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D5.1. Recommendation paper on the use of digitalisation in palliative care

WP5. INITIATING A DIGITAL ECOSYSTEM BASED ON AN OPEN-ACCESS PLATFORM

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Abstract

Methods

This recommendation paper has been created as a part of Erasmus+ Capacity Building Project, PalcNet as a Deliverable D5.1. It is based on a scoping review that was conducted following Joanna Briggs Institute (JBI) methodology and PRISMA-ScR guidelines. The Population–Concept–Context (PCC) framework guided study selection, focusing on patients, caregivers, healthcare professionals, and service providers in palliative care contexts. Fifteen sources, including qualitative, quantitative, mixed-methods, and review studies, were included. Data were synthesised thematically across care contexts, ethical principles, clinical safety, and implementation considerations. The scoping review will be published later.

Results

Digital palliative care was identified as a multi-level system encompassing clinical, relational, organisational, and patient-level dimensions. Digital approaches—including telehealth, asynchronous tools, and emerging technologies—enhanced access, continuity of care, and symptom management, while supporting patient autonomy, independence, and engagement in home environments. However, these benefits were context-dependent and accompanied by challenges. Digital care may compromise relational continuity, communication quality, and depth of therapeutic engagement, particularly in complex or emotionally sensitive situations. Risks were associated with limitations in remote clinical assessment, variability in patient-controlled environments, caregiver burden, and gaps in data governance. Digitalisation also introduced equity concerns, with disparities linked to digital literacy, access to infrastructure, and socio-economic factors. Effective implementation depended on hybrid care models, structured communication approaches, clearly defined escalation pathways, and organisational support.

Conclusions

Digital palliative care represents a reconfiguration of clinical, ethical, and organisational practice rather than a purely technical intervention. Its effectiveness depends on integrating technological capabilities with relational care, patient engagement, and system-level support. Safe and ethical implementation requires hybrid models of care, attention to equity and digital inclusion, structured workflows, and robust governance frameworks. Evidence-informed principles developed in this review provide practical guidance for embedding digital approaches while preserving person-centred, equitable, and relationally grounded palliative care in home-based settings.

Introduction

This recommendation paper has been created as a part of Erasmus+ Capacity Building Project 2024-2026, PalcNet as a Deliverable D5.1.

Palliative care (PC) has been widely recognised as a global public health priority, yet substantial inequities in access and availability persist. Approximately 56.8 million people require palliative care annually, but only around 14% receive it, with the majority of unmet need occurring in low- and middle-income countries (Connor, 2020; Connor et al., 2021). The burden of serious health-related

suffering is projected to nearly double by 2060, intensifying demands on already constrained health systems (Sleeman et al., 2019).

In response to increasing demand and constrained healthcare resources, palliative care delivery is progressively shifting from inpatient and specialist settings toward outpatient and home-based care (Sleeman et al., 2019). This transition reflects both patient preferences to remain at home and the need to provide more flexible, accessible, and sustainable models of care, with evidence indicating that most patients prefer to receive care and die in non-hospital settings (World Health Organization, 2020). However, delivering palliative care in these settings introduces unique challenges, including reduced direct clinical oversight, greater reliance on caregivers, and the need for effective coordination across services. These challenges highlight the importance of developing approaches that support safe, continuous, and person-centred care beyond traditional clinical environments.

At the same time, digitalisation has emerged as a key strategy for expanding access and improving efficiency in palliative care delivery. Technologies such as telehealth, mobile applications, and remote monitoring systems are increasingly used to facilitate care across settings, particularly in home-based contexts (Stockdill et al., 2021; Bauer et al., 2024; Jeon et al., 2025). These approaches can reduce travel burden, enhance continuity of care, and enable more active involvement of caregivers and multidisciplinary teams (Gordon et al., 2022; Pasanen et al., 2023).

Digital palliative care interventions encompass multiple functional domains, including symptom monitoring, communication, decision support, education, psychological support, and alert systems, highlighting that digital care is a multi-functional system rather than a single intervention (Tan et al., 2024). However, palliative care is fundamentally grounded in ethical, relational, and person-centred principles. The integration of digital technologies into this context raises critical concerns related to safety, communication, equity, and the preservation of therapeutic relationships (Wood et al., 2025; Ladds et al., 2025). Risks include limitations in clinical assessment without physical examination, potential miscommunication, privacy concerns, and increased reliance on informal caregivers (Agosta et al., 2023; Aldana et al., 2023).

Despite growing evidence, guidance for safe and ethical digitalisation in palliative care remains fragmented. This paper addresses this gap by synthesising evidence from a JBI-based scoping review and translating it into practical, evidence-informed recommendations, with particular emphasis on palliative home care. The aim is to support clinicians, service providers, and policymakers in implementing digital approaches that enhance care while preserving the core values of palliative practice.

While digitalisation is often presented as a technical or access-oriented solution, emerging evidence suggests it introduces complex ethical, relational, and organisational challenges. This recommendation paper therefore examines digitalisation not only as a clinical tool, but as a multi-dimensional practice requiring integrated ethical and governance frameworks.

Methods

This recommendation paper is based on a scoping review that followed the Joanna Briggs Institute (JBI) methodology and PRISMA-ScR guidelines. The Population–Concept–Context (PCC) framework guided the review.

- Population: Patients, caregivers, healthcare professionals, and service providers
- Concept: Correct, safe, and ethical digitalisation
- Context: Palliative care settings, with emphasis on home-based care

The primary review question was:

> What guidelines or best practices have been identified for ensuring correct, safe, and ethical digitalisation across palliative home care and stakeholder groups?

Included evidence sources comprised qualitative, quantitative, mixed-methods, and review studies, as well as policy documents and professional recommendations. Fifteen sources were included. Telehealth was dominant, supported by asynchronous tools and emerging technologies. Key themes included hybrid care, safety thresholds, relational care, caregiver involvement, and equity.

Microsoft M365 Copilot (GPT 5 chat model) was used to support language editing and manuscript structuring. All outputs were reviewed and validated by the authors, who take full responsibility for the accuracy and integrity of the work.

Characteristics of the Evidence Base

The included studies represented a diverse range of care settings, technologies, and stakeholder groups, with a predominant focus on home-based palliative care. This section summarises how digital palliative care was delivered across contexts, highlighting common features of care organisation, technology use, and stakeholder involvement that shaped subsequent ethical, clinical, and implementation considerations.

Digital palliative care was delivered across multiple care contexts, most commonly in home-based settings, supported by a range of technologies including synchronous telehealth, digital platforms, and remote monitoring tools. Table 1. summarises the characteristics of care contexts, associated delivery features, and technologies used across included sources of evidence.

Table 1. Characteristics of Digital Palliative Care Across Care Contexts, Delivery Features, and Technologies

Care Context / Setting	Description of Context	Key Features of Care Delivery	Digital Technologies Used	Sources of Evidence
Home-based palliative care	Care delivered primarily in patients' homes via digital modalities	Remote consultations; reduced travel; high caregiver involvement; need for symptom monitoring and escalation pathways	Video consultations; telephone calls; mobile apps; symptom reporting tools	Bauer et al., 2024; Guo et al., 2024
Outpatient / ambulatory specialist care	Digital care embedded within outpatient or clinic-based services	Scheduled follow-ups; improved efficiency; reduced missed visits; integration with hospital care; care delivered in	Video platforms; teleconsultation systems; scheduling tools; patient portals; patient-	Agosta et al., 2023; Pasanen et al., 2023

		patient-controlled environments	operated devices in non-clinical environments	
Integrated hospital–community models	Coordination between hospital-based specialists and community providers	Multidisciplinary collaboration; shared care planning; improved continuity; reduced fragmentation	Telehealth platforms; shared communication systems; EHR integration; virtual consultations	Pasanen et al., 2023; Bauer et al., 2024
Rural and remote care settings	Care delivered in geographically underserved or rural populations	Extended specialist access; reduced travel burden; reliance on tele-expertise; infrastructure challenges; interprofessional collaboration enabled remotely	Telemedicine platforms; videoconferencing; phone-based care; broadband systems; remote access tools	Sánchez-Cárdena s et al., 2023; Gordon et al., 2022
Caregiver and family care context	Informal care delivered by family members in home settings	Caregiver education; emotional support; decision-making assistance; high burden; need for flexibility	Web-based interventions; mobile apps; teleconsultations; educational platforms	Guo et al., 2024; Häger Tibell et al., 2024; Bauer et al., 2024
Technology-mediated multidisciplinary care	Digital collaboration between multiple healthcare professionals	Joint consultations; coordinated decision-making; structured care pathways	Video conferencing; shared digital workspaces; communication platforms; telehealth frameworks	Pasanen et al., 2023; Stockdill et al., 2021
Patient-controlled and relationally dynamic digital care environments	Care delivered in environments shaped by patients' social, emotional, and physical context (home, shared spaces, etc.)	Variable privacy; distractions; dependence on relational engagement; influence of isolation, belonging, and emotional needs; shift in patient–clinician power dynamics	Video consultations; mobile devices; telehealth platforms	Agosta et al., 2023; Aldana et al., 2023; Wood et al. (2025)

Digital palliative care effectiveness is shaped not only by technologies and care settings, but by patient-controlled environments, system-level determinants, and the relational and emotional mechanisms through which patients, caregivers, and professionals engage in care (Agosta et al., 2023; Jeon et al., 2025; Wood et al., 2025). These contextual characteristics also shape how digital interventions function in practice, influencing relational dynamics, caregiver roles, patient behaviour, and clinical safety across care settings. These variations in context illustrate that digital palliative care cannot be treated as a uniform intervention, but rather must be adapted to differences in environment, stakeholder roles, and care processes, which directly influence ethical, clinical, and implementation outcomes.

The characteristics of the evidence base demonstrate that digital palliative care was implemented across diverse care settings, technologies, and stakeholder groups. Across these heterogeneous models, common features included remote communication, increased caregiver involvement, and the need for structured monitoring and escalation pathways. These features do not only describe modes of service delivery but also shape the ethical conditions under which care is provided. In particular, the relocation of care into the home, combined with reliance on digital mediation, reconfigures responsibilities, communication dynamics, and access to care. Accordingly, understanding the ethical implications of digitalisation requires examining how these contextual and organisational characteristics influence autonomy, safety, equity, and relational care in practice.

Results

The results of this scoping review are presented across four interrelated domains: characteristics of the evidence base, ethical principles, clinical safety and risk management, and implementation and regulatory contexts. Together, these domains capture how digital palliative care is delivered across settings and stakeholder groups, and how its use shapes ethical, clinical, and organisational conditions in practice. Rather than representing distinct categories, these themes were closely interconnected, with ethical considerations underpinning clinical safety, implementation processes, and systemic governance. The findings highlight recurring patterns across heterogeneous care models, providing a structured basis for identifying best practice principles for safe, effective, and equitable digitalisation in palliative home care.

Ethical principles identified

Building on these contextual characteristics, the evidence consistently reflected core ethical principles shaping digital palliative care. This section examined how autonomy, beneficence, non-maleficence, justice, privacy, and relational care were enacted and challenged in practice, demonstrating how ethical considerations underpinned both clinical safety and care delivery in digitally mediated settings.

Digitalisation supported autonomy by improving access, enabling care at home, and facilitating family participation in decision-making; however, this was unevenly realised due to disparities in digital literacy, access to resources, and contextual limitations, which constrained engagement and contributed to digital exclusion (Bauer et al., 2024; Aldana et al., 2023; Tan et al., 2024; Kirby et al., 2025; Guo et al., 2024). The concept of digital determinants of health highlighted how individual, interpersonal, community, and societal factors collectively shaped access, engagement, and outcomes in digital palliative care (Jeon et al., 2025). Remote interactions also affected communication quality and therapeutic relationships, thereby influencing decision-making processes (Ladds et al., 2025; Stockdill et al., 2021).

Beneficence was reflected in evidence as digital approaches enhanced access, continuity, and symptom management, particularly in rural or underserved settings, while supporting quality of life and psychosocial well-being for patients and caregivers (Gordon et al., 2022; Sánchez-Cárdenas et al., 2023; Guo et al., 2024; Wood et al., 2025; Zhang et al., 2026). However, these benefits depended on appropriate intervention design, clinical integration, and organisational support, rather than technology alone (Pasanen et al., 2023; Zhang et al., 2026). Evidence from umbrella reviews indicated

that digital palliative care interventions were generally effective or non-inferior to standard care, supporting their safety and system-level impact (Guo et al., 2025).

Concerns related to non-maleficence emphasised the risks of reduced clinical assessment and communication fidelity in remote care. Limitations in physical examination and reduced access to non-verbal cues was reported compromising clinical judgement and delayed recognition of deterioration, while communication challenges weakened rapport and increased the risk of miscommunication or emotional distress (Agosta et al., 2023; Ladds et al., 2025; Stockdill et al., 2021; Wood et al., 2025). These findings consistently supported the use of hybrid models and clearly defined thresholds for escalation to in-person care (Aldana et al., 2023; Pasanen et al., 2023).

Justice and equity emerged as central and closely linked to safety. While digitalisation was described as reducing geographic barriers and improving access, it also exacerbated inequalities related to socioeconomic status, digital literacy, and access to infrastructure. Environmental factors, such as lack of private space, further shaped equitable participation, indicating that equity required targeted support, inclusive design, and attention to broader social determinants (Gordon et al., 2022; Kirby et al., 2025; Zhang et al., 2026; Ladds et al., 2025).

Additionally, digitalisation simultaneously expanded access and exacerbated existing inequities, particularly for older adults, socioeconomically disadvantaged populations, and those with limited digital literacy or infrastructure (Jeon et al., 2025).

Relational care was reported as foundational but difficult to sustain digitally. Video consultations partially preserved non-verbal communication; however, digital encounters were often perceived as less personal and less conducive to empathy. In-person care was generally preferred for initial or emotionally complex interactions, while continuity and deliberate communication strategies were required to maintain trust in ongoing digital engagement (Pasanen et al., 2023; Stockdill et al., 2021). Structured communication approaches, such as evidence-based conversation frameworks, were found to support difficult discussions and improve relational quality in telehealth encounters (Stockdill et al., 2021).

Privacy and confidentiality were presented as context-dependent challenges, particularly in home settings where shared or unsuitable environments limited secure and open communication. While secure technologies were necessary, studies emphasised that privacy was also shaped by situational and interpersonal factors, including control over the consultation environment and presence of others, whereas data governance and cybersecurity remained inconsistently addressed (Agosta et al., 2023; Pasanen et al., 2023).

The findings further indicated that ethical considerations were closely linked to clinical aspects of digital palliative care. Challenges related to autonomy, communication, relational care, and equity were reported alongside difficulties in clinical assessment and decision-making, demonstrating their interrelated nature in practice.

Clinical Safety and Risk Management

Clinical safety was consistently emphasised across the literature, reflecting inherent limitations of remote palliative care. This section reports the identified key risks associated with remote palliative care, including assessment limitations, communication challenges, and escalation processes, alongside strategies used to mitigate these risks in practice.

While digital tools supported structured symptom monitoring and timely follow-up, the absence of physical examination and reduced situational awareness increased the risk of underassessment, delayed recognition of deterioration, and misinterpretation of clinical cues (Aldana et al., 2023; Pasanen et al., 2023). Additionally, communication constraints were reported as factors that further reduced diagnostic accuracy by limiting access to non-verbal and contextual information, particularly in complex or unstable cases (Ladds et al., 2025; Sánchez-Cárdenas et al., 2023).

Remote palliative care was not only limited by technology but also shaped by patient-controlled environments. Evidence showed that patients attended consultations from public, distracting, or unsafe settings, which compromised privacy, communication, and clinical safety, and resulted in incomplete assessments or interrupted care (Agosta et al., 2023). Telemedicine in palliative care was conceptualised as a structured model involving patient selection, modality choice (synchronous versus asynchronous), and continuous monitoring of clinical and psychosocial needs (Sánchez-Cárdenas et al., 2023).

Risk management strategies across studies aimed to compensate for these limitations through structured and proactive approaches. These included the use of explicit triage criteria to determine suitability for digital care, predefined “red flags” triggering escalation, and hybrid pathways that ensured timely transition to in-person assessment when needed (Aldana et al., 2023; Pasanen et al., 2023). Preparation of the consultation environment, including attention to privacy, technical readiness, and patient support, were identified as critical for safety (Gordon et al., 2022).

Technical and operational risks further shaped safety. Connectivity issues, platform instability, and equipment failure was reported as a risk for disrupted care delivery and required fallback mechanisms such as telephone contact or alternative communication channels. At the same time, escalation processes and monitoring responsibilities often relied on caregivers, increasing their role in recognising deterioration and potentially contributing to burden and inequity in home settings (Pasanen et al., 2023; Häger Tibell et al., 2024).

Caregivers also reported uncertainty in recognising and managing symptoms at home, highlighting the need for clear support mechanisms and timely guidance (Guo et al., 2024).

Training emerged as a central safety mechanism. Clinicians were found as having a need to develop tele-assessment competencies, advanced communication skills, and ethical decision-making capabilities in the absence of physical presence. Similarly, patients and caregivers required digital literacy support to engage safely and effectively. The absence of such training increased variability in care quality and amplified safety risks (Tan et al., 2024; Stockdill et al., 2021).

These findings also indicated that addressing clinical safety risks required coordinated organisational, relational, and technical supports to enable safe and consistent implementation of digital palliative care.

Implementation supports

Building on the clinical safety challenges identified, the evidence highlighted the importance of organisational and system-level conditions in enabling safe and effective digital palliative care. This section examines the structures, resources, and processes associated with implementation, including hybrid care models, communication practices, caregiver support, and organisational infrastructure.

Effective implementation of digital palliative care depended on coordinated organisational, relational, and technical supports. Across studies, digital interventions achieved the greatest impact when embedded within hybrid care models that integrated remote and in-person care, allowing flexibility while maintaining clinical oversight and relational continuity (Pasanen et al., 2023; Sánchez-Cárdenas et al., 2023). Structured workflows, including pre-consultation preparation, consultation processes, and follow-up, were identified as critical for maintaining safety and continuity in digital palliative care (Aldana et al., 2023).

Relational and communication infrastructures were also identified as critical. Structured communication approaches, continuity of clinical care, and deliberate preparation of patients and caregivers were reported to help preserve trust and reduce miscommunication in digital encounters. The evidence indicated that maintaining relational quality required additional effort in digital contexts, including adaptation of communication styles and attention to emotional and psychosocial dynamics (Stockdill et al., 2021; Ladds et al., 2025). Digital palliative care was described as involving multiple actors, including patients, caregivers, and healthcare professionals, requiring coordinated interaction across roles and settings (Zhang et al., 2026).

Support for caregivers emerged as a key implementation requirement. Digital care models often increased reliance on informal caregivers for coordination, monitoring, and communication. Without explicit role definition, training, and emotional support, this was associated with a shift in responsibilities and an increase in caregiver burden, particularly in home-based care (Guo et al., 2024; Häger Tibell et al., 2024). Caregiver burden was reported to extend beyond practical responsibilities to include emotional strain, such as anxiety, stress, and difficulty coping with end-of-life situations (Guo et al., 2024). Digital interventions provided caregivers with access to education, emotional support, and preparation for end-of-life care, although preferences for in-person support remained (Häger Tibell et al., 2024).

Healthcare professionals' digital competencies were identified as a critical determinant of successful implementation, requiring education in digital tools, communication, and ethical decision-making (Jeon et al., 2025).

Organisational infrastructure, including interoperable digital systems, technical support services, and governance frameworks, was described as essential for sustainability. In their absence, clinicians resorted to informal workarounds, which compromised data integrity, privacy, and continuity of care. Ongoing evaluation and adaptation, supported by outcome measurement and feedback mechanisms, enabled alignment with evolving patient needs and illness trajectories (Gordon et al., 2022; Jeon et al., 2025; Zhang et al., 2026).

These findings further indicated that, alongside organisational and clinical supports, broader regulatory conditions also shaped how digital palliative care was implemented in practice.

Regulatory context

Alongside clinical and organisational factors, the broader regulatory environment shaped the conditions for digital palliative care delivery. This section summarised the limited and fragmented policy guidance identified in the literature, highlighting gaps between regulatory frameworks and the ethical, clinical, and relational realities of practice.

Across regions, regulatory frameworks prioritised access and service delivery while providing limited guidance on relational, ethical, and safety dimensions. Regulatory guidance for digital palliative care was characterised as limited and fragmented, focusing largely on data protection and telehealth delivery. This gap was reflected in practice, where clinicians often relied on informal workarounds that compromised privacy and governance (Häger Tibell et al., 2024; Ladds et al., 2025; Guo et al., 2024).

In high-income settings, regulations such as the GDPR provided general principles for handling health data, while telehealth policies primarily addressed licensure and reimbursement rather than care quality or relational aspects. Similarly, in China, regulatory development focused on enabling service expansion. The Personal Information Protection Law (2021) and telemedicine regulations emphasised data protection, traceability, and follow-up care, while recent policies supported the integration of palliative services into reimbursement systems.

However, these frameworks offered limited guidance on the clinical, ethical, and relational complexities of digital palliative care.

Overall, a consistent gap was identified between regulatory structures and real-world practice. Current policies were reported to insufficiently address how to manage risk, support decision-making, and maintain relational care in digital palliative contexts.

Implementation outcomes

Implementation outcomes demonstrated that digital palliative care was generally acceptable, feasible, and scalable, although it was strongly dependent on context and support structures. Acceptability was reported to be high among patients, caregivers, and professionals, reflecting improved access, reduced travel burden, and the ability to receive care at home.

However, acceptability was moderated by relational quality, technological usability, and individual preferences, particularly in emotionally sensitive situations (Bauer et al., 2024).

Telehealth was reported to enhance patient autonomy by promoting a sense of independence, control, comfort, and security, particularly when care was delivered in familiar home environments (Kirby et al., 2025). Additionally, it was associated with reduced caregiver burden by improving access to professional support and enhancing confidence in managing care at home, although these benefits depended on the responsiveness and usability of digital systems (Guo et al., 2024).

Feasibility was demonstrated across multiple care settings, including home-based, outpatient, and rural contexts, supported by the adaptability of digital modalities. The availability of alternative communication channels, particularly telephone-based care, was identified as critical in ensuring continuity where video-based platforms were not viable (Sánchez-Cárdenas et al., 2023; Guo et al., 2024).

Adoption increased rapidly during the COVID-19 pandemic, which normalised remote care practices; however, sustained integration depended on embedding digital services within routine workflows and organisational systems. Where implementation remained fragmented, adoption declined following initial uptake (Stockdill et al., 2021; Ladds et al., 2025).

Fidelity of implementation varied, with challenges reported to be arising from technical limitations, insufficient training, and reduced relational depth, sometimes resulting in more transactional interactions. Structured protocols, hybrid care models, and communication frameworks were identified

as improving consistency and alignment with palliative care principles (Agosta et al., 2023; Aldana et al., 2023).

Equity impacts were described as mixed. Digitalisation expanded access for patients in rural or underserved areas but also risked excluding individuals with limited digital literacy, inadequate infrastructure, or socioeconomic disadvantage. Equity outcomes therefore depended on the presence of targeted support measures, including training, accessible technologies, and flexible care modalities (Tan et al., 2024; Kirby et al., 2025; Bauer et al., 2024).

Discussion

Taken together, the findings of this review indicated that digitalisation in palliative care functioned as a reconfiguration of clinical, ethical, and organisational practice rather than a purely technological intervention. Its benefits and risks were closely shaped by context, particularly in home-based care where clinical, social, and environmental factors intersected (Pasanen et al., 2023; Bauer et al., 2024). Digital palliative care can therefore be understood as a multi-level system, in which clinical outcomes depend on the interaction between technological functions, organisational structures, relational processes, and patient-level factors.

A key insight was that ethical principles operated as practical conditions for safe care. Autonomy depended not only on patient choice but also on access to resources and digital competence, while equity directly influenced care quality and safety. These findings suggest that ethical principles were and should be structurally embedded within digital care delivery models rather than external considerations (Tan et al., 2024; Kirby et al., 2025). Further on, this implies that ethical considerations were not separate from clinical practice but were directly embedded in the conditions that determined safety and quality of care in digital environments. Furthermore, the findings reinforce that access to service alone is insufficient, and that successful digital care depends on patient adoption, engagement, and the usability of technologies in real-world contexts.

In line with these ethical and systemic insights, clinical safety challenges highlighted the limitations of remote care as a standalone modality. Reduced ability to perform physical examinations and interpret contextual cues increase the reliance on clinician judgement and patient and/or caregiver reporting, particularly in complex cases (Aldana et al., 2023; Ladds et al., 2025). Hybrid care models therefore functioned as adaptive safety mechanisms, enabling timely escalation and more responsive care (Pasanen et al., 2023). Furthermore, patient-controlled environments, including public or distracting settings, may compromise privacy, communication, and clinical safety, reinforcing the contextual nature of digital care risks (Agosta et al., 2023).

The findings also indicate a redistribution of responsibility within home-based care, where caregivers increasingly function as active participants in monitoring, decision-making, and communication processes in addition to their normal roles in the family. While this supported continuity of care, it also introduced risks related to burden, inequity, and variability, underscoring the need for explicit role definition and support (Guo et al., 2024; Häger Tibell et al., 2024). This shift in redistribution of responsibilities can be seen reflecting a broader transformation in care delivery, where responsibilities are distributed across patients, caregivers, and professionals rather than concentrated within clinical settings.

At the organisational level, these findings suggest that outcomes were shaped less by technology itself and more by the organisational systems, workflows, and human factors supporting its use. Effective digital palliative care depended on governance, infrastructure, and workforce training in digital competencies and readiness. Where these were lacking, informal workarounds emerged, compromising safety, continuity, and data governance (Gordon et al., 2022; Ladds et al., 2025).

Regulatory frameworks are currently reported as somewhat lacking, perhaps understandably when the field of digital care is evolving rapidly. However, they are reportedly influencing implementation but still remained misaligned with clinical realities. Existing policies focused primarily on access, reimbursement, and data protection, offering limited guidance on relational care or clinical risk management in digital contexts. This gap contributed to variability in practice and limited systemic support for safe implementation (Häger Tibell et al., 2024; Guo et al., 2024).

Overall, the findings indicate that digitalisation represents a complex transformation of palliative care delivery, requiring integration of ethical principles, clinical judgement, and organisational systems. In palliative home care, where both benefits and risks are amplified, safe implementation depends on hybrid models, structured communication, and strong governance. These findings support a shift toward principle-driven, context-sensitive approaches, ensuring that digital care strengthens rather than compromises person-centred palliative care (Ladds et al., 2025; Zhang et al., 2026).

Limitations

This recommendation paper has several limitations that should be considered when interpreting the findings.

First, the scoping review in which this paper is based had the aim to map and synthesise existing evidence rather than to evaluate study quality or establish causal relationships. While this approach enabled a broad and comprehensive overview of digital palliative care, it limits the ability to assess the strength of evidence for specific outcomes or interventions.

Second, the included evidence was heterogeneous in terms of study design, populations, technologies, and care contexts. The synthesis therefore required interpretative integration across diverse sources, which may reduce comparability and limit the generalisability of specific findings.

Third, the review focused primarily on studies conducted in high-income and technologically developed settings. This may limit the transferability of findings to low- and middle-income contexts, where infrastructure, cultural norms, and access to digital technologies differ significantly.

Fourth, much of the available evidence relies on qualitative studies and self-reported experiences from patients, caregivers, and healthcare professionals. While this provides valuable insight into relational and experiential aspects of care, it may introduce reporting bias and limits the ability to draw conclusions about clinical effectiveness.

Fifth, the rapid development of digital technologies means that some findings may become outdated as new tools, platforms, and models of care emerge. The evidence base may therefore not fully reflect the most recent technological advancements or implementation practices.

Sixth, the inclusion of diverse forms of evidence, including reviews and conceptual papers, may introduce overlap in findings across sources, potentially amplifying certain themes.

Finally, although this review aimed to synthesise evidence across multiple stakeholder perspectives, some groups, particularly patients in advanced stages of illness and certain caregiver populations, remain underrepresented in the literature.

These limitations highlight the need for cautious interpretation of findings and reinforce the importance of context-sensitive application of the proposed recommendations.

Conclusion

This recommendation paper demonstrated that digital palliative care represents a complex transformation of care delivery rather than a purely technological innovation. While it improves access and continuity, it also shapes patient experience, autonomy, and engagement with care. At the same time, it challenges key relational aspects of palliative practice, including empathy, trust, and therapeutic connection.

The findings further indicated that digital palliative care functions as a multi-level system involving patients, caregivers, and healthcare professionals, with increasing reliance on caregiver participation in home-based settings. This redistribution of responsibility highlights the importance of clear role definition and appropriate support mechanisms.

A central finding was that safety and ethics were inseparable, with equity constituting a core dimension of safe care. The appropriateness of digitalisation depended on conditions that enabled sound clinical judgement, meaningful communication, and inclusive access, rather than on technology alone.

Effective implementation therefore required hybrid care models, explicit escalation pathways, targeted support for patients and caregivers, and robust organisational governance. Taken together, the findings suggest that digital palliative care should be approached as a system-level intervention, requiring alignment between technological capabilities, clinical practice, ethical principles, and regulatory frameworks to ensure that digitalisation strengthens, rather than compromises, the person-centred foundations of palliative care.

Future research should focus on strengthening the evidence base for digital palliative care through longitudinal, outcome-oriented studies that address clinical effectiveness, relational quality, and patient and caregiver experiences. Attention is needed to understand how digital determinants of health influence access and equity, as well as to developing and evaluating models that support caregiver roles, clinical safety, and sustainable implementation. Advancing research in these areas

will be essential to ensure that digitalisation evolves in ways that are safe, equitable, and aligned with the person-centred foundations of palliative care.

Based on the synthesis, the following evidence-informed best practice principles for digital palliative care represent minimum conditions for safe, ethical, and effective digital palliative care.

Table 2. Evidence-informed best practice principles for digital palliative care

Domain	Best practice principle	Key actions / Operationalisation	Primary stakeholders	Relevant for palliative home care
Care model design	Digital palliative care **should be embedded within hybrid models**	Integrate digital and in-person care; define criteria for when in-person assessment is required	Patients; healthcare professionals; service providers	Hybrid models mitigate risks of underassessment and preserve relational care in home settings
Clinical safety	**Explicit criteria for digital appropriateness and escalation are required to ensure safety**	Assess patient stability and complexity; define red flags and escalation pathways	Healthcare professionals; service providers	Prevents delayed response to deterioration and unsafe remote management in home care
Autonomy and choice	**Patients and caregivers should have meaningful choice of care modality**	Offer and regularly reassess options (video, telephone, in-person) based on capacity and preference	Patients; caregivers; healthcare professionals	Supports fluctuating needs, energy, and privacy conditions in the home
Relational care and communication	**Therapeutic relationships and communication quality must be actively maintained in digital care**	Ensure continuity of clinicians; prioritise in-person care for initial and sensitive interactions; use structured communication approaches	Patients; healthcare professionals	Essential for maintaining trust and emotional support where care is primarily home-based
Caregiver support	**Caregivers should be supported and safeguarded from disproportionate clinical responsibility**	Clearly define roles; provide training and psychosocial support; avoid substituting professional care with informal care	Caregivers; healthcare professionals; service providers	Reduces burden and mitigates safety and equity risks in home-based care
Equity and inclusion	**Equity should be addressed as a core safety and ethical requirement**	Provide digital literacy training, technical support, and low-bandwidth alternatives; ensure inclusive design; address digital determinants of health (e.g., literacy, access,	Service providers; policymakers; organisations	Addresses digital exclusion and socioeconomic disparities amplified in home environments

		environment, social context) across multiple levels to ensure equitable care		
Privacy and confidentiality	**Privacy, dignity, and data protection must be actively ensured in digital care contexts**	Use secure platforms; support patients in creating private environments; minimise insecure workarounds	Patients; caregivers; healthcare professionals; organisations	Privacy risks are heightened in shared or constrained home settings
Professional competence	**Clinicians require specific competencies for delivering digital palliative care**	Develop healthcare professionals' digital competencies; Provide training in tele-assessment, communication ("website manner"), and ethical decision-making	Healthcare professionals; service providers	Supports safe clinical judgement in the absence of physical examination
Organisational governance	**Safe digitalisation requires robust organisational governance and infrastructure**	Establish clear workflows, interoperable systems, and technical support; define accountability structures; implement structured protocols and system-level supports to address variability in digital care delivery	Service providers; organisations; leadership	Prevents fragmentation, unsafe workarounds, and variability in care quality
Regulatory and policy frameworks	**Regulation should support safe, ethical, and context-sensitive digital palliative care**	Align policies with clinical realities; address data governance, liability, and cross-jurisdictional care	Policymakers; organisations	Lack of clear regulation increases variability and risk in home-based digital care
Evaluation and adaptation	**Digital palliative care should be continuously evaluated and adapted**	Monitor safety, quality, acceptability, and equity; adjust care according to changing needs and illness trajectories	Service providers; healthcare professionals; organisations	Supports responsiveness to rapid changes in condition and care needs in home settings

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