



eHealth tools for childhood cancer survivorship care: A qualitative analysis of survivors', parents', and general practitioners' views

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ABSTRACT

Objective: We assessed the acceptability of, and perceived benefits/barriers to, using Electronic health (eHealth) technology for childhood cancer survivorship care.

Methods: We interviewed survivors, their parents, and their nominated GP. We described a hypothetical eHealth tool to manage survivorship care and asked their likely use of, and perceived benefits/concerns for, the use of the tool.

Results: 31 survivors (mean age = 27.0), 29 parents (survivors' mean age = 12.6), and 51 GPs (mean years practising = 28.2) participated. Most survivors/parents (85%) and GPs (75%) indicated that they would be willing to use an eHealth tool. Survivors/parents reported that an eHealth tool would increase their confidence in their ability, and their GP's ability, to manage their survivorship care. GPs agreed that an eHealth tool would provide easier access to survivors' medical information and increase their capacity to provide support during survivorship. Some GPs (7%) and survivors (43%) reported being hesitant to use eHealth tools due to privacy/security concerns.

Conclusion: Overall, eHealth tools appear acceptable and may help to improve the management of late effects for childhood cancer survivors and assist their GPs to coordinate their care.

Innovation: Concerns raised by key stakeholders should be addressed in the design of eHealth technologies to optimise their uptake and effectiveness.

1. Introduction

Survivors of childhood cancer live on average 60 years post-diagnosis [1], during which their risk of developing cancer and/or treatment-related late effects increases [2]. Late effects may include second malignant neoplasms, life-threatening organ dysfunction, or poor psychosocial functioning [3]. Many late effects can be prevented, managed or treated with appropriate surveillance through long-term follow-up care, and patient education of risk-factors for the development of late effects [4]. However,

around 45% of patients disengage from follow-up care during survivorship [5], due to survivors ageing out of paediatric healthcare [6], limited follow-up clinics/specialists [7], distance to clinics [8], survivors' limited knowledge of late effects [9], and hospitals prioritising resources for high-risk survivors [10]. Consequently, many survivors become reliant on their general practitioner (GP) to manage their care, or forego survivorship-specific care.

GPs can assist survivors to manage their late effects by scheduling screening tests, providing preventative lifestyle advice for late effects (e.g. diabetes and cardiovascular disease), and making referrals to specialists

Abbreviations: GP, General practitioners; SCP, Survivorship care plans; ALL, Acute Lymphoblastic Leukemia.

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for complex co-morbidities [11]. Despite GPs' willingness, they report insufficient knowledge and confidence providing paediatric cancer follow-up care [12]. Survivors also report a lack of confidence in their GP's provision of cancer-related care [13].

Survivorship Care Plans (SCPs) may support GPs to deliver shared care with oncologist and other related specialists. SCPs provide personalised summaries of survivors' cancer history and treatment(s), and recommended screening or management [14]. However, there is mixed evidence that SCPs improve childhood cancer survivors' long-term outcomes (e.g. survivors' knowledge, adherence to follow-up recommendations) [15,16]. As typically static, paper-based documents, SCPs easily become misplaced or outdated, across several decades of survivorship.

Cost-effective and high-quality electronic and mobile health tools (herein "eHealth tools") have the potential to improve long-term survivorship care due to their inherently dynamic systems. eHealth interventions involve the promotion, prevention, treatment and maintenance of health (e.g. online programs), using technology (e.g. mobile applications) for the delivery of health-related services [17]. There is a growing interest in using digital technologies to mitigate late effects in childhood cancer survivors. Cancer patients and survivors report positive attitudes towards eHealth tools for care management [18,19], preferring eHealth tools that enable active and frequent self-monitoring and more convenient survivorship care delivery.

Previous studies assessing patient perspectives have been broad, and varied in eHealth intervention type and content, as well as participant type (i.e. adult and child, in-patients and out-patients perspectives) [17-19]. Additionally, the acceptability of eHealth tools to healthcare professionals (including GPs) or parents of childhood cancer survivors remains unexplored, as do the preferences of survivors, parents and healthcare professionals for different types of eHealth tools. Given GPs and parents play a central role in the management of long-term childhood cancer survivorship care, their opinions and likely uptake of eHealth tools must also be considered. In this study we therefore aimed to understand:

1. The acceptability of eHealth tools for the management of survivorship care for survivors of childhood cancer, parents of young survivors, and GPs caring for childhood cancer survivors.
2. Survivors', parents of survivors' and GPs' perceived benefits of and barriers to using eHealth tools for the management of survivorship care.

2. Methods

This study was approved by the ethics authorities at participating hospitals and endorsed by the Australian and New Zealand Children's Haematology Oncology Group (ANZCHOG). We followed the consolidated criteria for report qualitative data research (COREQ) guidelines in reporting this study [20].

We collected data as a part of the ANZCHOG Survivorship Study [21], in two stages. Stage 1 involved childhood cancer survivors and parents completing a questionnaire, in which they could opt-in to complete a telephone interview and nominate their GP for Stage 2. In Stage 2 we invited nominated GPs to a telephone interview. Interviews were conducted one-on-one by trained female clinical psychologists and researchers. Interviewers had no prior relationship with interviewees and were independent to the research topic. We audio-recorded interviews, which were professionally transcribed verbatim. Participants did not review their transcripts. Interviews took 30–60 min.

Interviewers described to participants a hypothetical eHealth tool (Table 1), defined as a free website or application to help survivors manage their survivorship care by: i) storing all of their cancer-related information (e.g., treatment(s), screenings); ii) synchronising to their calendars for personalised surveillance reminders; and iii) providing access to tailored survivorship information based on their cancer/treatment(s). The definition and features of the prospective eHealth tool stemmed from previously developed, validated and tested paediatric oncology eHealth tools [22].

Table 1

Interview schedule for survivors and parents, and General Practitioners.

<i>Survivors and Parents</i>	
We are thinking about developing a free web or app product for childhood cancer survivors to help them manage their care. This website or app would:	
<ul style="list-style-type: none"> - store all your information about your past treatments, tests, and screenings, - indicate a schedule, or lay out a plan, regarding which tests and screenings you should do in the future and when, synced to a calendar. - it could send you email reminders when something was due. - it could provide tailored information based on your cancer and treatments. 	
Questions:	
1.	Do you think you would use a product like this? [Probe: Why/why not?]
2.	Would you feel more or less confident that you were managing your (child's) health well if you had a tool like this? [Probes: In what ways? Could you explain more about why you think this might increase/decrease your confidence?]
3.	Would you feel more or less confident that your doctor(s) was able to manage your (child's) health well if they could use this tool? [Probes: In what ways? Could you explain more about why you think this might increase/decrease your confidence?]
4.	Are there any other features you think would be important to include? [Could you explain why you think that these features are important? Are there any others?]
5.	Are there any issues that would concern you? [Could you explain more about why these are important to you? Are there any others?]
<i>General Practitioners</i>	
Survivors often have complex care pathways, including multiple specialist follow-up appointments and screening schedules, and they must manage these alone or with their GPs help. Our team are currently developing a free web or app product for childhood cancer survivors to help them manage their care. This website or app would:	
<ul style="list-style-type: none"> - store patient information about their past treatments, tests, and screenings, - indicate a schedule, or lay out a plan, regarding which tests and screenings are needed in the future and when, synced to a calendar. - it could send email reminders to the patient or doctor when something was due. - it could provide tailored information based on the patients cancer and treatments. 	
Questions	
1.	Do you believe such e-tools may help survivors manage their care? [Probes: Why/why not? In what ways? Could you explain more about why you think this might (not) help survivors manage their care?]
2.	With your patient's permission, if you also had access to the information stored in this application, including their survivorship care plan, would you use this tool? [Probes: Why/Why not? In your opinion, what do you think might be some of the benefits/barriers of using a tool like this?]

After describing the eHealth tool, we asked participants about 1) their willingness to use an eHealth tool such as the one described, 2) the perceived impact that an eHealth tool would have on their confidence to manage survivorship care, and 3) any concerns they may have about using an eHealth tool. We collected survivor and parent demographics using their paper or online questionnaires, whilst GPs' demographics and practice-related data were collected during their interview.

2.1. Participant selection

We identified eligible survivors using the electronic hospital medical records of recruiting hospitals. Survivors invited to the study were diagnosed with cancer before 16 years, were more than 5 years post-diagnosis, had finished cancer treatment, and were proficient in English. Parents of survivors under 16 years were invited to participate on behalf of their child. Participants were invited via a letter mailed to their home address.

2.2. Data analysis

We used QSR NVivo12 Pro (QSR International Pty Ltd) for analysis. We analysed the data using directed content analysis to enable the thematic organisation of responses, categorising the data according to broad

predetermined themes based on our research questions (i.e. acceptability, willingness to use, and perceived benefits/barriers). This process was guided by the methodology described by Hsieh and Shannon [23]. Two researchers (MS, MB) read all of the transcripts for familiarity, developed the initial coding categories, and double-coded 15% of randomly selected interviews for consistency (99.4% agreement, $k = 0.3$ coefficient). The two coders reflected on the initial coding and the central ideas raised. Discrepancies were resolved through discussion and with reference back to the original transcripts. Given the sample size and high concordance, one author (MS) coded the remainder of the interviews.

3. Results

3.1. Sample characteristics (Table 2)

Of 636 questionnaire respondents, 380 (59.7%) volunteered to participate in the telephone interview. We interviewed 134 participants, of whom 60 participants (31 survivors and 29 parents) provided valid responses to

Table 2
Clinical and demographic characteristics of participating childhood cancer survivors and parents of young survivors and GPs.

Characteristic	Survivors of childhood cancer <i>n</i> = 31 (51.7%)	Parents of young survivors <i>n</i> = 29 (48.3%)	GPs of childhood cancer survivors
Survivor sex, <i>n</i> (%)			
Male	11 (35.5)	20 (69.0)	29 (56.8)
Female	20 (64.5)	9 (31.0)	22 (43.2)
Relationship to survivor, <i>n</i> (%)			
Father	-	5 (8.3)	
Mother	-	24 (40)	
Ethnic background, <i>n</i> (%)			
Australian	27 (87.1)	22 (75.8)	
European	1 (3.2)	7 (24.1)	
Asian	1 (3.2)	-	
Other	2 (6.4)	-	
Area of residence, <i>n</i> (%) ^a			
Major City	27 (87.1)	24 (82.8)	33 (64.7)
Inner/outer regional	4 (12.9)	5 (17.2)	18 (35.3)
Diagnosis, <i>n</i> (%)			
Leukaemia	14 (45.2)	15 (51.7)	
Lymphoma	6 (19.4)	-	
Brain	1 (3.2)	2 (6.9)	
Other	10 (32.3)	12 (41.4)	
Treatment received, <i>n</i> (%)			
Surgery	12 (38.7)	9 (31.0)	
Chemotherapy	31 (100.0)	28 (96.6)	
Radiation	15 (48.4)	13 (44.8)	
Bone marrow transplant	4 (12.9)	6 (20.7)	
Age of survivor in years, mean (SD)	27.0 (6.3)	12.6 (2.3)	
Range	18–45	8–16	
Time since diagnosis in years, mean (SD)	18.9 (8.9)	9.55 (1.7)	
Range	6–42	7–13	
Time since treatment completion in years, mean (SD)	16.2 (8.6)	8.0 (2.0)	
Range	6–41	4–12	
Years Practising (SD)			28.2 (11.6)
Range			8–60
Number of survivor patients (SD)			2.2 (2.1)
Range			1–11

Abbreviations: N: Number of participants; SD: Standard deviation, —: not assessed or not applicable, GP: General Practitioner, Numbers and percentages may not add up due to missing values and rounding errors.

^a According to Area of Remoteness Index Australia (ARIA) classifications.

the research questions for this analysis. The remainder could not be contacted or were lost to follow-up, declined to complete the interview, or did not answer the relevant questions (e.g., due to lack of time). As survivors and parents reported similar responses to eHealth tools during their interviews, their data was grouped together to report the findings.

Of the 160 GPs nominated by survivors and invited to participate via mail, 74 agreed to participate (46%) in an interview, of whom 51 were interviewed before we reached informational redundancy (i.e. no new information was arising) [24]. Of the GP sample, 29 (56.8%) were male and 33 (65%) worked in major cities. They reported practising for an average of 28.2 years (11.6, 8–60) and having seen an average of 2.2 (2.1, 1–11) childhood cancer survivors in their practice. GPs were reimbursed with a \$50 gift card for their time.

3.2. Acceptability of eHealth tools to survivors and GPs (Fig. 1)

Eighty-five percent of (*n* = 51) survivors and parents agreed it would be acceptable to use an eHealth tool to manage their survivorship care; 7% survivors and parents were hesitant (*n* = 4), and 8% were not interested in using an eHealth tool for their care management (*n* = 5).

Seventy five percent of GPs (*n* = 38) agreed that an eHealth tool would be acceptable and 25% (*n* = 13) did not believe an eHealth tool would be appropriate for the management of care for survivors.

3.3. Perceived benefits for survivors/parents (Fig. 1 and Table 3)

Among survivors and parents, perceived benefits associated with an eHealth tool included increased confidence in their ability to manage their care (63%; *n* = 38), greater confidence in their healthcare providers (55%; *n* = 33), and increased convenience navigating healthcare systems (30%; *n* = 18).

3.3.1. Potential to increase confidence in self-management

Participants reported that an eHealth tool could increase their own confidence to manage their or their child's survivorship care. Many noted that they “*simply can't remember everything that [they] need to do*” (father of Rhabdomyosarcoma survivor, aged 14) or were unsure of their cancer-related surveillance requirements. Participants noted that an eHealth tool might provide information to guide their care management. They also indicated that an eHealth tool would increase their confidence because the personalised surveillance alerts and schedules could ensure that they were “*doing the right thing*” (mother of Acute Lymphoblastic Leukaemia [ALL] survivor, aged 14).

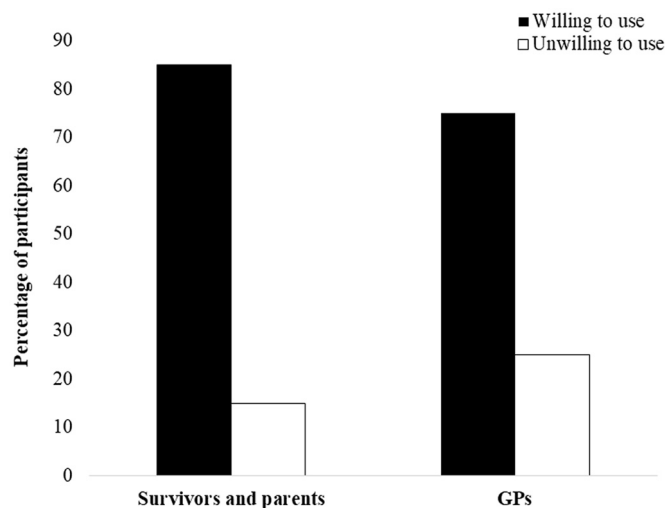


Fig. 1. Survivors', parents' and GPs' willingness to use eHealth tools for survivorship care coordination.

Table 3
Survivors, parents, and GPs reported perceived benefits relating to eHealth tools.

Theme	Illustrative quotes
Survivor and parents perceived benefits	
Potential increase confidence in self-management (N = 38, 63.3%)	<p>“More confident...because I would know exactly what I would have to do, especially if they were reminding you as well.” (ALL survivor, aged 30)</p> <p>“A lot more confident [in myself]... only because I, I don't feel like sick or anything, but I just feel like, if there was anything else out there that I could be having, like to make sure that like I was like doing the best I can for my health.” (Female Acute Lymphoblastic Leukaemia survivor, aged 24)</p> <p>“I think I would feel more confident, because, yeah, based on how you described it, it sounds pretty useful and comprehensive.” (Male Acute Lymphoblastic Leukaemia survivor, aged 21)</p> <p>“more confident ... because it would be like more information to help me around what I need to do and stuff, instead of guessing” (Male Acute Lymphoblastic Leukaemia survivor, aged 27)</p>
Potential increased confidence in health providers (N = 33, 55.0%)	<p>“I'd be more confident because, if [GP's] were a little unsure, they could go in, have a look, and sort of do their own research too and actually get a better idea of [my cancer].” (Brain cancer survivor, aged 25).</p> <p>“Yeah I'd feel more confident about that because at the moment the doctor relies on me to explain what I had and the treatment I had and I really don't know much about the treatment I had or about the nature of the cancer that I had” (Male Acute myeloid leukaemia, aged 29)</p> <p>“Yes I think if [GPs] had your entire history of course their care is going to be better.” (Female soft tissue Sarcoma survivor, aged 24)</p> <p>“I think they would feel more confident as well, because GPs treat people for such a broad range of things and I think sometimes we expect them to know everything and they don't and they can't” (Female Acute Lymphoblastic Leukaemia survivor, aged 29)</p>
Potential to improve healthcare system navigation (N = 18, 30.0%)	<p>“You could go [to your doctor and say] my last test was this and I had it here and this was the result and if you want to speak to such-and-such doctor, that's who did the test” (ALL survivor, aged 29).</p> <p>“Because [the information] is there any time” (Father of a Wilm's tumour survivor, aged 10)</p> <p>“Just having, the information in front of you all the time.” (Female Acute Lymphoblastic Leukaemia survivor, aged 34)</p> <p>“If I was going to see my adult endocrinologist for the first time, I would take that along, I would show him that and sort of give him that. If I was having my annual check-up with the GP or something like that, again, I would gladly take that and show that as well.” (Female Brain Cancer survivor, aged 25)</p> <p>“It would be good because then I guess I'd have it all at my fingertips, and I wouldn't have to wait that whole year to see my haematologists. If I had a question that might be answered by simply running to the app or online about my treatment or anything else.” (Female Hodgkin's Lymphoma survivor, aged 25)</p>
GP'S perceived benefits	
Potential for increased convenient access to survivorship information (N = 10, 19.6%)	<p>“if I had [my patient] in consultation and I needed to see something or check something up, that's where it would be useful” (female GP, 19 years practising).</p> <p>“I guess now that I think about it I encounter childhood cancer survivors ... so it's just helpful when you come across problems or issues that you see infrequently just to have that extra</p>

Table 3 (continued)

Theme	Illustrative quotes
Potential for greater patient support (N = 9, 17.6%)	<p>reminder.” (Male GP, 12 years practising)</p> <p>“Yeah. I think that it would be useful to have information available, that we could use in his care” (Male GP, 35 years practising)</p> <p>“would think authentic and concise, um [yep] guidelines on ... what I need to watch out for” (Male GP, 35 years practising)</p> <p>“Well, just information, that's all background information.” (Male GP, 60 years practising)</p> <p>“if [patient's] move countries, they move state, it's - there's uh, uh, an ongoing, um, ah, ongoing, ah, guide to be used” (Female GP, 60 years practising)</p> <p>“I think that the electronic stuff, you could oblige your patients and the doctors who are looking after them to use electronic health records... so that she could use that at any GP really. If it's an app that she can open up on her own phone that says this, then that's fine as well.” (Male GP, 43 years practising)</p> <p>“I think the use of modern technology and social media or links like that with reminders or calendar apps or all sorts of things, or information and links, is really helping the patients in all levels of care.” (Male GP, 29 years practising)</p>
Potential to increase patient responsibility (N = 8, 15.6%)	<p>“I would be very happy if a patient came along with a folder full of information, because, you know, it makes your life easy” (female GP, 14 years practising).</p> <p>“nowadays, with technology, and you know, people are a lot more empowered with their own health [yeah], that then I think helps if they depend on the person as to how active they are, but [yeah] I think it would be popular” (Female GP, 14 years practising)</p> <p>“I think that's good for them, so they don't get complacent, so they can keep a regular eye.” (Male GP, 23 years practising)</p>

3.3.2. Potential to increase confidence in health providers

It appeared that an eHealth tool could help to increase their faith in their healthcare provider. Survivors and parents asserted the belief that most GPs have limited knowledge of childhood cancer survivorship and were “by definition ‘generalists’... not ‘specialists’” (Hodgkin's lymphoma survivor, aged 32). Participants reported that providing patient-specific care recommendations to GPs and “giving [GPs] more information is going to make me more confident” (mother of Neuroblastoma survivor, aged 8).

3.3.3. Potential to improve healthcare system navigation

Survivors and parents valued the potential for an eHealth tool to store information about their cancer history. They noted that easy and convenient access to this information could significantly improve their information needs. Specifically, collating cancer-related information in one location as opposed to “a collection of pieces of paper and scraps” (mother of ALL survivor, aged 15) could minimise information loss and improve record keeping. Additionally, participants valued being able to easily transport their cancer history and show it to any healthcare provider.

3.4. Perceived benefits for GPs

GPs cited three key potential benefits of using an eHealth tool, including improved convenience to survivors information (19%, n = 10), being able to provide better support for their survivor patients (17%, n = 9), and increased patient responsibility (15%, n = 8).

3.4.1. Potential for increased access to survivorship information

GPs cited having more convenient access to survivors' cancer-related information as a potential benefit of an eHealth tool. Specifically, having “all

the information in one place... would be far better than having lots of books and brochures” (Male GP, 46 years practising). GPs noted that, as they rarely treat childhood cancer survivors, having increased access to clinically relevant information, in one place, would be helpful when co-ordinating a patient’s survivorship care, improving their efficiency.

3.4.2. Potential for greater patient support

GPs indicated that an eHealth tool could provide greater support for their survivor patients because of the portability of information “so if they move... there’s an ongoing... guide to be used” (female GP, 32 years practising). One female GP (12 years practising) recognised that “unfortunately people don’t always keep hold of [care plans]” and an eHealth tool could provide increased support “because the website can be stored rather than being lost [like] the piece of paper”. Recognising that survivors are often a mobile population, GPs suggested that an eHealth tool would make “people [feel] a lot more empowered” (female GP, 14 years practising) because their survivor patients would have access to cancer-related information and follow-up care recommendations.

3.4.3. Potential to increase patient responsibility

GPs noted that eHealth tools could increase patient responsibility and their ability to “come in and say, ‘Hey, Doc, I’m due for this, or due for that’” (male GP, 29 years practising). As a result, GPs’ expected that an eHealth tool would increase awareness, responsibility, and self-management skills in their survivor patients. They cited that an increase in patient self-management skills could reduce GPs’ high, and burdensome, level of survivor responsibility and create a shared and more equal level of care between the two.

3.5. Survivor and parent reported concerns (Fig. 2 and Table 4)

Survivors and parents raised several potential concerns with using eHealth tools, including worries about the privacy of their information

(43%, n = 26), difficulty using technology (11%, n = 7), and difficulty accessing eHealth tools (5%, n = 3).

3.5.1. Privacy

The most frequently reported concern regarding eHealth tools was the level of security surrounding their information, highlighting the importance for “secure access so the information couldn’t be corrupted ... or used by someone else that wasn’t supposed to” (father of solid tumour survivor, aged 8). They noted that storing personal information online posed a risk of “the information being hacked” (father of Acute Lymphoblastic Leukaemia [ALL] survivor, aged 9) or viewed by unapproved individuals (e.g. insurance companies or future employers). Participants also expressed concern about their information being viewed by non-consensual individuals if there was an eHealth tool fault, or they had their device stolen.

3.5.2. Difficulty using technology

Some participants reported hesitation towards using eHealth tools due to their limited knowledge of technology, expressing themselves as “not a computer person” (father of Langerhans cell histiocytosis survivor, aged 10) or “not ... super-duper [technologically] savvy” (mother of ALL survivor, aged 16). However, some respondents were open to developing their technological skills and knowledge to learn how to use an eHealth tool.

3.5.3. Difficulty accessing technology

Survivors and parents reported concerns about the accessibility of eHealth tools, for example lack of access to the internet or a compatible device. Accessibility was particularly concerning for survivors living rurally/remotely as “in rural areas we don’t always have internet” (mother of Sacrococcygeal Teratoma survivor, aged 11).

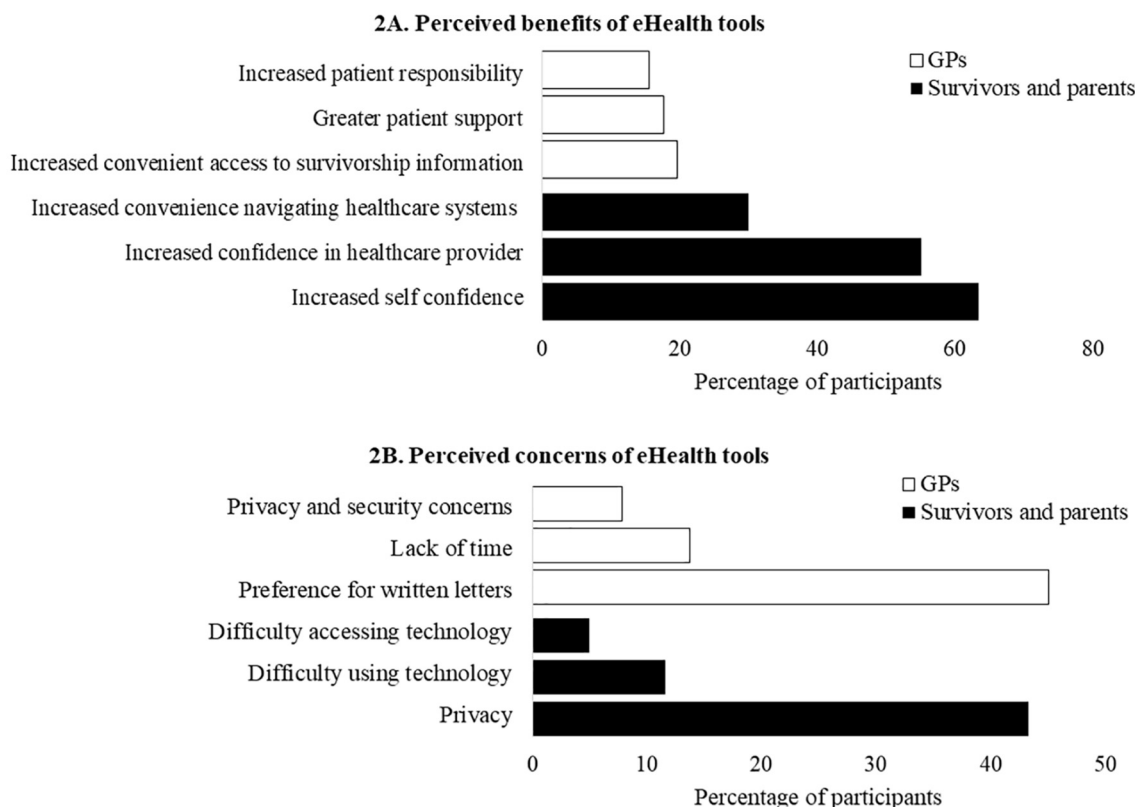


Fig. 2. Survivors, parents’ and GPs’ perceived benefits and barriers for eHealth use in survivorship care management.

Table 4
Survivors, parents, and GPs reported concerns relating to eHealth tools.

Theme	Illustrative quote
Survivor and parents perceived concerns	
Privacy (N = 26, 43.3%)	<p>“if someone picks up the app on my phone they can then get access to all my stuff” (Germ Cell Tumour survivor, aged 24).</p> <p>“I guess with anything I guess the confidentiality you wouldn't want anyone anybody tapping ... more or less the privacy issue” (Mother of a Rhabdomyosarcoma survivor, aged 15)</p> <p>“...just the security. So personalised information not getting out there. Um, only me having access to it.” (Male Acute myeloid leukaemia survivor, aged 29)</p> <p>“I'd probably have it password protected on each person's phone because I guess it's quite personal information.” (Male Hodgkin's lymphoma survivor, aged 25)</p> <p>“Oh, I mean, only the obvious which would be confidentiality and knowing that random people don't have access to information about [child]” (Mother of a Acute Lymphoblastic Leukaemia survivor, aged 15)</p>
Difficulty using technology (N = 7, 11.6%)	<p>“I am not tech savvy... if it was there in front of me, like for me to go like I'm not very good with stuff like that” (Father of Wilm's tumour survivor, aged 10)</p> <p>“Personally I still like to have paper copies, or um a stored file that's not on my phone ... I would still want there to be a person behind it, rather than just uh, completely automated.” (Male Acute myeloid leukaemia survivor, aged 29)</p> <p>“I'm really not good with technology” (Female Wilm's tumour survivor, aged 45)</p> <p>“I could give it a shot. I missed out on the computer stuff at school.” (Female, Hodgkin's Lymphoma survivor, aged 25)</p>
Difficulty accessing technology (N = 3, 5%)	<p>“Probably the phone, my phone's not an iPhone so...I've only got the HTC and isn't it Android or something like that? So I'd probably use the website more than the phone” (Mother of a solid tumour survivor, aged 11)</p> <p>“I do minimal even though I'm on my phone and stuff, got a smartphone and stuff, but I do what I need to do and kind of that's it.” (Father of Wilm's Tumour survivor, aged 10)</p>
GPs perceived concerns	
Preference for written letters (N = 27, 45%)	<p>“I don't know, I'd just like it all written down.” (Female GP, 30 years practising)</p> <p>“I normally prefer in a paper version so that I can take it around with me and read it whenever I like.” (Male GP, 39 years practising)</p> <p>“I'm of an age where letters are still important for me, because I can put them in the in basket and not lose them. Emails tend to drift out over the horizon and blow off the screen.” (Male GP, 43 years practising)</p> <p>“Yeah, I think a letter is best.” (Female GP, 28 years practising)</p> <p>“I think letter would be by far and away the most useful. A letters force you to read them, electronic things you, whilst you read them and scan them you can then park them and they don't seem to stick in my memory so well” (Male GP, 43 years practising)</p> <p>“I would never use [an eHealth tool] ...because you're going to ask me to have a login and a password and I'm not going remember one.” (male GP, 12 years practising).</p>
Lack of time (N = 7, 13.7%)	<p>“Look, to be quite frank I don't have time for a lot of the up to date technology and stuff and if I - I probably wouldn't have time to use it” (Female GP, 24 years practising)</p> <p>“I think the biggest issue is time.” (Male GP, 35 years practising)</p> <p>“well I guess in terms of barrier such as time” (Female GP, 19 years practising)</p>
Privacy and security concerns (N = 4, 7.8%)	<p>“We have a problem with this secure messaging stuff at a national level” (Male GP, 37 years practising)</p> <p>“I'm not sure how the privacy issues would relate to it but I would be thinking that the patient would get consent and they give consent to me to be able to access it as well” (Male GP, 12 years practising)</p>

3.6. GP reported concerns

GPs identified the following concerns towards eHealth tools use: a preference for letters (54%, $n = 27$), lack of time (13%, $n = 7$), and privacy/security concerns (7%, $n = 4$).

3.6.1. Preference for written letters

Many GPs (54%) preferred to receive patient-information as written letters, citing comfort in knowing where the patient information is stored. Conversely, they described eHealth tools as “*just not as easy to read as the usual mail*” (male GP, practising 24 years). GPs described a preference for existing practices stating that “*if it ain't (sic) broke, don't fix it*” (female GP, practising 24 years) noting the additional burden of having to remember a username and password.

3.6.2. Lack of time

GPs expressed a hesitation towards eHealth tools due to “*the time to use them*.” (female GP, 19 years practising), including learning how to use an eHealth tool, or adding information to it. Most GPs “*try to keep [consults] to 15 minutes...If [they're] looking after...someone with at least three system diseases... updating history is difficult let alone doing other things*” (male GP, 43 years practising). GPs suggested that eHealth tools would become undesirable if they consumed too much of their limited time.

3.6.3. Privacy/security concerns

GPs cited concerns regarding the privacy and security of patient data. GPs indicated that if they shared patient information between multiple platforms, it increased the risk of their patients' data being ‘hacked’ or viewed by non-consensual parties. GPs recognised the importance of therefore gaining patient consent and informing patients when, and in what way, their information would be shared.

4. Discussion and conclusion

4.1. Discussion

This study assessed the acceptability of eHealth tools, perceived benefits, and barriers, to use among childhood cancer survivors, their parents, and their GPs. Most survivors/parents (85%) and GPs (75%) indicated that they would be willing to use an eHealth tool for cancer survivorship care management, echoing previous research in adult cancer survivors [18,19]. Survivors/parents perceived benefits included increased confidence in their ability, and their GPs' ability, to manage their survivorship concerns, whilst barriers related mainly to their ability to use or access eHealth tools. GPs' perceived eHealth tool benefits included increased support for their patients and greater patient-initiated responsibility, however they indicated a preference for letters and a lack of time to learn/navigate a new system. Some participants agreed that eHealth tools would make survivorship care management convenient but also expressed concerns about the privacy/security of patient information.

Survivors' and parents' acceptance of eHealth tools may relate to its ability to meet more of their follow-up care needs. Survivors limited knowledge of their cancer history and follow-up [9,25], can lead to sub-optimal follow-up care engagement [26]. Survivors/parents in our study valued easy access to personalised late effects information and follow-up recommendation reminders, consistent with other literature [18,19]. Frequent self-monitoring and convenient access to past cancer-related information aligns with the survivorship trajectory. Survivors in early survivorship often move away from their family GP or treating oncology centre [27]. Convenient access to survivors' cancer-related information may provide survivors with the flexibility to visit any GP or healthcare professional to receive their recommended follow-up care. A storage feature could accommodate survivors' needs by having convenient, portable, and personalised information with them when needed.

Participants suggested that eHealth tools could improve cancer care management. GPs report feeling more capable of providing care to survivors when provided with prescriptive and patient-specific information [13]. Participants also suggested eHealth tools could improve patients' responsibility for their care, potentially fostering a partnership between survivor and GP. Previous research indicates that both GPs and survivors advocate for a shared decision making model in their survivorship care management, which could be facilitate by eHealth tools [28]. Some

participants reported being hesitant towards eHealth tools due to privacy/security concerns, aligning with adult cancer literature suggests mobile healthcare apps increase vulnerability to being hacked and medical record being revealed to non-consensual parties [29]. This reported barrier calls for potential developers to consider using formal privacy impact assessments and certifications as well as higher-level security measures, to provide users more confidence.

Our findings should be interpreted with the following limitations in mind. The interviewer introduced an eHealth tool to interview participants as something under consideration for development by the team, which may have increased the potential for social desirability bias leading participants to respond more favourably towards eHealth tools overall. The hypothetical eHealth tool proposed to participants in this study may not reflect all technology, possibly resulting in different perceived benefits and concerns. Participating GPs had been practising for nearly three decades on average, potentially influencing their desire to implement a new system into their practice.

4.2. Innovation

This study is the first to demonstrate that survivors, parents, and GPs find eHealth tools acceptable/desirable, reflecting increasing acceptance of the digitalisation of healthcare services and expectations for accessible and personalised health information [30,31]. The reported barriers demonstrated that eHealth tools should ideally be developed in collaboration with patient and provider users, who have potentially differing concerns (e.g. access to technology, or lack of time). Despite the importance of understanding and overcoming potential barriers to maximise the use and uptake of eHealth tools, this is yet to be evaluated [19]. Our findings highlight important features for the development of eHealth tools including an intuitive, easy-to-use interface, requiring little to no training, and capacity to store and share letters and upload patient information. It is also important that decision makers consider potential implementation challenges which could impact the feasibility of eHealth tool use in this population. eHealth software requires regular maintenance to keep pace with rapidly changing technologies and consumer expectations, which can be costly. Future research should more closely examine challenges of eHealth tool development, maintenance/ sustainability, and to assess if these costs outweigh the potential eHealth tool benefits (e.g. increased surveillance).

4.3. Conclusion

eHealth tools may reduce some of the known challenges in childhood cancer survivorship, including limited cancer survivorship-specific knowledge, low confidence in care management, and disengagement from follow-up care, by providing high-quality childhood cancer follow-up care information. Our qualitative study demonstrates that survivors, parents, and their GPs are generally willing to use eHealth tools for the management of survivors' follow-up care. However, participants identified concerns about eHealth tools that are critical to consider in the development of any new or existing tool.

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Data statement

These data are not available for sharing due to their confidential nature.

Declaration of competing interest

No author has any conflicts of interest to disclose in relation to this manuscript.

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References

- [1] Smith MA, Seibel NL, Altekruse SF, et al. Outcomes for children and adolescents with cancer: challenges for the twenty-first century. *J Clin Oncol.* 2010;28(15):2625.
- [2] Bhakta N, Liu Q, Ness KK, et al. The cumulative burden of surviving childhood cancer: an initial report from the St Jude Lifetime Cohort Study (SJLIFE). *Lancet.* 2017;390(10112):2569–82.
- [3] Robison LL, Hudson MM. Survivors of childhood and adolescent cancer: life-long risks and responsibilities. *Nat Rev Cancer.* 2014;14(1):61.
- [4] Landier W, Bhatia S, Eshelman DA, et al. Development of risk-based guidelines for pediatric cancer survivors: the Children's Oncology Group long-term follow-up guidelines from the Children's Oncology Group Late Effects Committee and Nursing Discipline. *J Clin Oncol.* 2004;22(24):4979–90.
- [5] Schwartz CL. Long-term survivors of childhood cancer: the late effects of therapy. *Oncologist.* 1999;4(1):45–54.
- [6] Nathan PC, Agha M, Pole JD, et al. Predictors of attendance at specialized survivor clinics in a population-based cohort of adult survivors of childhood cancer. *J Cancer Surviv.* 2016;10(4):611–8.
- [7] Signorelli C, Wakefield CE, McLoone JK, et al. Models of childhood cancer survivorship care in Australia and New Zealand: strengths and challenges. *Asia Pac J Clin Oncol.* 2017;13(6):407–15.
- [8] Berg CJ, Stratton E, Esiashvili N, Mertens A. Young adult cancer survivors' experience with cancer treatment and follow-up care and perceptions of barriers to engaging in recommended care. *J Cancer Educ.* 2016;31(3):430–42.
- [9] Carretier J, Boyle H, Duval S, et al. A review of health behaviors in childhood and adolescent cancer survivors: toward prevention of second primary cancer. *J Adolesc Young Adult Oncol.* 2016;5(2):78–90.
- [10] Signorelli C, Wakefield CE, Fardell JE, et al. The impact of long-term follow-up care for childhood cancer survivors: A systematic review. *Crit Rev Oncol Hematol.* 2017;114:131–8.
- [11] Streefkerk N, Heins MJ, Teepe JC, et al. The involvement of primary care physicians in care for childhood cancer survivors. *Pediatr Blood Cancer.* 2019;66(8):e27774.
- [12] Nathan PC, Daugherty CK, Wroblewski KE, et al. Family physician preferences and knowledge gaps regarding the care of adolescent and young adult survivors of childhood cancer. *J Cancer Surviv.* 2013;7(3):275–82.
- [13] Signorelli C, Wakefield CE, Fardell JE, et al. The role of primary care physicians in childhood cancer survivorship care: multiperspective interviews. *Oncologist.* 2019;24(5):710–9.
- [14] Horowitz ME, Fordis M, Krause S, McKellar J, Poplack DG. Passport for care: implementing the survivorship care plan. *J Oncol Pract.* 2009;5(3):110–2.
- [15] Yan AP, Chen Y, Hudson MM, et al. Impact of survivorship care plans (SCPs) on adherence to surveillance for second malignant neoplasms (SMNs) and cardiac dysfunction in the Childhood Cancer Survivor Study (CCSS). *American Society of Clin Oncol.* 2018;5(3):110–2.
- [16] Hill RE, Wakefield CE, Cohn RJ, et al. Survivorship care plans in cancer: a meta-analysis and systematic review of care plan outcomes. *Oncologist.* 2020;25(2):e351.
- [17] Borrelli B, Ritterband LM. Special issue on eHealth and mHealth: challenges and future directions for assessment, treatment, and dissemination. *Health Psychol.* 2015;34(S):1205.
- [18] Ramsey WA, Heidelberg RE, Gilbert AM, Heneghan MB, Badawy SM, Alberts NM. eHealth and mHealth interventions in pediatric cancer: a systematic review of interventions across the cancer continuum. *Psycho-Oncology.* 2020;29(1):17–37.

- [19] Chan RJ, Howell D, Lustberg MB, et al. Advances and future directions in the use of mobile health in supportive cancer care: proceedings of the 2019 MASCC Annual Meeting symposium. *Support Care Cancer*. 2020;28(9):4059–67.
- [20] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–57.
- [21] Signorelli C, Wakefield CE, McLoone JK, et al. A cost-effective approach to increasing participation in patient-reported outcomes research in cancer: A randomized trial of video invitations. *Int J Cancer*. 2021;148(4):971–80.
- [22] Mertens A, Williamson R, Gilleland-Marchak J, Meacham LR, Cherven B, Edwards P. Evaluation of the adoption, acceptance, and satisfaction of SurvivorLink as a communication tool for pediatric cancer survivors. *Am Soc Clin Oncol*. 2016;34(3) 89-89.
- [23] Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–88.
- [24] Lincoln YS, Guba EG. *Naturalistic Inquiry*. Sage; 1985.
- [25] Syed IA, Klassen AF, Barr R, et al. Factors associated with childhood cancer survivors' knowledge about their diagnosis, treatment, and risk for late effects. *J Cancer Surviv*. 2016;10(2):363–74.
- [26] Vetsch J, Fardell JE, Wakefield CE, et al. “Forewarned and forearmed”: Long-term childhood cancer survivors' and parents' information needs and implications for survivorship models of care. *Patient Educ Couns*. 2017;100(2):355–63.
- [27] Klosky JL, Cash DK, Buscemi J, et al. Factors influencing long-term follow-up clinic attendance among survivors of childhood cancer. *J Cancer Surviv*. 2008;2(4):225.
- [28] Ducassou S, Chipi M, Pouyade A, et al. Impact of shared care program in follow-up of childhood cancer survivors: An intervention study. *Pediatr Blood Cancer*. 2017;64(11):e26541.
- [29] Kim H, Goldsmith JV, Sengupta S, et al. Mobile health application and e-health literacy: opportunities and concerns for cancer patients and caregivers. *J Cancer Educ*. 2019;34(1):3–8.
- [30] Dallery J, Kurti A, Erb P. A new frontier: integrating behavioral and digital technology to promote health behavior. *Behav Anal*. 2015;38(1):19–49.
- [31] O'Reilly-Shah V, Easton G, Gillespie S. Assessing the global reach and value of a provider-facing healthcare app using large-scale analytics. *BMJ Glob Health*. 2017;2(3):e000299.