**Applying digital health in cancer and palliative care in Europe: Policy recommendations from an international expert workshop (MyPal project)**

**ABSTRACT**

**Background:** Digital health interventions are becoming increasingly important for adults, children and young people with cancer and palliative care needs but there is little research to guide policy and practice.

**Objectives:** To identify recommendations for policy development of digital health interventions in cancer and palliative care.

**Design:** Expert elicition workshop.

**Setting:** European clinical (cancer and palliative care, adult and pediatric), policy, technical and research experts attended a one-day workshop in London, England in October 2022, along with MyPal research consortium members.

**Method:** As part of the European Commission funded MyPal project, we elicited experts' views on global, national, and institutional policies within structured facilitated groups, and conducted qualitative analysis on these discussions.

**Results/Implementation:** Thirty two experts from eight countries attended. Key policy drivers and levers in digital health were highlighted.
  *Global level:* global technology regulation, definitions, access to information technology, standardizing citizens' rights and data safety, digital infrastructure and implementation guidance, and incorporation of technology into existing health systems.
  *National level:* country-specific policy, compatibility of health apps, access to digital infrastructure including vulnerable groups and settings, development of guidelines, and promoting digital literacy.
  *Institutional level:* undertaking a needs assessment of service users and clinicians, identifying best practice guidelines, providing education and training for clinicians on digital health and safe digital data sharing, implementing plans to minimise barriers to accessing digital health care, minimizing bureaucracy, and providing technical support.

**Conclusions:** Developers and regulators of digital health interventions may find the identified recommendations useful in guiding policy making and future research initiatives.


**Keywords**
Palliative care, digital health, cancer, pediatric, public policy, health policy

**INTRODUCTION:**

Digital health interventions are increasingly utilized in cancer and palliative care contexts. They can be used to monitor physical functions, provide information, offer support and enhance therapeutic consultations for adults, children and young people with cancer and palliative care needs[1,2]. These interventions include a wide range of diagnostic and monitoring sensors and devices, remote communication apps, decision-support tools and can incorporate electronic health records[1]. There is evidence that the COVID-19 pandemic rapidly accelerated the use of digital technology in cancer and palliative care, with telehealth used to support patients at home in response to social restrictions to reduce infection rates[3]. As populations (especially children and young people[2]) become more familiar with digital technologies in everyday life, and devices and internet connectivity become more affordable and accessible, there are potentially many benefits to the use of digital tools in healthcare.

There is limited high-quality research supporting the efficacy and acceptability of digital health interventions in pediatric palliative care[2], and a meta-review suggests the same issues in adult palliative care[4]. A Delphi study which identified priorities for researching digital health interventions in palliative care stressed the need to ensure human-centered design and robust governance systems to prevent unintended consequences[5]. There is also evidence that the majority of digital health interventions tested either fail or are not sustained after the end of projects[6]. The complexity of designing and conducting research at the intersection of digital health, cancer and palliative care was reported by the MyPal project[7], which included the building of a digital health platform designed for adults, children and young people with cancer. The MyPal project, involving a large European consortium, aimed to develop and test electronic patient-reported outcome systems for adults with hematological cancers and children and young people with hematological cancers or solid tumors[8]. MyPal developed a mobile application for adults to self-report physical and psychological concerns, coupled with electronic movement sensing through smartphones, tested in a randomized control trial in four countries (Czech Republic, Greece, Italy and Sweden)[9,10]. A gamification approach was employed for children and

young people to self-report physical and psychological concerns through smartphones and portable devices, evaluated in a prospective observational feasibility cohort study conducted in Germany and the Czech Republic[11,12]. Both interventions aimed to enhance quality of life, facilitate better patient outcomes, and support effective communication between patients and healthcare providers. The project involved research organisations, clinical cancer centers, and commercial technology companies from six countries, as well as two international organizations in palliative care: the European Association for Palliative Care (EAPC) and International Children's Palliative Care Network (ICPCN)[8].

At a policy level, there are emerging initiatives assessing the integration of digital health tools in healthcare practice. In 2018, the European Commission outlined their commitment and vision to "accelerate the meaningful use of digital solutions in public health and healthcare in Europe" (p.3)[13] and proposed a subsequent 'digital decade' policy[14]. In 2020, World Health Organization (WHO) European Region Member States endorsed "empowerment through digital health" as one of four "flagship initiatives" as part of the European Program of Work 2020–2025[15]. In 2021, the WHO published a five-year global strategy on digital health, with the vision of improving health for everyone, "by accelerating the development and adoption of appropriate, accessible, affordable, scalable and sustainable person-centric digital health solutions"[16]. These international policy drivers indicate an overall trend towards promotion of digital health but there is also a lack of specificity in how to implement them.

In the context of emerging international policy drivers, a lack of robust evaluative research in cancer and palliative care, and the challenges of conducting the MyPal project[7], we suggest that there is a lack of expert and evidence-based recommendations to support policy initatives and practice. This paper aims to identify recommendations for implementing digital health interventions in cancer and palliative care contexts. These are based on an international expert workshop, where participants discussed what the key issues were and how they should be addressed.

**MATERIALS AND METHODS**

A qualitative international expert elicitation study was informed by consensus based approaches[17], specifically using deliberative workshops, which are appropriate to capture collective multidisciplinary wisdom in complex enviroments of rapidly changing knowledge, technical innovation and practices. These approaches are typically characterized by: (1) a group of experts who are required to make judgements about the topic under consideration; (2) structured presentations of information pertaining to the topic; (3) facilitated and recorded discussion of the topic; and (4) qualitative synthesis of the documented discussions, taking account of multiple perspectives. The reporting has followed best practice guidelines[18].

*Population, sample and recruitment*:

*Population:* To select the panel of experts, purposive sampling was employed[15]. Expertise in this context was defined as knowledge about digital health from the perspectives of information technology, clinical care (cancer, hematology and/or palliative care), research or policy development within an European context. We identified key organizations and individuals operating in these areas in Europe, predominantly using existing networks of the MyPal consortium partners.

*Sample and recruitment of experts:* All of the 21 eligible expert participants were sent an invitation email, with details of the purpose of the workshop, its date and venue. Ten accepted the invitation, and nine attended, a response rate of 43%. The main reason for declining was unavailability to travel to London. In addition, representatives of the MyPal consortium were invited to attend, with 23 choosing to do so. In all, 32 participants attended (see Supplementary File 1 for list of workshop attendees).

*Expert elicitation procedure*: A face-to-face one day workshop was organised on 14th October, 2022 in central London, England. The primary objective of the workshop was to identify recommendations

on a framework for policy development on the implications of digital health interventions in cancer and palliative care contexts, drawing upon the MyPal project. It aimed to bring together MyPal partners with international clinical, policy, technical and research experts in the fields of palliative care, hematology, cancer and digital health. The workshop had a structured format with five 10 minute presentations, followed by three structured, facilitated, round-table discussions of 30-40 minutes focused on three levels of policy and practice (global, national, institutional), as shown in Table 1.

*Insert Table 1 about here*

Participants were allocated to one of three groups (with 10-11 people) based on their involvement in cancer and palliative care (one group focussed on pediatric services, two focussed on services for adults). Consideration was also given to country of origin and disciplinary background. Each group was led by a facilitator, with a dedicated scribe. The groups all followed a structured format with specific questions and prompts to enhance discussion and elicit wide-ranging perspectives (see Table 2 and Supplementary File 2). Each group discussed all three topics and plenary feedback was given by the facilitators to all participants at the end of the day.

*Insert Table 2 about here*

*Analysis*: After the workshop, a list of the key issues and discussion points which arose from each group was compiled. Data for analysis consisted of notes taken by the three scribes and synthesis of the wider discussion and reflections from each of the three facilitators. These data were submitted to content analysis by AN, SP, DB, and YS. This involved careful reading of all texts. Coding was initially done by AN, followed by discussion of discrepancies within the team to ensure agreement and multidisciplinary perspectives. This was followed by interpretation from CP, JL, and JD, using the

overarching framework of macro (international), meso (national) and micro (institutional) policies and practices[19, 20].

***Ethics***: This work forms part of the MyPal project (child study - ClinicalTrials.gov Identifier: NCT04381221,  May 8, 2020; adult study - ClinicalTrials.gov Identifier: NCT04370457, May 1, 2020) although specific approval for the workshop was not required [9,11].  At the workshop, participants signed a written informed consent form, indicating that they were aware that discussion data would be published.

**RESULTS**

This section describes the participants, the main issues identified in each discussion and outlines the recommendations from the workshop.

### *Participation in the workshop*

Thirty two people participated (17 female) as shown in Table 3. They came from Greece (9), the United Kingdom (9), Germany (6), Belgium (3), the Czech Republic (2), Italy (1), Switzerland (1) and the United States (1).

*Insert Table 3 about here*

### *Expert recommendations*

Each of the three sessions yielded recommendations on the topics specified in Table 4. Due to the structure of the questions, there was overlap in the content of the discussions between the three sessions, and similar themes and issues were found to recur at different policy levels. Findings of each session are briefly presented, followed by recommendations arising across all three sessions.

*Session One: Global policy perspectives*

Participants were asked to consider policy issues at the global level. It was suggested that, to address the challenges arising from the discussions, the concept of digital health needed to be defined and clarified, and appropriate terminology should be used consistently across all countries. Similarly, there was agreement that the rights of citizens related to digital health must be systematically described and standardized, both nationally and internationally. When it came to integrating digital interventions into existing healthcare systems, participants noted that it is important to view these as complementary to, rather than wholly replacing, conventional care. An important issue identified was the need for suitable infrastructure to be in place for digital health interventions, based on policy guidelines, which should ensure equitable access to digital health. Digital literacy also needed to be addressed. Experts agreed that governments need to integrate this into healthcare professional education and training, to establish dedicated jobs for digital facilitators, and to support digital literacy of patients and families.

Finally, concerns about overlapping and/or contradictory regulatory regimes led to agreement that issues around patient data, its safe storage and responsible use must be tackled at a global level, with a coordinated regulatory approach to avoid confusion and allow data resources to be used productively. There is a need for a balance between ensuring the security of sensitive data and enabling clinicans and researchers to access valuable data, leading to potential development of broader knowledge bases. The possibility of developing dynamic and flexible consent systems was seen as one way to address this.

*Session Two: Organizational and country policy perspectives*

This session addressed organizational and country-level policy issues and potential solutions for using digital health. The importance of investing in the infrastructure necessary for establishing sustainable digital health systems was emphasised, as well as the need for strategic integration, planning and training of relevant professionals who could help establish and maintain the required systems. One

issue raised by several workshop participants related to the fact that, despite some digital health tools already being integrated into healthcare systems and institutions, these are not necessarily utilized effectively. Some of the identified barriers related to technical or clinical aspects, but participants also envisaged a role for policy makers in identifying and addressing obstacles to effective use. It was suggested that better integration could be achieved by providing adequate practical guidance for healthcare professionals and patients, outlining their rights and responsibilities in using digital health.

Data storage and use of data were also identified as key issues. Two types of data use (primary, aimed at patient care, and secondary, aimed at research) were considered, and it was suggested that different guidelines and security mechanisms were required for each. Participants felt there was a need to balance making access available for researchers, with protection of sensitive data. Some existing legislation and regulations (such as the European Union's General Data Protection Regulation, and the European Health Data Space[21]) contribute to this. However, at the level of individual countries and organizations or healthcare systems, it was agreed practical frameworks are also needed. Furthermore, the need to adopt flexible reimbursement schemes which could support the adoption of relevant software by patients was also actively discussed and innovative approaches (such as the Digital Health Applications initiative in Germany[22]) were mentioned as good examples which other countries should adopt.

*Session Three: Clinician and patient focused perspectives*
The last session focused on the needs of clinicians and patients in developing digital health in cancer and palliative care contexts, as their feedback in developing best practice guidelines and new tools is crucial. Participants suggested that professional regulatory bodies may have a role in ensuring clinicians act according to their legal obligations, especially when it comes to handling digital patient data. While guidance and oversight from relevant professional bodies was seen as necessary, there was

also concern amongst the workshop participants about the burden of bureaucracy, which may result in less patient contact time. An important policy goal therefore is to minimise the burdens imposed by bureaucratic procedures, to ensure effectiveness and better uptake of digital health interventions.

A key issue identified by the group looking at pediatrics was the complex ethical landscape of developing and using digital health intervention with children and young people with cancer. There is a need for robust ethical guidelines and highlighting of key considerations which should inform any policy discussion related to digital health in the pediatric setting, such as evading an oversimplified perception of children and young people with cancer as a homogenous group, and ensuring the focus remains on what intervention is in the best interest of each individual child[23]. In addition, the challenge of those children and young people who are unable to provide consent and what happens to their data when they reach adulthood, including the question of reconsent for data storage and sharing, needs addressing.

*Insert Table 4 about here*

## DISCUSSION

This study is the first to identify policy recommendations from European experts on digital health interventions for cancer and palliative care, drawing upon discussion of evidence-based interventions and research highlighted in our systematic review[24]. We propose a model based on these recommendations that could be implemented at global, national, and institutional levels (see Table 5). The experts noted the multifaceted challenges of enhancing the benefits and uptake of telehealth and digital health interventions in cancer and palliative care contexts, given rapid advances in technology.

*Insert Table 5 about here*

The workshop findings indicate that although digital health interventions are increasingly utilized in cancer and palliative care, research relating to digital health policy in this area is sparse[25] and more work is needed to address this deficit. During the COVID-19 pandemic, the widespread challenges to healthcare systems and the social restrictions imposed by governments highlighted effective uses of digital health for patients with cancer and palliative care needs[3]. The pandemic also challenged clinicians to embrace the implementation of telehealth and the use of digital health as an adjunct or replacement for face-to-face care delivery[26-28]. In addition, experts noted potential financial benefits to the utilization of digital health which can reduce the need to access healthcare services in person, reduce travel costs, improve communication with clinicians, empower patients, and offer personalized medicine[29]. However, these rapid changes, accentuated by the pandemic, have exposed the gaps in policy and highlight the need for greater understanding of the potential barriers to the implementation of digital health interventions[30].

The participants noted that developers and regulators of digital health interventions need to consider the accessibility and utility of these interventions for vulnerable and older persons, while recognizing the diversity of these populations. Digital health interventions should not risk reinforcing pre-existing inequalities in service provision and other options should be available, especially for those people who may be unable or unwilling to access healthcare that is digitally mediated[5].

### *Implications for policy and future research*

The outcomes from this workshop concur with, and give clarity to, the vision of the European Commission for digital interventions and the WHO digital health agenda[13-15]. For example, the need for greater standardization and common agreement on the definition of digital health was highlighted as an

essential starting point. This may help to address the need for ensuring compatible regulatory frameworks that balance the requirements for innovation with data protection and personal safety. Our recommendations reflect and expand those highlighted in a Scottish expert consultation on palliative care service needs, where access to digital health scored highly[31]. This shows the resonance of our findings with current strategies, but also their ability to complement these, demonstrating the value in bringing experts from various backgrounds together.

Moreover, a number of other practical challenges were discussed, including the need for novel reimbursement schemes which would enable the prescription of mobile app usage, the need for co-design of software applications to increase usability and thus adoption, and finally, the emphasis required to adapt these applications to diverse groups, focusing on the need for unobtrusiveness and personalization.

An important finding is that certain key issues were found to recur across groups and at different levels of discussion, such as the need for overarching guidelines, infrastructure and training. That these were identified by participants from a variety of European backgrounds and specific expertise, suggests the applicability of our conclusions, if not worldwide, then at least in countries with similar healthcare systems and of comparable economic status.

### *Strengths and Limitations*

The main strengths of our work include the diverse expertise, broad European coverage and gender parity of our participants. We utilized robust methods designed for palliative care[19,32]. Topics were selected to focus from macro to micro levels[19]. Some limitations are noted. Response rates of invited experts were low and those from the Global South and North America, were unrepresented. Greater involvement using online discussions might be more inclusive in future expert elicitation workshops.

Another limitation is the inherent difficulty of integrating experts' widely different experience of cancer and palliative care systems. We relied on scribes to document the discussion rather than audio-recording which presents a potential bias. Future research should include greater patient and public involvement.

**Conclusions**

These recommendations highlight areas of agreement and debates across European experts regarding the policy drivers in digital health including need standardized definitions, greater digital literacy and more training for healthcare professionals. The model (Table 5) may facilitate digital health innovations in cancer and palliative care, promoting greater involvement and collaboration between governments and regulatory bodies. Our findings suggest the need to increase support to clinicians to address barriers to digital literacy. We recommend that, to ensure that the development and implementation of digital health is grounded in real world contexts, there is greater involvement with patients and the public. Developers and regulators of digital health interventions may find the recommendations useful in guiding further work. Future research should identify patients' and frontline clinicians' perspectives on optimizing benefits of improved policies, strategies and guidelines on digital health innovations.

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**Author confirmations/contribution statement (CRediT statement)**

Conceptualization and funding acquisition: SP, JL, JD

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**Data availability statement**
All data are archived at Lancaster University and may be obtained from the corresponding author.

**Authors disclosure (conflict of interests) statement**

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Supplementary material (**Supplementary material for this article is available online.)
Supplementary File 1: list of workshop attendees
Supplementary File 2: MyPal Policy Workshop Briefing sheet for facilitators and scribes

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