OPEN ACCESS

Digital legacy in palliative care and end-of-life care planning: a scoping review

Sarah Stanley ,[1,2] Julie Ann Hayes,[1] Caroline Mogan,[1] Mari Lloyd-Williams,[1] Amara Callistus Nwosu ,[2,3] Cristina Mihaela Vasilica,[4] Karen Higginbotham[1]

► Additional supplemental material is published online only. To view, please visit the journal online (https://doi.org/10.1136/spcare-2026-006205).

[1]Faculty of Health, Innovation, Technology and Science, School of Nursing, Public and Allied Health, Liverpool John Moores University, Liverpool, UK
[2]Marie Curie North West, Liverpool, UK
[3]Palliative Medicine, Lancaster University Faculty of Health and Medicine, Lancaster, UK
[4]School of Health and Society, University of Salford, Salford, UK

Correspondence to
Sarah Stanley;
S.Stanley@2023.ljmu.ac.uk

Received 26 February 2026
Accepted 30 March 2026

To cite: Stanley S, Hayes JA, Mogan C, *et al*. *BMJ Supportive & Palliative Care* Epub ahead of print: [please include Day Month Year]. doi:10.1136/spcare-2026-006205

ABSTRACT

Background The need for palliative care is increasing, and it is essential to consider emerging technologies that have the potential to enhance care for palliative patients and their carers. The creation of online content and digital media stored on devices is often described as a digital legacy. There is limited knowledge about how digital legacy is included in planning for the end of life.

Aims To conduct a scoping review of the literature to describe healthcare professionals, patients receiving palliative care, caregivers and bereaved people's experience of including digital legacy in planning for the end of life.

Methods A scoping review of the literature was carried out. The question was formulated using the Population, Exposure, Outcome format as follows: 'What is known from the existing literature about healthcare professionals, patients receiving palliative care, caregivers, and bereaved people's experience of including digital legacy in planning for the end-of-life?'

Results 506 records were screened and 11 were included in the review. A number of examples of the use of digital legacy were identified. Themes identified from the literature include digital legacy showing the authentic person, digital legacy evoking emotion, digital legacy to maintain a connection and preparing digital legacy.

Conclusion People receiving palliative care use digital legacy to make memories and capture the essence of their character, often finding time for reflection and creating a sense of empowerment. A person's digital legacy could be discussed with healthcare professionals and others who are important to support in planning for the end of life.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The creation of digital legacy has become a fundamental aspect of contemporary society carrying significant implications for palliative care. However, conversations around digital legacy planning are not taking place in current practice.

WHAT THIS STUDY ADDS

⇒ Consideration of digital legacy when planning for the end of life is emerging as a key consideration: (1) to support people receiving palliative care by ensuring that their wishes in relation to digital legacy are met, (2) to support bereaved people to maintain access to digital legacies of people important to them and support the grieving process and (3) to ensure healthcare professionals are discussing the topic of digital legacy in good time.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study identifies key gaps in the literature, including cultural, generational, practical and financial factors related to digital legacy providing a foundation for future research.

INTRODUCTION

Rationale

Increasing palliative care need[1] means that globally service providers need to consider appropriate ways to use resources efficiently to support increasing palliative care need.[2] Digital health/technologies are increasingly being used by both healthcare professionals and the public to support delivery of care and self-management of palliative care need. Recent data suggest a greater adoption of personal technology usage across all age groups prior to the pandemic,[3] with many people spending time creating and broadcasting their own online content.[4] Globally, people create vast amounts of digital content through social media activity, online communication, cloud-stored files and continuous data trails. For example, Statista reports that around 6 billion people use the

internet worldwide,[5] spending an average of 6 hours online every day.[6]

Digital legacy: discussion and definition

The creation of online content and digital media stored on devices is frequently described as a digital footprint or a digital legacy.[7] Around 92.3% of the public have not made any social media or digital will outlining what they would like to happen to their social media accounts following their death.[8] In a survey of 210 palliative healthcare professionals, 96% had not asked their patients about their digital legacy.[9] For the bereaved, digital legacy can provide an important connection to the deceased person, keeping their memory alive.[10] Consequences of a lack of advance care planning (ACP) for digital legacy may lead to issues with financial management (eg, online banking, digital wallets, cryptocurrency), access to digital content (eg, photographs and videos), digital presence (eg, social media, online communities, gaming) and admin subscription (eg, Amazon, Google). This lack of planning could lead to significant burden, worry and concern in caregivers who currently have no guidance to help support them. Therefore, it is important that we further explore how digital legacy can be incorporated into planning for the end of life and assist patients with palliative care needs to manage their own digital legacies.

Although we did not identify any reviews within the healthcare or palliative care literature that focus on digital legacy, a recent review from the human–computer interaction and social computing fields highlights that research on digital legacy in computer-supported cooperative work and broader human–computer interaction mainly examines how people navigate identity in the transfer of digital assets, how these legacies are interacted with, how they are brought to closure and how digital technologies intersect with traditional, offline forms of legacy.[11]

However, there is limited knowledge about how digital legacy is included in planning for the end of life by healthcare professionals, patients receiving palliative care, caregivers and bereaved people. A scoping review was deemed appropriate for this study as it is helpful for identifying existing knowledge and evidence on a particular topic while also identifying gaps where further research is needed.[12–15]

Aims of the scoping review

This scoping review was conducted in order to systematically map the research carried out in this area, as well as to identify any existing gaps in knowledge.

METHODS

This review has followed the framework developed by the Joanna Briggs Institute (JBI)[16] which describes nine steps to carrying out a scoping review: (1) defining and aligning the objective and question, (2) developing and aligning the inclusion criteria with the objective and question, (3) describing the planned approach to evidence searching, selection, data extraction and presentation of the evidence, (4) searching for the evidence, (5) selecting the evidence, (6) extracting the evidence, (7) analysis of the evidence, (8) presentation of the results and (9) summarising the evidence in relation to the purpose of the review, making conclusions and noting any implications of the findings. The study was reported based on the Preferred Reporting Items for Systematic Review and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) checklist.[17] The research question was discussed and refined within the study team, which consisted of researchers with expertise in palliative care, qualitative methods, digital health and ethics. Due to the qualitative nature of this study, the research question was formulated using the Population, Exposure, Outcome question format in order to provide structure and guidance to the search strategy of this scoping review.[18]

The following research question was formulated: *What is known from the existing literature about healthcare professionals, patients receiving palliative care, caregivers and bereaved people's experience of including digital legacy in planning for the end of life?*

Inclusion and exclusion criteria were discussed and agreed within the study team (table 1). The search was restricted to adults (>18 years of age), as adults in palliative care were the focus of this review. To refine the search and align with advances in the use of digital technology,[19 20] a 10-year time frame from 2013 to 2023 was applied. The 2013–2023 time frame was selected to capture the rapid expansion of smartphones, social media and computational tools. These technologies have significantly increased the volume of data that constitute a modern digital legacy. Only

Table 1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
► Studies that explore digital legacy ► Studies that explore social practices through social media for memorials ► Studies that explore how memory making as part of end-of-life planning can impact bereavement ► Studies that explore the impact of advance care planning on end-of-life care and bereavement ► Studies undertaken between the years 2013 and 2023	► Studies not written in the English language ► Studies that do not relate directly to the subject of digital legacy, memory making, planning for the end of life or the impact this may have on bereavement ► Studies that may involve children or young adult patients up to and including 18 years of age

Table 2 Search terms

Keywords	Alternative terms, Boolean operators and truncation
Healthcare professionals, patients receiving palliative care, caregivers and bereaved people	Healthcare professional* OR Doctor* OR Nurs* OR Multidisciplinary OR Patient* OR caregiver* OR carer* OR relative* OR Bereave* OR Grief OR Grieve*
AND	
Palliative care	Palliative OR Terminal OR "life-limiting" OR "End of life" OR death
AND	
Digital legacy	Digital AND legacy OR Digital AND memor* OR digital AND asset* OR digital AND belonging* OR "social media"
AND	
Advance care planning	Manag* OR Preparation OR plan* OR "advance care planning" OR "anticipatory care planning"

sources of information in the English language were included as this was the first language of the research team.

A list of search terms was developed within the research team. Keywords, alternative terms, synonyms, Boolean operators and truncation used to search the literature are presented in table 2. A data extraction guide (online supplemental appendix 2) was developed and agreed by the research team to ensure data items were relevant to the review question.[15] As the aim of this review was to identify healthcare professionals, patients receiving palliative care, caregivers and bereaved people's experiences of including digital legacy in planning for the end-of-life data extraction included description of the use of digital legacy and key findings in relation to experiences.

Five databases were searched to provide a comprehensive overview of the literature. The databases included covered a range of literature including healthcare, sciences, behavioural and social sciences, and arts and humanities. The five databases were: Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, Scopus, PsycInfo and Web of Science. Grey literature was sourced through Google, Google Scholar, ProQuest Dissertations & Theses Global, relevant organisation websites, government websites and media. The scoping process also included hand searching using reference lists. A search of literature was undertaken between September 2023 and December 2023 and was repeated in September 2025 to identify any further sources of evidence. Following the search, all identified records (n=747) were collated and uploaded to Rayyan, an online management resource for systematic reviews,[21] and duplicates were removed (n=241). Titles and abstracts of potentially relevant papers (n=506) were initially screened by five independent reviewers (SS, KH, JAH, CM, CMV), following the inclusion criteria for the review. Papers that did not meet the inclusion criteria were excluded (n=424). Full-text review of 53 papers was conducted, and a further 30 papers were excluded with reasons recorded on the PRISMA-ScR flow diagram (figure 1). Throughout the review processes described here, following independent review, reviewers were paired up to discuss any records that they were uncertain met the review criteria. This provided rigour to the study selection process, with reviewers discussing reasons for inclusion or exclusion of papers that did not clearly meet the criteria set out for the review.

Data charting included summaries from each paper regarding author, year, publication type, country, description of the use of digital legacy, population and key findings in relation to experiences. Online supplemental appendix 1 lists the included papers and data extracted. In line with JBI scoping review guidance, data were analysed using an inductive qualitative content analysis process.[22] Elo and Kyngäs[23] describe three main phases of qualitative content analysis in which data are prepared, organised and reported. For this review, the data were prepared using a data extraction guide. Data were organised by coding each individual manuscript manually, jotting down codes and notes in the margins to describe the content. Codes were then categorised into themes in order to describe experiences of including digital legacy in planning for the end of life.

RESULTS

Description of papers

This scoping review found 11 papers reporting on experiences of including digital legacy in planning for the end of life. The review papers originated from Australia (n=1), UK (n=4), USA (n=4), Cyprus (n=1) and Germany (n=1). Paper methodologies were varied and included quantitative,[24 25] qualitative,[10 26–30] feasibility[31 32] and scoping reviews.[33]

How digital legacy is used

From the scoping exercise, 11 records (n=11) were included in the review. The majority of these looked at experiences of bereaved people (n=7), four included experiences of people receiving palliative care (n=5) and one included the experiences of healthcare professionals (n=1). No records were found to describe the experiences of caregivers including digital legacy in planning for the end of life.

To support their grieving process, bereaved people used digital legacies in various ways. While

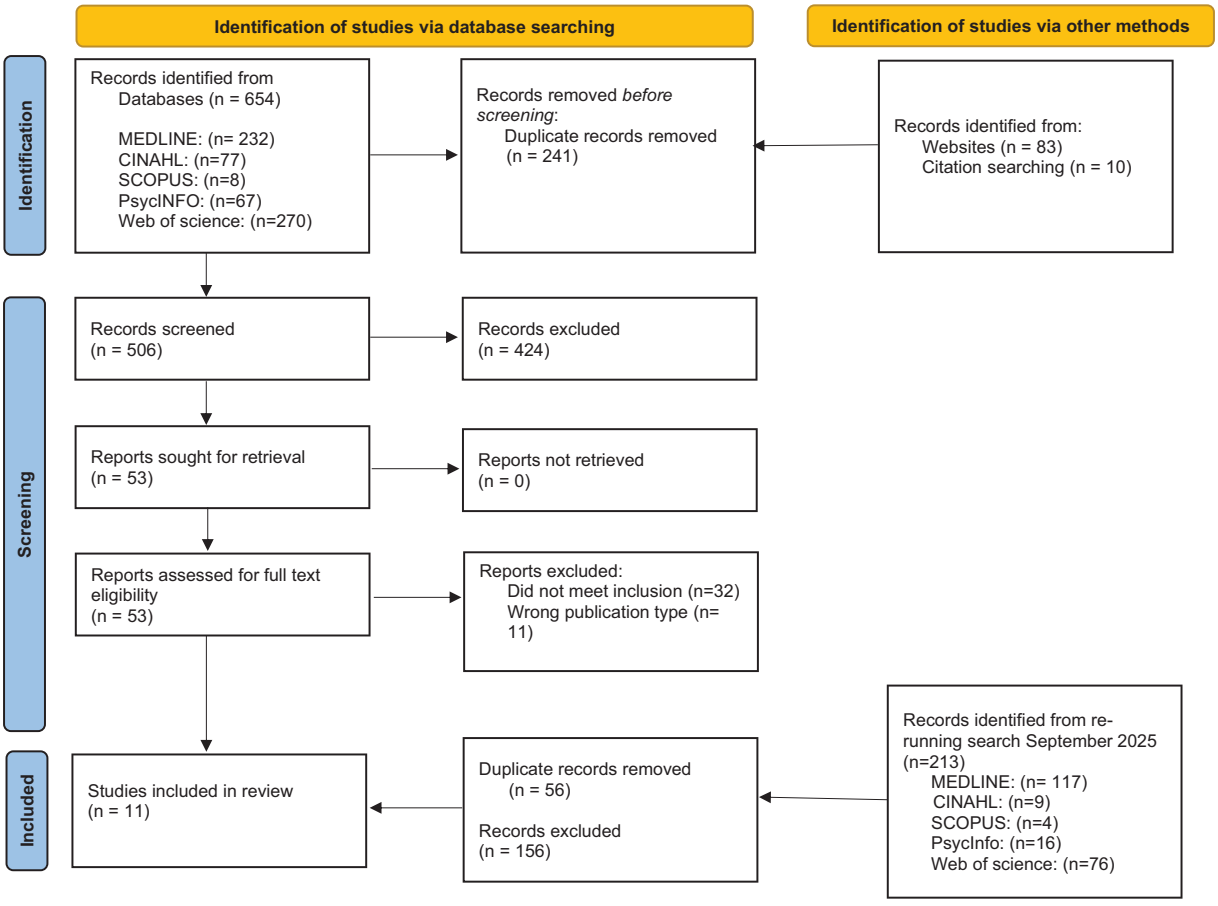

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram illustrating the identification, screening, eligibility assessment and inclusion of studies in the review.

the majority focused on social media and posthumous messages,[24 26 27] individual cases also explored the use of video legacies[10] and digital photographic memories.[30]

For people receiving palliative care, the main use of digital legacy was through the creation of digital videos.[10 31] One paper looked at the feasibility of an avatar-facilitated life review.[32] The remaining papers did not focus on a particular use of digital legacy but considered management of digital legacy.[25 28 29 33] A qualitative content analysis of the findings is reported under the following themes: *digital legacy showing the authentic person*, *digital legacy evoking emotion*, *digital legacy to maintain a connection* and *preparing digital legacy*.

Theme 1: digital legacy showing the authentic person

Three articles mentioned how digital legacy could be used to show the authentic person,[10 29 30] including three subthemes: *capturing character, the person before the illness* and *filling in the gaps*. For a person with a life-limiting illness digital legacy can be a powerful way to express their self and capture their character in a way that they wish to be remembered.[10 30] This could be achieved in a number of ways, including personal narratives, for example, social media and archived conversations,[29] and digital multimedia such as photographs and videos.[10 30] For the bereaved, digital legacy enabled memories to be preserved, capturing glimpses into the life of the deceased before they became unwell.[10 30] Benefits to this included a sense of comfort in bereavement[10] and a reminder that there was a 'normal' life lived prior to the person's illness.[30] Digital media allows the bereaved to 'fill in the gaps' of a loved one's history. By accessing previously unseen photographs, survivors can reconstruct areas of that person's life that were previously unknown to them.[10] While viewed as mainly positive, there was recognition of the emotional challenge faced in bereavement when there were no new photographs to uncover,[30] and how a non-intentional recording may lack biographical information and narrative of a person's life.[10] In contrast, a purposefully recorded video could help the bereaved to know that their loved one was prepared and had come to terms with their illness, meaning that they would not need to make assumptions and fill in the gaps themselves.[10]

Theme 2: digital legacy evoking emotion

Six articles in this review refer to digital legacy evoking emotion,[10 24 26–28 32] including two subthemes: *the right timing* and *balancing positive and negative emotions*.

Timing was noted as key aspect of digital legacy planning. Healthcare professionals recognised the importance of integrating digital asset management into standard ACP. As the volume of digital data generated after death increases, timely discussions are essential to ensure there is a plan to ensure these belongings are properly stored and preserved. Healthcare professionals also considered it important to ensure that opportunities were given to patients to create new digital memories, for example, the use of photographs or video recordings.[28] However, creation of digital memories should be carried out with caution to avoid the risk of the individual looking or sounding too unwell. Concerns were reported for bereaved people who would eventually receive the digital memory and the potential this would cause a negative or distressing experience. In bereavement, timing was important to those who received digital memories, and in order to prevent distress it was important for them to maintain control over how and when they could access the digital legacy.[10 26]

For people receiving palliative care, the process of creating digital legacy can be deeply personal. It may help them to reflect on their life but can also feel overwhelming. From the perspective of people receiving palliative care, it was important when creating a digital legacy to acknowledge their own emotions. While emotional responses to digital legacy were not perceived negatively,[32] challenges faced by people receiving palliative care included the importance of having a level of acceptance of their own mortality, ensuring that they were equipped to deal with their emotions when creating digital legacy, and the overwhelming emotions as a result of reflecting on their prognosis.[10] For bereaved individuals, digital legacy can offer comfort, connection and a sense of control—particularly when they can choose how and when to engage with it.[27] However, digital content such as messages or social media posts could also trigger painful emotions, particularly if received unexpectedly or without context.[24] A thoughtful balance of emotions is key to ensuring digital legacy supports, rather than complicates, end-of-life care planning.

Theme 3: digital legacy to maintain a connection

Three articles mentioned how digital legacy could be used to maintain a connection,[10 26 27] including two subthemes: *remaining present* and *continuing bonds*. As more people use digital technology, there is a growing chance that our online presence will remain following death. For those in grief, digital memories can provide comfort and a lasting connection to the deceased. But while most digital reminders are now widely accepted, artificial intelligence-generated content may feel intrusive.[27] For people nearing the end of life, creating a digital legacy could be a meaningful way to leave behind guidance, values or memories for others.[10]

Posthumous digital technologies have the potential to connect worlds—both the living and the dead. Social media platforms could be used by the living to maintain a connection with the dead, enabling survivors to continue to write about the deceased, and tag them into online posts. Bereaved people expressed how posthumous messages could provide comfort in bereavement and provide a mechanism to maintain a 'connection' with the deceased.[26] The ability to receive new messages after a person has died may help survivors continue interactions with the dead. However, this is not universally welcomed, as some bereaved people described these posthumous messages as distressing.[10 26]

Theme 4: preparing digital legacy

Nine articles in this review refer to preparing digital legacy,[10 25–29 31–33] including three subthemes: *empowering, time for reflection* and *digital legacy management*. Healthcare professionals working in palliative care viewed the act of preparing a digital legacy as empowering. Although such discussions are not yet routine, they recognised that initiating these conversations could enable patients to make informed decisions about the future of their digital possessions, and importantly people receiving palliative care want to discuss their digital belongings.[25] People receiving palliative care reported that they had a positive experience with creating digital legacy projects, with some describing how the project had helped them to process their own cancer experience which they also viewed to help others,[31] and others describing how, as their physical condition deteriorated, they were able to channel their time and efforts into a project which helped to instil a sense of purpose.[10] These views were also reflected by the bereaved who recognised how creating a digital legacy could provide a person with life-limiting illness opportunities to explore topics that matter.[29] For people receiving palliative care, digital legacy also provided an opportunity to reflect and support life review.[32 33]

Digital legacy management was described as an important practice to prevent the loss, or loss of access, to digital legacy. There were concerns highlighted around the growing volume of digital belongings[28] and the importance of practices such as preparation, curation, tidying up and delegation of digital belongings as well as practices to support bereavement such as archiving, talking to the dead and feeling close.[33] One of the key issues with a lack of digital legacy management is loss of memories, whether that be through lack of access or deletion of data, which could lead to feelings of distress in bereavement[26] and feeling like there had been a 'second loss'.[27]

DISCUSSION

To the best of our knowledge, this is the first scoping review to focus specifically on experiences of digital

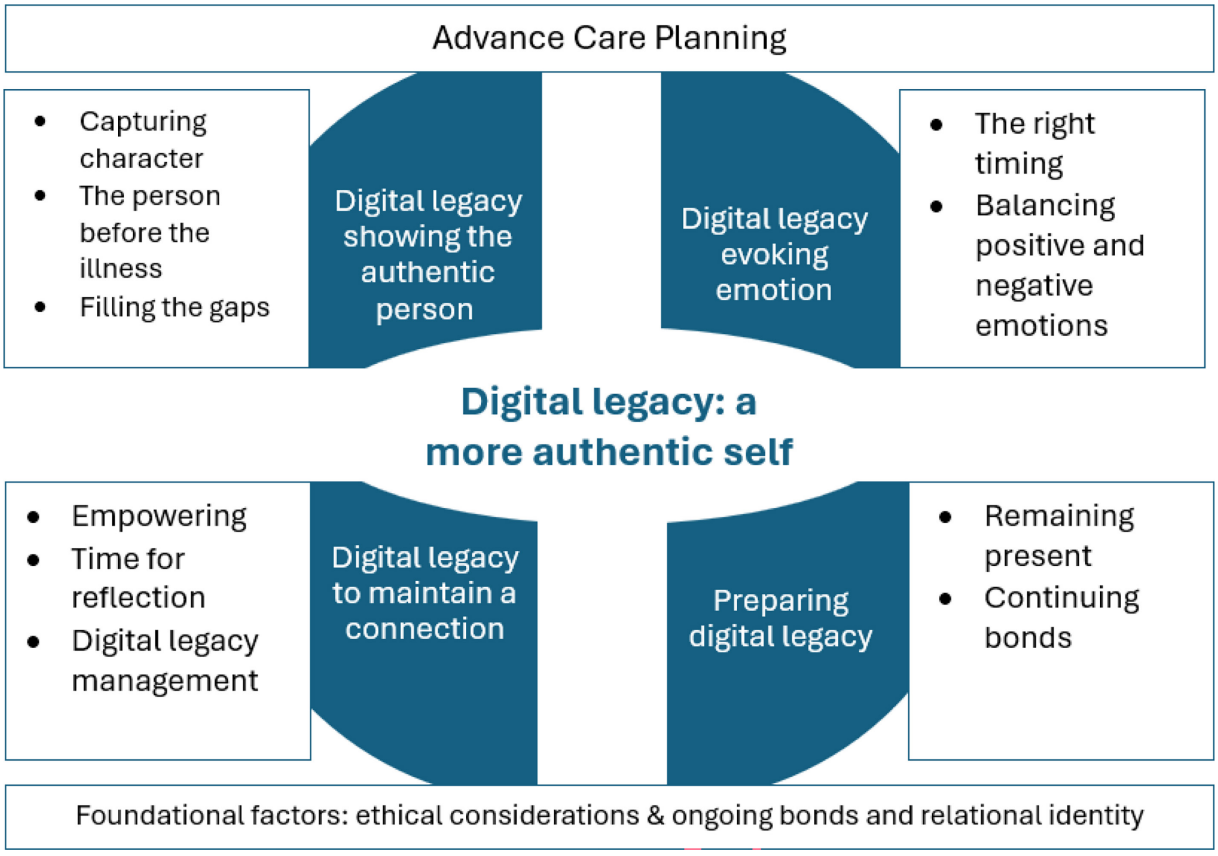

Figure 2 Diagram demonstrating key findings from the scoping review.

legacy within palliative and bereavement care. As healthcare systems globally and nationally continue to shift from analogue to digital,[34 35] this work is both timely and highly significant. This digital focus means that individuals now generate vast amounts of digital content across their lives, making questions around digital legacy, access and post-death data management increasingly important.

Findings from this review (figure 2) indicate that considering digital legacy during end-of-life planning is emerging as a key area for practice development. This is important for several reasons: (1) to support the person receiving palliative care by ensuring that their wishes in relation to digital legacy are met, (2) to support bereaved people to maintain access to digital legacy and support the grieving process and (3) to ensure healthcare professionals are discussing the topic of digital legacy in good time. Notably, no evidence was found to reflect the experiences of caregivers, highlighting a significant gap for future research.

Across included studies in this review, digital legacy was commonly characterised as a means of representing a person in ways perceived as more authentic than traditional memorials.[10 29 30] Content such as photographs, voice recordings, social media posts, messages and videos was framed as capturing the identity of the deceased through normal, everyday interactions. This reflects a shift from traditional memorials (eg, obituaries, memorial services) following a person's death to a memorial developed by the person and their networks over time prior to their death.[26 29 30] The authenticity of digital memories is linked to their multimedia qualities, for example, images, voice and movement, which convey nuance and depth. In this review, the bereaved viewed digital memories that capture a person's character as particularly important.[10 29 30] This finding aligns with a previous review in the human–computer interaction and social computing literature, which similarly describes digital legacy as a means of representing identity that persists beyond death.[11]

Across the literature, digital legacy was frequently described as evoking powerful emotional responses among people receiving palliative care and the bereaved. Encountering digital memories such as messages or videos enabled moments of closeness and comfort, while in some cases also provoking distress or longing. While these reminders may offer comfort to some bereaved individuals by maintaining a sense of connection, they can also provoke distress by reactivating grief without warning or consent. These unexpected encounters may be viewed as intrusive, leading to feeling a loss of control during bereavement and potentially complicating grieving processes. This raises the importance of ethical considerations in relation to bereavement and the presence of unexpected digital

reminders, such as automated notifications and resurfaced memories. These ethical challenges highlight tensions between platform design and the emotional needs of bereaved individuals, emphasising the importance of greater sensitivity and choice in how digital memories are viewed and managed after death.[11 36]

Continuing bonds is a concept in bereavement theory that challenges the traditional idea that healthy grieving requires cutting ties with the deceased. Instead, it suggests that maintaining an ongoing, evolving relationship with the person who has died can be a natural and even beneficial part of the grieving process.[37] Findings from this review align with continuing bonds theory. In this review, bereaved individuals described returning to digital items to revisit shared moments through photographs, videos, social media and reading messages to or from the deceased. This indicates that digital legacy functions as a mechanism through which ongoing bonds are maintained.[38] The literature differentiates passive connection (viewing and listening) from active connection (writing messages, posting tributes and curating content), with each enabling different relational practices.[10 25 26] In addition, these interactions support relational identity, enabling the bereaved to continue roles, relationships and a sense of connection with the deceased in ways that feel authentic and meaningful.[39] However, consideration must be given to how digital remains can blur the boundaries between presence and absence, which may in some cases contribute to prolonged grief.[40]

Finally, this review identified preparing digital legacy as an important and multifaceted practice. It expresses identity, engages emotion and sustains relationships, all of which are profoundly shaped by whether and how preparation occurs. Preparation of digital legacy was widely described as an empowering process. Importantly, evidence from this review indicates that people receiving palliative care want to engage in conversations about their digital belongings. This challenges any assumptions that digital legacy discussions may be inappropriate or burdensome in end-of-life contexts and is consistent with literature around wider ACP practices.[41 42] Instead, preparing a digital legacy may offer individuals a sense of ownership over how their digital lives are curated, preserved or passed on, aligning with broader aims of palliative care to support person-centred and holistic approaches.[43]

Curating digital content—such as old photographs, videos, voice recordings and personal messages—may hold therapeutic value for people receiving palliative care. While much of the existing research on reminiscence therapy and legacy building interventions comes from dementia care, where these approaches have been shown to support identity, emotional connection and well-being,[44 45] the underlying principles are applicable more broadly. In palliative care settings, engaging with meaningful digital memories could help individuals to reflect on their life story, reinforce relationships and gain a sense of continuity and dignity at the end of life. For some, creating or organising digital content becomes a way of leaving something personal for loved ones, aligning with psychological and existential aspects of legacy work.[46] Additionally, the ease of accessing digital archives, from shared family albums to social media histories, may make reminiscence more flexible and inclusive than traditional methods.

Our scoping review has identified that research in this area is limited. The majority of studies focused on the experiences of bereaved people and no literature was found to represent the experiences of informal caregivers. A key area requiring further exploration concerns the inclusion of non-English literature to capture culturally diverse understandings of digital legacy and its role in end-of-life planning. Broadening the evidence base in this way may illuminate how cultural norms, values and technological practices shape individuals' preferences for creating, managing and transferring digital assets. Additionally, there is a need for more systematic investigation into the broader impacts of digital legacy, including the financial, administrative and emotional burdens that arise when digital information is poorly documented or inaccessible. Understanding these impacts could inform the development of more responsive ACP tools that support decision-making and help mitigate the consequences of inadequate digital legacy preparation. Important questions remain regarding the optimal format and delivery of ACP tools—whether digital, paper based, hybrid or embedded within existing health systems—and the timing of discussions about digital legacy across the illness trajectory. Moreover, generational differences in digital literacy, technology use and attitudes towards online identity and legacy highlight the need for tailored support strategies. Younger cohorts such as Generation Z and Alpha may require guidance on curating extensive digital footprints, whereas older generations, including Baby Boomers and Generation X, may need assistance navigating technological systems or recognising the relevance of digital legacy to end-of-life planning. Addressing these gaps will be essential for developing equitable, culturally sensitive and generation-appropriate approaches to digital legacy within palliative care and ACP frameworks. Addressing these gaps will require interdisciplinary collaboration, bridging qualitative depth with quantitative breadth and engaging stakeholders across communities, care systems and technology sectors.

Strengths and limitations

To strengthen this scoping review, structured systematic frameworks[14] were adhered to. However, scoping reviews are naturally constrained by their broad research questions and search strategies, which means some relevant literature may have been overlooked during the search or screening stages. This review was also limited by a 10-year searching time frame; however, this time frame aligns with the increased personal use of technology,[20] which means that creation of digital legacy is likely increasing. A key

limitation of this review was the inclusion of only English language papers due to time, language and resource constraints. This restriction may have reduced the range and diversity of studies considered, and it is acknowledged that a search without language limitations would likely have yielded more comprehensive results. Consequently, the findings may not be generalisable to non-English-speaking countries.

Implications for policy, practice and research

First, the review identified that people receiving palliative care wish to discuss what happens to their digital belongings, which means that policymakers should consider digital legacy into national end-of-life care frameworks. Second, it is also important to understand the practical implications of digital legacy for end-of-life care, including how prepared services are to address it, the level of training required for staff and the associated financial and ethical considerations. From a practice perspective, healthcare services require clear and workable processes to support patients in managing their digital legacy as part of routine care. This involves creating straightforward workflows for identifying digital assets, documenting patient preferences and signposting to relevant legal or technical support where needed. Staff may also need access to practical tools, such as conversation guides, checklists and referral pathways, to feel confident initiating these discussions sensitively and at the appropriate time. Additionally, organisations must consider how digital legacy planning integrates into existing care pathways in a way that addresses patient needs without creating undue burden for clinicians. Embedding digital legacy into practice will therefore necessitate coordinated efforts across clinical teams, information technology services, legal support and organisational governance to ensure these conversations can occur safely, consistently and compassionately. Finally, the review found limited available evidence, highlighting the need for stronger research and clearer policy direction. Additional research is needed to explore digital legacy in the context of palliative care, particularly from the perspective of patients and caregivers, as well as its impacts and challenges during bereavement. It is also important to investigate which healthcare professionals are best suited to initiate digital legacy discussions and to identify the practical limitations of doing so in clinical settings. Moreover, further work should extend beyond palliative care to examine how other healthcare specialties approach digital legacy.

CONCLUSION

This scoping review charts the literature on including digital legacy in planning for the end of life, identifying ways in which digital legacy might be used to support end-of-life care planning. Digital legacy is dynamic, personal and contextual. By identifying themes and key gaps in the literature, this review provides a foundation for future research. Gaps exist in understanding the importance of including digital legacy in planning for the end of life, the potential for cocreation of digital memories prior to death and support needed to manage digital legacy. Use of digital technologies is increasing as is the need for palliative care, and therefore it seems timely and important to explore this area further.

Acknowledgements The post's of ACN and SS were funded by Marie Curie

Contributors SS conceived the study. SS, KH, JAH, CM and CMV conducted the literature review. SS drafted the manuscript. SS, KH, JAH, CM, CMV and ML-W contributed to study design and provided critical revisions. SS, KH, JAH, CM, CMV, ML-W and ACN contributed to the final manuscript review. All authors approved the final version of the manuscript. SS is the guarantor.

Funding This work was carried out as part of a PhD funded by Liverpool John Moores University.

Disclaimer The funder did not influence the results/outcomes of the study despite author affiliations with the funder.

Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

ORCID iDs
Sarah Stanley https://orcid.org/0000-0002-7120-8680
Amara Callistus Nwosu https://orcid.org/0000-0003-0014-3741

REFERENCES

1 World Health Organisation. Palliative care. Available: https://www.who.int/news-room/fact-sheets/detail/palliative-care [Accessed 30 Oct 2023].
2 Nwosu AC, Collins B, Mason S. Big Data analysis to improve care for people living with serious illness: The potential to use new emerging technology in palliative care. *Palliat Med* 2018;32:164–6.
3 Office for national statistics. n.d. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2020

4 Ofcom. Available: https://www.ofcom.org.uk/about-ofcom/latest/features-and-news/uk-internet-use-surges [Accessed 7 Apr 2021].
5 Statista. Number of internet users worldwide from 2005 to 2025 (in millions). Available: https://www.statista.com/statistics/273018/number-of-internet-users-worldwide/February [Accessed 3 Feb 2026].
6 Statista. Average daily time spent using the internet by online users worldwide from 3rd quarter 2015 to 3rd quarter 2024 (in hours.minutes). Available: https://www.statista.com/statistics/1380282/daily-time-spent-online-global/ [Accessed 3 Feb 2026].
7 Digital legacy association. Available: https://digitallegacyassociation.org/ [Accessed 26 Jun 2025].
8 G T Norris J, Sofka C. Why digital assets planning and digital legacy safeguarding should form a holistic approach to advance care planning. 7th International African Palliative Care Conference 2022; 2022 Available: https://digitallegacyassociation.org/about/reports-2/
9 Coop H, Marlow C. Do we prepare patients for their digital legacy? A survey of palliative care professionals. *Palliat Med* 2019;33:114–5.
10 Clabburn O, Knighting K, Jack BA, *et al*. The use of digital legacies with people affected by motor neurone disease for continuing bonds: An interpretative phenomenological analysis study. *Palliat Med* 2019;33:812–22.
11 Doyle DT, Brubaker JR. Digital Legacy: A Systematic Literature Review. *Proc ACM Hum-Comput Interact* 2023;7:1–26.
12 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32.
13 Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010;5:69.
14 Peters MDJ, Godfrey CM, Khalil H, *et al*. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 2015;13:141–6.
15 Pollock D, Peters MDJ, Khalil H, *et al*. Recommendations for the extraction, analysis, and presentation of results in scoping reviews. *JBI Evid Synth* 2023;21:520–32.
16 G C Peters MDJ, McInerney P, Munn Z, *et al*. Chapter 11: scoping reviews. In: *JBI Reviewer's Manual*. JBI, 2020.
17 Tricco AC, Lillie E, Zarin W, *et al*. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med* 2018;169:467–73.
18 Butler A, Hall H, Copnell B. A Guide to Writing a Qualitative Systematic Review Protocol to Enhance Evidence-Based Practice in Nursing and Health Care. *Worldviews Evid Based Nurs* 2016;13:241–9.
19 Office for National Statistics. Internet users, UK: 2019. Available: https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2019 [Accessed 14 Aug 2022].
20 Petroc Taylor. Smartphone subscriptions worldwide 2016-2021, with forecasts from 2022 to 2027. Available: https://www.statista.com/statistics/330695/number-of-smartphone-users-worldwide/ [Accessed 13 Mar 2023].
21 Ouzzani HHM, Fedorowicz Z, Elmagarmid A. Rayyan — a web and mobile app for systematic reviews. systematic reviews. 2024.
22 Pollock A, Campbell P, Struthers C, *et al*. Stakeholder involvement in systematic reviews: a scoping review. *Syst Rev* 2018;7:208.
23 Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008;62:107–15.
24 Blower J, Sharman R. To grieve or not to grieve (online)? Interactions with deceased Facebook friends. *Death Stud* 2021;45:167–81.
25 Khan R, Tschanz J, De La Cruz M, *et al*. Patient considerations of social media account management after death. *Support Care Cancer* 2024;32:696.
26 S Jamison-Powell P, Briggs SL, CL, *et al*. PS. i love you": understanding the impact of posthumous digital messages," San Jose, California, USA', 2016. 2016. Available: https://doi.org/10.1145/2858036.2858504
27 Bassett DJ. You Only Live Twice: A constructivist grounded theory study of the creation and inheritance of digital afterlives. 2019.
28 Stanley S, Higginbotham K, Finucane A, *et al*. A grounded theory study exploring palliative care healthcare professionals' experiences of managing digital legacy as part of advance care planning for people receiving palliative care. *Palliat Med* 2023;37:1424–33.
29 Sokol LL, Jordan SR, Applebaum AJ, *et al*. Social Media Perceptions of Legacy-Making: A Qualitative Analysis. *Palliat Med Rep* 2020;1:326–30.
30 Widmaier L. Digital photographic legacies, mourning, and remembrance: looking through the eyes of the deceased. *Photographies* 2023;16:19–48.
31 DeSanto-Madeya S, Tjia J, Fitch C, *et al*. Feasibility and Acceptability of Digital Legacy-Making: An Innovative Story-Telling Intervention for Adults With Cancer. *Am J Hosp Palliat Care* 2021;38:772–7.
32 Dang M, Noreika D, Ryu S, *et al*. Feasibility of Delivering an Avatar-Facilitated Life Review Intervention for Patients with Cancer. *J Palliat Med* 2021;24:520–6.
33 Albers R, Sadeghian S, Laschke M, *et al*. Dying, death, and the afterlife in human-computer interaction. a scoping review," Hamburg, Germany', 2023. 2023. Available: https://doi.org/10.1145/3544548.3581199
34 Fit for the future: 10 year health plan for England. 2025. Available: https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future/fit-for-the-future-10-year-health-plan-for-england-executive-summary
35 World Health Organisation. Global initiative on digital health. 2026. Available: https://www.who.int/publications/m/item/global-initiative-on-digital-health
36 Zaleppa P, Dudley A. Ethical, legal and security implications of digital legacies on social media. In: Cham GM, ed. *Social Computing and Social Media. Design, Ethics, User Behavior, and Social Network Analysis*. Springer International Publishing, 2020: 419–29.
37 Klass D, Silverman PR, Nickman SL. *Continuing Bonds*. Washington DC: Taylor and Francis, 1996.
38 Hewson H, Galbraith N, Jones C, *et al*. The impact of continuing bonds following bereavement: A systematic review. *Death Stud* 2024;48:1001–14.
39 Akinyemi C, Hassett A. "He's Still There": How Facebook Facilitates Continuing Bonds With the Deceased. *Omega (Westport)* 2023;88:620–37.
40 Riaz F, Mustafa A. Digital Mourning and the Evolution of Grief: A Review of Social Media's Role in Shaping Contemporary Bereavement Practices. *Sch J Arts Humanit Soc Sci* 2025;13:179–86.
41 Scott IA, Mitchell GK, Reymond EJ, *et al*. Difficult but necessary conversations--the case for advance care planning. *Med J Aust* 2013;199:662–6.
42 Wolff JL, Scerpella D, Giovannetti ER, *et al*. Advance Care Planning, End-of-Life Preferences, and Burdensome Care: A Pragmatic Cluster Randomized Clinical Trial. *JAMA Intern Med* 2025;185:162–70.
43 McClement S, Thompson G. Identity, the dignified self and person-centred approaches in palliative care. In: *Palliative Care Nursing: Principles and Evidence for Practice*. 2018: 187.
44 Woods B, Spector AE, Jones CA, *et al*. Reminiscence therapy for dementia. *Cochrane Database Syst Rev* 2005;CD001120.

45 Abu Khait A, Shellman J, Sabo K. Metasynthesis of Patients' Perspectives about Reminiscence in Dementia Care. *West J Nurs Res* 2020;42:852–66.

46 Nwosu AC, Stanley S, Norris J, *et al*. Technology to support care at the end-of-life. In: Nwosu AC, Stanley S, Norris J, et al, eds. *Technologies in Palliative Care for Older People*. Cham: Springer Nature Switzerland, 2026: 87–101.