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The e-QuoL project: enhancing long-term follow-up care for childhood cancer survivors through digital innovation, results of an exploratory questionnaire

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Abstract

Purpose Childhood, adolescent, and young adult cancer survivors represent a growing population with unique long-term follow-up (LTFU) needs, including managing late effects of treatment and ensuring psychosocial well-being. The e-QuoL project aims to develop digital tools tailored to enhance survivorship care.

Method An online survey comprising 424 questions was distributed across 16 European countries. The distribution plan ensured engagement from diverse stakeholders, including patients, parents, and healthcare professionals. Descriptive and thematic analyses of survey data identified key content, functionalities, and features for the design of such tools.

Results For participants ($n=53$), the inclusion of a follow-up plan for the risk of sequelae in the first 5 years of follow-up was the highest priority (mean score, 9.62). Supportive care items were deemed important. In terms of functionalities, the most highly rated was the ability to send reminders to patients to not forget exams (mean score, 9.25). The inclusion of an algorithm to propose follow-up plans based on selected sections was also particularly valued (mean score, 9.10). Finally, the user experience of digital tools, including the need for these tools to be engaging, easy to use, and customizable, was highlighted by 66.7% of participants.

Conclusion This study emphasizes the need for customizable, accessible, and user-centered digital tools to bridge disparities in LTFU care. Collaborative efforts to address technological, financial, and ethical barriers are essential to achieving equitable, effective survivorship support.

Implications for Cancer Survivors By developing and implementing comprehensive digital tools, a more personalized, holistic, and effective model of survivorship care can be achieved.

Keywords Cancer survivorship · Digital health tools · Long-term follow-up · Childhood cancer · Adolescent oncology · E-Health · Patient-centered care · Psychosocial support

Introduction

The remarkable progress in pediatric oncology over recent decades has significantly improved survival rates for childhood, adolescent, and young adult cancer survivors (CAYACS). In Europe alone, the 5-year survival rate for childhood cancers now exceeds 80%, contributing to a growing population of survivors requiring long-term follow-up (LTFU) care [1]. However, survivorship comes with its own set of challenges, including the risk of late effects from cancer treatments, psychosocial issues, and an elevated risk of chronic health conditions [2]. Comprehensive and coordinated follow-up care is essential to manage these risks and optimize quality of life (QoL) for survivors [3, 4]. Despite the recognized need for LTFU care, significant gaps remain in its implementation globally, including access disparities, fragmented care, and a lack of standardized follow-up protocols [5].

To address these barriers, digital tools have emerged as promising innovations in survivorship care, offering a scalable and patient-centered approach to improve health outcomes, care continuity and patient experience [6, 7]. Digital tools, such as survivorship care plans, e-health platforms,

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and mobile health (mHealth) applications, facilitate personalized follow-up care, provide educational resources, and enhance communication between survivors, parents, and healthcare providers. These tools demonstrate the potential of digital innovation to bridge existing gaps in follow-up care and improve patient outcomes [5, 8–10]. By leveraging technology, digital tools offer a transformative opportunity to advance patient-centered survivorship care and improve long-term health outcomes for CAYACS. Specifically, digital tools can enable the creation of personalized care plans tailored to each survivor's unique needs and treatment history [4, 8]. These plans can be easily accessed by patients through personal accounts, allowing them to actively participate in their care and communicate directly with healthcare providers [6, 10]. Additionally, digital platforms facilitate the coordination of care by involving multiple healthcare professionals, providing a shared space for real-time monitoring of the care plan's implementation [5, 9]. Alerts can be triggered in case of deviations from the established plan, ensuring timely interventions and reducing the risk of adverse outcomes [6]. These features empower survivors to take an active role in their health while promoting a more coordinated and responsive care approach [4, 5].

To tackle these multifaceted issues and improve the quality of survivorship care, the e-QuoL project (e-Health tools to promote Equity in Quality of Life for childhood to young adulthood cancer patients after treatment/survivors and their families) was initiated as a European collaborative effort involving 16 countries and 32 partners. This participatory project aimed to identify stakeholders' critical needs, preferences, and barriers, and to develop user-centered digital tools for the LTFU pathway, thereby enhancing the health outcomes and QoL of CAYACS. A previous article outlined (cf. the other manuscript proposed to submission) the general aims of a digital tool for survivorship care, along with potential barriers to its implementation. Here, we present the second part of the results, focusing on the key contents and functionalities identified as essential for such tools.

Method

Survey design and dissemination

An online survey, available in English, was conducted using the Sphinx platform between February 28 and April 30, 2024. Participants were recruited across Europe through multiple channels: e-QuoL partners (by email), PanCare members (via newsletter), and national survivor associations (by email). Respondents were also encouraged to share the survey within their own professional and institutional networks.

The survey was specifically developed for this study to identify needs and priorities regarding digital tools in survivorship care. It assessed two types of digital tools relevant to survivorship care as follows:

- The "Passport", aimed at preventive care, provides patients and families with structured information on cancer diagnosis, treatments received, and a personalized follow-up plan (e.g., cardiac or secondary cancer screening).
- The "e-PSCT" (Personalized Supportive Care Tool) focuses on supportive care delivery and includes thematic modules addressing psychosocial and quality-of-life domains (e.g., fear of recurrence, anxiety, sexuality, fatigue), often integrated with patient-reported outcome measures such as QoL questionnaires.

Survey structure and content

The questionnaire was designed by professionals with expertise in survivorship, including clinicians directly involved in long-term follow-up as well as in the development or coordination of digital follow-up tools across several European countries and the three digital health technology partners from the e-QuoL project. The content was informed by a review of existing digital tools used in survivorship care and aimed to capture the expectations and requirements of end users for future digital solutions. Although not derived from previously validated instruments, selected items were informed by established frameworks such as the Mobile App Rating Scale (MARS), a validated and widely used tool for evaluating the quality of mobile health applications [11]. While originally developed for app assessment, MARS has also been used to guide the design and development of new, high-quality health apps. It includes five broad domains: four objective quality criteria (engagement, functionality, esthetics, and information quality) and one subjective quality criterion. In this study, only the four objective domains were used.

The survey comprised 424 items organized into two parts and covered five main thematic domains:

- Part A:
    1. Survey responder profile—mapping long-term follow-up (LTFU) care pathways in the respondent's country or center.
    2. Specification of needs—identifying essential content and features for future digital tools.
- -Part B:

3. Descriptive and technical information—assessing the importance and feasibility of selected items based on the MARS framework.
4. Enabling digital tools—exploring usability aspects and potential barriers to implementation.
5. Current engagement with digital tools—capturing experiences, satisfaction levels, and perceived benefits and concerns among users and non-users.

To identify key priorities, participants rated each item along two dimensions: importance, using a 10-point scale (1 = useless, 10 = absolutely necessary), and feasibility, for both (a) retrospective data collection (for previously treated patients) and (b) prospective data collection (for newly treated patients), using a scale from 1 (very difficult; e.g., data unavailable or too time-consuming) to 10 (very easy; e.g., data readily available or easily linkable to existing databases).

Ethical considerations

The survey began with an introductory section presenting the study's aims and clearly stating that completion of the questionnaire would be considered as providing informed consent. Participation was entirely voluntary and anonymous. No compensation was offered.

As no personal health data were collected and the survey remained fully anonymous—including for patients and parents, with no collection of data on cancer type, treatment center, or age at treatment—ethics committee approval was not required. This was confirmed by the ethics committee of CHU Angers. In addition, the Robert Debré Clinical Investigation Center (CIC, France), the e-QuoL partner responsible for regulatory and ethical oversight, reviewed the protocol and procedures.

Participant characteristics and categorization

Participants included patients, parents, healthcare professionals (e.g., oncologists, nurses), and others (e.g., researchers, association representatives). Multiple roles could be selected. To ensure analytical clarity, participants were categorized based on the role most likely to shape their perspective when completing the survey. For example, a respondent identifying as both patient and physician was classified as a healthcare professional; a patient and researcher as a patient; and association members who were also patients were grouped with patients. This classification approach, while subjective, was applied consistently. The "other" category included five individuals: two epidemiologists, one data manager, and two respondents who self-identified as "other" without further detail.

Participants were also grouped into three geographical regions for analysis: Northern Europe—Finland, Sweden, UK, and Ireland; Western Europe—France, Belgium, Spain, Italy, Netherlands, and Germany; Eastern Europe—Romania, Bosnia and Herzegovina, Hungary, Croatia, and Slovenia.

Data analysis

Descriptive analyses were performed for all variables. Mean scores were used to summarize collective priorities. Items were categorized according to mean importance as follows: ≥ 9.0 = mandatory, 8.0–8.9 = highly relevant, 6.1–7.9 = moderately relevant, and < 6.0 = low relevance.

To assess consensus, standard deviation (SD) was used: an SD < 1.5 indicated strong agreement among respondents.

Results

Participant

This study included a diverse cohort of participants to explore perspectives related to cancer survivorship—out of the 53 participants, 46 completed more than 75% of the survey, including 39 who completed both parts A and B of the questionnaire, and 34 who answered all questions. Additionally, seven participants responded only to Part B of the survey. Characteristics of the responders are detailed in Table 1. Among the 46 participants who completed the majority of the survey, 76% identified as female, 20% as male, and 4% preferred not to specify their gender. Age distribution showed a relatively even spread, with the largest groups being those aged 36–45 years and 56–65 years (each 28%), followed by those aged 26–35 years (22%). Participants under 25 years accounted for 9%, while those over 65 years made up only 2%.

Geographically, participants represented a wide range of countries, with the largest proportions from France (24%) and Germany (20%). Other countries included Romania (11%), Finland (9%), and a variety of smaller representations across 13 additional countries, each contributing 2–4% of the cohort (Belgium, Bosnia and Herzegovina, Hungary, Ireland, Italy, Sweden, Croatia, Netherlands, Slovenia, Spain, United Kingdom). The participants brought diverse expertise, with 33% identifying as patients or patient association representatives, 22% as pediatric oncologists, and 13% as radiotherapy oncologists. Other professional roles included nurses, general practitioners (GPs), and specialists such as epidemiologists and data managers. When asked to rate their self-estimated expertise in survivorship on a scale of 1 to 10, the majority (61%) of participants rated themselves high with scores of 8–10.

Table 1 Characteristics of the responders who completed more than 75% of the survey

Characteristics	%	*n*
Sex		
Male	20%	9
Female	76%	35
Do not wish to specify	4%	2
Age		
≤ 25 years	9%	4
26–35	22%	10
36–45	28%	13
46–55	11%	5
56–65	28%	13
> 65 years	2%	1
Countries		
France	24%	11
Germany	20%	9
Romania	11%	5
Finland	9%	4
Belgium	4%	2
Bosnia and Herzegovina	4%	2
Hungary	4%	2
Ireland	4%	2
Italy	4%	2
Sweden	4%	2
Croatia	2%	1
Netherlands	2%	1
Slovenia	2%	1
Spain	2%	1
United Kingdom	2%	1
Personal/professional background		
Patient or Patient association representative	33%	15
Parent representative	6%	3
Pediatric oncologist	22%	10
Radiotherapy oncologist	13%	6
Pediatrician	2%	1
Gynecologist	2%	1
General practitioner	2%	1
Resident doctor	2%	1
Nurse	6%	3
Other (epidemiologist, data manager)	11%	5
Self-rating of survivorship expertise (on a scale up to 10)		
10	20%	10
8–9	37%	18
6–7	35%	17
5	4%	2
2	4%	2

Ntot = 46

Specification regarding an after-cancer digital tool

Content

The survey questions focused not only on the level of importance but also on the feasibility of implementation of after-cancer digital tools. The analysis of responses revealed a significant degree of consensus among participants, as reflected by an overall mean standard deviation of 2.3, indicating general agreement on most items. Notably, 15 items had a standard deviation of less than 1.5, reflecting strong consensus. Agreement was higher for questions on importance of tool implementation (mean standard deviation, 1.9) compared to those on feasibility of implementing digital tools, where the standard deviation was 2.7 for already treated patients and 2.4 for newly diagnosed patients.

The survey results underscore the critical need for comprehensive summaries of disease and treatments within digital tools for LTFU care, while also highlighting differences in priorities across respondent profiles (Table 2). Key elements, such as treatment history and follow-up plans, were consistently identified as essential (Table 2). Among all respondents, the inclusion of a follow-up plan for the risk of sequelae in the first 5 years of follow-up was the highest priority, with an average score of 9.6 among patients, parents, and associations. Similarly, a LTFU plan was rated highly across all groups, with healthcare professionals (HCPs) slightly favoring this component as their top priority (9.3). The specification of the type of follow-up required (e.g., cardiac or pulmonary monitoring) was also highly valued (9.0) for HCPs. Regarding which complications should be registered, balancing the level of importance and the level of feasibility for former patients and newly diagnosed ones, the results show that sequelae that remain unresolved at the initiation of the survivorship should be taken into account (mean score of 8.3 versus all mean score of 6.9, grade III or more mean score of 7.7 or selected ones mean score of 8.1).

Supportive care items, such as fertility preservation, were widely deemed important, with patients and HCPs assigning higher scores (respectively, 9.1 and 9.2).

The items to be included in the digital tool with the highest level of agreement (standard deviation < 1.5) and a high importance score (≥ 9) include being treated with allogeneic stem cell transplantation, fertility preservation, unresolved complications (permanent complications), selected complications (e.g., cardiac, pulmonary), follow-up plans for the risk of sequelae in the first 5 years of follow-up, long-term follow-up plans, date of birth, an algorithm to propose follow-up plans based on the other selected sections, and

Table 2 Specification of the contents of a survivorship digital tool

Content items	All	Patients, parents, associations	Healthcare professionals	Other*		
	Mean **score**	Mean score	Mean score	Mean score	Range	*N*
Information about past oncologic treatments						
Stem cell transplantation						
Including allogeneic stem cell transplantation	**9.2**	**9.1**	**9.5**	7.3	5–10	40
Including autologous stem cell transplantation	**9.1**	**9.2**	**9.4**	6.8	5–10	40
Including type of allogeneic stem cell transplantation	8.6	**9.2**	8.7	6.8	2–10	40
Radiotherapy						
Including field of radiotherapy and dose prescribed	**9.0**	**9.6**	8.8	8.5	2–10	39
Including some approximate information about irradiated organs (min, max, mean)	8.9	**9.3**	8.8	8.3	5–10	39
Including type of radiotherapy (proton, photon, electron, brachytherapy…)	8.9	**9.7**	8.7	7.8	2–10	39
Including precise dose/volume of irradiated organs	8.7	**9.0**	8.7	8.3	2–10	40
Including center where the radiotherapy was delivered	7.3	7.45	7.3	6.8	2–10	40
Chemotherapy						
Including cumulative dose of main substances (alkylating agents as CED1, anthracyclines as DIE2…) based on which screening or surveillance is usually recommended	8.9	**9.1**	**9.2**	7.5	5–10	39
Including cumulative dose of each chemotherapy substance (IV, per os, new drugs/targeted therapies, immunotherapies, intrathecal)	8.6	**9.1**	8.6	7.5	2–10	39
Including cumulative doses of corticosteroids	7.5	8.9	6.9	6.5	4–10	37
Surgery						
Including type of surgery	**9.0**	**9.6**	8.6	8.5	5–10	38
Including existence of prosthesis	8.8	**9.3**	**9.1**	6.5	4–10	37
Including surgical treatment because of previous complications	8.0	**9.7**	7.5	5.5	2–10	38
Including surgery for reconstruction	7.7	8.9	7.6	5.0	2–10	37
Including center where the surgery was done	6.8	7.9	6.4	5.3	2–10	39
Including biopsies	6.7	8.9	9.6	4.8	1–10	37
Other information						
Dates of each treatment	8.4	**9.4**	7.7	8.5	2–10	37
Rare treatments as radiofrequency, hyperthermic chemotherapy	7.8	**9.3**	7.5	5.3	1–10	38
Supportive CARE						
Fertility						
Including fertility preservation	**9.1**	**9.1**	**9.2**	8.0	5–10	40
Including type of fertility preservation	8.4	**9.1**	8.3	6.5	2–10	39
Including place where the fertility preservation is conserved	7.7	8.9	7.2	5.5	1–10	40
Including date of fertility preservation	7.6	8.9	7.1	6.0	1–10	38
Transfusion and febrile neutropenia						
Including number of red cells transfusion	6.3	7.8	5.5	5.8	1–10	38
Including number of episodes of febrile neutropenia (i.e., lot of IV antibiotics)	6.0	7.3	5.3	6.3	1–10	38
Including number of platelets transfusion	5.6	7.8	4.4	5.8	1–10	38
Information about complications during treatment						
Including all complications (including those resolved)	7.4	**9.4**	6.1	8.0	1–10	38
Including all complications grade III or more (including those resolved)	8.4	**9.2**	7.9	**9.3**	1–10	38
Including all complications that have not resolved (permanent complications)	**9.3**	**9.7**	**9.2**	8.8	6–10	38

Table 2 (continued)

Content items	All	Patients, parents, associations	Healthcare professionals	Other*		
	Mean **score**	Mean score	Mean score	Mean score	Range	*N*
Including some selected complications (as cardiac, pulmonary…)	**9.2**	**9.5**	**9.1**	8.8	7–10	38
Information about other health history						
Including some specific items about personal health history	8.1	8.8	7.8	7.8	5–10	38
Including all items of personal health history (with ICD10 classification for example)	7.5	8.0	7.1	8.3	3–10	38
Including personal congenital anomalies/syndromes	8.6	8.4	8.8	7.8	4–10	38
Including personal genetic predisposition to cancer	8.8	8.3	**9.2**	8.3	5–10	38
Including familial cancer history	8.5	8.3	8.8	7.8	5–10	38
Including some specific item about familial health history	7.3	7.1	7.6	6.5	4–10	36
Including other permanent/chronic illnesses at the time of cancer diagnosis (static section)	8.6	8.5	8.8	7.5	6–10	37
Including other new chronic illnesses diagnosed after the cancer diagnosis (evolutive section)	8.8	**9.2**	8.7	7.8	6–10	36
Personalized follow-up plan						
Including follow-up plan for risk of sequelae in the first 5 years of follow-up	**9.3**	**9.6**	**9.2**	**9.0**	6–10	39
Should include follow-up plan for risk of relapse	8.3	**9.3**	8.1	6.3	2–10	39
Including long-term follow-up plan	**9.2**	**9.5**	**9.3**	8.0	6–10	39
Specifying the type of follow-up (cardiac, pulmonary…)	**9.0**	**9.2**	**9.0**	8.8	1–10	39
Specifying the type of screening (ultrasound, blood test, …)	8.9	**9.2**	8.7	8.5	1–10	39
Indicating a schedule (at which frequency each screening should be done)	8.9	**9.3**	8.8	8.0	4–10	39
Including synchronization to a calendar	8.2	**9.3**	7.8	6.8	2–10	39
Follow-up section						
Registering the results of the screenings (question per exam)	8.1	**9.3**	7.5	7.7	1–10	37
Registering the results of the subnormal or abnormal screening only (question per exam)	8.1	8.0	8.2	7.0	1–10	35
Registering the health status at each follow-up	8.0	8.7	7.5	8.5	1–10	39
Registering the health status at regular intervals (for example each 4 or 5 years)	8.3	**9.1**	8.0	7.8	3–10	36
Allowing only the declaration of a significant health event with the date according to a predefined listing of events	6.9	6.9	6.9	6.8	1–10	36
Allowing only the declaration of a significant health event with the date according to ICD 10 classification	7.0	6.8	7.1	6.7	2–10	34
Allowing only the declaration of a significant health event with the date according to CTCAE classification	7.1	6.9	7.2	6.8	2–10	34
Administrative section						
Including names of doctors who treated the patient (oncology, surgery, radiotherapy)	6.7	7.6	6.0	6.5	1–10	40
Including name and surname of the patient	7.9	8.9	7.2	7.8	1–10	40
Including place of residence at time of diagnosis	6.4	8.0	5.4	6.0	1–10	40
Including place of residence during the follow-up	7.0	8.1	6.1	7.8	1–10	40
Including date of birth	**9.2**	**9.3**	**9.5**	7.3	3–10	39

Mean score for level of importance

Other*: epidemiologist, data manager

the ability to send reminders to patients or their representatives. Conversely, 11 items had a standard deviation > 3. Of these, nine pertained to the feasibility of implementation for patients already treated, one related to newly diagnosed patients (cumulative corticosteroid dose), and one to the importance of items (name and surname).

Geographic and professional variations further influenced the perceived importance of certain items. Differences between HCPs and patients responses were particularly pronounced for items related to the feasibility of documenting data for older patients and the importance assigned to specific items. Patients and parents consistently expressed a need for much more detailed information than HCPs, assigning higher scores across 46 items, particularly in areas such as radiotherapy, chemotherapy, and surgical treatments. For example, patients and parents prioritized detailed tracking of cumulative chemotherapy doses (9.1), precise information on irradiated organs (9.3), and specifics on surgical interventions (9.6), whereas HCPs generally preferred broader or partially summarized information for these categories.

Interestingly, some radiotherapy oncologists who rated their survivorship expertise as ≥ 9 scored items with precise radiotherapy data, such as field, prescribed dose, specific data on organs at risk, and type of radiotherapy (e.g., proton, brachytherapy, photon), above 9. When considering the level of importance and feasibility, for newly diagnosed patients, detailed information seemed feasible (min, mean, and max dose for organ at risk, mean score 8.8—precise dose/volume data, 8.3—field and prescribed dose and type of radiotherapy, 9.0). For 11 items, the difference in scores between patients and HCPs exceeded one point, specifically for items such as autologous stem cell transplantation, allogeneic stem cell transplantation, and the center where radiotherapy was delivered. The largest discrepancies (greater than 1.9 points) were observed for items deemed more important by patients and parents, and included cumulative doses of corticosteroids, biopsies, surgical treatment due to previous complications, number of episodes of febrile neutropenia (e.g., requiring IV antibiotics), number of red cell transfusions, number of platelet transfusions, all complications (including those resolved), and place of residence at the time of diagnosis or during follow-up. For items where the discrepancy exceeded three points (e.g., biopsies, number of platelet transfusions, and all resolved complications), this gap tended to narrow among patients who self-identified as experts (score ≥ 8) in LTFU, with the most noticeable reduction seen for platelet transfusions. The location of care, such as radiotherapy centers, exhibited wide score ranges (2–10) across all groups, with no clear patterns based on country size or respondent profiles. Similarly, rare treatments like hyperthermic chemotherapy showed significant professional differences, with notably lower ratings from epidemiologists (scores of 1 and 2, respectively). Administrative data, such as the inclusion of the patient's place of residence at diagnosis, showed substantial variability, with patients and parents assigning an average score of 8, while HCPs rated it lower at 5.4. These discrepancies reflect differing perspectives on the level of detail necessary for effective follow-up care.

Key functionalities for digital tools

The survey results highlight critical functionalities for a digital tool in LTFU care, reflecting diverse needs and preferences across different user groups (Table 3). The most highly rated feature was the ability to send reminders to patients or their representatives, to GPs, and to hospital physicians, with respective mean scores of 9.3, 8.0 and 7.7. Agreement was highest for patient-directed reminders (SD = 1.2), while variability was greater for GPs and hospital physicians (SD = 2.2 and 2.4, respectively). The inclusion of an algorithm to propose follow-up plans based on selected sections was also particularly valued with an overall score of 9.1.

Patients also rated a calendar feature designed to integrate follow-up schedules highly. This feature received lower scores among non-specialists such as GPs and nurses (scores below 5) compared to oncology specialists, who rated it significantly higher (range 8–10). Other functionalities, such as the ability to download personalized follow-up plans and documents, were also highly valued, especially by patients (9.3). The inclusion of auto-questionnaires for follow-up care (8.9 for patients) and research (9.0 for patients) also received strong support (SD = 1.2 and 1.8, respectively).

Key features for digital tools

The user experience of digital tools, including the need for these tools to be engaging, easy to use, and customizable, was highlighted by 66.7% of participants (Table 4). Entertainment was not an important feature (6.0). Regarding the MARS, Mobile Application Rating Scale, a multidimensional instrument to assess digital tools quality, the features focusing on "improving engagement", like being fun, interesting, customizable, interactive (e.g., sends alerts, messages, reminders, feedback, enables sharing, and well-targeted to audience), got score 7.80 (in more detail: entertainment 6.0, interest 7.9, customization 8.0, interactivity 8.1, target group 9.0). Functionality was scored as 9.0 (performance 8.7, ease of use 9.1, navigation 9.1, gestural design 9.0) and esthetics 8.5. Information (contains high quality information from a credible source) was scored at 8.3 with quality as the most important point (9.3).

Table 3 Prioritized functionalities for digital tools in LTFU care

Functionalities	All	Patients, parents, associations	Health care professionals	Other		
	Mean score	Mean score	Mean score	Mean score	Range	*N*
Include the possibility to send reminders to the patients or their representatives	**9.3**	**9.1**	**9.2**	**9.8**	5–10	40
Include an algorithm to propose a follow-up plan based on the other selected sections	**9.1**	**9.1**	**9.1**	8.8	6–10	40
Indicating a schedule (at which frequency each screening should be done)	8.9	9.3	8.8	8.0	4–10	39
Include the possibility to do exports of your own data (from your hospital)	8.7	8.8	8.6	8.5	4–10	38
Possibility to download some documents (summary, personalized follow-up care plan,…)	8.7	**9.3**	8.3	8.8	1–10	38
Possibility to add auto-questionnaires used for follow-up care	8.6	8.9	8.4	8.8	5–10	38
Possibility to upload/store additional files/documents	8.5	9.0	8.4	7.8	4–10	38
Email or alarm when something is wrong/needs attention (questionnaire/result of exam…) (for professionals)	8.5	8.7	8.3	9.0	1–10	42
Email/SMS reminders when something is due (for patients)	8.5	8.7	8.3	9.0	4–10	43
Possibility to add professional questionnaires used for research (e-CRF hosting)	8.5	8.7	8.4	8.5	1–10	38
Possibility to add auto-questionnaires used for research	8.4	9.0	8.1	8.8	1–10	38
Capacity to discuss with health care professionals	8.4	9.5	7.8	8.3	2–10	40
Include the possibility to do regular imports of data from a registry or a local database or to be linked with them	8.3	8.6	8.2	7.5	1–10	39
Include the possibility to screen/search for specific patients from your own hospital regarding some characteristics (i.e., possibility of filters)	8.3	8.2	8.2	8.8	1–10	39
Include the possibility to do one import of data from a registry or a local database	8.2	8.3	8.3	7.3	1–10	38
Possibility to generate letter/report on a pdf sheet including some points recorded in the software	8.2	8.2	8.1	8.8	3–10	39
Internet access without the necessity to download a software	8.2	8.5	8.0	7.5	3–10	39
Possibility to change the language of the user interface	8.1	9.3	7.7	7.3	2–10	36
Include the possibility to send reminders to the general practitioners	8.0	9.1	7.6	6.3	1–10	40
Change in appearance (on the patient list) of deceased patients	7.8	7.5	8.1	6.5	1–10	38
Software or application to download	7.7	8.3	7.5	7.0	2–10	39
Include the possibility to send reminders to the hospital health care professionals	7.7	8.4	7.5	6.3	1–10	40
Multilanguage support to generate letter/report	7.7	7.6	8.0	6.5	2–10	39
Capacity to discuss between patients (app community)	7.5	8.4	7.1	6.3	2–10	40
Email/SMS reminders when something is due (for professionals)	7.3	7.9	7.0	6.3	1–10	43

Discussion

The results of this study highlight the key content and functionalities required for digital tools in LTFU care for CAYACS. Respondents emphasized a strong consensus on critical features, including follow-up algorithms, automated reminders, and the ability to download personalized care plans. These functionalities were consistently rated as essential for improving adherence to follow-up protocols and reducing the burden of care management on survivors and their families. These findings align with previous research demonstrating the value of structured follow-up plans and automated features in supporting care continuity and enhancing survivor engagement [3, 5].

The study also revealed notable divergences in preferences regarding the level of clinical detail provided by digital tools. In fact, our results showed that patients and parents consistently assigned higher importance scores than HCPs to items involving detailed clinical information—such as cumulative chemotherapy doses, specific radiotherapy data, and surgical history—indicating a preference for comprehensive data. In contrast, HCPs rated

Table 4 Prioritized features of the MARS questionnaire by subset of interface (passports, e-PSCT for patients, or e-PSCT for health care providers)

Type of tool/profile of user		Mean	Median	Range	*N*
Engagement: fun, interesting, customisable, interactive (e.g., sends alerts, messages, reminders, feedback, enables sharing), well-targeted to audience					
Entertainment *(should it be fun/entertaining to use? Should it use any strategies to increase engagement through entertainment (e.g., through gamification)*	Passports	5.5	5.0	1–10	45
	e-PSCT	6.5	8.0	1–10	45
Interest *(should it be interesting to use? Should it use any strategies to increase engagement by presenting its content in an interesting way?)*	Passports	7.6	8.0	1–10	45
	e-PSCT	8.2	9.0	1–10	45
Customization *(should it provide/retain some settings/preferences for apps features, e.g., sound, content, notifications,* etc.*)*	Passports	7.8	8.0	1–10	45
	e-PSCT	8.1	8.0	1–10	45
Interactivity *(should it allow user input, provide feedback, contain prompts as reminders, sharing options, notifications,* etc.*)*	Passports	7.8	8.0	1–10	45
	e-PSCT	8.4	9.0	1–10	45
Target group *(should the content (visual information, language, design) be appropriate for the target audience, i.e., designed specifically for the target population)*	Passports	8.9	9.0	5–10	45
	e-PSCT	9	9.0	5–10	45
Functionality: app functioning, easy to learn, navigation, flow logic, and gestural design of app					
Performance (*how accurately/fast should the features (functions) and components (buttons/menus) work?)*	Passports	8.6	9.0	5–10	44
	e-PSCT (patients)	8.7	9.0	5–10	44
	e-PSCT (HCP)	8.7	9.0	5–10	40
Ease of use (*should be pay attention how easy it is to learn how to use the app; how clear should the menu labels/icons and instructions be?)*	Passports	9.2	10.0	4–10	45
	e-PSCT (patients)	9.2	10.0	4–10	45
	e-PSCT (HCP)	9.0	10.0	6–10	41
Navigation *(should navigating between screens be logical/accurate/appropriate/uninterrupted; should be paid attention that all necessary screen links are present)*	Passports	9.1	10.0	6–10	45
	e-PSCT (patients)	9.0	10.0	6–10	45
	e-PSCT (HCP)	9.1	10.0	6–10	40
Gestural design *(should we pay attention that interactions (taps/swipes/pinches/scrolls) are consistent and intuitive across all components/screens?)*	Passports	9.0	10.0	4–10	44
	e-PSCT (patients)	9.0	10.0	4–10	45
	e-PSCT (HCP)	8.9	10.0	4–10	41
Esthetics: graphic design, overall visual appeal, color scheme, and stylistic consistency					
Layout *(should we pay attention that the arrangement and size of buttons/icons/menus/content on the screen are appropriate or zoomable if needed?)*	Passports	8.8	9.0	6–10	45
	e-PSCT (patients)	8.8	9.0	6–10	45
	e-PSCT (HCP)	8.2	8.0	4–10	41
Graphics *(should we pay attention how high is the quality/resolution of graphics used for buttons/icons/menus/content?)*	Passports	8.4	8.0	4–10	45
	e-PSCT (patients)	8.5	8.0	4–10	45
	e-PSCT (HCP)	8.0	8.0	4–10	41
Visual appeal *(how good does the software/app look?)*	Passports	8.7	9.0	5–10	44
	e-PSCT (patients)	9.0	10.0	5–10	44
	e-PSCT (HCP)	8.0	8.0	3–10	41
Information: contains high-quality information from a credible source					
App/software description *(should it have a page of description)*	Passports	8.2	8.0	1–10	44
	e-PSCT (patients)	8.0	8.0	1–10	44
	e-PSCT (HCP)	8.4	8.0	3–10	40
Goals *(should it contain a page with information about the goals? Should it precise specific, measurable and achievable goals?)*	Passports	7.8	8.0	1–10	44
	e-PSCT (patients)	7.8	8.0	1–10	44
	e-PSCT (HCP)	8.1	8.0	5–10	40
Quality of information *(how important is wording, clarity of items*)	Passports	9.4	10.0	7–10	44
	e-PSCT (patients)	9.4	10.0	7–10	44
	e-PSCT (HCP)	9.2	10.0	6–10	40
Quantity of information (1) *(should we pay attention that information is comprehensive but concise?)*	Passports	9.0	9.5	1–10	44
	e-PSCT (patients)	8.9	9.0	1–10	44
	e-PSCT (HCP)	8.9	9.0	5–10	40

Table 4 (continued)

Type of tool/profile of user		Mean	Median	Range	*N*
Quantity of information (2) *(should links to more information and resources be present?)*	Passports	8.4	9.0	5–10	44
	e-PSCT (patients)	8.7	9.0	5–10	44
	e-PSCT (HCP)	8.2	9.0	1–10	40
Visual information *(should we pay attention that visual explanations of concepts—through charts/graphs/images/videos,* etc.*—are clear, logical, correct?)*	Passports	8.9	10.0	5–10	44
	e-PSCT (patients)	9.0	10.0	5–10	44
	e-PSCT (HCP)	8.6	9.0	2–10	39
Credibility 1 *(should information on how it has been built, the references be described?)*	Passports	7.1	7.0	2–10	44
	e-PSCT (patients)	7.0	7.0	2–10	44
	e-PSCT (HCP)	7.5	8.0	2–10	40
Credibility 2 *(should the strategy of maintaining up to datedness be described?)*	Passports	7.6	8.0	3–10	42
	e-PSCT (patients)	7.3	7.00	3–10	43
	e-PSCT (HCP)	8.0	8.00	4–10	40
Evidence based *(should information about eventual trials going on or published results be mentioned somewhere?)*	Passports	7.6	8.00	2–10	43
	e-PSCT (patients)	7.7	8.00	2–10	43
	e-PSCT (HCP)	8.4	9.00	2–10	40

these items slightly lower, suggesting a preference for more concise or practical data formats. Different studies reported that patients valued detailed treatment summaries to manage long-term risks but are lacking information [12]. HCPs encountered challenges coordinating LTFU care due to limited time and lacking specific knowledge [6, 13, 14]. Blaauwbroek et al. [15] similarly noted challenges faced by general practitioners in accessing and integrating survivor data into workflows. Another qualitative study revealed that GPs considered digital tools highly beneficial for managing survivorship by facilitating easier access to survivors' medical information [16]. However, with only one GP represented in our survey, drawing conclusions specific to this profile remains challenging.

Feasibility was explicitly rated by participants for each content item. Scores were systematically lower for retrospective data collection, especially for older data such as cumulative drug doses, historical complications, or transfusion episodes. This aligns with known challenges in accessing complete historical records for long-term survivors, particularly for older survivor cohorts [5]. Tools designed for LTFU must address these limitations by offering adaptable approaches to data integration that maintain clinical relevance, as cyclophosphamide equivalent dose, cumulative anthracycline dose, etc., are known to increase morbidity and decrease quality of life, while acknowledging practical constraints associated with historical data gaps.

Personalized follow-up plans tailored to individual survivor needs were also recognized as a critical component of digital tools. Tools incorporating evidence-based guidelines, such as those developed by the International Guidelines Harmonization Group (IGHG), were highlighted as particularly valuable for optimizing survivorship care [17]. Personalized plans are also pivotal in preventing late effects and enhancing the quality of care by ensuring that survivors receive timely and appropriate follow-up interventions.

Although not specifically addressed in this part of the current survey, another technical challenge was the need for interoperability with existing healthcare systems [18] or, at least the capacity to import data from other databases. Features like automated reminders and integrated calendars were highly valued. However, these functionalities must be carefully designed to balance usability, avoid overwhelming patients, and accommodate the time constraints faced by HCPs. Questions regarding target audiences for reminders and their frequency need to be addressed for optimal implementation.

Strategies to improve the communication of health risks and provide robust psychological support are also crucial for mitigating stress and anxiety among survivors [19]. Digital tools offer a promising opportunity to alleviate the mental load for both survivors and HCPs. For example, the LOG-after tool includes such functionalities, and a feasibility study reported that CAYACS felt a reduction in their mental burden when using the tool [8].

Existing tools, such as SurPass, SALUB, and LOG-after, offer valuable functionalities like personalized care plans, educational materials, and reminders, focusing on preventive care. Others, including Kaiku-Health® and Resilience®, emphasize supportive care through ePRO-based monitoring and self-care programs. [5, 7, 20]. These tools illustrate the growing potential of digital innovation to bridge gaps in follow-up care, and their integration into healthcare systems remains a priority for improving survivorship care.

Finally, although no formal sample size calculation was conducted, this exploratory study aimed to gather a wide range of perspectives from stakeholders involved in LTFU care across Europe. Particular attention was paid to ensuring diversity not only in respondent roles (patients, parents, healthcare professionals, and association members), but also in healthcare settings and digital infrastructure. Several participants reported working in contexts without structured long-term follow-up programs or existing digital tools, which enriched the data by highlighting practical barriers and unmet needs in less-resourced environments. Nevertheless, the availability of the questionnaire only in English can be seen as a limitation, as it may have unintentionally contributed to the exclusion of participants with lower levels of education. Consequently, the use of other languages might have allowed for a broader recruitment of participants and should be considered in future research.

Otherwise, while 45.7% of respondents were affiliated with the broader e-QuoL project (e.g., through working groups or institutional partnerships), they were not directly involved in the design or development of the questionnaire itself. Their responses should therefore be interpreted as those of stakeholders and end-users, not as contributors to the tool's construction. Notably, many of these respondents also self-identified as having a high level of expertise in long-term follow-up (LTFU). This dual positioning—being both engaged in survivorship care at the European level and personally experienced in the field—may have enhanced the depth, contextual awareness, and practical relevance of their input.

This heterogeneity strengthens the contextual richness and potential generalizability of the findings. Although the relatively small sample size may be seen as a limitation, the diversity of participants in terms of gender, age, professional background, and geographic origin broadens the applicability of the results across varied European settings. Moreover, the involvement of patients and parents who are active in advocacy associations added valuable perspectives by combining lived experience with collective insight from supporting others. In addition, these results are accompanied by qualitative data with responses to open-ended questions, not reported here but in another article (in progress to publication), which offer valuable insights that could also help guide the development of the most appropriate tool. Thereby, the variety of perspectives captured, particularly from settings with differing levels of LTFU structure or digital maturity, provides a valuable foundation for the co-development of adaptable and scalable digital tools.

Thus, the e-QuoL project builds upon these advancements, aiming to co-develop tools like $\text{MyCare}_{\text{e-QuoL}}$, an e-PSCT, interoperable with existing platforms. This innovative approach emphasizes tailoring digital solutions to survivors' medical and psychosocial needs while addressing challenges such as resource disparities and ensuring usability across different healthcare settings. Future efforts will involve clinical evaluations to refine these tools further and maximize their impact on survivors' QoL.

Conclusion

In conclusion, the e-QuoL project represents a pivotal step toward advancing survivorship care for CAYACS across Europe. By leveraging participatory research methods and existing digital innovations, it strives to develop scalable, personalized, and equitable solutions that meet the diverse needs of survivors and healthcare providers. These efforts align with Europe's Beating Cancer Plan, aiming to ensure that every CAYACS has access to comprehensive, high-quality follow-up care tailored to their unique journey.

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Declarations

Competing interests The authors declare no competing interests.

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