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Addressing survivorship care gaps through digital innovation: opportunities, challenges, and ethical considerations in the e-QuoL project

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Abstract

Background Childhood, adolescent, and young adult cancers (CAYAC) present unique challenges in oncology. Advances in treatment Have led to an 80% 5-year survival rate; however, CAYAC survivors (CAYACS) remain at high risk of long-term medical and psychosocial complications, significantly impacting their quality of life. Short and long-term follow-up care is recommended, but is often fragmented, with considerable disparities in availability and accessibility across Europe. Many existing digital tools primarily address medical needs, leaving psychosocial challenges unaddressed. The e-QuoL project aims to bridge these gaps by leveraging existing digital health solutions to provide equitable, person-centered survivorship care.

Methods The e-QuoL project employs a participatory approach involving survivors, families, healthcare professionals (HCP), and researchers. Using the FormIT methodology, the project follows three phases: Explore, Create, and Evaluate. The Explore phase includes a large-scale cross-sectional survey across 15 European countries to assess the unmet needs of CAYACS and their families. The Create phase involves co-creation workshops to develop and refine digital tools, including MyCare$_{\text{e-QuoL}}$ tool, which will supplement survivorship care passports, to provide personalized medical and psychosocial support. The Evaluate phase comprises usability testing and clinical studies in at least seven European countries to assess effectiveness, scalability, and real-world applicability.

Discussion The e-QuoL project builds on existing digital health innovations while adapting them to diverse European healthcare systems. By developing MyCare$_{\text{e-QuoL}}$, the project fosters a decentralized, person-centered model of survivorship care to promote equal access to quality survivorship support for CAYACS and HCPs. Ethical considerations, including data privacy, patient consent, and equitable access, are central to the project, with dedicated Ethics and Social Challenge Groups guiding implementation. Digital disparities remain a challenge,

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particularly for survivors from lower socio-economic backgrounds or remote areas. To mitigate this, e-QuoL will work with healthcare professionals to offer additional in-person support to complement digital interventions. The project aligns with Europe's Beating Cancer Plan, aiming to improve quality of life and reduce disparities in care. By fostering collaboration among 30 partners across 15 countries and hosting resources on the PanCare website, e-QuoL seeks to ensure long-term impact, contributing to the goal of high-quality, equitable survivorship care across Europe.

Keywords Childhood, Adolescent and young adult cancer, Follow-up, Support, Needs, Psychosocial, Late effects

Introduction

Childhood, adolescent, and young adult cancers (CAYAC) represent a unique challenge in oncology. Each year, over 16,000 new cases are diagnosed across Europe, and with significant advances in treatment, the 5-year survival rate now exceeds 80% [1]. However, after cancer and treatment, CAYAC survivors (CAYACS) face a high risk of long-term complications, so-called late effects, that can severely impact physical and psychosocial functioning thereby reducing quality of life (QoL) [2]. Any organ system can be impacted by late effects, including secondary cancers, cardiovascular and pulmonary issues, or hormonal disturbances [3]. Psychosocial consequences of cancer, such as fatigue, fear of cancer recurrence, anxiety, depression, post-traumatic stress symptoms, and difficulties in social reintegration and professional advancement are commonly reported [2, 4, 5]. Given these on-going risks, short and long-term follow-up (LTFU) care is recommended [6]; however, such care is often fragmented, with considerable disparities in availability and accessibility across Europe [7]. Many survivors do not receive adequate follow-up, and if so it is most commonly medical-oriented [8]. Further, the families, who play a critical role in health management [9], often lack the necessary psychosocial support and information to navigate this new stage of life. Thus, adequate accessibility and comprehensibility of follow-up care as well as complete integration of medical and psychosocial needs are both lacking from most current care models. As such, there is an urgent need to improve follow-up care for all European CAYACS population.

The e-QuoL project aims to bridge these care gaps by providing accessible and personalized digital follow-up care tools for CAYACS and their families. Its goal is to promote equity in access to LTFU care across Europe through innovative solutions, including up-scaling the use of exiting digital survivorship care passports (SCPs) and the development of the electronic personalized supportive care tool, MyCare$_{\text{e-QuoL}}$. In combination, the SCP and MyCare$_{\text{e-QuoL}}$, aim to deliver tailored care plans, which address both medical and psychosocial needs. We will use a participatory approach, in which survivors, their families, and healthcare professionals are employed in co-creating solutions that meet the unique needs of the growing CAYACS population.

CAYACS' challenges and needs

The challenges at the end of active anticancer treatment and in survivorship

Physical challenges By the age of 45 years, CAYACS face a disease burden twice as high as the general population, with a higher risk of chronic and life-threatening health conditions [3, 10–12], and the prevalence of these complications increases over time without plateauing [13].

Psychological challenges When diagnosed with cancer, CAYACS may be at key developmental stages, forming their own identity and transitioning to independence, making this group particularly vulnerable to the consequences of cancer and treatment [14]. When curative treatments for primary cancer are completed, CAYACSs and their families may experience mixed emotions including relief, but also uncertainty and anxiety [15]. Over time, feelings of psychological distress, including symptoms of post-traumatic stress and fear of cancer recurrence, fatigue and concerns about their future may persist, impacting long-term QoL. [2, 16–19] Entering adulthood, including transition of health care from pediatric to adult health care, may also influence survivors' health behaviours, bringing new physical or psychosocial problems that impact their QoL [20, 21].

Social challenges Survivors may also be at risk of social isolation due to prolonged hospitalizations and physical limitations [22, 23], Due to their cancer treatment CAYACS may face difficulties in career progression and social reintegration, resulting in lower educational attainment and unemployment [24–31]. While there is consensus on the need for educational and occupational assessments during LTFU [29], effective interventions for these are still lacking.

Family challenges A diagnosis of cancer at an early age also profoundly affects family members, particularly parents [32]. Parents' distress can linger, impacting family functioning and relationships [33–35]. While parental distress tends to normalize over time, a significant number continue to report anxiety, emotional disturbances, or even post-traumatic stress [32, 36–39], highlighting the importance of psychological support for both survivors and their families [40].

CAYACS' and families' needs

To help manage physical challenges and medical risks after CAYAC, SCPs, or"passports", are critical tools. They summarize treatment history, inform about potential late effects, and provide individualized recommendations for LTFU care based on evidence-based guidelines like those from the International Guideline Harmonization Group (IGHG [41]) and the PanCare Guidelines Group [42, 43]. Passports are available across Europe [44–46], though access to LTFU care remains inconsistent [7]. Furthermore, among CAYACS in LTFU care, attendance rates may be modest, presumably because the LTFU care provided does not meet their needs [47–50].

However, CAYACS and their families also report a need for psychosocial support [50–52]. In a Dutch study, three out of four CAYACS wanted help with lifestyle and health risks after cancer, while many sought guidance on the physical consequences and fertility [52]. Support needs tend to increase with age and time since diagnosis [51], and CAYACS experiencing psychological distress report higher information needs than those who do not [53–55]. Survivors of brain tumors and their families face particularly significant challenges in finding the support they need, such as educational support [56]. Many survivors have expressed that better access to information would empower them to self-manage their health in survivorship [50, 55, 57].

Families' involvement during treatment makes them long-term advocates for their child's health; however, as children grow older, parents often struggle to transfer responsibility [9, 58]. Overprotectiveness can lead to lower self-esteem and hinder identity formation in survivors [59]. However, parents themselves may need support, both to manage their own psychological health and to aid in the gradual transition of responsibility to their children [60, 61]. Providing parents with survivorship education and psychological support can help them strike a balance between guidance and independence as their children transition into adulthood.

The importance of psychosocial care after cancer

The Multinational Association of Supportive Care in Cancer (MASCC) defines supportive care in cancer as "the prevention and management of physical and psychological symptoms and side effects across the continuum of the cancer journey from diagnosis through treatment to post-treatment care" [62]. Thus, supportive care involves all areas of life and should continue into survivorship, as personalized as possible, to meet each survivor's individual needs [63]. Evidence showed that establishing personalized medical follow-up and psychosocial care has a positive impact on CAYACS including better knowledge of their disease, the treatments received and potential side effects, as well as better overall health [64]; however, studies have specifically investigated the psychosocial care needs of CAYACS beyond the domain of information and communication [50, 65–68]. Based on systematic needs assessments, psychosocial care, including patient information and self-management support, should be co-created by survivors, family and healthcare providers (HCPs) [69].

Digital tools in LTFU

Digital (or"e-") health technology has become an emerging topic, not only in pediatric oncology [70]. It covers a broad range of applications such as mobile health (mHealth), health information technology (IT), text messaging, apps, wearable devices, telehealth and telemedicine, digital gaming, virtual reality, robotics, online support groups, podcasts and social networks. These technological solutions have the potential to significantly improve self-management skills and health care system navigation, as well as increase the confidence of CAYACS in HCPs [71]. They can be used to promote, prevent, treat, and maintain health, health care, and psychosocial care, and have been evaluated for CAYACS in different studies [72–75]. Digital tools targeting electronic patient-reported outcomes (ePROs) may play a prominent role in moving from a hospital-based, physician-centered approach towards a decentralized and patient-oriented, participatory co-decision-making model.

In Europe, three innovative digital tools Have been developed to support a person-centered approach to information sharing and survivorship care planning with CAYACSs: 1) *SurPass* (www.survivorshippassport.org) [44], an Italian initiative certified Health Data Hosting (HDS), and recognized as a class 1 medical device, currently available in Italy, Lithuania, Austria, Belgium, Germany, and Spain. 2) The *SALUB (Swedish Working Group for Long-term Follow-up after Childhood Cancer)-type passport*, certified HDS, is available in Sweden [76] and integrated into the quality registry system, and in Finland [77], where it is integrated into the journal system as a medical device. 3) The *LOG-after tool*, [78] a French initiative certified HDS, which received the 1st prize of "connected oncology", 2019-RCFr and the 2nd prize for innovation regarding preventive care in 2024. These tools aim to provide CAYACS and HCPs with the necessary information for lifelong survivorship care, support shared decision-making and reduce inequities by improving access to information on late effects, recommended screenings, and health promotion. They include an end-of-treatment summary and personalized SCP, based on internationally approved follow-up care guidelines or expert consensus where needed. Studies among CAYACS (and parents) who received an SCP found that while most experienced a positive impact [79–81], some reported increased anxiety about side effects (in survivors of adult cancer) [82]. Until now, the available tools mainly focus on medical needs, leaving psychosocial challenges largely unaddressed.

Some digital tools, primarily developed for cancer survivors in adulthood, provide psychosocial care to help support survivors' QoL (Fig. 1). In Finland, the SCP tool for adult childhood cancer survivors includes a supportive care module powered by Kaiku-Health® using machine learning to assess QoL. Based on these responses, the system provides access to digital mental health support or prompts communication with HCPs [83]. Similarly, the *IAM portal*, [84] available for patients aged 16–25 in the United Kingdom, is a self-assessment tool enabling survivors to monitor different life areas and share their data with HCPs. Also in adult oncology, the *Resilience tool* [85]—a medical device co-developed with Gustave Roussy Institute—supports ePRO-based monitoring through a mobile app and follow-up dashboard for HCPs [86–88]. The app offers personalized education, self-care programs, and peer support. Resilience's impact on patient engagement, QoL, and adherence to treatments has led to its recommendation by the European Society of Medical Oncology (ESMO) for routine oncology care [89].

Objectives of the e-QuoL project

The main objective of the e-QuoL project is to leverage the digital transformation of healthcare to improve the QoL and well-being of CAYACS and their families using a personalized and person-centered approach. We aim to.

1. Build a consensus-based list of needs of CAYACS and their family members (parents, and siblings), prioritized according to perceived importance.
2. Develop $\text{MyCare}_{\text{e-QuoL}}$ tool, by improving and scaling up the Resilience tool, to support self-monitoring, self-management and care delivery for CAYACS, facilitating personalized, continuous care, and create a corresponding web-based tool for family and local supportive network members, HCPs and other professionals. This will include personalized counselling approaches and supportive care to empower and motivate self-advocacy, self-management, and healthy lifestyles.
3. Assess the specifications of digital tools (passports, $\text{MyCare}_{\text{e-QuoL}}$ tool) aiming to empower CAYACS with neurocognitive impairments, to reduce socio- and educational inequality in access and usability of these tools.
4. Assess the specifications of digital tools (passports, $\text{MyCare}_{\text{e-QuoL}}$ tool) aiming to empower young CAYAC patients and survivors (aged < 15 years).
5. To improve and scale up existing digital tools (e-passports, films explaining LTFU guidelines and $\text{MyCare}_{\text{e-QuoL}}$ tool) and best practices, taking advantage of several large-scale projects in Europe.

Method

The e-QuoL project employs a participatory, user-centered approach to ensure that digital tools developed for CAYACS and their families effectively address their long-term needs. The methodology involves a combination of quantitative and qualitative research, co-creation workshops, and clinical evaluations to produce tailored digital solutions that enhance CAYACS' QoL across diverse European healthcare systems. In 7 work packages, digital tools for survivors and their social network will be developed, implemented, evaluated and disseminated in seven work packages (Fig. 1).

Participatory action research, FormIT methodology, and co-creation of digital tools

Central to the e-QuoL project is its participatory approach, which supports active involvement of CAYACS, their family members, and HCPs, together with members of e-QuoL's consortium, throughout the project. This approach is structured using the FormIT methodology, which is a user-centered framework that guides the development of digital tools through three key phases: Explore, Create, and Evaluate [90].

"***Explore***": In this initial phase, comprehensive data is gathered through surveys, interviews, and workshops to explore the real-world needs of survivors and their families. This exploration helps identify the psychosocial, educational, and healthcare challenges CAYACS face during and after their cancer journey, laying the foundation for designing tools that address these unmet needs.

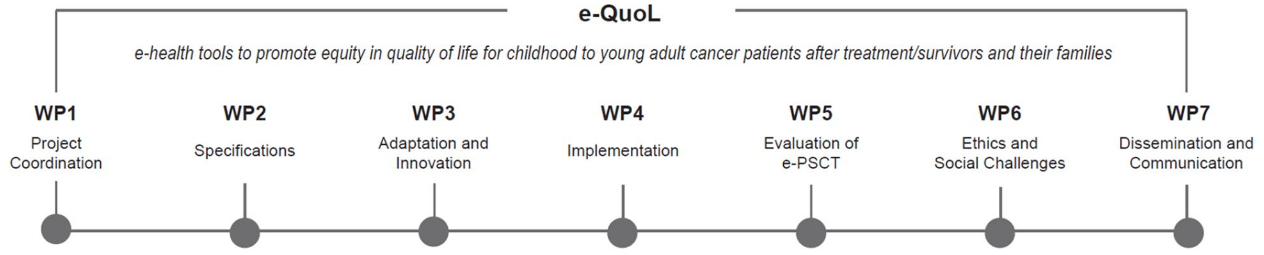

Fig. 1 Work packages of the e-QuoL project

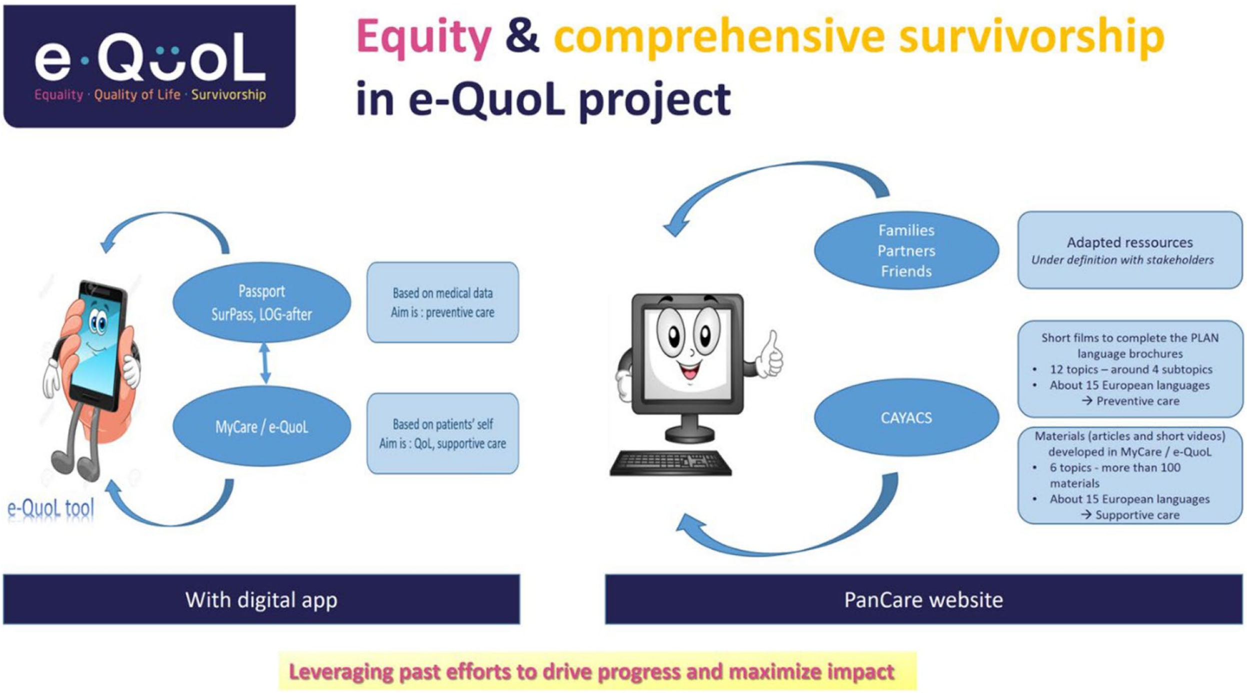

Fig. 2 Co-creation of digital tools for CAYACS and their social networks. Abbreviation: CAYACS Childhood adolescent and young adult cancer survivor

To inform the development or adaptation of the digital tools, e-QuoL is conducting a large-scale cross-sectional survey across 15 European countries. This survey aims to assess the psychosocial, educational, and medical needs of CAYACS, their families and additional persons from their social networks such as friends, teachers etc., providing data on gaps in existing follow-up care, barriers to self-management, and unmet needs. Special attention is being paid to vulnerable groups, including survivors with neurocognitive impairments, to ensure that the tools developed are inclusive and meet diverse needs.

"***Create***": Based on the insights from the "Explore" phase, the e-QuoL project conducts co-creation workshops with survivors, families, and HCPs to collaboratively design digital tools like MyCare$_{\text{e-QuoL}}$ and survivorship passports. These workshops will ensure that the tools tailored to meet the specific requirements of end-users are intuitive to use and integrate seamlessly into healthcare systems across different European countries. Co-creation is necessary to accomplish this because it centers on the experiences and preferences of the potential end users. Survivors, their families, and HCPs will contribute their input to the design of the tools, which will be used to create further iterations of the tool prototypes, thereby ensuring that they align with the voiced needs of the users. MyCare$_{\text{e-QuoL}}$ will provide survivors with personalized information on their long-term health risks, recommended screenings, and self-management strategies. It will be interoperable with existing digital survivorship passports and available in multiple languages to promote accessibility and usability.

"***Evaluate***": The final phase involves usability testing and clinical evaluation of the developed tools. MyCare$_{\text{e-QuoL}}$ will be tested in clinical studies conducted in seven European countries. These studies will evaluate the effectiveness of the tools in improving survivors'QoL, patient activation, and self-management. The studies will also explore the usability of the digital tools in real-world healthcare settings, identifying any barriers to adoption.

Continuous feedback from survivors, their families and HCPs will also be integrated to refine the tools, ensuring they are user-friendly, effective, and adaptable to various healthcare environments (Fig. 2). This iterative cycle of exploration, creation, and evaluation ensures that the tools remain relevant, useful and valuable to the end-users. By involving CAYACS, their families, and HCPs directly in the design and development process, the e-QuoL project ensures that the tools created are not only functional, but also provide meaningful support for managing long-term survivorship issues. The e-QuoL project recognizes that certain subgroups of CAYACS, such as those with neurocognitive impairments, face additional challenges in managing their health. MyCare$_{\text{e-QuoL}}$ will be specifically tailored to meet the needs of these survivors by incorporating features like simplified user interfaces and caregiver support functions. This ensures that all survivors, regardless of their cognitive ability, can benefit from the tool's functionalities.

Ethical and social challenges

To ensure ethical integrity and best address social disparities, e-QuoL has established an Ethics Reflection Group to oversee ethical considerations such as data privacy, patient consent, and equitable access to digital tools, and a Social Challenge Group guiding the project in addressing the social challenges faced by CAYACS from different socio-economic backgrounds. This will ensure that the developed tools are inclusive and accessible to all. Data security is of paramount importance, especially considering the sensitive nature of health information, and the e-QuoL project is committed to adhering to the strictest data protection standards.

Results

In the first year of the e-QuoL project, besides setting up the Ethics Reflection Group and a Social Challenge Group, we Have published 3 reviews on psychosocial needs among survivors and their families [91–93], Have run 3 workshops with CAYACS, their family members, parents advocacy group members and HCPs, and have completed a survey on psychosocial needs among CAYACS, family members and other social network members with > 1000 participants from 17 European countries. In addition, another survey with 53 responders in 15 European countries assessed the specification of an ideal digital tool for Survivorship.

Discussion

The e-QuoL project stands at the forefront of an effort to build on, rather than reinvent, existing innovations in digital health and survivorship care for CAYACS. By leveraging successful digital tools and initiatives, such as survivorship passports already in use in several European countries, the project aims to up-scale and adapt these tools for broader implementation with focus on the young population, while developing new innovations such as MyCare$_{\text{e-QuoL}}$. This collaborative approach underscores the consortium's commitment to working together to advance survivorship care, rather than duplicating previous efforts.

A core principle of the e-QuoL project is not merely translating existing tools but adapting them to local healthcare systems and cultural contexts across Europe. Survivorship passports, already proven to be effective, will be implemented in additional European countries. This will not only involve translation in other languages but also adapting the passports to align with each country's healthcare policies, and survivorship follow-up care protocols. Such regionality ensures that the tools remain relevant, useful and valuable for survivors and HCPs in diverse environments. The e-QuoL project will help to make these tools scalable and customizable, so they can be seamlessly integrated into additional healthcare systems.

The e-QuoL project will also develop and introduce MyCare$_{\text{e-QuoL}}$, a new digital tool providing survivors with personalized, dynamic care plans tailored to their unique health risks and LTFU needs. MyCare$_{\text{e-QuoL}}$ can be linked with existing digital tools, such as survivorship passports, and will offer personalized recommendations on screenings, health behaviors, as well as psychosocial and self-management support and interventions. It will serve as a comprehensive tool for survivors to access on their devices to manage their long-term health, track their progress, and engage with HCPs in real-time.

The resources developed in the e-QuoL project will be hosted on the PanCare website (www.pancare.eu), ensuring that they are available and accessible to all survivors, HCPs, and policymakers across Europe. This approach ensures that the tools and innovations developed during the e-QuoL project period will continue to have an impact long after the project concludes, promoting sustainability and encouraging widespread adoption across the continent.

The implementability and effectiveness of the SCPs and MyCare$_{\text{e-QuoL}}$ will be evaluated in a clinical study involving at least seven European countries. This study will not only assess the impact of these tools on CAYACS' QoL and healthcare engagement but will also provide important data for the implementation of these tools into existing healthcare systems. Such knowledge will be crucial for determining the scalability and long-term sustainability of the tools across Europe. By collecting and analyzing data from diverse healthcare environments, e-QuoL will demonstrate the broad applicability of these tools and contribute to shaping future guidelines for survivorship care.

While the e-QuoL project presents a unique opportunity to transform survivorship care across Europe, challenges remain in ensuring that these digital tools are accessible to all survivors. The digital divide continues to be a major barrier, particularly for survivors in lower socio-economic groups or remote areas who may not have access to reliable internet or digital devices [94]. To mitigate this, e-QuoL will work with HCPs to offer additional in-person support and ensure that digital tools are complemented by traditional healthcare services where needed. Training for healthcare professionals will also be a critical part of this effort.

In conclusion, the e-QuoL project represents a major step forward in improving survivorship care for CAYACS across Europe. By focusing on improving QoL and reducing disparities in care, e-QuoL aligns with the objectives of Europe's Beating Cancer Plan [95], supporting CAYACS across Europe to thrive after cancer. We build on existing innovations and adapt them to local contexts;

thereby e-QuoL avoids reinventing the wheel and instead focuses on expanding and enhancing survivorship tools. The collaborative, pan-European nature of the consortium, combined with its participatory approach, ensures that the tools developed will be relevant, scalable, and sustainable. With the support of 30 partners from 15 countries, and with all materials available through the PanCare website, e-QuoL will make a lasting impact on the lives of cancer survivors, while contributing to the long-term goal of equitable, high-quality survivorship care across Europe.

Abbreviations

CAYAC	Childhood, adolescent and young adult cancer
CAYACS	Childhood, adolescent and young adult cancer survivors
ePRO	Electronic patient-reported outcome
ESMO	European Society of Medical Oncology
HCP	Healthcare providers
HDS	Health Data Hosting
IT	Information technology
LTFU	Long-term follow-up
IGHG	International Guideline Harmonization Group
MASCC	Multinational Association of Supportive Care in Cancer
mHealth	Mobile health (mHealth)
QoL	Quality of life
SALUB	Swedish Working Group for Long-term Follow-up after Childhood Cancer
SCP	Survivorship care passports

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Authors' contributions

CDG prepared the first draft, and GM revised it. JR, ITC, KT, PL MG and HL commented and revised the manuscript. CDG and KT prepared the figures. All authors have read and approved the final manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Ethics approval have been requested for all parts of the project. For a complete list of all approvals see.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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