although not all CARE-PAC users were aware of the e-library, those that were had accessed it and found it useful.

Reflections and satisfaction

This theme related to participants' reflections about what CARE-PAC meant to them as well as the wider palliative care community and the feelings of satisfaction they got from its use. Sub-themes identified were personal reflections and perceived added value.

Personal reflections

CARE-PAC's ease of use was consistently reported by patients, carers and health professionals. This ease facilitated its integration into the daily habits of patients and carers and practice for health professionals. Further supporting this notion is that patients and carers reported a sense of 'loss' when they came to the end of their participation in the project.

That technology such as CARE-PAC presents opportunities for healthcare and will likely play a bigger part in future healthcare, was not only recognised by patients, carers and health professionals, but it was seen as vitally needed to address the current challenges experienced in healthcare.

However, participants also recognised that embracing technology is not for everyone, with the digital divide and ensuring equality of access to healthcare a concern. More specifically, increased feelings of anxiety and stress, physical challenges and a daily reminder of the user's illness and personal situation were seen as potential downsides of CARE-PAC.

All participants felt positively about their participation in the project and the opportunity to be involved. Health professionals were enthusiastic about the opportunities of co-design and found the pilot project a positive experience. Patients and carers consistently thanked the researcher at the end of qualitative interactions for the opportunity to be involved in the project.

Perceived added value

Patients, carers and health professionals saw value in the alerts sent to health professionals of clinically concerning symptoms by the CARE-PAC system, with the early detection of symptoms and the associated opportunity for timely interventions a real bonus of CARE-PAC.

Another advantage of CARE-PAC was the inclusion of the carers' perspective. Given the important role that carers play in supporting their loved ones receiving palliative care, all users could see the benefits of including carers' perspectives in CARE-PAC as this would not only give another view of the patient's condition, but also helped to support carers both in their caring role as well as their own well-being.

Enhancing communication between patients and carers was also identified as an added benefit of CARE-PAC. Though not a requirement of the use of CARE-PAC, patients and carers reported sharing their responses to the daily questionnaire which, on occasion, seemed to have prompted discussions about each other's perspectives on symptoms and issues, sometimes raising awareness of an issue that the other was unaware of or highlighting differences in perspectives of how each other were feeling.

Health professionals saw value being able to track and review patients' and carers' symptom trends over time within the clinician website. Firstly, in relation to having some insight into the current situation before making contact with patients, for example a home visit or telephone call. And secondly being able to use the information to prioritise their workload based on clinical need, for example, avoiding unnecessary clinic reviews if the patient was well and stable.

Challenges in project implementation

While the challenges in project implementation were mainly identified by health professionals, there were some challenges identified by patients, with four sub-themes of technical issues, project population, recruitment and resources, workload and staffing identified.

Technical issues

Health professionals felt that some parts of the clinician website were less than user-friendly and awkward. This awkwardness was also identified by patients in specific sections of the daily questionnaire.

Project population

Patients, carers and health professionals saw the digital divide and some people's lack of confidence in engaging with technology as a challenge to the project. Health professionals took this concept further to explain that some people just don't see themselves as able to engage with healthcare more generally.

While the eligibility criteria for patients was very general, health professionals reported that patients are being referred much later in their illness trajectory meaning that they have advanced disease and are deteriorating quickly. It was often the case that patients' conditions had declined significantly between being informed about the project and subsequent visits to explore their participation. Furthermore, the fact that patients' conditions were so advanced, meant that the additional effort of engaging with one more thing was simply too much for them.

CARE-PAC is a dyadic system developed for patients and their carer. This presented challenges in relation to recruitment with some patients not having a carer to participate alongside them or a carer being reluctant to do so (or vice versa). The terminology of 'carer' was also a barrier to recruitment, with patients' loved ones feeling uncomfortable with the term 'carer'.

Recruitment

The actual process of recruitment as part of a research project was seen as a challenge by health professionals. While health professionals did manage to streamline the process in many cases, research-related tasks such as provision of information sheets, contact for consent and set-up of the app with patients and carers inherently required extra time.

There was also some frustration from health professionals who were reliant on other teams/clinics to identify and refer patients and carers, with the sense that, there was a substantial pool of potential participants but that those who could identify them were, for whatever reason, not doing so.

Health professionals also recognised that they themselves were often gatekeeping and were reluctant to encourage patients who were undecided to participate as they didn't want to have patients feel that they were 'pushing' them to take part in the project.

Resources, workload and staffing

Despite acknowledging that the actual participation in the project and managing alerts were not an arduous task and in fact had advantages, health professionals continued to express concerns around staffing levels, associated workload and available resources to conduct the project.

Future directions

In recognition of the positive experiences, participants were keen to make suggestions about the future directions that CARE-PAC should follow with two sub-themes of sustainability and suggestions for improvements identified.

Sustainability

In line with the challenges identified in the implementation of the project, adequate resourcing for the CARE-PAC system was identified by all groups as a necessity for future sustainability.

However, health professionals also identified the importance of a snowball type effect in encouraging future uptake of CARE-PAC, in that the more people use it, the more its worth will be demonstrated and so attract more people to use it.

The transferability of CARE-PAC to include patients with a range of conditions receiving palliative and end-of-life care was seen by patients, carers and health professionals to be important in future sustainability.

Finding the most appropriate window of opportunity for the introduction of CARE-PAC to patients and carers was also identified as important in relation to sustainability. Establishing the best time for people to start using CARE-PAC, that is, when it has clear benefits for them and they are well enough to engage with the process involved, was identified as an important consideration for clinical implementation of CARE-PAC.

Alongside this appropriate window, health professionals also saw making CARE-PAC part of normal care as important to its sustainability. Having CARE-PAC as a routine tool in their toolbox, removing the additional time-consuming research-based requirements would be helpful in implementing the system.

Suggestions for improvements

Suggestions for improving the CARE-PAC system related mainly to the tailoring of the system to the individual. For example, the timing of alerts, how health professionals are notified of alerts, adjusting the frequency of the reporting.

This tailoring also related to patients and carers. For example, being able to add context to their daily reports, which would provide additional information to health professionals and may negate the need for them to be contacted by their healthcare team. Patients felt that being able to review and track their own symptom reports would be helpful in furthering their understanding of how they have been feeling and being able to add notes to that, such as pain medication, would provide added insight for them.

Integration of the CARE-PAC system across all healthcare teams caring for patients was also a suggested improvement. Patients were disappointed that not all those involved in their care could view the clinician website, especially given the range of health professionals involved in their care.

Discussion

Principal Results

CARE-PAC is a usable and useful remote monitoring and support system that contributes to the growing body of work on digital palliative care systems, with patients, carers and health professionals reporting positive experiences and making recommendation for future implementation and sustainability.

Comparison with prior work

The CARE-PAC (Care and Support System for Patients and Carers) proof-of-concept study contributes to the growing body of work on digital palliative care systems, which aim to improve patient well-being and caregiver support through enhanced communication, symptom monitoring, and early intervention through the integration of a clinical algorithm to alert the healthcare team of clinically concerning reports. Comparing this study to prior work in the field reveals several key similarities and areas of advancement.

Symptom monitoring, early detection and timely intervention

Digital systems that provide electronic monitoring for palliative care have shown benefits in early detection of symptom escalation, allowing healthcare providers to intervene promptly, quality of life and patient reported outcomes [45,46]. Many of these systems focus on regular symptom reporting, enabling healthcare teams to monitor pain, distress, and physical changes in real time. For example, the MyPal platform for symptom monitoring and similar tools used in oncology that improve communication between patients and healthcare providers through routine data sharing [47,48] and advantages such as improved access to clinicians, quick responses, and enhanced care efficiency in palliative care services in rural areas [30,49]. As with these other systems, participants in the CARE-PAC project identified symptom monitoring, early detection and intervention as important aspects, but CARE-PAC's unique dyadic approach, including carers in the system with their specific questionnaire to identify caring concerns as well as carer well-being, takes the concept of early detection and intervention further, allowing the system to alert healthcare teams to proactively respond to carers' needs and so avert crises arising from situations such as carers feeling overwhelmed and under-supported.

Patient and carer engagement

CARE-PAC employed many of the established methods known to enhance user engagement in research, including involving patients and carers in the co-design and testing phases to ensure that digital interventions are meaningful, useful and usable [50,51]. While the importance of user involvement has grown over recent years, involving people nearing the end of life in research activities remains an under-developed area due to factors such as resistance from individuals, including healthcare professionals [52] to discuss and invite research participation as assumptions are held about patient and family members' vulnerability and associated burdens towards the end of life [53]. Practical and ethical obstacles to research participation have also been documented with barriers including issues with gaining consent, additional burdens on patients and families (including distress and anxiety) and balancing care and research needs [54-56]. However, the positive experiences reported by patients and carers during their co-design and use of CARE-PAC, and by health professionals on their behalf, challenge assumptions that to do so is somehow difficult practically and/or ethically.

Previous studies have used feedback loops within monitoring systems to facilitate patient/carer engagement, for example, having health professionals review the information submitted by patients at regular intervals who then intervene if necessary [48,49]. CARE-PAC provided two types of feedback, the first an overview of patient and carer daily reports over time that allowed health professionals to monitor and review patients remotely, with the second being an alerting clinical risk algorithm that generated real-time alerts for health professionals when patients or carers submitted clinically concerning reports. Patients and carers were informed to contact their healthcare teams as normal should they have any concerns, and not to rely on CARE-PAC as a means of sharing information or problems with their healthcare team. That said, patients and carers reported an increased sense of security and reassurance from knowing that CARE-PAC would flag any clinically concerning reports to their healthcare teams. The value they placed on this is demonstrated in the compliance rates for daily questionnaire completion (patient 72.9% and carers 65.5%), more than the completion rates for the outcome data (QoL and SUS), the completion of which had no direct impact on patients and carers. A third feedback loop will be included in future iterations of CARE-PAC to provide patients and carers with the ability to review their own daily reports/symptoms over time. This has potential to further increase the engagement levels of those using CARE-PAC.

Usability and feasibility

Usability and feasibility are understandably a focus of prior digital health systems, as poor design can negatively impact participant compliance and participation. Remote monitoring systems in palliative care offer potential benefits but can face challenges relating to user adherence and system complexity. For example, patients can find physical monitoring obtrusive, leading to reduced adherence [57] and barriers to technology use, such as seeing it as intrusive and a threat to privacy, as well as inflexible reporting of complex symptoms remain significant challenges [58]. However, despite these challenges, mobile phone-based symptom monitoring systems have shown promise in rural communities, proving usable and acceptable to both patients and healthcare professionals [30] with user-centered design approaches and exploring user experiences helping to address challenges and improve system effectiveness [57,59]. CARE-PAC's mixed-methods approach, combining quantitative data with qualitative feedback, offers a well-rounded perspective on user experience and the improvement in CARE-PAC’s usability scores over time suggests that the system becomes more intuitive with prolonged use. This progression contrasts with some earlier systems where usability issues remained barriers to adoption throughout the project [58,60].

Research-related and sustainability challenges

A significant finding from the CARE-PAC project is the need to integrate the system into normal offerings of ‘standard’ care, thereby removing specific research-related, and often time-consuming, tasks such as provision of information sheets, repeat visits for consent. Challenges of balancing research-related duties with routine clinical care are not uncommon and it is perhaps telling that while several pilot and feasibility studies are reported, there are yet to be any publications detailing longer term application of remote monitoring systems within palliative care. The sub-themes around resourcing and triaging identified by health professionals in the CARE-PAC project may reflect the challenges of implementing remote monitoring systems in the longer term.

USP of CARE-PAC

CARE-PAC advances prior work by combining several elements: high compliance, real-time data-sharing, information provision and tailored responses from healthcare teams as well as involving carers both in relation to their caring role and own well-being. Its emphasis on early detection and clinical interventions to avoid crises, ensure appropriate healthcare utilisation and improve distress management reflects a move toward a more proactive, comprehensive, crisis-preventative approach in palliative care. CARE-PAC builds on established successes of earlier digital palliative care systems while addressing gaps in usability and engagement to set the stage for longer term implementation and further exploration of its impact on palliative care delivery and quality of life.

Strengths and Limitations

A significant challenge associated with measuring experiences and outcomes in palliative care is that it is possible for a patient to have a positive experience but poor outcomes and vice versa [61]. Although ideally, both would be good, it may not always be possible to achieve outcomes that are positive when a person's health is rapidly deteriorating [61]. This challenge was relevant to the CARE-PAC patient population who, perhaps despite early interventions, symptom management and appropriate support through using the app, may have continued to experience deteriorating health and associated outcomes.

Strengths

Involving people receiving palliative care in research can present several challenges including concerns about over-burdening people when they are at their most vulnerable, symptom severity and misconceptions about the benefits of research [62]. There can also be challenges in relation to a lack of research infrastructure and funding dedicated to palliative care, limiting the capacity to conduct research [63]. However, many patients and their families express a willingness to participate in research even at this time in their lives, often driven by a desire to contribute to improvements in care for people in the future [64,65]. Co-designing the CARE-PAC system with patients, carers and health professionals ensured that the final prototype used for the pilot test was not only functional but also deeply aligned with the real-world needs, unique perspectives and challenges of its future users. During the pilot test, patients and carers consistently expressed their thanks for the opportunity to be involved in the research, supporting the theory that, even during difficult times, people are keen to engage with research and have positive experiences while doing so.

This study was conducted across five different clinical sites in Scotland and England. The consistency in experiences regardless of clinicians' clinical setting (hospice, hospital, community) and patient and carer location (home, hospital, hospice) and diagnosis suggests that, despite the small number of participants, the results can be generalised across clinical areas with positive impacts for patients and carers regardless of their location and health condition.

Patients and carers were invited to participate in the project for up to 12 weeks, a relatively lengthy period for people receiving palliative care. In recognition of the potential for patient attrition during participation, CARE-PAC opted to collect outcome data at regular 3-weekly time points. This meant that, should a participant choose to withdraw from the project or die during their involvement, their outcomes and experiences were still included in the final evaluation.

The real-time nature of data sharing through CARE-PAC meant that the information inputted to the app by patients and carers was instantly available to their healthcare team for review along with any alerts that were generated by the clinical algorithm. This meant that the healthcare professionals could provide proactive rather than reactive interventions, picking up clinical issues early and acting appropriately. While this early intervention was not measured as part of the project outcomes, anecdotal accounts from patients and carers described instances where they felt that the information inputted to the app had a direct impact on the treatment, care and support that they subsequently received.

The dyadic nature, including both patients AND their carer, was a unique strength of the project as few, if any, remote monitoring systems include both carer as well as patient. Informal carers play a central role in the delivery of palliative care and assume multiple caregiving roles including physical, emotional, psychological and existential care [66]. While there are many positive aspects to this role, it can also have detrimental consequences with negative impact on their own health, psychological distress and sense of overload ([67]. Ensuring carers are adequately supported in both their caring role and own well-being will prevent instances of carer crises which can lead to unnecessary hospital admission for patients. Incorporating carers' views of the current situation and their own well-being in the system was viewed, especially by patients and carers, as extremely valuable. Health professionals could also see value in understanding the carer’s perspective but felt they lacked information, such as past medical history, to fully address carer specific alerts. Alternative suggestions included triaging of carer alerts via existing carer support services, for example telephone support offered by palliative care charities.

Limitations

The first set of limitations relates to the study sample. This was a small population of 13 patients (12 of whom had a cancer diagnosis) and 13 carers, and health professionals found the process of recruitment to the project challenging. This sample size makes it difficult to generalise the results and draw any broad conclusions or statistically significant results. There may also have been an element of selection bias in relation to participants as health professionals acknowledged their gatekeeping role in the process of participant identification and recruitment. Those who agreed to participate may not be reflective of the wider palliative care population, they may have been more comfortable with technology, leading to biased results regarding usability and acceptance. Additionally, recruitment may have been biased towards people who were more ‘well’ than those who were poorly, indeed rapid deterioration was seen as a challenge to recruitment by the health professionals who gave feedback at the end of the project. That participants had to take part as a dyad (a patient and a carer), can also be seen as a limitation. This not only affected recruitment, when patients either didn’t have a carer or their carer didn’t identify as such, but also on two occasions, participants opted to withdraw from the project, forcing the other participant to also leave the project despite their willingness to continue. Furthermore, only small teams of health professionals from each clinical site were involved so it is difficult to draw conclusions about the scalability of the system with the broader healthcare system.

The second set of limitations relates to the study design. Twelve weeks is a reasonable duration to participate in a study, especially for people receiving palliative care who are likely to experience physical decline, increased symptom burden and emotional and psychological challenges that could impact on ability to continue to participate in a study. However, limiting participation to 12 weeks restricted the evaluation of longer-term usability, sustainability and effectiveness of the system in monitoring changes in health status and quality of life over time. Further, anecdotal evidence from some participants suggests that they would have continued to use the system for longer than 12 weeks had that been permitted and that it felt strange not to have the system at the end of the project. A more flexible approach to duration of participation in future projects could be helpful. In relation to data collection, although health professionals were required to add a ‘note’ on the clinician website to close alerts, the project didn’t evaluate the information about alerts and the subsequent clinical intervention and their impact. Patients and carers were able to anecdotally explain when they felt that alerts based on their symptom reports had directly resulted in treatment/care from their clinical teams, but future studies should formalise this evaluation. In addition, the small QoL data set makes it difficult to draw anything other than cautious thoughts about QoL improvements.

Future work to evaluate the CARE-PAC system will consider these limitations and include a larger sample size of patients, carers and clinicians, consider allowing patients and carers to participate together or alone, look to include patients with a range of diagnoses, have no specified end date, so allowing people to continue to use the system for as long as wished, develop a system that can be as integrated as possible with various health care digital systems and deploy the system across a range of health and social care services.

Future implications

The COVID-19 pandemic has accelerated demand for palliative care services by approximately 20 years, meaning levels are currently at those not expected until 2040 [68], with the number of people requiring palliative care in England and Wales by 2040 estimated to grow by 25-42.4%, primarily driven by an aging population and increased prevalence of chronic illnesses, particularly dementia and cancer [8]. In 2021, nearly three-quarters (395,438) of people who died spent time in hospital during their final six months, accumulating a total of 7.7 million days, almost two-thirds (63.5%) experienced at least one emergency admission in their last three months of life, with 7.1% experiencing three or more emergency admissions [69].

These statistics put significant strain on NHS resources, with end-of-life costs exceeding £1.2 billion in 2018-19 alone [5] and the projections underscore the need for reform of palliative care services to meet future demands. Implementing palliative care tailored to individuals is crucial to enhance quality of life, while depressurising overburdened health and social care systems, ultimately providing more compassionate and cost-effective care. New ways of identifying those most in need and triaging care services appropriately are needed.

The CARE-PAC system addresses these issues through proactively remotely monitoring patients and families, allowing appropriate health professionals to identify needs in real-time and intervene early to prevent predictable crises that typically result in hospital admissions, promoting better coordination and support for palliative and end-of-life care. Further high-quality research with standardised follow-up and established outcome measures is needed to better understand the benefits of this dyadic remote monitoring system for people nearing the end of life and their carers and demonstrate its clinical and cost-effectiveness across various settings in the UK.

Conclusions

In conclusion, the co-design and pilot testing of the CARE-PAC system has demonstrated significant promise, offering meaningful improvements in patient and carer experiences. Positive outcomes include improved quality of life, early detection of symptoms allowing for timely interventions, increased reassurance and support for both patients and carers and provision of information. These positive outcomes highlight the potential of digital solutions to alleviate some of the burdens and uncertainties associated with palliative care and enhance the quality of care by fostering a more proactive approach to patient needs.

However, challenges in recruitment and the need for adequate resourcing present important considerations for future implementation. Recruiting participants in a population that is often frail and declining over time proved difficult, and the system would require dedicated resources to scale and support its use effectively in real-world settings. Currently, palliative and end-of-life care services struggle to meet existing demands, and with an aging population, the gap between need and availability is only expected to widen. Digital advances such as the CARE-PAC system developed and tested in this project offer a real opportunity to address these challenges by promoting proactive care and providing accessible, timely support—ensuring that all individuals receive the compassionate, high-quality care they deserve as they approach the end of life.

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Authors contributions

All authors contributed to the conceptualisation, writing and editing of the paper.

Conflicts of Interest

None declared.

Abbreviations

CARE-PAC: the care and support system for patients and carers
UK: United Kingdom

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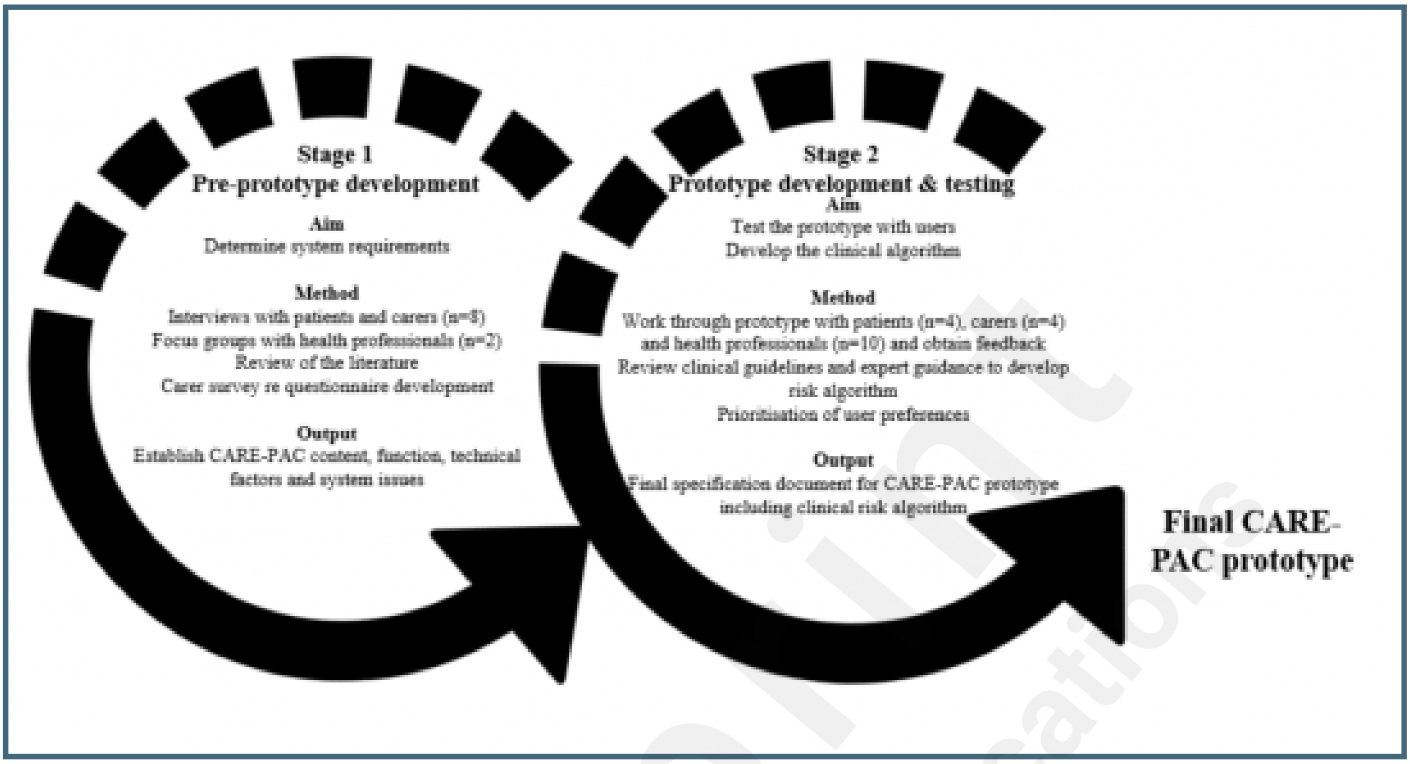
Supplementary Files

Figures

Co-design and development of CARE-PAC system.



Final version of CARE-PAC.