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Beyond Hospice Walls – A year-long evaluation of St Columba's Hospice Virtual Ward

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BACKGROUND: In 2023, St Columba's Hospice Care—Scotland's largest hospice—pioneered the nation's first Virtual Ward (VW), delivering daily face-to-face medical and nursing care to patients in their own homes. This groundbreaking service now undergoes its first annual evaluation, supported by a year of robust data collection.

AIMS: To analyse 12 months of VW utilisation and assess its financial impact on hospice and health services.

METHODS: Prospective data were collected over 12 months, including demographics, duration in the service, and outcomes. Informal feedback from patients and families was also reviewed. We calculated the total annual 'bed days' provided by the VW and conducted a comparative cost analysis using published Scottish end-of-life care data.

RESULTS: VW patients closely resembled those in the hospice inpatient unit (IPU) in terms of diagnosis and phase of illness. The average VW stay was 7 days:

- 41% died at home, in line with their expressed wishes
- 33% transitioned to community palliative care
- 20% were admitted to the IPU
- 2% required hospital admission

Patient and family feedback was overwhelmingly positive.
The VW delivered **1,141 bed days**, representing a **£935,620** saving to the hospice had these patients required IPU care. For the NHS, the estimated saving—based on a 7.7-day average hospital stay for end-of-life patients—was **£1,029,182**.

CONCLUSION: The Virtual Ward is a transformative, compassionate, and cost-effective alternative to inpatient care—honouring patient choice while significantly reducing strain on NHS acute services

Proactive symptom monitoring to initiate timely palliative care for patients with advanced cancer: a randomized controlled trial

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Purpose: To deliver timely palliative care in response to supportive and palliative care needs as they arise, we developed "Supportive and Palliative care Review Kit in Locations Everywhere" (SPARKLE), which comprises regular remote symptom monitoring using the Integrated Palliative care Outcome Scale (IPOS); early identification and prompt treatment of palliative care symptoms and concerns identified; and referral to specialist palliative care if follow-up is required.

Methods: A prospective randomized controlled trial of SPARKLE versus usual care was conducted among patients with advanced cancers. The primary endpoint was Functional Assessment of Cancer Therapy-General (FACT-G) scores at 16 weeks post randomization.

Results: A total of 239 patients were randomized—119 patients to usual care and 120 patients to SPARKLE intervention. There was no statistically significant difference in total FACT-G score (baseline-adjusted difference 0.8, 95% CI − 3.5 to 5.1, p = 0.73). There was statistically and clinically significant difference in physical well-being – better in SPARKLE group compared to usual care group (baseline-adjusted difference 1.9, 95%CI 0.4 to 3.4, p = 0.01). There were no statistically significant differences in the other FACT-G domain scores, palliative care referrals, occurrence of emergency department visits, or hospital admissions.

Conclusion: Although there was no significant difference in overall quality of life, better physical symptom control could have been achieved through proactive identification and treatment of symptoms and concerns by the SPARKLE nurse.

Future plans: Based on study findings, we will revise SPARKLE to SPARKLE-2 and conduct a hybrid type 2 effectiveness-implementation randomized controlled trial of SPARKLE-2.

Declaration: These results have been published recently in Supportive Care in Cancer.
Yang GM, Ke Y, Ng XH, Neo PSH, Cheung YB. Proactive symptom monitoring to initiate timely palliative care for patients with advanced cancer: a randomized controlled trial. Support Care Cancer. 2025;33(3):249.

AI-based Tool for Training in Person-Centred Communication in Palliative Care – Development and Usability

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Background: Communication in palliative care is crucial to meet the needs of patients and their families, especially in challenging conversations about life, the future, treatment and symptoms. A person-centred approach requires health professionals to listen and adapt the conversation based on the individual's needs. There is however a lack of structured and accessible tools available for person-centred conversation training including feedback. Artificial intelligence (AI) opens new possibilities for training in realistic scenarios.

Aim: To develop and investigate the usability of an AI-based tool for training in person-centred conversations in palliative care, particularly difficult conversations.

Method: The project uses three steps according to the ADDIE model and MRC guidelines: (1) develop realistic patient cases and AI-generated feedback; (2) usability testing; and (3) impact evaluation. Development is user-centred, collaborating with professionals and people with experience in palliative care. This abstract focuses on steps 1-2.

Results: Five patient cases were designed focusing on communication challenges such as difficulties in accepting one's situation, having underage children, symptom management, and existential issues. Initial testing with clinical palliative care experts suggests that the cases are authentic and realistic. The feedback was mostly positive, although one participant found the first case too complex to function as an introduction. Adjustments of case structure and difficulty level are ongoing.

Conclusion: AI communication training has the potential to meet a clear need in palliative care. The tool allows training difficult conversations that can contribute to confidence, reflection, and quality in care encounters. Feasibility testing continues iteratively including tool development.

Integration of palliative care into phase I oncology trials: A qualitative interview study with patients, informal caregivers and healthcare providers

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Background: Patients with advanced cancer who enroll in phase I oncology trials often face significant symptom burdens and limited survival prospects. While early integration of palliative care (PC) can improve quality of life (QoL) for patients and families, its role in phase I settings remains underexplored.

Aim: This study aimed to explore: (1) how QoL is currently addressed in the care of phase I trial participants; (2) the perceived benefits and strategies for integrating PC into phase I studies; and (3) barriers to such integration, from the perspectives of patients, informal caregivers, and healthcare providers.

Methods: We conducted semi-structured interviews with 48 participants: 16 patients, 5 informal caregivers, 12 phase I staff, 6 referring oncologists, 5 palliative care providers, and 4 general practitioners at three Belgian university hospitals. Data were analyzed using qualitative content analysis.

Results: QoL was inconsistently addressed, with patients generally reporting a positive trial experience but highlighting unmet needs beyond symptom management. PC was rarely discussed proactively; patients often equated it with terminal care and resisted engagement. Providers acknowledged potential benefits of PC integration, including holistic support and advance care planning, but identified key barriers: patients' negative associations with PC, concerns about conflicting messages of hope, time constraints, and fragmented communication between providers.

Discussion: Despite the recognized benefits of PC, integration into phase I trials is limited. Systematic, patient-centered strategies – such as offering flexible PC discussions early and at trial exit – are needed to support patients holistically while maintaining realistic hope.

Ethical Challenges and Opportunities of AI in End-of-Life Palliative Care: Integrative Review

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Introduction: The integration of Artificial Intelligence (AI) into palliative medicine, particularly in end-of-life care, offers promising improvements in prediction, communication, and symptom management. However, it also introduces ethical challenges that require careful reflection, especially regarding the risk of dehumanisation, data privacy, and equity.

Objective: This integrative review aims to explore the main ethical implications of AI use in palliative care at the end of life. Drawing from Lévinas' ethics of otherness, it examines how these technologies can either reinforce or undermine the human dignity and uniqueness of patients in vulnerable situations.

Methods: A systematic search of the literature (2020–2025) was conducted in PubMed, Scopus, and Google Scholar. Inclusion criteria focused on studies addressing AI in palliative medicine with ethical analysis or patient experience considerations. Twenty-nine articles were selected and thematically analysed across six areas: clinical prediction, symptom management, communication, automation, ethical challenges, and recent advances.

Results: The review identified both potential benefits—such as improved care efficiency, personalised interventions, and enhanced communication—and risks, including algorithmic bias, reduced human interaction, and inequitable access. Ethical concerns centred on non-maleficence, autonomy, and distributive justice.

Conclusions: AI can contribute meaningfully to palliative care, but its implementation must be patient-centred and ethically grounded. Clear regulatory frameworks, humanising design, and multidisciplinary collaboration are essential to mitigate risks and preserve the dignity and wellbeing of patients at the end of life.

Keywords: *Palliative Care; Artificial Intelligence; Medical Ethics; Terminal Care; Patient-Centred Care*

Enhancing palliative care capacity in Lithuania through university-based training and legislative change

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Palliative care provision in Lithuania has undergone a significant transformation following the update of national legislation on September 30, 2022 (Order No. V-1510). This change broadened the clinical criteria for palliative care eligibility, effectively increasing access across inpatient and outpatient services. As a result, healthcare institutions reported a marked rise in the number of professionals seeking relevant qualifications. Between March 2023 and May 2025, 804 healthcare professionals participated in accredited training programmes - a substantial increase following the legislative change, as reported by training institutions. Participants included nurses (209), physicians (182), physiotherapists (86), psychologists (34), and social workers (10), among others.

Despite the absence of palliative medicine as a formal specialty or a full university degree in Lithuania (as confirmed by the EAPC Atlas of Palliative Care 2025), accredited courses are delivered at the university level and are open to all members of the interdisciplinary care team. Each programme consists of 44 academic hours, including 36 hours of theoretical instruction and 8 hours of practical training, in accordance with national standards approved by the Ministry of Health.

Survey data (n = 351) demonstrate high satisfaction: participants rated course organisation, theoretical and practical relevance at ≥9,3/10. Moreover, starting in September 2025, Lithuania will launch advanced nursing education programmes, including a dedicated palliative care module.

These findings illustrate how policy changes can drive service expansion and professional engagement. In countries lacking formal specialty recognition, structured interdisciplinary education is a key strategy to develop and strengthen palliative care capacity.

Referral of patients to Palliative Care using predictive Artificial Intelligence models

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Abstract

Artificial Intelligence (AI) is increasingly influencing various sectors, including healthcare, where it holds the potential to transform how care is delivered. One promising area is the timely identification and referral of patients to Palliative Care. Palliative Care aims to provide support for patients with serious illnesses by alleviating symptoms, improving quality of life, and addressing emotional and psychological needs for both patients and their families. By harnessing predictive power and self-learning capabilities, AI offers a novel approach to enhance early access to Palliative Care services.

This dissertation is a systematic review with narrative synthesis, aiming to analyze AI-based predictive models already developed for Palliative Care referral and to assess whether their use by healthcare professionals improves patient outcomes. Only peerreviewed original studies were included, applying quality assessment criteria. Grey literature was excluded. The population of interest focused on patients with life-limiting illnesses, institutional mortality data, or healthcare service user data.

Out of 217 articles initially identified, 22 were included. Most were quantitative studies with varying sample sizes and populations. Both retrospective and prospective designs were represented. AI algorithms consistently outperformed traditional referral methods, such as manually populated prognostic tools or standard statistical approaches. Evidence showed improvements in patient quality of life, earlier and more frequent Palliative Care consultations, decreased hospital mortality, reduced 30-day readmissions, and lower admission and hospitalization durations. Home-based Palliative Care referrals also increased, further enhancing patient wellbeing.

AI should be regarded not as a replacement for human judgment but as a decision-support tool. When properly applied, these algorithms may significantly improve timely access to individualized, holistic Palliative Care.

Key words: *End-of-life care; Palliative Care; Artificial Intelligence; Machine Learning; Patient referral; Decision support tools*

Cognitive function in patients with long-term survival after brain metastases

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Background: Few studies have examined cognitive function in long-term survivors with brain metastases (BM). The study aim was to assess observer-rated cognitive function and compare it with normative samples.

Methods: Patients with ≥ 2-year survival after a first-time BM diagnosis completed neuropsychological tests assessing key neurocognitive domains: processing speed, executive functioning, mental flexibility, visual learning and memory, verbal learning and memory, attention and working memory. Test scores were converted into standardized z-scores using normative sample means and standard deviations (SD). The proportions of patients with an individual z-score of ≤ -1.5 SD below the normative sample means were calculated to indicate clinically significant impairment.

Results: Forty-one patients (mean age 61, 24 women) completed assessments at a median of 32 months (min-max: 26-47) after the BM diagnosis. On a group-level, patients performed poorer than normative samples in tests within all domains except verbal learning and memory. For the other domains, mean z-score ranged from -0.3 (visual learning and memory) to -0.9 (executive functioning and mental flexibility). The proportion of patients with clinically significant impairment ranged from 7% (attention and working memory) to 51% (executive functioning and mental flexibility) between domains.

Conclusions: Long-term survivors with BM performed poorer than normative samples within nearly all neurocognitive domains, particularly executive functioning and mental flexibility. This domain is important for daily living and social functioning, and clinicians should provide information about implications of BM, and tailor patient care to optimize functioning and quality of life.

Post-Biographical Dignity at the end of Life: A critical review of Digital Identity, narrative, and ethics

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Abstract

Background: The digitalisation of human experience is transforming how patients live, share, and are remembered at the end of life. Traditional notions of dignity (based on autonomy, bodily integrity, and interpersonal respect) are increasingly challenged by digital practices such as online storytelling, social media memorials, and digital legacy planning. These advances raise new ethical questions that have not yet been sufficiently explored in end-of-life care.

Objective: To critically examine how contemporary literature conceptualizes and addresses the influence of digital technologies, online narratives, and virtual identities on the experience of dignity in the context of death and palliative care.

Methods: An integrative systematic review was conducted following PRISMA 2020 guidelines. A total of 46 Peer-Reviewed articles published between 1994 and 2024 were included, covering empirical research, theoretical essays, and meta-reviews. Databases consulted included PubMed, Scopus, Web of Science, PsycINFO, and PhilPapers. Thematic synthesis was employed to identify emerging ethical and conceptual paradigms.

Results: Five central themes emerged: (1) the persistence of the digital self beyond death; (2) narrative dignity in public digital spaces; (3) digital adaptations of dignity therapy and legacy creation; (4) ethical challenges involving visibility, consent, and control over digital remains; and (5) the proposal of a new concept: Post-Biographical Dignity. Digital tools offer opportunities for expression and meaning making but also entail risks of overexposure, inequality, and decontextualised care.

Conclusions: There is an urgent need for digital ethics of end-of-life care. The concept of Post-Biographical Dignity demands a broader ethical framework that includes patients' digital identities, narratives, and relational legacies. Dying with dignity in the 21st century increasingly involves navigating both physical and digital realms, requiring ethically attentive, technologically informed, and narratively sensitive care.

Key Words: *Dignity; digital legacy; narrative identity; digital bioethics; post-biographical dignity.*

Patient-reported outcomes in long-term brain metastases survivors with and without cognitive impairment

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Introduction and Objectives: Little is known about the impact of cognitive impairment on patient-reported outcomes (PROs) in long-term survivors with brain metastases (BM). The study aim was to assess quality of life and activities of daily living in patients surviving > 2 years after BM diagnosis and compare PRO scores in patients according to observer-rated executive functioning.

Methods: Patients with ≥ 2-year survival after a first-time BM diagnosis completed PRO measures and neuropsychological tests assessing executive functioning and mental flexibility. Test scores were converted into standardized z-scores using normative sample means and standard deviations (SD). Patients with an individual z-score of ≤ -1.5 SD below the normative sample means were calculated to indicate clinically significant impairment. Differences in PROs >10 points were considered clinically meaningful.

Results: Forty patients (mean age 61, 23 women) completed assessments at a median of 32 months (min-max: 26-47) after the BM diagnosis. At group level, patients' scores varied between domains. Patients with impairment in executive functioning and mental flexibility (55%) reported clinically significantly poorer scores for fatigue, drowsiness, weakness of legs and most scales assessing BM-related activities of daily living, but not for global quality of life, physical and emotional function or scales assessing more BM-related symptoms (headaches, visual disorder, seizures, motor dysfunction and communication deficit).

Conclusions: Long-term survivors with BM with impaired executive functioning and mental flexibility experience challenges in activities of daily living and social functioning. Patients and their caregivers must be informed of potential long-term consequences of BM and related treatments.

Towards interoperable Advance Care Planning in palliative care: aligning FHIR-based profiles with modular clinical information models.

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Background: High-quality palliative care requires timely, coordinated, and person-centred communication across healthcare settings. To ensure that patients' preferences are accessible and actionable at the point of care, seamless integration of Advance Care Planning (ACP) data into different electronic health records (EHRs) is essential. However, interoperability and standardization of ACP data remain challenging, particularly in fragmented digital health systems.

Methods: We examined how a digital infrastructure built on HL7® FHIR® (Fast Healthcare Interoperability Resources) and Dutch national standards could support ACP in pilot projects involving hospitals, general practitioners and community nursing organisations. A digital information management (DIM) standard was developed based on the Dutch ACP guideline. The DIM facilitates integration of FHIR-based ACP profiles with modular clinical information models (Zorginformatiebouwstenen, ZIBs), developed in collaboration with Nictiz, the national center for digital health information.

Results: By using Single Sign-On within the healthcare providers' own EHRs, ACP data could be securely accessed and viewed across systems, while complying with the General Data Protection Regulation. Authorized healthcare professionals were able to view and update ACP data efficiently, enhancing care continuity and coordination. A beta-version of the DIM-standard will be released shortly to support further implementation.

Conclusion: Aligning FHIR-based ACP profiles with ZIBs improves semantic consistency, data reuse and interoperability. As FHIR-based ACP profiles near completion, the established infrastructure already effectively enables the integration of patient preferences into care delivery. Continued investment in technical alignment, user-centred design, and legal frameworks is needed to scale the benefits and ensure sustainable, high-quality palliative care across the Netherlands

Opioid Prescription Trends in End-of-Life Care: A protocol for cohort Analysis of patients with cancer (2012-2023)

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Cancer pain is often treated with opioids. However, access to opioids varies due to economic and psychosocial factors. Low-income countries face barriers such as limited availability, costs, and misinformation. Conversely, high-income countries have exhibited increased opioid use and related harms, exemplified by the opioid crisis in the United States. In response, in the last decade updated prescribing recommendations, also in Denmark, have been introduced, which may affect cancer pain treatment, including in palliative care.

Therefore, this project will aim conduct the first Danish cohort analysis based on national register data to examine redeemed opioid prescriptions among cancer outpatients during the last six months of life.

It will comprise two population-based register studies. Study 1 focuses on adult outpatients (≥18 years), while Study 2 examines pediatric patients (<18 years), both covering the period from 2012 to 2023. Data will be sourced from Danish national registers. Opioid prescription patterns will be categorized based on following criteria: (1) extend of received opioids (continuous opioid user, periodic opioid user, non-opioid user), (2) type of opioid and (3) dosage of opioids over the period. Variables include sociodemographic characteristics and for Study 1 health-related quality of life (EORTC QLQ-C15-PAL).

A comprehensive overview of opioid prescription patterns with nationwide data at the end of life can help raise awareness about possible inequalities, understand the impact of health policy regulations on opioid prescriptions, improve prescribing practices, and advocate for policies that enhance cancer pain management and access to palliative care.

Feasibility of a Multidimensional Clinical Decision Support System in Palliative Care among General Healthcare Providers

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Introduction: Palliative care patients often experience multiple symptoms, but management is suboptimal because of limited time, experience, and structured approach. Guidelines challenge general healthcare providers (GHCPs) by overlooking symptom interactions and offering unidimensional recommendations, increasing symptom burden and reducing quality of life. Clinical Decision Support Systems (CDSS) have proven effectiveness in symptom management. We investigated GHCPs' willingness to use a CDSS that supports structured assessment and multidimensional management of symptoms.

Methods: The Multidimensional Strategy for Palliative Care (MuSt-PC) CDSS was developed (Figure1) using the Utrecht Symptom Diary-4 Dimensional for structured symptom assessment and the Dutch palliative care guidelines for management recommendations. Primary care and hospital-based GHCPs used the MuSt-PC and provided feedback. We evaluated intention to use, perceived usefulness, ease of use, and overall satisfaction.

Results: Seventy GHCPs were enrolled, and 42 (60%) completed the evaluation. The tool was used 202 times. Among participants who completed the evaluation, most (71%) viewed benefits, particularly in increasing awareness of multiple symptoms and using a systematic symptom assessment. The recommendations provided by the tool were also appreciated. Twenty-six (61%) identified disadvantages, especially extra time during consultations and the tool's learning curve. Improvement was suggested by 33 (79%), namely integration of recommendations into a concise overview and development of a step-by-step plan.

Conclusions: The MuSt-PC supports GHCPs by improving symptom assessment and offering management guidance. Enhancements based on participant feedback using innovative technology will facilitate its adoption in daily practice, increasing willingness to use beyond the current 60%.

Leveraging electronic health records to support pragmatic palliative care needs identification in oncology inpatients

Authors

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Introduction: Timely palliative care in oncology remains suboptimal due to delayed referrals and inconsistent identification of patient needs. Digital platforms such as electronic health records (EHR) present opportunities for automated screening in busy inpatient settings. This study assessed the feasibility and appropriateness of applying EHR-based screening criteria to identify oncology inpatients who may benefit from palliative care.

Methods: We conducted a prospective cohort study involving 202 consecutively admitted oncology inpatients at Singapore General Hospital from 26/06/2024-07/07/2024. Screening criteria spanned patient-related (pain, medical social worker involvement), disease-related (metastatic disease, not on cancer therapy, comorbidities), and healthcare utilization-related (prior admissions and palliative care use) domains. Feasibility was assessed by EHR data completeness and appropriateness by associations between screening results and acute healthcare utilization.

Results: The mean (SD) age of the cohort was 64.6(13.6) years, comprising 52.0% female and 78.2% Chinese. Common cancer types included gastrointestinal (28.7%), lung (18.8%), and breast (13.9%). EHR data fields were >90% complete, except for pain (86.6%). Patients meeting disease-related and one other criterion (n=127) had longer hospital stays [median(IQR)=6(3-12) vs. 4(3-7)days, P=0.027] and greater likelihood of 30-day emergency department (ED) return (49.6% vs. 33.3%, P=0.024). Patients meeting all three domains (n=40) also had higher 30-day ED return rates (60.0% vs. 39.5%, P=0.019), but not longer hospitalization. Neither was associated with 30-day unplanned readmission.

Conclusions: EHR-based screening is feasible and flags patients with greater acute care needs, though not predictive of unplanned readmissions. Embedding automated algorithms offers a pragmatic, low-burden approach to support timely palliative care integration in oncology.

Specialized palliative telemedicine for patients with advanced cancer at home: results of a pilot study

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Background: This study proposed a specialized palliative care (SPC) intervention, enriched with a dyadic psychological component for patients with advanced breast cancer and their caregivers. Delivered via telemedicine, the intervention aimed to improve patient's health related quality of life (HRQoL). The primary objective was to assess its feasibility and potential impact on HRQoL.

Methods: A prospective, single-center, pilot randomized controlled trial was conducted with adult patients receiving non-curative treatment and reporting at least 1 symptom/problem scoring≥ 3 on the EORTC QLQ-C30. The intervention included SPC consultation within 5 days from randomization, video follow-ups as needed, and 2-5 dyadic psychological sessions. Monthly multidisciplinary conferences involving SPC team, oncology team, general practitioner, and district nurse were held to coordinate care. Control group: standard care. Assessments at baseline and after 2/4/8 weeks and 6 months. A significance level of 0.05 was applied.

Results: A total of 29 patients completed the study in each group (mean age 62 years, 98% women). The primary sector and the oncological team participated in very few conferences. No sociodemographic differences were observed. Improvement was noted in physical functioning (2, 4 and 8 weeks), role functioning (2 weeks and 6 months), sleep (2 weeks and 6-month), social functioning (8 weeks), pain (2 weeks), dyspnea (8 weeks), diarrhea (4 weeks) and global quality of life (at 4 weeks).

Conclusion: The intervention showed potential to improve HRQoL, despite limited integration between SPC, oncology and primary sector. These findings support the further development of the intervention.

Palliative Care Unit for Inter-Specialty Cancer Training Programme: Case Study of Development

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Background: To enhance collaboration in cancer care continuum for effective, person-centred care, an Inter-Specialty Cancer Training Programme (ISCTP) was developed in INTERACT-EUROPE100 -project. ISCTP is piloted in over 100 cancer centres across Europe. As palliative care (PC) is essential part of cancer care, in addition to specialty integrated PC content, ISCTP has a dedicated unit for PC.

Aim: To Develop Palliative Care online training unit for ISCTP.

Methods: Curriculum, learning outcomes and content topics for the PC unit were developed by interprofessional team and reviewed by project consortium. Furthermore, learning activities (LAs) were defined and nine experts from six professions and specialties (palliative nursing, nursing education, medical oncology, social sciences, palliative medicine and midwifery) participated in production of the materials. The materials were reviewed by interprofessional team based on grading system. The quality of content, language, visualisation, understandability and appropriate difficulty were evaluated on a scale from 0-5. If needed, revisions were required.

Results: The PC online training unit consists of 2,5h learning; two video lectures, four podcasts, one reflection exercise, one textbook, a summary and learning test. Review mean scores varied from 3.3-5. 75% of materials required revision after initial review.

Discussion: LA materials produced individually by experts resulted many of content requiring retouch, especially to establish a holistic perspective. Some cases, the LA method was changed if in advance planned LA was evaluated unsuitable.

Conclusions: Due to the holistic approach of PC, development of PC training and learning materials should be conducted within interprofessional teams in every stage

Early palliative care intervention in patients with advanced lung cancer using an e-health ecosystem: a randomized, controlled, and blinded clinical trial (AIRPAL-010521).

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Introduction: Early integration of Palliative Care (PC) into standard oncology improves patients' symptom control and Quality of Life (QoL). Advanced lung cancer, characterized by high prevalence and poor prognosis, involves unpredictable symptoms that require continuous care. In this context, telehealth facilitates remote monitoring, enabling early detection of clinical worsening and reducing healthcare resources use.

Main Aim: To compare QoL in patients with advanced non-small cell lung cancer (NSCLC) followed through an e-Health ecosystem versus standard in-person follow-up.

Methods: A multicenter, randomized and controlled trial with blinded outcome assessment. Eligible participants are ≥18 years old, diagnosed with stage III–IV NSCLC, identified for early PC intervention and with basic digital literacy and access to required equipment. Sample size: 260 patients. The intervention group receives follow-up through the ICOnnecta't-AIRPAL platform, including virtual visits, telephone follow-ups, and remote assessments for symptom control. The control group receives standard in-person follow-up. The primary outcome is QoL, measured with the Functional Assessment of Cancer Therapy – Lung (FACT-L) at 3, 6, 9, and 12 months. Secondary outcomes include symptom burden (ESAS-r), pain (BPI), functional status (PPS), opioid use and side effects (CTCAE v5), emotional distress (HADS), treatment adherence (ARMS-e), patient satisfaction and cost-effectiveness analysis.

Expected Results: It is expected the e-Health follow-up improve QoL, reduce hospital visits and optimize healthcare resources.

Study Limitations: Partial blinding, variable acceptability depending on age and education level and potential technological barriers.

Ethical approval: PR274/21.
Funding: Instituto de Salud Carlos III (ISCIII), PI21/00834.
Status: Recruitment phase ongoing.

Symptom clusters in palliative radiotherapy using the Edmonton Symptom Assessment System

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Aims: Effective palliative care depends on careful identification and management of symptoms, particularly in patients referred for palliative radiotherapy (PRT). This study aimed to identify symptom clusters (SC)—defined as ≥2 interrelated symptoms—in patients evaluated at a multidisciplinary Radiotherapy and Palliative Care (RaP) outpatient clinic, using the Edmonton Symptom Assessment System (ESAS).

Methods: We analyzed data from patients evaluated at RaP outpatient clinic between February 2017 and April 2020. Demographic and clinical information, including ESAS scores at first visit, were collected. ESAS evaluates nine symptoms on a 0–10 scale. SCs were identified using principal component analysis (PCA) and hierarchical cluster analysis (HCA). Associations with ECOG performance status (PS) and PRT indication were also explored.

Results: Among 215 patients (median age 71 years; 53% male), the mean total ESAS score was 24.03 ± 15.28. PCA identified 4 SCs: (1) tiredness, drowsiness, dyspnea, and well-being; (2) depression and anxiety; (3) nausea and appetite loss; (4) pain. HCA identified 3 SCs: (1) nausea and appetite loss; (2) tiredness, drowsiness, dyspnea, well-being; (3) depression, anxiety, and pain. Higher ECOG PS correlated significantly with all SCs ($p<0.05$), reflecting overall symptom burden rather than symptom type. A non-significant trend linked Cluster 2 to increased PRT use. Notably, lower psychological burden correlated with higher PRT likelihood, while psychological symptoms combined with pain increased the likelihood of receiving RT.

Conclusions: SC analysis could be a valid support for decision-making in PRT. Psychological symptoms appear influential in treatment decisions, particularly when not associated with pain.

HOPE4Kids – Holistic Oncological Palliative care for Europe's Kids; an EU4Health project

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Background: About 14,000 children and adolescents in Europe are yearly diagnosed with cancer. Current care for young patients with cancer focuses primarily on disease treatment, and specialized pediatric palliative care (PPC) is often not offered. However, PPC focuses on the relief of suffering for all children with life-limiting or life-threatening conditions, regardless of diagnosis or stage of disease.

Aims: The overall aim of HOPE4Kids is to advance PPC in pediatric oncology. Over four years, this Joint Action will focus on six cross-cutting themes: symptom management, advance care planning, shared-decision making, psychosocial care, pre-loss and bereavement care and models of care.

Methods: Starting in October ‘25 our task group will ● extract recommendations from identified guidelines to evaluate concordance/discordance and gaps in recommendations ● Formulate clinical questions based on discordant guideline areas and evidence gaps ● Identify available evidence for formulated clinical questions by systematic literature searches ● Summarize evidence and appraise quality of evidence using the GRADE methodology ● Formulate and grade recommendations based on the evidence, clinical considerations, and patient values.

Results: Oslo University Hospital will lead a task group in WP6 aiming at the development of a harmonized and evidence-based guideline for advance care planning and shared decision-making in PPC. The guideline will consist of elements which to some degree will be adjustable to local needs. These elements will potentially provide indicators for benchmarking and quality assessment of PPC on the European level.


WP1 Coordination
WP2 Dissemination
WP3 Evaluation
WP4 Sustainability
WP5
Landscape of European PPC
WP6
Evidence-based guidelines for PPC
WP7
Pilots
WP8
Education, Training & Information

Tailoring and evaluating a remote patient monitoring service in home-based palliative care for patients with cancer

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Background: The increasing number of patients with cancer in need of palliative care and the shortage of healthcare professionals call for accessible and flexible models for home-based palliative care, responsive to patients' and families' needs. Remote patient monitoring could be a promising approach to deliver high quality home-based palliative care. However, there is a lack of evaluation of the effectiveness of such services.

Aim: To tailor and evaluate feasibility and effectiveness of a remote patient monitoring service for patients with cancer in need of palliative care, delivered by municipality healthcare professionals.

Methods: The project will employ the Medical Research Council Framework for Complex Interventions including (1) co-design of a tailored remote patient monitoring service where patients, families, healthcare professionals and researchers discuss ideas in workshops, (2) a multi method feasibility study to evaluate procedural, methodological, and clinical issues and explore patients' and healthcare professionals' experiences with the service and (3) a randomized controlled trial to evaluate the final service for effectiveness on patient quality of life, spiritual well-being, digital health literacy, and number of hospital admissions.

Conclusions: We expect the proposed project to enable remote patient monitoring in a tailored and flexible way for patients with cancer in need of palliative care and healthcare services. The results of our project are warranted, as existing remote patient monitoring services do not meet the needs of patients with cancer in home-based palliative care.

Solar Nutrition in Palliative Oncology: Bhaskara Nada Yoga and Homeopathic Topical Applications as Digital Self-Care Tools

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This pilot study presents a digital, non-invasive, and spiritually uplifting self-care model that delivers what may be called “nutrition from the sun”—a holistic approach integrating Bhaskara Nada Yoga (therapeutic sound healing) with external homeopathic applications to support symptom relief and emotional-spiritual nourishment in palliative oncology settings.

The intervention is delivered through digital platforms such as WhatsApp, Zoom, and Skype, enabling patients and caregivers to receive personalized guidance remotely. Bhaskara Nada Yoga uses sound and breath as subtle solar energies, offered via recorded mantra chanting, rhythmic breathing, and vibrational meditative sessions.

These are paired with digital instructions for the topical application of sun-charged homeopathic dilutions (e.g., Arnica, Calendula, Sol) on the solar plexus region, a symbolic and energetic center of vitality.

A preliminary case series (n = 10) suggests improvements in pain relief, anxiety reduction, sleep quality, and caregiver-patient emotional connection. The combined use of solar-informed remedies and sound-based practices fosters a deeply human and spiritual sense of comfort.

By bridging ancient healing traditions with modern digital communication tools, this model becomes scalable, cost-effective, and inclusive—relevant for rural, home-based, or low-resource settings. It offers an innovative direction for the digital transformation of palliative oncology, promoting self-care, caregiver support, and emotional resilience during end-of-life care.

We invite collaboration for further development, research validation, and integration into palliative care pathways

Adherence and response to supervised home-based exercise prehabilitation of unfit patients scheduled for pancreatic surgery

Category: original article

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Abstract

Introduction: Pancreatic surgery remains the only curative option in pancreatic cancer, a disease that causes significant frailty. Prehabilitation might help prepare patients for major surgery. Most prehabilitation studies focus on effectiveness. Objectively assessed adherence data supporting feasibility of preoperative physical exercise programs are scarce. This study aimed to assess adherence, and effectiveness of a partly supervised, home-based exercise prehabilitation program in unfit patients scheduled for pancreatic surgery.

Methods: In this prospective multicentre study, thirty unfit patients (oxygen uptake [VO_2] at ventilatory anaerobic threshold [VAT] ≤13mL/kg/min and/or VO_2 at peak exercise [VO_2peak] ≤18mL/kg/min) participated in a four-week home-based exercise prehabilitation program consisting of three personalized high-intensity interval training sessions per week on a remotely monitored cycle ergometer. The primary outcome was adherence to frequency, intensity, and time of each training session. Secondary outcomes were individual responses to the program.

Results: Participation rate was 63.8% (30/47 eligible patients, median age 71 years [IQR 65-76], 16 females, 80% malignancy). Five patients dropped out. Adherence to all training sessions was 91.1%. Adherence to frequency and intensity diminished during the second half of the program. Nevertheless, aerobic capacity improved (VO_2peak+12.4%, $p<0.001$; VO_2 at the VAT +16.3%, $p=0.002$). Ultimately, twenty patients underwent surgery, without mortality but major complications in 25.0%.

Conclusions: Objective assessment of adherence to a 4-week partly supervised home-based exercise prehabilitation program by unfit patients scheduled for pancreatic surgery was high, suggesting that even suboptimal execution of a training program still improves aerobic capacity, especially in the frailest patients, making possibly curative surgery feasible.

Bridging the Gap: A Decade of Change in Undergraduate Palliative Care Education and Academic Capacity in Europe (EAPC Atlas 2025)

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Undergraduate education in palliative care (PC) is essential to preparing the future health workforce and achieving early integration of PC into health systems. This abstract presents updated data from the EAPC Atlas of Palliative Care in the European Region 2025, focusing on PC education for medical and nursing students, and the availability of full professorships in the field.

In 2015, only 6 countries reported mandatory PC education in all medical schools. In 2025, this figure has risen to 15, while 17 countries still report no mandatory inclusion. Optional teaching remains scarce across most of the region. In nursing, 19 countries now offer mandatory PC instruction in all schools, but 24 remain below 50% coverage.

Academic leadership has improved: the 2025 Atlas identifies 121 full professors across 23 countries, compared to 17 countries reporting any in 2015. However, many countries still lack formal academic infrastructure in palliative care.

Among the countries surveyed, the United Kingdom, the Netherlands, and Finland stand out as examples of best practices. The UK leads with 35 full professors, broad mandatory teaching in medicine, and comprehensive nursing education. The Netherlands ensures mandatory teaching in all medical schools and broad coverage in nursing, supported by 15 full professors. Finland combines national curricula in both disciplines with four full professors and a developing national competency framework.

In parallel, Joint Action JANE2 – WP6 Task 3 is advancing the development of core competencies and educational models to promote harmonisation. These findings highlight persistent gaps and offer strategic benchmarks for policy and reform.

DigiPall: Adapting Digital Healthcare Innovation for Clinical Practice in Palliative Care

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Background: Digital health technology translation to clinical implementation faces significant barriers, particularly for vulnerable populations like palliative care patients. Systematic evaluation frameworks are essential for successful healthcare technology adoption.

Objective: To demonstrate how structured testing environments accelerate evidence-based digital health intervention development, using DigiPall platform development as a case study.

Methods: Nine wearable devices and ten chatbot platforms were evaluated using validated instruments including the User Experience Questionnaire and System Usability Scale. Patient-centered testing with palliative care recipients informed technology selection and refinement.

Intervention: DigiPall combines validated components: the Corsano CardioWatch 287-2 for continuous physiological monitoring and a WhatsApp-based AI chatbot for daily symptom assessment. The intervention delivers personalized daily check-ins, adaptive symptom management guidance, and continuous biomarker capture to enhance patients' security while maintaining home-based care. Targeting the critical gap where 50% of palliative care emergency visits are potentially avoidable, DigiPall leverages Anthropic's Claude large language model (LLM) to enable natural patient-initiated conversations alongside structured symptom assessments, creating a more companion-like experience.

Study Design: A randomized controlled trial (n=382) will evaluate DigiPall's effectiveness in reducing unplanned hospitalizations while measuring quality of life and security impacts.

Results: Systematic evidence on technology usability, acceptability, and feasibility was generated, enabling rapid DigiPall development based on patient feedback and reducing development time through established frameworks.

Conclusions: Structured digital health methodologies successfully transform exploratory concepts into evidence-based clinical interventions, exemplifying effective user-centered design translation for vulnerable populations. Recruitment begins June 2025.

Clinical Trial Registration: NCT06615349

Keywords: *Digital health, palliative care, wearable technology, chatbot intervention, randomized controlled trial, technology translation*

Proteomic changes in urinary extracellular vesicles involving water homeostasis and hormonal stress signaling before death in cancer patients

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Introduction: Recognizing the dying phase in cancer patients is crucial for tailoring end-of-life care, but no reliable markers exist to identify this stage. Extracellular vesicles (EVs) from biofluids reflect their tissue of origin and may serve as biomarkers by indicating physiological changes that occur as death approaches. This study explores the urinary EV proteome in the final days of life as a step toward predicting the dying phase.

Methods: Urine was collected twice a week from cancer patients with a life expectancy shorter than three months admitted to hospice care. Longitudinal sample collection from 11 to 0 days before death took place and samples were grouped as early (7-11 days), middle (3-4 days) and late (0-1 day) based on days before death. EVs were isolated using the ME-kit and proteomes profiled (n=8 patients, 35 samples) by LC-MS/MS based proteomics. Statistical analyses were performed using Limma and differential proteins were annotated for biological processes using Gene Ontology and String-network.

Results: In total 2805 urinary EVs proteins were identified. Protein abundance increased at the late stage (Fig 1. B), with 118 proteins significantly increased compared to the early samples. Of these, 35 proteins were found to be significant upregulated across four patients with a complete time-point profile (Fig 1. C). Upregulated proteins were highly connected and mainly involved in water homeostasis and stress-hormonal signaling (Fig 1. D). Furthermore, protein time-dependent changes were observed between early and late time-points (Figure 1. E).

Conclusions: Urinary EVs proteome changes shortly before death. Whether these changes are exclusively related to death and can act as predictors of the dying process requires further exploration.

Uncovering Fluctuations In Daily Symptoms And Wellbeing Of Patients With Advanced Breast And Lung Cancer: An Experience Sampling Methods Study

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Abstract

Introduction: Experience sampling methods (ESM) involve repeated self-report questionnaires on patients' experiences in daily life, typically using smartphones. Compared to traditional patient-reported outcome measures, ESM counteracts memory biases and offers unique insights into symptom and wellbeing fluctuations. Yet, ESM is rarely used in advanced cancer. We aim to highlight the potential of ESM in oncology by exploring daily fluctuations in symptoms and wellbeing among individuals with advanced cancer.

Methods: We conducted an observational ESM study involving patients with advanced breast or lung cancer, who completed up to 10 self-report assessments per day for 7 days (up to 60 assessments per person). Assessments captured physical, psychological, social, and existential symptoms and wellbeing, alongside global wellbeing and daily contexts (e.g., current activities). We investigated fluctuations using time series visualizations and within-person standard deviations.

Results: Thirty-seven of 40 participants completed 1703 of 2400 scheduled responses. Symptoms and wellbeing fluctuated greatly within and across days, particularly for participants with higher severity levels across the week. Tiredness (M_{SD}=16.7, SD=7.7), feeling relaxed (M_{SD}=13.0, SD=7.3), and activity limitations (M_{SD}=12.4, SD=9.9) showed the greatest within-person fluctuations over the week. Fluctuation patterns varied between participants: some participants showed regular daily rhythms, while others exhibited unpredictable changes.

Conclusions: Unlike traditional methods that generalize across patients, ESM emphasizes patients' uniqueness by capturing their individual symptom and wellbeing fluctuations in daily life. This approach holds promise for advancing patient-centered care. For example, by uncovering contextual factors that drive fluctuations in chronic complaints, thereby guiding more personalized treatment and support.

Defining a Target Architecture for Digital Symptom Monitoring in Palliative Care in the Netherlands

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Background: Digital symptom monitoring holds great potential to improve quality of life of patients in a palliative care trajectory. Scaling implementation requires integration into clinical workflows, IT systems, and research infrastructure. In the Netherlands, a five-year national project (OPTIMISM - funded by KWF Dutch Cancer Society), has been launched to enable this integration, starting in academic hospital oncology departments.

Aim: To develop an initial target architecture as a concrete, testable framework for realising symptom monitoring at scale in palliative care.

Methods: A *target architecture* describes the intended future setup of digital systems, roles, and processes needed to achieve a shared goal—in this case, large-scale monitoring of physical and psychological symptoms and social and existential concerns using the Utrecht Symptom Diary-four dimensional[2]. The target architecture acts as a blueprint to guide implementation. The initial version was co-developed with two academic hospitals and national digital health partner[1]. It outlines: (1) core functions for patients, clinicians, and researchers; (2) required data and flow logic; (3) technical components and standards; (4) roles and governance; (5) legal and security safeguards; and (6) migration steps. The architecture aligns with national Dutch digital health strategies.

Results: This version outlines symptom reporting and monitoring, integration into EHRs, and research data pipelines. It is specific enough to guide decisions, yet broad enough for co-design and refinement. The next phase will focus on stakeholder consultation and technical validation.

Conclusion: Early design of a target architecture supports structured development, long-term focus, and early alignment across technical, legal, and clinical domains.

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Development of a nurse-led outpatient clinic to male caregivers using a bottom-up approach at Oslo University Hospital

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Background: Male caregivers of women with gynecological cancer have unmet needs. However, there is no evidence-based support service for these in Norway and digital support tools are underexplored. We aim to develop a nurse-led outpatient clinic for male caregivers of women with gynecological cancer hopefully resulting in increased empowerment, better coping strategies and improved quality of life.

Methods: The project will employ phase 1 and 2 of the Medical Research Council Framework for Complex Interventions. Phase 1a: map existing support services for male caregivers, map existing support needs including need for digital support tools in male caregivers of women with gynaecological cancer through a systematic mixed studies review and perform quantitative analysis of caregiver data on satisfaction with care in the NSGO-CTU/GCIG-SB-001/PEACE study. Phase 1b: Co-design workshops where male caregivers and healthcare professionals will discuss their expectations for a nurse-led clinic for such male caregivers. Phase 2: a multi-method feasibility study to evaluate the acceptability, feasibility and satisfaction with the developed nurse-led clinic.

Results: Approximately 30% of those who contact publicly available support services are male caregivers. 24 studies were included in the systematic mixed studies review and preliminary results suggest that male caregivers experience anxiety, depression, loss of intimacy and social isolation. Four co-design workshops will be conducted in August and September 2025 which will be used to build a protocol for a nurse-led outpatient clinic for male caregivers.

Conclusion: We aim to develop a nurse-led outpatient clinic that is tailored to the needs, resources and circumstances of male caregivers.

Process Evaluation of a Cluster Randomised Pilot Trial Embedding Routine Cancer Pain Assessment in UK Oncology Outpatient Services

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Background: Despite advances in pain medications, uncontrolled pain remains prevalent and inadequately managed among cancer patients. A key barrier to optimal management is standardised routine assessment in oncology outpatient services. The CAPTURE study is a multi-centre cluster randomised pilot trial assessing the feasibility and acceptability of integrating a systematic pain assessment and management toolkit (EPAT+) into routine care. An embedded process evaluation explores the fidelity and acceptability of intervention trial procedures and contextual factors that influence implementation in real-world settings. This abstract presents preliminary findings from the process evaluation.

Methods: Quantitative data are captured via case report forms and clinic records; qualitative data are gathered through semi-structured interviews with patients and healthcare professionals (HCPs), complemented by researcher fieldnotes. Thematic analysis is guided by the Framework of Acceptability and implementation science.

Findings: Preliminary analysis suggests routine cancer pain assessment is acceptable to HCPs, who recognise its value in managing under-treated pain. Patients report that being asked about pain at each appointment is acceptable and does not detract from consultation priorities. However, screening criteria limiting eligibility to patients reporting moderate to severe pain within 72 hours excluded over 70% of those screened, highlighting that cancer pain is more episodic and less frequent than expected. Expanding the timeframe to one or two weeks may improve trial eligibility and efficiency.

Conclusions: This process evaluation provides valuable evidence on embedding pain assessment into oncology clinics and informs adaptations to maximise feasibility and acceptability in a definitive trial. Data collection and analysis will conclude in August 2025.

A comparative analysis of somatosensory profiles of active versus placebo CIPN responders in a randomized controlled trial of topical menthol: Secondary analysis of the MINT trial

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Background: One of the challenges in pain studies is differentiating between active and placebo responders beyond patient reported outcomes.

We use our double blind RCT of topical menthol in CIPN to investigate the correlation between subjective improvement in CIPN reported by patients receiving 3% Menthol gel compared to those receiving placebo gel and Quantitative Sensory Testing (QST) profiles.

Methods: Adult patients suffering from painful CIPN underwent baseline assessments including validated questionnaires and QST. The painful areas were treated with active or placebo gel twice daily for six weeks and then assessments were repeated. Our primary outcome was the correlation between QST profiles and a minimum of 30% improvement in the Brief Pain Inventory (BPI).

Results: Fifty-two participants were enrolled and forty-nine were evaluable on the primary outcome.

Using the baseline binary QST outcome variable (normal versus abnormal), a correlation between the BPI based responder status and the wind up measure was observed in the menthol arm (p= 0.044), but not in the placebo arm (p=0.194). Considering only normal and increased wind up, patients with increased wind up were more likely to be a responder in the menthol arm (p=0.029), but not in the placebo arm (p=0.224).

Conclusion: our study indicates a potential sub-group of patients who are more likely to respond to 3% menthol gel for painful CIPN symptoms, it suggests the possibility of integrating a simple bedside QST assessment into routine clinical practice to help manage a troublesome condition as CIPN and it emphasises the role of biomarkers.

Supporting caregivers in children's palliative care through digital access to responsive and equitable services

Authors:

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Background: Children's palliative care (CPC) target children (age 0-18 years) with life-limiting conditions. Caregivers (e.g., parents) provide extensive care for their child, while support for the caregivers often remains limited. Subsequently, caregivers' quality of life is compromised, with a risk of health problems and increased morbidity, challenging their abilities to support their child, siblings and spouse. CPC teams have been established to support continuous care. However, current services are vulnerable to unforeseen events because the needs of the heterogeneous population outnumber current resources. Consequently, CPC is at risk of being inequitable and unresponsive to the changing needs in CPC.

Aim: We will explore the needs and experiences of families in CPC and how digital health solutions can meet the needs of children, caregivers, and healthcare professionals in homebased CPC, enabling responsive and equitable CPC.

Methods: This study will take on several methods. First, we propose developing and implementing a tailored digital version of the Carer Support Needs Assessment Tool Intervention Paediatric (CSNAT-I (Paediatric)) in a CPC team service, then evaluate the feasibility of addressing caregiver support needs in CPC. We will develop and tailor a digital health intervention procedure together with caregivers and health professionals, explore this intervention, and profile the support needs of the caregivers. The intervention will be tailored in an existing digital health solution, increasing sustainability and knowledge on how to adapt existing digital health solutions to the benefit of caregivers in CPC.

Gathering evidence for evidence-based health technology to support communication in homebased pediatric palliative care – CHIP homeTec

Participants/ co-authors

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Pediatric palliative care concern children with life-limiting and/or life-threatening conditions. The majority of children receive palliative care over many years, and even as they transition into adulthood. Homebased pediatric palliative care combined with health technology is highlighted as an important means to support care and communication, however, there is a lack of fundamental data to develop evidence-based solutions.

The CHIP homeTec project comprises a thorough investigation of multiple aspects relevant for the design of such health technology. Through a multi-methods project combining qualitative, quantitative and review methods we have explored aspects concerning health technology in home-based pediatric palliative care. The needs among children and families are explored through interviews and focus groups with children and parents, healthcare personnel needs are explored through cross-sectional data, focus groups and review, and prior experiences and the ethical, legal and social consequences are explored through two reviews. Altogether, we will present findings to support a draft for an evidence-based protocol for health technology to support families and healthcare personnel in homebased pediatric palliative care.

Project start 2021, project end 2026.

Pain at the end of life in cancer patients: a population-based study on prevalence, relief and the role of pain assessment

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Purpose: Pain is common in advanced cancer and its assessment is recognized as crucial for effective management. However, real-world evidence on pain prevalence, relief, and the impact of structured pain assessment across cancer types at the end of life remains limited.

Methods: We analyzed data from 215,317 patients who died from cancer reported to the Swedish Register of Palliative Care(2011-2023). Data are based on validated end-of-life questionnaires completed by healthcare providers after the patient's death. Patient characteristics and provider-reported pain outcomes (prevalence of pain, severe pain, structured pain assessment usage, pain relief) were evaluated. Pain prevalence and relief across cancer types were examined through multivariable logistic regression analyses.

Results: Overall, 82% of patients experienced pain and 35% severe pain during their final week of life. Highest pain prevalence occurred in pancreatic, prostate and bone/soft tissue cancer; lowest in brain/ CNS cancers. Complete pain relief was reported in 77% of patients, with lowest odds in patients with prostate and bone/soft tissue cancer and highest odds in patients with brain/CNS cancer. Structured pain assessment was significantly associated with higher odds of complete pain relief both overall (adjusted OR: 1.27, 95%CI: 1.24-1.30) and across most cancer types.

Conclusion: Pain remains highly prevalent in cancer patients at the end of life, with variation in both occurrence and relief across cancer types. Structured pain assessment was consistently associated with higher odds of complete pain relief. These findings underscore the importance of routine, systematic pain assessment and tailored pain management strategies in end-of-life cancer care.

Analysis of attitudes of oncologists, general practitioners and palliative care specialists with NarrCat a text analysis tool based on narrative psychology

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Background: Despite growing global awareness of palliative care, referrals are often hindered not by a lack of medical knowledge but by physicians' attitudes and underlying emotions. Traditional qualitative methods used to explore these attitudes—such as manual text analysis—are typically time-consuming, complex, and require extensive professional collaboration.

Aim: This study aimed to identify an AI based method that enables rapid, reliable, and reproducible analysis of long texts while also allowing for statistical evaluation.

Method: In our study, we analysed three focus group discussions about palliative care referral involving oncologists, general practitioners (GPs), and palliative care physicians using *NarrCat*, a computer-based tool grounded in narrative psychology. *NarrCat* conducts narrative categorical content analysis by pairing compositional and psychological categories, interpreting word combinations and grammatical structures to extract deeper meaning.

Results: Our findings demonstrated that *NarrCat* operated reliably and produced statistically analysable outputs. For instance, both oncologists and palliative care specialists used significantly more expressions of activity compared to GPs ($p=0.000$). The theme of compulsion appeared more frequently among oncologists ($p=0.000$), while palliative care physicians demonstrated significantly more cognition-related language ($p=0.000$). Oncologists expressed the least emotional content ($p=0.000$).

Conclusion: These results confirm that fixed-code narrative psychology tools like *NarrCat* can simplify and accelerate qualitative text analysis, making it more objective and statistically interpretable. This approach provides for instance a new insight into the implicit attitudes of healthcare providers towards palliative care, enabling the development of better strategies to deliver appropriate care to cancer patients at the right time.

Implementation of a novel digital Palliative Care Referral System (PCRS) to enhance integration between medical oncology and specialized palliative care: preliminary data.

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Background: Although early palliative care (PC) improves quality of life (QoL) and care outcomes in oncology, standardized referral criteria for clinical practice are still missing. The Palliative Care Referral System (PCRS, including 14 predefined criteria generating a referral recommendation) was developed to guide referrals using patient-reported outcome measures, clinical signs, and prognostic indicators (founded by the Italian Ministry of Health, NCT04936568).

Aim: To evaluate the impact of PCRS digital implementation on healthcare resource use, QoL, patients' and caregivers' satisfaction, and end-of-life (EoL) care aggressiveness in patients with advanced cancer.

Methods: In this monocentric quasi-experimental study, 190 patients were enrolled before (PRE) and 190 after (POST) PCRS digital implementation into outpatient oncology care. Patients belonged to six oncologic categories: genitourinary, thoracic, gastrointestinal, breast, sarcoma, and head & neck. During implementation, oncologists completed the PCRS form monthly for 6 months. Assessment of care trajectories and EoL aggressiveness was also performed monthly. Time to PC referral was estimated via Kaplan–Meier; Cox regression tested its association with PCRS domains.

Results: Referral rates decreased in POST by 24% vs. 29 % in PRE. In POST, referral occurred earlier in prostate and colorectal cancers and later in thoracic and biliopancreatic cancers, reflecting a shift toward more individualized patient-centered decisions. Analysis of other outcomes (EoL aggressiveness, QoL, and satisfaction) is ongoing.

Conclusion: PCRS optimizes oncology care pathways, enhancing patient-centered PC referral.

Exploring alignment between HiT innovation and hospital IT systems: Findings from the MyPath Project

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Background: Achieving the effects of Healthcare Information technology (HiT) is promising yet difficult to achieve. For quality improvement and increased effectiveness to occur, HiT innovations must align with best practice medicine and be adopted in routine clinical practice. In addition, successful implementation requires careful navigation of information governance, technical infrastructure and relevant stakeholders of hospital IT.

Aim: To understand the installation process of "MyPath", in 9 sites. MyPath is an EU sponsored public industry research and innovation partnership for best practice patient centered care (PCC).

Methods: Exploratory mixed-methods case study. The researcher was embedded and followed the installation processes of the "Fundamentum platform" in 9 study sites over 3 years. Data material was the researchers' diary, project activity log, passive meeting observations, meeting reports and a pre-process IT checklist. (N338). The material was coded inductively with Nvivo 14,5 and the process was mapped out per site.

Results: Our results show both unique and common attributes of the 9 sites, which will be presented. Technical integration was not achieved at any site at the time of writing. Executive approval was needed from more than one axis on 7/9 sites. There was no single point of entry on 8/9 sites, making the process to install drawn out in time and involving a multitude of stakeholders.

Conclusion: Our findings raise questions about the absorptive capability of hospital IT to research-based HiT innovation.

Barriers and facilitators for implementing patient-reported outcome measures in oncology practices: an umbrella review.

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Purpose/Objective: This umbrella review aimed to synthesize existing evidence on the barriers and facilitators to Patient-Reported Outcome Measures (PROMs) implementation in routine oncology care, applying the Consolidated Framework for Implementation Research (CFIR).

Material/Methods: The review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and was registered on PROSPERO (CRD42017055306). Eligible studies included systematic and scoping reviews published in English between inception and 15/04/2024 that focused on barriers and facilitators to PROMs implementation in cancer clinical practice. Comprehensive searches of MEDLINE, Embase, Cochrane CENTRAL, CINAHL, and Web of Science were conducted. Two reviewers screened studies and reviewed full texts. Data from included studies were extracted and analysed using qualitative content analysis, with an inductive coding approach to categorize codes into the four domains of the CFIR. The quality of the included reviews was assessed using the AMSTAR 2 tool.

Results: A total of 17 reviews, published between 2004 and 2024, were included. Applying the CFIR, most barriers and facilitators (n=34) were categorized as *Innovation Characteristics*, with key barriers identified as lack of perceived clinical value of PROMs and additional burden on patients. Barriers related to the *Inner Setting* (i.e. organizational context) included poor integration with electronic health records and workflow disruptions, while facilitators encompassed alignment with clinical guidelines and adequate staff training. *Individual factors*, such as healthcare providers' lack of knowledge and patients' low e-health literacy, were also highlighted.

Conclusion: To advance PROM implementation, it is essential to prioritize staff awareness of the value of PROMS, seamless integration with electronic health records, optimize clinical workflows, and enhance staff training in PROM utilization and interpretation. Patient support efforts should focus on improving e-health literacy and ensuring equitable access to digital tools. Furthermore, the overall low quality of the included reviews highlights the need for higher quality evidence when conducting scoping/systematic reviews.

Improving the Quality and Value of Care for People with Stage 4 Cancer: A Longitudinal Interview Study

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Background: Around one third of people with a new diagnosis of cancer in Scotland survive less than one year. A lack of policy and guidelines around advanced cancer care risks variation in care experience and outcomes.

Methods: Longitudinal, in-depth interviews were conducted with individuals with a new diagnosis of an advanced cancer and their unpaid caregivers in two NHS Scotland Health Boards (Lothian and Fife). Interviews were conducted around diagnosis and at further timepoints, allowing exploration of changing needs and care experiences. Bereaved caregiver interviews were offered. Qualitative, thematic analysis was undertaken.

Findings/Discussion: 20 people with advanced cancer were interviewed along with 13 caregivers (n= 57 interviews).

Key themes included the value of being understood and treated as an individual; the importance of care continuity; and the burden of navigating fragmented services. Participants on active treatment were typically better supported. Those not on treatment often felt disconnected or uncertain about where to seek help.

People worried about whether the right care could be put in place quickly. Honest conversations were highly valued but inconsistently offered.

Significant, unwarranted variation in access to care and support was driven by a variety of factors.

Our study findings provide powerful evidence that care quality standards are needed for the advanced cancer population and their caregivers, including critical detail about where these should focus. We are assimilating our interview findings with a regional study of cancer pathway data, collectively providing yet more evidence of the need to reduce unwarranted variation in care, experience and outcomes.

The MyPath Implementation Toolkit: A Toolkit for implementing standardized Patient-Centred Care through Digitalization

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On behalf of the MyPath consortium*

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Background: The MyPath project aims to integrate patient-centred care (PCC) into oncology practice across nine European cancer centres by implementing PCC pathways and clinical change management strategies supported by health information technology. However, many digital systems are not well adapted to end users, who often lack guidance on their roles, tool usage, and how to adjust clinical routines.

Aim: To support adoption of MyPath and integration into clinical workflows, we are developing a living Implementation Toolkit. This resource is aimed at guiding both patients and healthcare providers (HCPs) by outlining roles and providing usability instructions.

Methodology: A dedicated group conducted webinars with consortium partners and end users to inform the first version of the toolkit. Additional insights from interviews with HCPs identified key needs for successful implementation.

Results: This first version of the toolkit provides an overview of the MyPath solution, and step by step guidance for implementation across three phases: pre-implementation, go-live and post-implementation. For each phase recommended activities and checklists are provided, with detailed instructions on how and when to conduct them. The toolkit also provides training resources to support usability for both HCP and patients. Detailed guidance and instructions for the clinical use of the MyPath solution and how to assess real-time implementation effectiveness are included.

Conclusion: The tutorial is a" living document" and will be updated and improved throughout the implementation to ensure that it meets the needs at the clinical centres. The Tutorial is constructed with potential for local adaptions according to needs before and during the implementation phases.

What is required to achieve reliable and sustainable population-level quality-of-life data collection and utilization across the cancer care landscape: Developing a conceptual implementation model

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Background: As cancer care transitions from hospitalization to digitalized outpatient follow-up, European policymakers are encouraged to incorporate population-level quality-of-life data (QoL) to evaluate the success of European and national cancer strategies [1, 2]. The EU-funded EUonQoL project aims to facilitate this effort by developing a unified cancer-specific QoL assessment tool (EUonQoL-Kit) for systematic data collection across Europe [3]. However, structured implementation is essential for reliable and sustainable QoL data collection and utilization. This study aims to develop a conceptual model for the implementation process of long-term collection and use of population-level QoL data.

Methods: Pan-European and national stakeholders comprising policymakers, clinicians, patient representatives, researchers, and co-researchers participated in formal and informal digital meetings, workshops, and conferences, where their insights were gathered. Following two years of data collection, clustering, and refinement through agile co-design cycles [4], overarching levels of willingness were identified as important for reliable and sustainable QoL data collection and utilization.

Results: Across the cancer care landscape, four levels of willingness (governmental, individuals, institutional, and policymakers) were categorized into a conceptual model (Figure 1). Comprehensively addressing all four levels of willingness is necessary for establishing an effective and long-lasting implementation process that enables population-level QoL data to be collected and utilized in European countries.

Conclusion: In order to assess the impact of European and national cancer strategies on individuals affected by cancer, population-level QoL data needs to be collected and analyzed systematically. Achieving this goal will require following a four-level conceptual model that mobilises coordinated willingness from governing authorities, policymakers, institutions, clinicians, researchers, and individuals.

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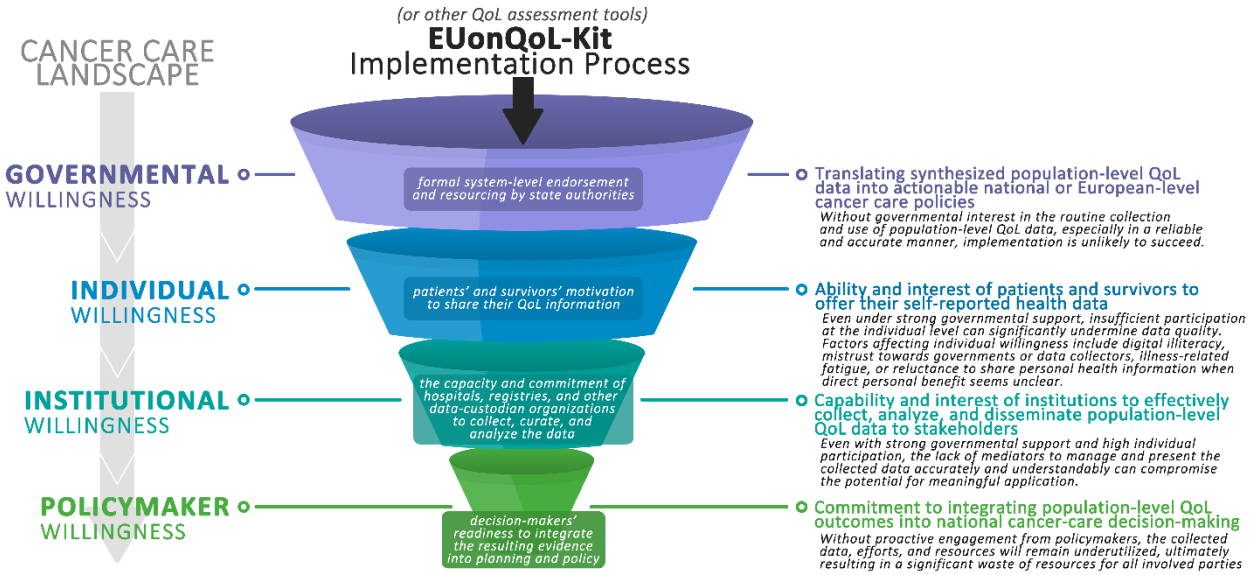
Figure 1. Conceptual implementation model of four willingness levels across the cancer care landscape required for reliable, sustainable population-level QoL data collection and use



Influence of the Medical Background of the Palliative Care Service Team on Pain Reduction in Oncological and Non-Oncological Inpatients

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Introduction: In Germany specialized palliative care is provided by both oncologist and non-oncologist physicians. The non-oncologist physicians are oftentimes anesthesiologists. This study evaluates the effect specialized palliative care (PC) service support on pain reduction in general and stratified by medical background of the PC providers in oncological inpatients.

Methods: In a retrospective analysis, 975 patients were included. Pain intensity was measured using the Numeric Rating Scale (NRS) at the time of the beginning of PC support and again after 48 hours. A subgroup analysis was performed comparing the different teams by medical background (anesthesiology vs. oncology).

Results: Significant pain reduction was observed within 48 hours across all patients ($p < 0.0001$). The reduction was particularly pronounced in patients with higher initial pain levels (NRS ≥ 4). The oncology team achieved a significantly greater pain reduction compared to the anesthesiology team. Among oncological patients, pain reduction was more pronounced in those treated by the oncology team than by the anesthesiology team. Across three time points (admission, 48 h, discharge), a continuous decline in pain intensity was observed.

Conclusions: The results highlight the positive impact of specialized palliative care services on pain management in hospitalized patients. The advantage in pain reduction achieved in the oncology team may reflect cancer-specific expertise and a deeper understanding of complex cancer-associated influences on symptom burden. Further prospective studies should explore differences between disciplines to optimize palliative care delivery.

Advance care planning in oncology: designing a pragmatic approach with digital support

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Study funded by the European Union [grant number 101057514] and supported by Innovate UK and the Swiss State Secretariat for Education, Research and Innovation (SERI).

Background: Advances in anti-cancer treatment have led to longer, more complex care trajectories, increasing the risk of non-beneficial treatment (NBT) near the end of life. Advance care planning (ACP) enables patients to discuss preferences for future care with family and healthcare providers (HCP). Although recommended in oncology, ACP remains underused. An international, multi-center project aims to integrate ACP into routine oncology practice, supported by the MyPath digital solution. In phase one, we will develop the structure and content for an ACP approach.

Methods: A review of literature and international guidelines on ACP in oncology was conducted. An international steering group of oncology and palliative care physicians and nurses was established. Using a consensus-based approach, the group will build on existing evidence to develop an ACP approach. Future iterations will involve co-creation with key stakeholders.

Results: Although ACP is associated with improved communication, care satisfaction, and reduced health care cost, evidence for other proposed benefits remains limited. Implementation challenges include inconsistent definitions, multi-level barriers (patient, provider, and system), and heterogeneity of approaches, outcomes, and strategies, highlighting the need for clear guidance. The group has reached consensus on the ACP definition, eligible patients and providers, timing, documentation, and a semi-structured conversation guide. Next steps include further content development, information and training resources, and adaptation to the MyPath digital solution.

Conclusion: A pragmatic approach based on consensus in an expert panel, grounded on implementation science and supported by digitalisation may facilitate the integration of ACP into routine oncology practice.

Why is inclusion in palliative intervention trials so difficult?

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Background: Intervention trials in palliative care should be designed to ensure a good inclusion rate, low attrition and reflect current clinical practice. The ParaStop study investigates the analgesic effectiveness of paracetamol in patients with cancer pain using WHO step III opioids.

Methods: ParaStop is a pragmatic, international multicentre non-inferiority RCT with 11 Norwegian and one Ugandan study centre. The intervention period is seven days, primary endpoint is average pain intensity day 8. Inclusion criteria are: adult patients with cancer related pain, average pain intensity ≥2-≤7 (NRS 0-10) using paracetamol and WHO step III opioids (not i.v./s.c.), and life expectancy ≥2 months.
Sample size estimation is 204 patients. We report inclusion- and qualitative data 42 months after study initiation.

Results: From September 2021 153 patients have been recruited. In 2023, systematic screening identified 641 potentially eligible participants: 41 did not wish to participate, 48 had too low level of pain intensity, 39 had too short life expectancy, 128 were deemed not able to comply with study procedures, 77 used i.v./s.c. opioids, and in 78 cases reasons were not given.

Each centre's inclusion rate was not associated with the centres' population.

The clinical personnel reported fear of the study being a burden to participants (gate-keeping). Screening for patients required great effort. The personnel found the eligibility criteria simple, that the participants understood the study intention and that most patients wanted to participate.

Conclusion: The inclusion rate in the ParaStop study has been slow, which increase the risks of bias or a underpowered study. Health personnel found the study important. However, gate-keeping was frequent.

Exploring Guilt and Self-Blame as Components of Total Pain: A Qualitative Study Among Patients with Advanced Cancer in Palliative Care

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Abstract

Objective: Subjective theories of illness influence how disease is experienced. This study examines the cognitive constructions of persons with a terminal oncological diagnosis regarding the nature and origin of their disease, and whether feelings of guilt or personal responsibility form part of their explanations.

Methods: The study is based on qualitative methodology. It comprises 23 semi-structured interviews with patients living with cancer admitted to the Division of Palliative Medicine at the Medical University of Vienna. The interviews were digitally recorded and transcribed verbatim. The data were analyzed using thematic analysis and MAXQDA 2022 software.

Results: The following three main themes could be identified within the interviews: patients shared their 1) understanding of the situation and ideas about the origin of the disease, before they were 2) evaluating the self: non-guilty, guilty, or avoiding a judgment when applying the possible causes to their individual situation and shared their subjective theory of illness. Finally, the interviews showed 3) individual actions that supported and resulted from asking why.

Conclusion: Many patients with advanced cancer at the end of life experience guilt and blame themselves. Therefore, more emphasis should be placed on providing patients with information on the origins of oncological diseases at an early stage. Addressing patients' subjective theories of illness sensitively and being aware of them will enable clinicians to improve end-of-life care.

Integrated nutritional care in cancer; about time?

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Abstract

Background: Nutritional care remains a consistently overlooked component in oncology, despite broad acknowledgment of its importance. This gap leaves many patients with cancer without appropriate nutritional support during treatment.

Key findings: There are notable inconsistencies across leading cancer nutrition guidelines, including those from ESPEN, ESMO, and ASCO. Some emphasise comprehensive nutritional assessments, others focus on pharmacological interventions. Although aligning guideline recommendations with the Global Leadership Initiative on Malnutrition (GLIM) diagnostic criteria for malnutrition into practice poses challenges, several shared principles exist that support early identification and effective management of malnutrition and cachexia. Persistent barriers in clinical settings – including limited time, training, and resources – hinder implementation.

Conclusion: There is a need for a standardised, pragmatic approach in assessment and management of nutrition in patients with cancer. Harmonising practice with shared principles from major guidelines – and aligning them with GLIM criteria – can support more consistent identification and treatment of malnutrition and cachexia. To overcome clinical barriers, emerging digital tools – such as MyPath – offer a promising way forward by streamlining evidence-based care. This improves communication between patients and clinicians and integrates nutrition as a core component of routine cancer care.

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The importance of Communication and Role Clarity in developing Health Information Technology: A case study of an innovation and implementation project within HIT

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Background: Many Health Information Technologies (HIT) achieve limited success and weak clinical integration (Kværner & Hoholm, 2023; Subramanyam et al., 2010), and effective interprofessional collaboration is seen as essential for user-friendly and clinically valuable solutions (Bliksvær & Breimo, 2020; Riksrevisjonen, 2023). This study examines interprofessional collaboration in an innovation and implementation project in HIT, and the challenges that arise related to social aspects such as communication and role clarity, an area that previous research has identified as requiring greater attention (Kotlarsky & Oshri, 2005).

Purpose: This study explores the interprofessional collaboration between clinicians and technologists in the co-development of a HIT solution. It highlights role clarity and communication, aiming to optimize future HIT collaborations.

Methodology: A qualitative interpretive case study was conducted using semi-structured interviews with 11 technologists and clinicians during the autumn of 2024. Thematic analysis was employed for data interpretation (Braun & Clarke, 2006).

Key findings: Several challenges emerged in the interaction between the technologists and clinicians during the project. Although the combination of clinical and technological expertise was considered valuable, differences in professional perspectives often led to misunderstandings about responsibilities and limited mutual understanding of clinical practices and technological possibilities. Effective communication was hindered by domain-specific terminology and the absence of a shared language, contributing to confusion and inefficiency.

Conclusion: Successful interprofessional HIT development critically depends on addressing social aspects (Kotlarsky & Oshri, 2005). Strengthening role clarity and optimizing communication through clear communication and common terminology are vital for producing effective, clinically relevant HIT solutions with long-term clinical value (Kotlarsky & Oshri, 2005; Pagliari, 2007; Saiedian & Dale, 2000).

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Bridging Tumour- and Patient-Centred Cancer Care: A Qualitative Meta-Synthesis of Stakeholder Perspectives in Digital Implementation

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Abstract

Background: Patient-centred care (PCC) aims to improve outcomes but is often sidelined in cancer care due to institutional and professional traditions favouring tumour-centred care[1]. Digital tools incorporating patient-reported outcome measures offer promise in enhancing PCC through systematic collection of patients' needs and preferences[2]. However, they are not routinely adopted in clinical practice[3]. The EU-funded project MyPath aims to develop and implement a digital PCC system in cancer care[4]. Understanding the perspectives of stakeholders, both barriers and facilitators, is essential in identifying strategies for successful implementation[5].

Aim: To explore key implementation factors of MyPath from the perspectives of patients, caregivers and healthcare providers from ESMO designated centres (DC) and MyPath-centres in Norway.

Methods: We synthesized qualitative data from individual interviews, focus groups, and qualitative surveys with 86 participants: healthcare providers (n=45), ESMO DC representatives (n=26), patients (n=9), and caregivers (n=6). Each stakeholder group's data was analysed separately, two of which are submitted or in preparation for publication. This study presents a cross-study thematic synthesis identifying implementation factors across stakeholder groups.

Results: Four key implementation factors were identified, illustrated in figure 1:

1) *Aligning PCC with Clinical Culture and Workflow*
2) *Integration, Responsiveness, and Actionability of the digital system*
3) *Balancing Standardization with Flexibility*
4) *Ensuring Inclusion for Patients with Complex Needs*

Conclusion: Successful implementation goes beyond technical development of the digital system. It requires aligning PCC with existing tumour-centred cultures, strong change-management processes to integrate PCC into existing workflows, inclusive and flexible design of the digital system, and continued stakeholder involvement to ensure its usefulness in clinical practice.

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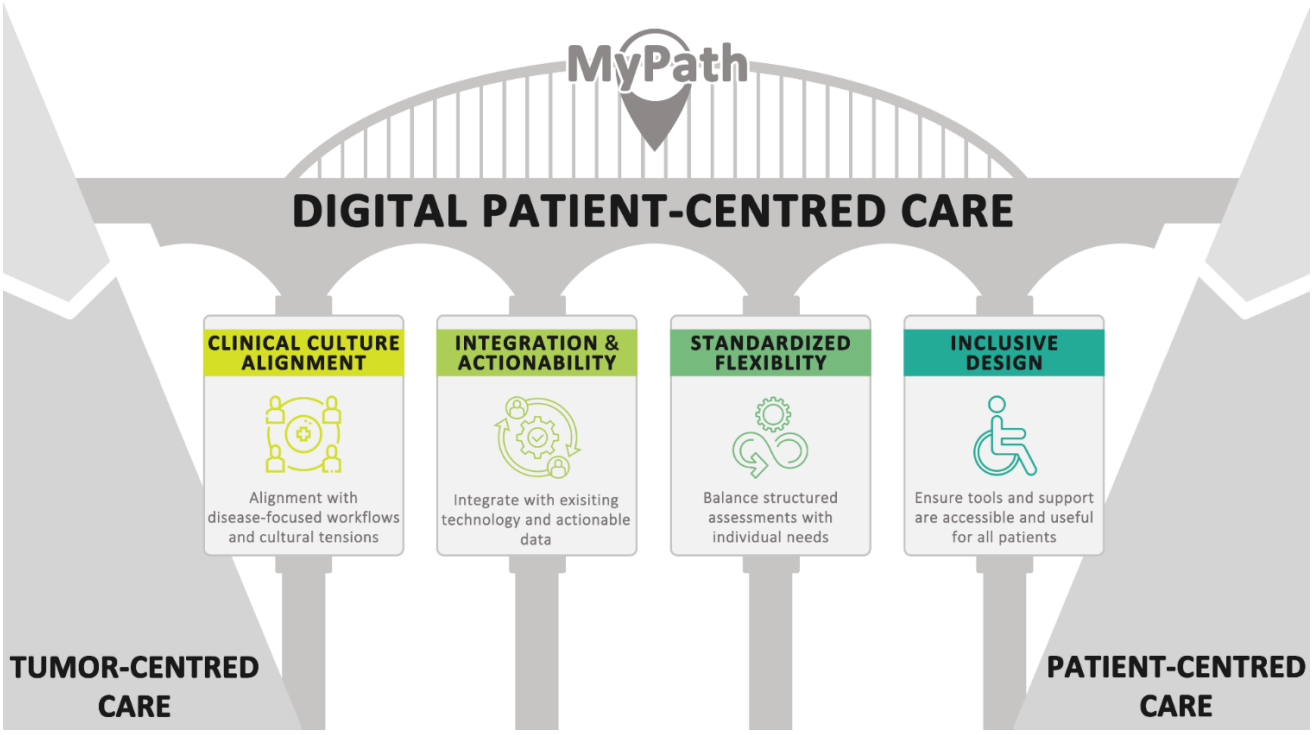

Figure 1: Illustration of the need to bridge the gap between tumour-centred and patient-centred care, with the necessary key implementation factors to support digitally enabled PCC in cancer care

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Depression and treatment response in patients receiving radiotherapy for painful bone metastases

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Aim: We aimed to assess if patients with depression prior to radiotherapy (RT) for painful bone metastases experience poorer treatment response than those without depression.

Material and methods: We included 492 of 574 patients from the Palliative Radiotherapy And Inflammation Study who completed Patient Health Questionnaire (PHQ-9) and pain assessments at baseline and week 8. Depression was defined as a sum score (≥6/15) using the 5 psychological items of PHQ-9. RT response at 8 weeks was defined as ≥2 units pain reduction (NRS 0-10) without increased opioid use, or 25% opioid reduction without increased pain at the treated site. We used multivariate logistic regression to analyze depression's impact on pain relief after RT, adjusted for age, gender, Karnofsky status, Charlson comorbidity score, and cancer type.

Results: Mean age was 65.8 years, 61% male, and most frequent cancer types were prostate (26%), breast (21%) and lung cancer (18%). 219 patients responded to RT, 226 had no and 47 had unknown response. At baseline, 19% of non-responders and 18% of responders reported depression, 4% of both non-responders and responders reported suicidal thoughts more than half of the days past two weeks. Depressed patients showed lower mean Karnofsky score at baseline than non-depressed ($p<0.005$), with mean pain scores of 5.2 ± 2.5 versus 4.5 ± 2.0 in non-depressed patients ($p=0.004$). Odds ratio for treatment response in depressed patients was 0.95 ($p=0.84$), compared to non-depressed.

Conclusion: We could not find a significant association between RT response after 8 weeks and depressive symptoms at baseline based on the five psychological items of PHQ-9.

Development of a digital solution supporting patient-centred cancer care

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Background: Patient-centred care (PCC) improves clinical outcomes but is not routinely implemented in cancer care. The MyPath project is developing a digital solution to support changes in clinical management and new workflow needed to deliver PCC systematically. The digital solution is being tested and improved as part of an implementation study involving 9 cancer centres in Europe.

Methods: In September-22, the development of the digital solution begun, using standardized care pathways, consensus-based content aligned with clinical practice. Following agile methodology, co-creation and iterative testing with end-users and relevant stakeholders have ensured clinical relevance.

Results: As of June 2025, the MyPath digital solution consists of three integrated applications supporting PCC. 1) The PROMs application collects electronic patient reported outcomes (ePROs) on a scheduled and as needed basis bringing the patient's voice into clinical consultations; 2) The Patient list application supports workflow management by presenting an overview of all patients, sorted by site-specific criteria; 3) The MyPath Clinician application provides a visual summary of ePROs for clinicians to review before consultations. Future updates will support and enhance personalised PCC plans based on international guidelines. All applications are configurable to local workflows. Data from the implementation phase (2025-2026) will guide further improvements to the solution and clinical process.

Conclusion: The MyPath digital solution combined with changes in clinical workflow can support the systematic delivery of PCC.

Piloting digital symptom reporting in pancreatic cancer patients: User experiences and process insights for MyPath digital tool development

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Background: Inoperable pancreatic cancer patients experience high symptom burden and limited life expectancy. Tailored digital symptom monitoring may improve care. As part of the MyPath EU project (Horizon 2020), we piloted an existing digital tool to gather insights for MyPath integration.

Methods: Multidisciplinary workshops mapped current and desired workflows for digital symptom management at Oslo University Hospital. We piloted digital symptom self-reporting in two phases: (A) 11 newly referred patients completed ESAS before their first oncology visit, with coordinator follow-up for scores ≥4 or non-reporting; (B) 10 patients under follow-up used ESAS for weekly monitoring during treatment, with nurse follow-up for score increases ≥2. We evaluated triage, task delegation, workflow integration, and expedited consultations. Patient engagement was assessed via access logs, and health personnel involvement was registered from the electronic patient records, including the proportion of consultations where ESAS prompted care plan adjustments.

Results: In phase A, 9/11 patients completed digital ESAS; 4/11 required expedited consultations. Coordinator follow-up addressed barriers such as low digital literacy. In phase B, nurse-led triage managed most alerts, reducing doctor consultations. Workflow integration requires predefined escalation criteria and staff training. User feedback from patients and clinicians highlighted needs for patient triage (dashboard) and individual patient symptom overview.

Conclusion: Digital symptom reporting is feasible in pancreatic cancer patients but requires tailored staff training and workflow adaptation to allow task delegation and prompt symptom management. This pilot provides critical insights for MyPath implementation, emphasizing patient-centred monitoring, task delegation, and integration into clinical practice.

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