Designing A Provincial Surveillance and Support System for Childhood Cancer Survivors

Jennifer Shuldiner (✉ jennifer.shuldiner@wchospital.ca)

Women's College Hospital

Nida Shah

Hospital for Sick Children Research Institute: SickKids Research Institute

Catherine Reis

Women's College Hospital

Ian Chalmers

Pivot

Noah Ivers

Women's College Hospital

Paul Nathan

The Hospital for Sick Children

Research

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Abstract

Background Survivors of childhood cancer are at lifelong risk of morbidity (such as new cancers or heart failure) and premature mortality because of their cancer treatment. These are termed late effects. Therefore, they require lifelong, risk-tailored surveillance. However, most adult survivors of childhood cancer do not complete recommended surveillance tests such as mammograms or echocardiograms. Working with survivors, family physicians, and health-system partners, we are designing a provincial support system for high-priority tests, informed by principles of implementation science, behavioral science and design-thinking.

Methods Our multi-phase process was as follows: Step 1: a qualitative study to explore intervention components essential to accessing surveillance tests; Step 2: a workshop with childhood cancer survivors, family physicians and health system stakeholders that used the Step 1 findings and 'personas' (a series of fictional but data-informed characters) to develop and tailor the intervention for different survivor groups Step 3: intervention prototype development; and step 4: iterative user-testing.

Results The qualitative study of 30 survivors and 7 family physicians found a high desire for information on surveillance for late effects. Respondents indicated that in addition to providing personalized information, the intervention should help patients book appointments when they are due. Insights from the workshop included the importance of partnering with both family physicians and survivorship clinics and providing emotional support for survivors that may experience distress upon learning of their risk for late effects. In our user-testing process, prototypes went through iterations that incorporated feedback from users regarding usability and functionality. We sought to address the needs of survivors and physicians while balancing the capacity and infrastructure available for a life-long intervention via our health system partners.

Conclusion In partnership with childhood cancer survivors, family physicians, and health-system partners, we elucidated the barriers and enablers to accessing guideline-recommended surveillance tests and designed a multi-faceted solution that will support survivors and their family physician. The next step is to evaluate the intervention in a pragmatic randomized control trial.

Contributions To The Literature

- Design thinking and behavioural theory can be leveraged to address complex system problems in a manner that is compassionate and user-focused while also relying on insights from behavioral science.
- This paper outlines a multi-step approach to the development of scalable and long-term health system approach to address the surveillance needs of a childhood cancer survivors.

Introduction

Approximately 80% of childhood cancer survivors will develop a serious, life threatening or disabling late effect from their curative treatment by age 45(1). Cardiomyopathy and subsequent malignant neoplasms (particularly breast or colon cancer) are among the late effects with the greatest impact on both serious morbidity and premature mortality. North American guidelines(2,3) include recommendations for cancer surveillance (e.g., mammography/breast MRI in women with a history of chest radiation; colonoscopy in survivors treated with abdominal/pelvic radiation) and echocardiographic assessment in survivors at risk for cardiac dysfunction due to exposure to radiation to the heart or anthracycline chemotherapy.

Unfortunately, most adult survivors of childhood cancer do not receive recommended surveillance, placing them at risk for preventable harm(4). Our recent study of over 10,000 North American adult survivors of childhood cancer revealed that only 13%, 37% and 41% of high-risk individuals were currently adherent to recommended breast, colorectal, and cardiac screening, respectively(5).

A systematic review assessed the effectiveness of interventions promoting adherence to surveillance guidelines in adult survivors of childhood cancer(6). Only three trials assessed interventions to improve uptake of our targeted tests (colonoscopy, breast imaging and echocardiograms) in survivors of childhood cancer(7-9). These interventions were found to be resource intensive and as such, do not represent sustainable programs at a population level. Furthermore, interventions in these trials relied on survivors sharing educational materials with their primary care provider, rather than purposefully educating primary care professionals on the needs of childhood cancer survivors(7,8). This review, coupled with a recent review of interventions in routine risk populations to improve uptake of cancer screening,(10) indicated that personalizing the invitation for surveillance(11), ensuring primary care endorsement(12), and providing reminders(13) could each play an incremental role in increasing completion of recommended tests. In summary, a two-pronged intervention that engages both survivors and their primary care clinician has the potential to significantly reduce morbidity and mortality by improving adherence to surveillance guidelines.

Therefore, working with cancer health system partners, we embarked on a rigorous design process for an intervention to address cancer surveillance for late effects among childhood cancer survivors. Our approach used behavioral science and design-thinking. Behavioral science allowed us to employ relevant theories of behavior change to understand the factors that might influence surveillance adherence. We also used methods from design thinking, a “human-centered approach to innovation—anchored in understanding customer’s needs, rapid prototyping, and generating creative ideas”(14). Design thinking has recently been applied in healthcare to address patient experiences, clinical outcomes, and health care spending(15-17). We used such methods to gain a deeper, empathic understanding of the experience of adult survivors of childhood cancer. This paper outlines how we used these two methodologies in a multi-step process in the design of a provincial surveillance and support system for childhood cancer survivors.

Methods

We used a four-step approach to design a childhood cancer surveillance and support system to facilitate completion of surveillance tests (echocardiograms, breast MRI, mammograms and colonoscopy) among childhood cancer survivors (Table 1).

Step 1: We conducted a **qualitative study** among childhood cancer survivors and family physicians to explore intervention components that are essential regarding accessing evidence-based, high-yield surveillance tests. Semi-structured interviews with adult survivors of childhood cancer who were eligible for one or more of the surveillance tests of interest (but had not attended a specialized survivor clinic in over five years) were completed. Survivors were asked to specify the details of their primary care provider/family physician, who were then invited to participate in an interview. We have reported on a previous analysis, using the Theoretical Domains Framework (TDF)(18,19) and Behavior Change Techniques(20,21) to identify influences on accessing surveillance tests among survivors(22). In the current analysis we used qualitative methods, supported by the TDF, to identify specific barriers and enablers to accessing and providing surveillance tests as they relate to intervention components. Interview transcripts were coded line-by-line, thematically analyzed and described regarding how they were to be used to guide and shape the intervention.

Next, using design thinking methodology, we created personas(23) and journey maps based on our interviews and analysis. Personas are fictional characters that represent an archetype character. They helped identify the user's needs and wishes and enabled the team to engage and empathize during the design process. Journey maps are a visualization of the process that a person goes through to accomplish a goal. We used this tool to dissect the process a survivor goes through from discharge from pediatric care to various life stages. It helped the team to think about the different moving parts of follow-up for a childhood cancer survivor and assisted with illuminating areas of potential interest.

Step 2: We organized a one-day **co-creation workshop** in July 2020 that brought together childhood cancer survivors, primary care physicians and cancer health system partners. The objective of the workshop was to validate findings from Step 1 and then elicit ideas on design and content of the surveillance system. Our team worked with Pivot Design Group, a design firm, to develop and facilitate the workshop. Select childhood cancer survivors and physicians who participated in Step 1 were invited to participate. We purposively invited a diverse group of survivors who varied in age, location, and screening recommendations. After presenting findings from Step 1, including personas and journey maps we divided participants into three groups. Each group was assigned a persona and tasked with developing solutions regarding accessing surveillance for their persona (Figure 1). We wanted to evoke, understand and overcome pain points by idea generation and develop a long-term solution together. At the end of the session, each group presented their solutions followed by a discussion with the larger group. The session and breakout groups were recorded and data was extracted into broad categories: (1) content, (2) functionality, (3) design, and (4) barriers. Data was then compared across the different breakout groups, looking for similarities and differences.

Step 3: Working with survivors, physicians and health system partners, our team **developed the following prototypes:** (1) survivor invitation letter; (2) survivor information kit; (3) website; (4) survivor reminder letters; (5) physician information letter. Based on Steps 1 and 2, the following actions were taken to ensure the content was effective. First, we identified goals for each prototype and made sure that all components necessary to overcome barriers and enhance enablers (Behavior Change Techniques(20,21) from Step 1) were addressed. We also incorporated principles of design, including decisions on font, colors, logos. Finally, we made all decisions while considering the emotional impact that engaging with these materials would have on childhood cancer survivors.

Step 4: We used **user-centred design** methodology to iteratively refine the intervention materials and gain feedback on usability, feasibility and acceptability of the materials. Childhood cancer survivors who were eligible for the surveillance tests of interest (echocardiogram, mammogram/breast MRI and/or colonoscopy) but had not attended a specialized survivor clinic in over five years were invited from three such clinics in Ontario (some survivors were re-invited for an interview from Sept 1). Family physicians were recruited through social media and family medicine networks. In the first round, prototypes were low fidelity and screen share technology was used to show the materials to participants. Materials were then updated based on feedback and the design was improved with the help of a designer. In the second round of testing, materials were mailed to survivors and were opened during the interview. We used the “think-aloud” method – where participants were encouraged to share thoughts, likes and dislikes as they go through the materials. Interviews were recorded, data extracted, synthesized and thematically analyzed to understand the user experience. The team then reviewed results and made design decisions iteratively.

Research Ethics

This multi-step and multi-site study involved several components of research ethics approval. Step 1 of our study was approved by Clinical Trials Ontario, with The Hospital for Sick Children's Research Ethics Board acting as the Board of Record. Steps 2 and 4 were conducted using Women's College Hospital's QI approval process. Institutional approvals were sought at all relevant participating sites, as applicable.

Results

Step 1: Qualitative Study

We interviewed 30 survivors and 7 family physicians (Table 2). Childhood cancer survivors were keen to learn more information on their risk for late effects and surveillance recommendations. Concurrently, it was deemed crucial that survivors' emotions, including cancer-related anxiety, are addressed in the intervention. We learned that information on late effects and how to access surveillance may help empower survivors with the knowledge and tools necessary to complete tests, but that the intervention must also reduce the burden of remembering when tests are due and scheduling appointments. Based on the barriers and enablers identified, we developed personas and journey maps (Figure 1).

Our analysis of interviews with family physicians revealed that barriers to supporting childhood cancer survivors in their practice included physicians' unfamiliarity with long-term follow-up care guidelines for childhood cancer survivors, time constraints in each patient interaction, and limited support in unpacking the unique needs of childhood cancer survivors. It was vocalized that personalized information about their patient's needs would ensure that they could support their patient in accessing surveillance tests. Based on these interviews, we developed a surveillance concept which involved three components (Figure 2): (1) help reconnect childhood cancer survivor to the health system; (2) provide information on recommended screening tests; (3) remind survivors of upcoming screening tests.

Step 2: Workshop

Six childhood cancer survivors, three family physicians and three health system partner stakeholders attended the workshop. Stakeholders represented relevant provincial health system partner organizations. The workshop validated our surveillance concept (Figure 2) and provided key insights regarding the development of the intervention components. In terms of the invitation letter, we learned from survivors how receiving a letter regarding their cancer can be stressful and anxiety provoking. Interestingly, survivors were not concerned about privacy in receiving a letter identifying them as a childhood cancer survivor in the mail. The importance of involving the family physician in the intervention was highlighted. Family physicians expressed the desire to receive concise, clear information regarding the individual patient's history and next steps required. Survivors preferred different options regarding methods of communication (i.e., mail, e-mail, text messaging). Survivors communicated the importance of additional information if required, and a website for more information. Finally, survivors appreciated the idea of an "opt-in" program where the initial outreach only had general information and then they could choose if they wanted to receive personalized information regarding their risks and screening recommendations, including periodic reminders.

Step 3: Prototype Development

Prototypes were developed by establishing goals for each prototype, ensuring the content addressed the specific barriers and enablers from the qualitative study and the Behaviour Change Techniques identified (22) were implemented as intervention components (Table 3), and that the intervention components from the workshop were incorporated. For example, in the introductory letter and information kit for the survivors, we addressed the following: (1) personalized information on how to complete surveillance tests and information about health consequences of late effects, delivered in a impactful manner; (2) Prompts/cues to perform the required tests, and supports to enable surveillance while conserving mental resources; (3) persuasive information on the health benefits of surveillance; and (4) offering support to reduce fear of cancer and negative emotions linked to surveillance.

In recognition that survivors may feel anxiety or fear in receiving a letter about their childhood cancer, it was important to choose a colour scheme that would help survivors feel at calm and safe. We chose a blue as a dominant color since it has been shown to be associated with trust and confidence (24,25). To ensure buy-in from survivors, we knew it would be important to include recognizable logos. To lend

credibility to the program we included logos to link it to an already established and recognized organization.

Step 4: User Testing

Round 1: In the first round of user testing, we interviewed five survivors and two physicians (Table 4). Key insights and areas for improvement are highlighted regarding each prototype.

Invitation letter: Survivors did not find the letter overwhelming and were glad to learn about late effects. They appreciated our acknowledgment that learning this information could be stressful and that we provided a point of contact for additional support. There was some confusion related to the program flow (i.e., how do they access surveillance tests?), for which adjustments were made. Survivors expressed hesitancy in joining the surveillance program, with our analysis suggesting that this may stem from lacking a family physician, the survivor not feeling at risk for late effect(s), uncertainty of the benefits of the program, or experiencing fear related to surveillance tests. In the next iteration, we addressed these issues by highlighting benefits (physical and emotional benefit) and clear information on accessing a family doctor. Website: Survivors were glad to have a website with more information on late effects and the program. However, some were uncertain how to sign up. Survivors also found the website stale and boring and in the next iteration we strove to make the website aesthetically pleasing while maintaining a sense of importance and urgency. Information kit: Survivors' interest in the program increased after they saw the information kit. This demonstrated that it would be beneficial for survivors to have a better understanding of the information kit when then received the introductory letter. There was a range of desire for information and therefore we decided that the website would be a good forum to include additional information. There was also some confusion on "what's next" and the role of the survivor in the program. Changes were made to highlight the program flow and we highlighted the importance of bringing this information kit to their family doctor. Some survivors felt overwhelmed with the responsibility of taking on these surveillance tests. In the next iteration, we included empowering language and emphasized that their family physician would help them through the process. Reminders: Survivors wished to receive reminders via email. They also wanted more information regarding when their test was due instead of a simple message that they were due for a test. They felt that these reminders looked official and that would encourage them to book a test. Some expressed that they wished that these tests could be booked without a family doctor but that was not something we could address in the confines of this provincial health system in Ontario.

Physician information letter: We interviewed two physicians in the first round and the information letter was well received by both. These physicians were glad to know that the survivor would also be receiving their screening recommendations. They found the letter clear and concise but requested additional information on accessing tests and what to write on the requisition. They requested reminder letters to ensure that they could help their patients keep on track with their surveillance tests and this was developed for the next round of testing. It was important to them to see the logos of provincial health organizations on the letter.

Round 2: In the second round of interviews, we spoke with six childhood cancer survivors and six family physicians (Table 4). Overall, the design of the materials was well received and there were minimal suggestions for changes. Invitation letter: Survivors appreciated the opportunity to choose to learn more information on late effects and screening recommendations. They felt empowered with the new knowledge and supported to complete the recommended surveillance. They were enthusiastic to learn more through the program website and felt that this gave the program legitimacy. Some survivors questioned the credibility of the program and wondered how they knew their personal health information. Changes were made to explain the organizations that were supporting this program and why they had access to their personal information. Information kit: survivors found the kit clear, concise, and thought it would be useful to bring in to show their family physician. Reminders: were appreciated and thought of as an essential component of the program

Physician information and reminder letter: Some physicians found the tone of the letter to be prescriptive rather than collaborative. They also requested more information on their patient's cancer diagnosis and treatment history so they could have a more informed conversation with their patient. It was highlighted that it should be clear to physicians that it is possible the survivor did not receive information on late effects and surveillance. It was important for physicians that the patient was also engaged in the program and received a letter. They wanted the patients to be partners in their care and share responsibility of initiating contact with the physician to order the surveillance tests.

Finally, careful consideration of the feasibility of the study in the context of the infrastructure of our stakeholders was considered during this phase. For example, some users wanted a highly tailored information kit including that included many follow-up recommendations - this was not feasible with existing datasets that are being leveraged for this intervention. Survivors also requested an online portal where they could view their screening recommendation; however, stakeholders were concerned with privacy and were not interested in creating and maintaining a website with this type of information.

Discussion

Our design process used both behavioral theory and design thinking to develop a complex intervention aimed at increasing adherence to surveillance guidelines for late effects among childhood cancer survivors. We began with a discovery stage, where we identified important barriers, such as the burden of managing care and lack of knowledge among both survivors and physicians through a behavioral theory led process. Survivors' emotions, including cancer and surveillance related anxiety, required careful consideration. It was further emphasized by survivors that the support system must help with reducing the burden of remembering when tests are due and scheduling appointments. Personas and journey maps enabled our team to empathize and design with different types of survivors in mind (e.g. different stages of life and geographical location). During our design and build phase, we tailored the prototypes to best empower survivors, give them sufficient and clear information, address their fears, and provide them with necessary support, directions, and reminders to promote access to surveillance tests.

The result of this process is a design for a centralized system to identify high-risk survivors and provide them and their family physicians with personalized information about recommended surveillance and periodic reminders. Our surveillance and support system builds on existing recommendations put forth by the National Cancer Policy Board of the Institute of Medicine and the National Research Council to design systems of care that are responsive to the long-term needs of childhood cancer survivors as they transition from pediatric to adult care, improve awareness of late effects and their implications among survivors and augment professional education and training regarding late effects for primary care clinicians(26). Our next step is to implement and evaluate this intervention in a pragmatic randomized control trial with an embedded process evaluation.

Our discovery and iterative design process described in this manuscript led to new insights for this population and may help the development of other surveillance systems aimed to increase screening. For example, our discovery process highlighted the importance of engaging both physicians and patients simultaneously in the intervention so they can both be partners in care, a component missing from most previous interventions for childhood cancer survivors(6). We also demonstrated that by addressing and supporting emotional needs, and empowering individuals to take control of their health, outreach to a population with a complex health history is not only feasible but also welcomed. This barrier has not been thoroughly described or addressed in previous interventions aimed to improve adherence of surveillance guidelines in survivors of childhood cancer(6).

This study adds to the growing literature on the design of interventions using user-centered methodology and behavioral(27-31) and psychological(32,33) theory. According to our experience, we found using these two methodologies are compatible and beneficial. We were able to design for childhood cancer survivors in a user-centered empathetic fashion while also infusing rigor and systematic thinking by incorporating behavioral theory. There is growing need to address complex system problems in a manner that is compassionate and user-focused while also relying on insights from behavioral science at the various stages of design and evaluation.

To maximise the likelihood of implementation, we made sure to engage relevant stakeholders who will ultimately be rolling out the intervention if it is shown to be effective when tested in a pragmatic control trial. Therefore, during the design and build phase, we had to ensure that the design of our intervention would be compatible with operationalization. For instance, survivors voiced preference on which organization they would prefer to receive surveillance information from; however, we had constraints based on privacy and could not align our design with this preference. We also had to rely on the existing outreach infrastructure; therefore, we could not accommodate the physician preference to receive information on late effects and surveillance recommendations via fax. Other elements that were expressed as important during the co-creation workshop, such as a nurse navigator, were removed from the design as they were costly and not compatible with creating a sustainable intervention. This process has highlighted the importance of designing an intervention in tandem with ongoing conversations of the necessary stakeholders who will be delivering the program.

This work highlights the feasibility and value of using behavioral science and design-thinking in the development of a scalable and long-term health system approach to address the surveillance needs of a childhood cancer survivors. However, there are some limitations to our work. First, although we aimed to design the system based on needs of our users, we had to balance their wishes with the capacity and infrastructure of our health system partners. Second, we were only able to work with survivors who responded to our invitations, and the extent that these insights are generalizable to the general childhood cancer survivor community is unknown.

Conclusion

In this article we present an example of intervention design using behavioral theory and design thinking. In partnership with survivors, family physicians and health-system partners, we have elucidated actionable barriers and enablers related to completion of guideline-recommended surveillance by adult survivors of childhood cancer and designed a multi-faceted solution that will support survivors and their family physician. Further directions include evaluating this intervention through a pragmatic randomized control trial.

Declarations

- **Ethical Approval and Consent to participate:** This study obtained ethical approval and all participants consented to participate. The study was approved by Clinical Trials Ontario (project ID #1906), with The Hospital for Sick Children's Research Ethics Board acting as the Board of Record. All survivors and physicians gave informed consent to participate in the research study.
- **Consent for publication:** Authors have given their consent for publication.
- **Availability of data and materials:** Data collected in this study are interview transcripts and excerpts are available upon request, as per REB ethics.
- **Competing interests:** Authors have no competing interests to declare.
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- **Author Contributions:** JS, NS, NI, PN, IC contributed to the design and implementation of the research. JS, NS, CR, contributed to the data collection. JS, ND, NI, PN, IC, CR were involved in the analysis. JS drafted the manuscript and all authors reviewed and provided substantial input.
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Tables

Table 1: Stages of development of childhood cancer surveillance system

Intervention Stage		Objective	Methods used	Products produced
Discover	Theory-informed qualitative study(22)	Identification of key barriers, facilitators, needs, and challenges the intervention must address	Qualitative interviews	Personas and Journey maps
			Thematic analysis	Theoretical Domains Framework thematic framework
			Behavioral theory - Theoretical Domains Framework	Behavior Change Techniques to be addressed in intervention
			Design thinking	
Design and build*	One-day workshop	Creation of guiding principles to help summarize and easily refer to features of the intervention identified as central to achieving its objectives	Design thinking	Personas and journey maps Intervention components "worksheet" Validation of concept
	Development of prototype			Design of prototypes: survivor invitation letter; survivor information kit; website; survivor reminder letters; physician information letter
	User-testing design*	All intervention components evaluated in detail and optimized from survivor and physician perspective	Two rounds of iterative user-testing Think-aloud methodology	Iterative changes to prototypes developed with each round Documented changes
Evaluate	Pragmatic randomized control trial[∞]	Intervention evaluated in real-life context(s), modified to improve implementation in future contexts		

*we met regularly with stakeholders to review the emergent intervention design

[∞] To be completed in 2022-2023 (not reported in this paper)

Table 2: Characteristics of childhood cancer survivors, N=30 and family physicians, N=7

	Characteristics	N	%
Childhood cancer survivors	Age, mean SD	41.0 ±10.5	
	Frequency of doctor visits		
	≤ once a year	27	90
	> once a year	1	3
	Undetermined/Very infrequently	2	7
	Location		
	Urban	22	73
	Rural	8	27
	Gender		
	Female	18	60
	Male	12	40
	Highest level of education attained		
	Less than high school	1	3
	High school	1	3
	College/University/Graduate	28	94
	Type of Cancer		
	Lymphoma	10	33
	Leukemia	7	24
	Neuroblastoma	2	7
	Wilms' Tumour	3	10
	Bone tumour	5	16
	Liver tumour	3	10
	Age, mean SD	45, ±14	
	Years in practice, mean SD	17, ±14	
Family physicians	Age, mean SD	45, ±14	
	Years in practice, mean SD	17, ±14	

SD-standard deviation

Table 3: Prototype development

Discovery phase				Design and build
Item	Goals	Domains of the Theoretical Domains Framework(18,34)	Behavior Change Techniques addressed*(20)	Opportunities to implement the Behaviour Change Techniques as intervention components
Survivor invitation letter	Generate awareness of late effects and surveillance guidelines	Knowledge (of late effects)	Biofeedback	Information on how to obtain surveillance
	Reconnect childhood cancer survivors to the health system		Instruction on how to perform behaviour	Information about health consequences of late effects
	Confirm identity		Information about antecedents	
	Offer personalized information		Information about health consequences	
	Determine preferred method of contact (email, mail, text)		Information about social and environmental consequences	
	Confirm primary care provider	Emotion (fear of cancer)	Reduce negative emotions	Advise on ways to reduce fear of cancer and negative emotions linked to surveillance
Survivor information kit	Provide tailored information	Beliefs about consequences (of surveillance)	Information about health consequences	Provide information on health benefits of surveillance in an effective and memorable manner and awareness of possible regret if surveillance is not performed
	To enlist action: share with primary care provider		Salience of consequences	
			Information about social and environmental consequences	
			Anticipated regret	
			Information about emotional consequences	

		Intention (to complete surveillance tests for late effects)	Goal setting (behaviour) Information about health consequences Self-incentive	Provide information about emotional benefit of completing surveillance and tips regarding self-incentive if surveillance is performed.
Website	Increase legitimacy of program A place to find more information if desired	<i>See knowledge, emotion, beliefs about consequences</i>		
Survivor reminder letters	Ensure survivors do not forget about surveillance test To enlist action: reach out to physician to book test	Memory, attention, and decision-making (Reminders)	Prompts/cues Conserving mental resources	Prompts/cues to perform surveillance Enable surveillance completion while conserving mental resources
Physician information letter	Education on patient history and surveillance recommendations To enlist action: contact survivor and use their electronic medical record to schedule reminders	Knowledge (of late effects)	Instruction on how to perform behaviour Information about antecedents Information about health consequences Information about social and environmental consequences	Information on patient's cancer history, risk of late effects and surveillance recommendations

* An international consensus project identified a list of 93 Behavior Change Techniques as elemental components of interventions. It was developed to help intervention designers, researchers and theorists in the development and evaluation of theory-based interventions. Published linkage of Behavior Change Techniques s to Theoretical Domains Framework domains is based on triangulating relationships found in published studies and by expert consensus [see <http://www.ucl.ac.uk/behaviour-change-techniques>].

Table 4: Characteristics of participants in user-testing, N=11

	Round 1, N=5	Round 2, N=6
Gender		
Male	3	2
Female	2	4
Age, mean SD	35±8	37±10
Location		
Urban	3	3
Rural	2	3

Figures

Persona: Justin

Age: 35 years old
Location: Elmvale
Sex: Male
Marital Status: Single

Traits:

Unwell ----- [Well]
[Unaware] ----- Aware
Avoidant ----- [---] Engaged
[Anxious] ----- Relaxed

Cancer History: Justin had bone cancer as a teenager. He was in and out of treatment for 3 years and received radiation to the pelvis and anthracycline chemotherapy.

Scenario Story: Justin went to the After-Care clinic once but had a bad experience— he also lives far away. He never went back. He is nervous about his health and went to his family but all she did were blood tests and he hasn't been back in 6 years.

At risk for colon cancer and heart issues

Cardiogram / 2 years
Colonoscopy / 5 years

"I haven't had a checkup in probably six years. But- it still bugs me a little bit, because obviously there's a greater chance of getting cancer."

JUSTIN'S JOURNEY MAP TO SCREENING – 35 years old

	Transition from SickKids Age 18	Follow up at PMH Age 19	No follow-up Age 20+
Screening 		Echocardiogram/2years	Echocardiogram/2years Colonoscopy (30 years)/5 years
Medical Activities 	discharge from SickKids referral to adult clinic	blood work echocardiogram	no doctor in 8 years
Pain points 	sad to leave providers abandoned nervous for the real world	doesn't like being in hospital care is impersonal	forgotten vulnerable no support
Experiences 		long travel long wait lack of information	unaware of screening want follow-up want support
Insights 			connect with family doctor education for survivors / providers Need for support

Figure 1

Example of personas and journey maps

Figure 2

Childhood cancer survivor surveillance concept