JOURNAL OF ADOLESCENT AND YOUNG ADULT ONCOLOGY
Volume 00, Number 00, 2026
Mary Ann Liebert, A Part of Sage
DOI: 10.1177/21565333261445409

Development and Pilot Evaluation of REFLECT: A Digital Health Application Supporting Fertility and Genetic Decision-Making in Adolescent and Young Adult Oncology

Sarita Pathak Desai, PhD,[1] Lindsay Fuzzell, PhD,[2] Paige W. Lake, PhD,[2] Moran Snir, MSc,[3]
Emilie Simmons, MS,[3] Tara Schmidlen, MS, CGC,[3] Jonathan Metts, MD,[4] Gwendolyn P. Quinn, PhD,[5,6]
and Susan T. Vadaparampil, PhD, MPH[2,7]

Purpose: Adolescent and young adult (AYA) patients with cancer face complex decisions about family building, often compounded by misconceptions about hereditary cancer risk. Although guidelines recommend early discussion of fertility- and genetics-related risks, these topics are inconsistently integrated into routine care. To address this gap, we developed *Reproductive Education and Fertility Links for Cancer Treatment* (REFLECT), a digital health application designed to provide education and decision support related to fertility, genetic risk, and future family building for AYAs with cancer. This study developed and pilot-tested REFLECT to support informed decision-making.

Methods: REFLECT was developed using evidence-based content and implemented on a web-based platform integrating multimedia education and decision support. Two iterative rounds of user testing were conducted with AYA survivors (ages 18–39) using a Learner Verification framework to assess comprehension, usability, relevance, and acceptability. Participant feedback informed iterative refinements.

Results: Participants ($N = 16$) reported that REFLECT was engaging, easy to navigate, and relevant to fertility, genetics, and future family-building concerns. Iterative testing identified opportunities to improve navigation, accessibility, and content organization, which were addressed through refinement. Participants reported increased confidence in discussing fertility preservation and genetic risk with providers and emphasized the value of an integrated patient-centered tool, particularly at the time of diagnosis.

Conclusion: This pilot demonstrates that REFLECT is feasible, acceptable, and usable among AYAs. By integrating fertility and genetic risk education with decision support in an accessible digital format, REFLECT addresses a critical gap in AYA oncology care. These findings support further evaluation in clinical settings.

Keywords: Adolescent and Young Adult (AYA) Oncology, Oncofertility Care, Family Building, Genetic Risk, Decision-Making, Digital Application

Introduction

Adolescent and young adult (AYA) patients with cancer face complex decisions related to future family-building options, often compounded by concerns of hereditary cancer risk and long-term effects of cancer treatment. Although approximately 10% of AYA cancers are hereditary,[1–3] many perceive their cancer as hereditary regardless of clinical confirmation.[4] Notably, 65% of female AYA cancer survivors reported concerns about transmitting

---

[1] Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, New York, USA.
[2] Department of Health Outcomes and Behavior, H. Lee Moffitt Cancer Center & Research Institute, Tampa, Florida, USA.
[3] Nest Genomics, New York, New York, USA.
[4] Sarcoma Department, Moffitt Cancer Center, Tampa, Florida, USA.
[5] NYU Grossman School of Medicine, New York, New York, USA.
[6] Department of Obstetrics and Gynecology, NYU Grossman School of Medicine, New York, New York, USA.
[7] Community Outreach & Engagement, H. Lee Moffitt Cancer Center & Research Institute, Tampa, Florida, USA.

cancer risk to future offspring, regardless of mutation status.[4] Such misconceptions can influence reproductive decision-making, highlighting the need for accurate, developmentally appropriate education early in the cancer care continuum.[5–11]

Recognizing these challenges, professional societies (American Society for Reproductive Medicine,[12] American Society of Clinical Oncology,[13] National Comprehensive Cancer Network[14]) recommend early counseling regarding fertility risks, reproductive options, and referral to genetic services for patients undergoing gonadotoxic therapies. Despite these guidelines, the majority of AYA patients report not engaging in discussions regarding fertility preservation (FP) or genetic risks at diagnosis.[15–25]

Consultations with reproductive and genetic specialists can clarify hereditary risk and inform decisions related to genetic counseling (GC), genetic testing (GT), and reproductive planning.[26,27] Yet, these services are not uniformly integrated into standard AYA oncology care.[17,28–31] AYA patients express strong preferences for receiving this information before or during treatment planning rather than after treatment completion.[27,32] However, access to reproductive and genetic specialists is often limited, and referral practices are inconsistent across clinicians and institutions.[17,27–31,33] Furthermore, patients who decline genetic services often report a desire for better education about genetic risk,[34–37] while others outside typical referral criteria still seek information to guide family-building decisions.[27]

Psychosocial barriers further complicate addressing AYAs' genetic risk and future family-building concerns.[38] Uptake of GC/GT among eligible patients remains low (14%–36%), with even lower rates among racial and ethnic minority populations.[39–41] Common reasons for declining GC/GT include limited knowledge of genetic risk, cost-related concerns, and fears of discrimination.[34–37] Awareness of reproductive technologies such as preimplantation GT is also limited.[26] Despite substantial fertility-related distress and preferences for earlier communication, discussions about fertility and genetic risk are often delayed or absent.[27,38,42] Thus, interventions must address psychosocial barriers while optimizing the timing, format, and accessibility of education and decision support.

Psychoeducational interventions have demonstrated efficacy in bridging knowledge gaps, addressing psychosocial barriers, and facilitating behavior change.[43–47] Digital health applications are increasingly utilized in oncology to deliver education and support decision-making.[48–50] AYA patients demonstrate a strong preference for digital formats over traditional paper-based education and show enhanced engagement with mobile and web-based technologies.[51,52] Use of mobile health (mHealth) applications has been associated with improvements in AYA patients' cancer knowledge, treatment adherence, and communication with clinicians.[53]

However, although digital tools have been developed to address genetic risk in hereditary cancer populations (e.g., Rosa chatbot for BRCA-related cancers[54] and NEST CRC, an educational platform for early-onset colorectal cancer[55]) and fertility-related concerns among AYAs (e.g., the Fex-Can Fertility program[56]), existing interventions typically focus on either genetics or fertility, rather than the intersection of both. Moreover, many tools are tailored to adult populations or address single domains such as distress management or self-help.[52,57] Currently, there is no integrated digital intervention designed to support both genetic risk communication and fertility in AYA oncology.

In response to these gaps, this study presents the development and preliminary evaluation of the *Reproductive Education and Fertility Links for Cancer Treatment* (REFLECT) digital health application, a theory-informed digital health tool designed to deliver integrated education and decision support for AYA patients with cancer. The overarching objective was to develop and iteratively refine the REFLECT application through successive rounds of user testing and to present preliminary findings on its feasibility and potential to enhance informed family-building decision-making among AYA patients with cancer.

Methods

Intervention description

REFLECT is a web-based digital health application that provides integrated education and decision support related to FP, genetic risk, and future family building for AYA patients with cancer. The educational framework was informed by prior formative research with AYA survivors and providers examining the intersection of these domains.[27]

Developed in partnership with Nest Genomics, REFLECT adopts their customizable, HIPAA-compliant, cloud-based platform. The Nest Platform[55] functions as a "genetic companion," supporting patient engagement through delivery of educational content and care-related tasks. The platform incorporates accessibility features (e.g., adjustable font size, audio content, inclusive imagery) and delivers developmentally appropriate content for clinical settings and home use.

REFLECT adapts the Nest platform to deliver multimedia education to AYAs with cancer. The adapted application includes core sections addressing fertility and genetics in cancer and future family building. Specifically: (1) "Learn Library": self-paced educational resources; (2) "Understanding how cancer impacts fertility": effects of cancer and treatment on reproductive health; (3) "Reviewing FP options": pathways for future family building; (4) "Paying for fertility treatment": financial considerations and resources; (5) "The

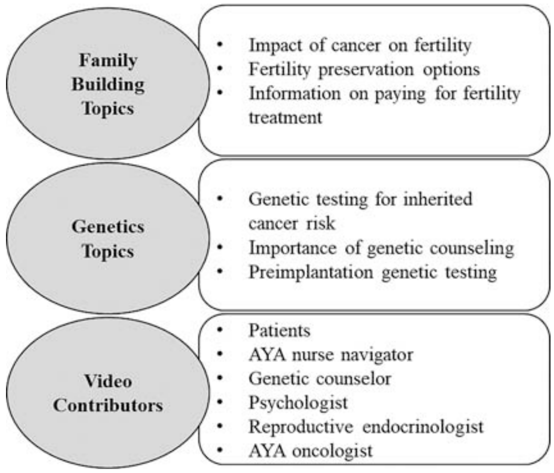
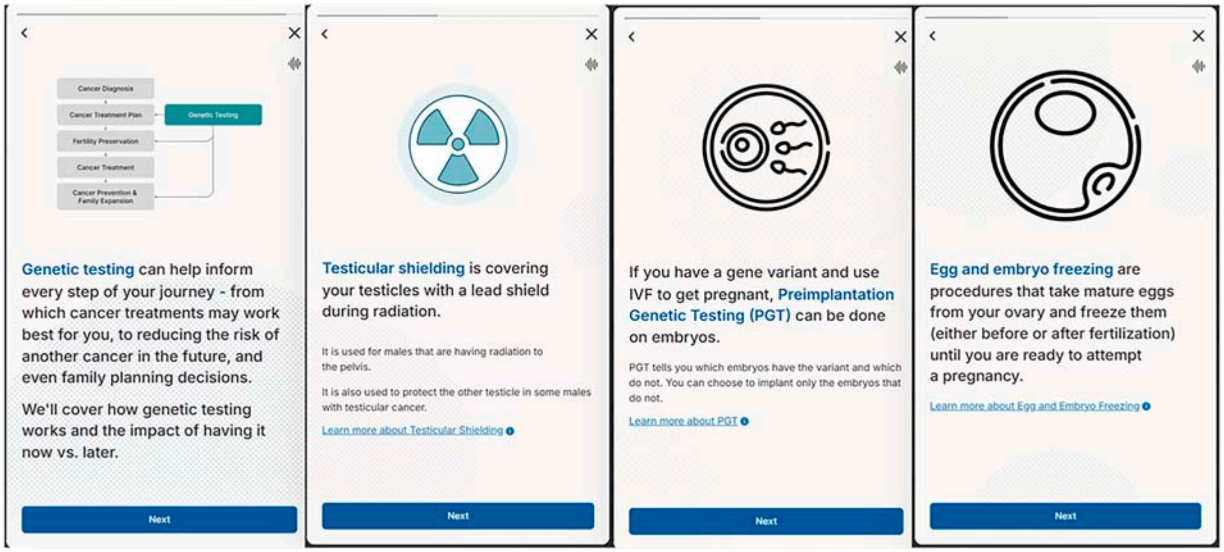


FIG. 1. Topics included in REFLECT. REFLECT, *Reproductive Education and Fertility Links for Cancer Treatment.*



Genetic testing can help inform every step of your journey - from which cancer treatments may work best for you, to reducing the risk of another cancer in the future, and even family planning decisions.

We'll cover how genetic testing works and the impact of having it now vs. later.

Testicular shielding is covering your testicles with a lead shield during radiation.

It is used for males that are having radiation to the pelvis.

It is also used to protect the other testicle in some males with testicular cancer.

Learn more about Testicular Shielding

If you have a gene variant and use IVF to get pregnant, **Preimplantation Genetic Testing (PGT)** can be done on embryos.

PGT tells you which embryos have the variant and which do not. You can choose to implant only the embryos that do not.

Learn more about PGT

Egg and embryo freezing are procedures that take mature eggs from your ovary and freeze them (either before or after fertilization) until you are ready to attempt a pregnancy.

Learn more about Egg and Embryo Freezing

FIG. 2. Example REFLECT screenshots depicting educational and interactive features.

importance of genetic testing": hereditary cancer risk, GC/GT, and reproductive implications; and (6) "Decision-Making": a values-based decision support tool[58] to clarify priorities, assess readiness for services, and support question generation for clinical encounters (Figs. 1 and 2). The content is modular, allowing flexible engagement based on individual needs.

Prior to piloting, the prototype underwent expert review by clinicians and researchers in oncology, oncofertility, and cancer genetics, with feedback informing refinements to clinical accuracy, clarity, terminology, and educational flow.

Participant recruitment

Participants were AYA cancer survivors aged 18–39 who had received care at an NCI-designated comprehensive cancer center. Eligibility criteria included (1) history of cancer diagnosis, (2) ability to speak and read English, (3) consideration of having children in the future, and (4) access to an internet-enabled device. All participants had completed primary cancer treatment at the time of participation and reflected on their experiences with fertility- and genetics-related decision-making. Participants were recruited through institutional referral networks, AYA program listservs, and targeted outreach. All participants provided verbal informed consent. The study was approved by the Moffitt Cancer Center Scientific Review Committee and Advarra Institutional Review Board (MCC #22569).

Learner Verification interviews

User testing was conducted using a two-round iterative design. In each round, participants interacted with REFLECT during individual semistructured interviews conducted via Zoom. Interviews were guided by a Learner Verification (LV) framework[59,60] and incorporated a Concurrent Think-Aloud[61] approach, in which participants were asked to verbalize their thoughts, reactions, and interpretations while navigating the tool in real time. Semistructured interview guides assessed key domains central to application development, including (1) comprehension and ability to process information, (2) usability and navigation, (3) relevance to personal decision-making needs, (4) accessibility and design features, and (5) overall acceptability and cultural appropriateness.[59,60]

Participants were additionally encouraged to identify areas of confusion and recommendations for improvement. Round 1 participant feedback was synthesized to identify usability challenges and guide refinements in collaboration with Nest Genomics. A second group of participants then evaluated the revised version of REFLECT in Round 2 using identical procedures. This iterative process ensured that participant feedback directly informed successive refinements of the tool.[59,60]

Usability was assessed using five items adapted from the System Usability Scale (SUS)[62,63] at the conclusion of each interview. Participants rated each item on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree), with negatively worded items reverse-coded. Items assessed perceived ease of use, complexity, confidence using the tool, integration of features, and likelihood of future use.

Data analysis

Qualitative data were analyzed leveraging a thematic analysis approach[64] integrating both deductive and inductive coding. Domains were guided by LV constructs[59,60] with additional emergent domains identified inductively. A preliminary codebook was developed through independent coding of two transcripts by two coders (S.P.D., P.W.L.), followed by consensus meetings. All transcripts thereafter were double-coded, and discrepancies were resolved through discussion. Inductive themes were developed through pattern recognition across transcripts. Saturation was defined as no emergence of new themes during interim analysis.[65] Findings were synthesized after each round to inform iterative refinement of REFLECT.

Qualitative analyses were conducted in MAXQDA[66] and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research guidelines.[67] Quantitative data were analyzed descriptively. Given the adapted version of the SUS, usability data were summarized using item-level descriptives rather than a summed score.

Results

Participant characteristics

Two independent samples participated in two rounds of user testing (Round 1, $N = 10$; Round 2, $N = 6$), for a total sample of 16 participants. Participants had a mean age of 34 years (range 26.9–39.7); were primarily female (75%), White (62.5%), and non-Hispanic (93.8%); and had completed a college degree or higher (87.5%). Cancer diagnoses included breast cancer (18.8%), lymphoma (18.8%), colorectal/rectal cancer (18.8%), thyroid cancer (12.5%), and other malignancies (Table 1).

LV-guided qualitative findings

Findings were consistent across rounds, with no substantively new domains emerging in Round 2. LV-guided domains and emergent themes are summarized in Table 2 by interview round.

Attraction. Participants across both rounds described REFLECT as engaging, visually appealing, and easy to approach. Concise text, structured layout, and visual design were perceived to reduce information overload, particularly when engaging with fertility- and genetics-related content.

Comprehension. AYAs demonstrated strong comprehension of the REFLECT content. Across rounds, participants reported that the information presented was clear and understandable, with several highlighting the benefit of the multimedia format and opportunity for self-directed learning. Participants described content as digestible and appropriately paced, with one noting, *"the micro learning per slide is how society works today, with attention span…"* (male, colorectal cancer). Specific to the genetics content, one participant noted, *"I think genetics can be very overwhelming. And that broke it down to be easy to read, or easy to understand, not too overwhelming, too stressful"* (female, AML). Others noted that breaking topics into smaller sections and embedding links enhanced comprehension.

Cultural acceptability. Participants consistently reported that REFLECT was culturally acceptable and respectful of

Table 1. REFLECT Pilot Sample Characteristics ($N = 16$)

	Round 1	*Round 2*	*Total* N = *16*
Sociodemographic characteristics			
Age (mean)	34.1	34.3	34.2
Gender			
Male	3	1	4
Female	7	5	12
Race			
American Indian/Alaska Native	—	—	—
Asian	2	—	2
Black/African American	—	1	1
Native Hawaiian or other Pacific Islander	—	—	—
White	7	3	10
More than 1 race	1	2	3
Ethnicity			
Hispanic/Latino	1	—	1
Not Hispanic/Latino	9	6	15
Completed years of education			
8 or Less	—	—	—
Some high school	—	—	—
High school graduate or GED	—	—	—
Some college	2	—	2
College graduate or beyond	8	6	14
Health insurance (Yes)	10	6	16
Employment			
Not employed	1	—	1
Full time	9	3	12
Part-time	0	3	3
Retired	—	—	—
Student	—	—	—
Other	—	—	—
Cancer characteristics			
Cancer type			
Breast	3	—	3
Lymphoma (large B-cell, hematological)	2	2	4
Colorectal/Rectal/Colon	3	1	4
Thyroid	1	1	2
Acute myeloid leukemia	—	1	1
Bladder cancer	1	—	1
Sarcoma	—	1	1

Table 2. Key Qualitative Domains and Exemplar Quotes Informing Iterative Refinement of the REFLECT Tool

	Exemplar quotes	
Domains	*Round 1*	*Round 2*
Learner verification-guided domains		
Attraction	"I do like that there's not that many words on a page. I think that's probably the most important thing to me, because it's very overwhelming when you get into this stuff. And every new layer is like, 'Oh, my god. This is a thing I have to think about, too.' So, it's hard to focus, especially on the adult stuff, when you can't even just be like, 'Let me just get my chemo and move.'" (Male, colon cancer) "That I wished that I had it when I was diagnosed... almost five years ago. I really thought it was very user friendly. I liked that it stepped me through different options of fertility preservation. I liked that there were gender specific questions in there because those options change based on what gender you are. I don't have to sit through looking at what male fertility preservation looks like, you know, and vice versa. I thought that was very thoughtful." (Female, breast cancer)	"I think everything is nice and concise. You have short sentences that get right to the point. In this one, you had really good graphics to help you understand the information. You had bullet points. I think it's laid out very simply and effectively." (Female, rectal cancer) "I think it's the fact that you guys do a good job, or whomever created it, if you did. I think it's good amount of information per slide and then I think you also do a good job giving a synopsis first in a large—In this particular slide, it's like you give the hard-hitting info in big letters and then you talk about it a little bit more or give more further information below. It's very digestible amounts of information at the moment as you're reading, again, to encourage you through the story." (Female, thyroid cancer) "I do like all the little imagery, the colors. It's clean, easy to understand, it's organized nicely, there's no typos that I found. And I like the examples of questions, that's helpful." (Female, large B-cell lymphoma)
Comprehension	"Very easy. I think the micro learning per slide is how society works today, with attention span. So, I think it's great so far. I think we started out with some definitions, and helping give somebody a clear understanding." (Male, colorectal cancer) "Oh, and I like this one because I understood it more. Because I was like, 'Hmm, I could have cancer that could get in the way of infertility. Because I've heard people say it before, but then I guess I didn't know for sure if it could happen to me type of thing. So, then this part helped me understand it more with how it could happen.'" (Female, bladder cancer) "I thought that was good, too, because I didn't really understand what they meant. I knew it was about being able to get pregnant or not, but I like how it goes more in depth about infertility and then about the 12% of people being born with infertility and just how it goes more in depth of those definitions." (Female, bladder cancer)	"Yeah, this is very easy to understand. It's asking me, 'Is embryo freezing an option you're considering?' Yes, at the time I would've considered all of this. Or, 'Is ovarian tissue freezing an option?' Yes. And I like how at the bottom it explains what ovarian tissue freezing is, 'cause a lot of people didn't even know that was a thing.'" (Female, heme-malignancy) "I think it's the amount that you guys have broken up the topics and then adding in—like in this slide on immunotherapy, you can learn more about immunotherapy. Having those links is helpful and then, again, the amount of information per page is digestible. It doesn't make you feel like you have to read a novel per page." (Female, thyroid cancer)
Cultural acceptability	"No, I think it was very inclusive. For my values and cultural experience, it was fine." (Male, colorectal cancer)	"As a Catholic, or growing up Catholic, maybe there's some feelings like, 'Let God decide,' kind of a thing. But I think if you are looking for that scientific base background to help you on your decision, everything that's on this tool, I think, is very clear and understand and is not offensive in any way." (Female, rectal cancer)
Perceived relevance	"I think it's relevant to my age group. I think it's very, again, well-presented and easy for my age group to understand, even with minimal or no background in health care terminology." (Female, breast cancer) "Well, I'm going to get extremely philosophical. I was diagnosed with Stage 4 colorectal cancer. Colorectal cancer has seen a huge uptick in early onset colorectal cancer in younger adults. So, in my opinion, it might become the number one cancer for that age group, in which people are probably looking to reproduce. And so, arguably, I would think it's extremely important, extremely important; especially for this age group, this particular cancer, even. A lot of reasons." (Male, colorectal cancer)	"I think it's very relevant. I'm 39 so either people are having kids or have just had kids. I think if someone my age was going through cancer treatment, I think this would be very important for them." (Female, rectal cancer) "I like that one because... So, the lady on there, she does not look like she's in her 20 seconds or she's a teen. So, for me, she's a little older, but that makes me feel not alone in being older and still wanting kids, if that makes sense." (Female, heme-malignancy)

(*continued*)

TABLE 2. (CONTINUED)

Domains	*Exemplar quotes*	
	Round 1	*Round 2*
	"I think I mentioned at the beginning of the interview—this would have been really, really helpful to have at the beginning of my diagnosis. It lays it out in a very simple manner. It reminds me of how I've been through these questions. I've looked at this information. This is the decision that I came to without having to flip back through it again. I really have to say if you keep anything in this tool, please keep the questions to your care team at the end. I think that's just a huge, huge thing." (Female, breast)	
Usability	"Very easy to use. Very easy, intuitive. It wasn't too burdensome, didn't overload me with information. And then, the links at the end after I completed my to-dos, showing me the repository of all the videos and other pages that I could go through. Very helpful." (Male, colorectal cancer) "I thought that everything was very organized and easy to find everything, too. When you click on the things, it's very fast, too, like when you click 'Next' and all that and being able to get to all the different tabs that you wanna get to. So, it's easy to navigate, and I like the colors and everything with it, too, because they're easy to read. But having some of them in different color text, that helps stand out for other places, like in this paragraph and other paragraphs and stuff." (Female, bladder cancer)	"Yeah. So, you're telling them you call the number on the back of your card and ask these questions. I love that part. That way you'll know before you even do the testing if you gonna qualify according to your health insurance." (Female, heme-malignancy) "I thought it was great. I thought it was highly effective. I thought it was easy to get through. It was digestible. I didn't feel like I was taxed having to click through it. I thought it was quick to get through but still highly effective." (Female, thyroid cancer)
Related emergent domains		
Accessibility and navigation	"I mean, honestly, it was easy just from the link that you sent. It logs you in automatically, so you don't have to worry about saving credentials or remembering them or anything. Just going and clicking right from the link, I like that. And it was straightforward and pretty intuitive." (Female, large B-cell lymphoma) "Yeah, because it's not overwhelming. It's very like you can put it down and come back to it like to do the to do list. You can kind of check through each option. You can look at the videos that interest you. You can watch the stories that interest you. Then, you can skip what doesn't apply to you. It's not huge in terms of time commitment. I think time is so precious right at the beginning of a diagnosis. Right. You're trying to figure out what to prioritize. It probably took me 15 minutes to go through it." (Female, breast cancer)	"I thought it was really straightforward. I think it gave me some initial questions and then it gave me tasks on the to dos that it says I'm all good here. It was very straightforward of once you go through all of the to dos, you've seen the content that they've recommended to you. I thought it was very straightforward." (Female, thyroid cancer)
Communication self-efficacy	"I think it gives you a lot of knowledge and empowerment to ask questions that are important to you without having to search google and listen to podcasts and all of that stuff to learn more about it. It's kind of an all-in-one thing tool." (Female, breast cancer) "I feel like it would definitely help. Like I said, the information in a short and simple way, that way you can already start coming up with what questions you wanna ask yourself, or questions you wanna ask your spouse, or significant other, and then what questions you wanna ask your doctor. And it definitely starts the brain going, which is key, especially in the younger generation; getting them to ask themselves questions to make sure they're making educated decisions rather than just going all willy nilly into it. Yeah." (Male, rectal cancer)	"Yes. 'Cause even if you don't like talking, or you're shy, you could print this out and give this to the nurse and just be like, 'Hey, this is something I wanna talk about today.' And hand this to them." (Female, heme-malignancy) "I definitely think it posed new questions that I didn't think I would need to ask, but knowing now the information that I do from the tool, it definitely has sparked the question of I need to make sure that this okay for me. Or, if I need to take any steps to preserve my reproductive health going forward. Then, that's definitely given me a good place to start having those conversations." (Female, thyroid cancer)
Perceived usefulness	"I found what was most useful was him sharing his personal experience as well as giving tips and also being realistic in a sense of, again, sharing his experience, giving the reality of the facts of it, that it is a process, but he was still able to manage to make it positive and not	"I think by having this tool, it's helpful for a patient to know that this is an important part of their future. Because I feel like when I was going through my initial chemotherapy and cancer treatment, it felt almost like 'You're fighting for your life, how dare you think about

(*continued*)

TABLE 2. (CONTINUED)

Domains	*Exemplar quotes* *Round 1*	*Round 2*
	focus so much on the negative, scary parts of it." (Female, breast cancer) "I think it's very nice. It's really helpful. I'm glad that *y*'all are coming up with something like this for cancer patients because it's definitely something that's needed in our area." (Female, large B-cell lymphoma)	having children in the future?' That kind of feeling. By having this and talking about this, it feels like there is a place for it when you're talking about your cancer treatment." (Female, rectal cancer) "I think this is great. This is a wealth of knowledge all in one place. And you can just do it at your leisure, so that's good." (Female, large B-cell lymphoma)

personal values. Content was perceived as inclusive and nonoffensive across both rounds.

Perceived relevance. Participants described the tool as highly relevant to their needs related to fertility, genetics, and future family building. Several participants highlighted the value of having FP and genetic risk information integrated within a single, patient-centered digital platform, noting that this addressed gaps in prior care experiences. One participant stated, *"My overall impression was that it was very helpful, and especially with my past experience, because with my past experience, to be honest, I was just given a couple pieces of paper, like a pamphlet..."* (female, breast cancer).

Usability. Across both rounds, REFLECT was described as user-friendly, intuitive, and easy to navigate. The organization and pacing of content were viewed as facilitating efficient engagement without contributing to cognitive overload. One participant noted, *"Very easy to use. Very easy, intuitive. It wasn't too burdensome, didn't overload me with information... I thought it was quick to get through but still highly effective"* (male, colorectal cancer). Clear navigation and visual design further supported usability.

Related emergent domains

Accessibility and navigation. Participants noted that the application was accessible, describing the layout as intuitive and the content as easy to locate and navigate. Audio features and visual organization supported accessibility, particularly for alternative learning preferences.

Communication self-efficacy. Participants reported that REFLECT supported communication self-efficacy by clarifying priorities, reducing pressure around sensitive treatment decisions, and preparing them for conversations with providers. One participant explained, *"I like that it's very clear that there's no right or wrong choice... Decisions can feel like there's a lot of pressure. Having that statement feels very low pressure... I liked being able to go within a rating system... especially if this is a tool that gets shared with a provider. I think that allows you to communicate your desires with your provider more clearly"* (male, colon cancer). Participants attributed these effects to the values-based decision support component, which helped structure thinking, articulate preferences, and build confidence navigating clinical interactions. As one participant noted, *"You're giving us guidance on how to go into our appointments... you don't know what to ask. You don't even know what that doctor is called"* (female, heme-malignancy).

Perceived usefulness. REFLECT was found highly useful due to its ability to consolidate fertility and genetic information that had previously been fragmented or difficult to access. Several participants noted that having integrated, patient-centered content in a single digital tool made information easier to engage with and apply to their own care. One participant reflected, *"I think that it helps give people the confidence that they need to talk to their oncologist... I spent a lot of time during my cancer journey trying to get this information and I felt like a lot of it was in that tool"* (female, rectal cancer).

Iterative refinement of REFLECT

Despite overall positive perceptions, participants identified minor usability and accessibility challenges during Round 1 testing. Areas for improvement included difficulty locating resources, clearer "Learn Library" navigation, requests for audio features, and streamlined content organization. One participant requested, *"Is there any way that we could maybe change the organization of it or anything like that to make it more useful or intuitive?"* (female, thyroid cancer). Another emphasized the importance of making the "Learn Library" more visible, stating, *"I don't really have much other than maybe put the learn section in the dashboard or homepage, because I definitely didn't look all into that. Because sometimes, with these new apps, you don't really go to look at the little page thing"* (female, large B-cell lymphoma).

In response to this feedback, the study team collaborated with Nest Genomics to update the platform. Revisions included restructuring the "Learn Library" to improve content discoverability, enhancing navigational cues, adding audio functionality, and refining the visual layout and flow of the decisional support component. Subsequent user testing indicated improved ease of navigation and clarity.

Systems usability scale across both rounds

Patterns of responses to the adapted SUS items were consistent across both rounds of user testing. Item-level descriptives demonstrated high agreement with ease of use (M = 3.83), confidence using the tool (M = 3.50), and likelihood of future use (M = 3.25) on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree). Participants reported low agreement on items assessing unnecessary complexity (M = 2.00) and inconsistency (M = 2.00), indicating minimal perceived usability barriers.

Discussion

This pilot study demonstrates that REFLECT is a feasible and acceptable digital health application for AYAs seeking information about FP, genetic risk, and future family building after a cancer diagnosis. Across two iterative rounds of user testing, participants described the application as engaging, easy to navigate, and relevant to their needs. Participants also reported increased confidence in discussing FP and genetic services with providers and emphasized the value of integrating both domains within a single, patient-centered, digital platform. Collectively, these findings suggest that REFLECT addresses a critical gap in AYA oncology care[27–29,38,68] by providing structured, accessible education and decision support during a period of high informational and emotional burden.

The strong acceptability and perceived usefulness of REFLECT highlight unmet needs in timely, integrated fertility and GC among AYAs with cancer. Despite guidelines recommending early discussion of fertility risks, FP options, and appropriate referral to genetics services, many AYAs report these conversations as delayed, inconsistent, or absent.[12–15,69] Prior research indicates that insufficient knowledge about fertility risks, preservation options, and hereditary cancer contributes to decisional conflict, distress, and missed opportunities for intervention.[4,5,32,38,70]

Digital health applications are increasingly recognized as tools to support patient education and decision-making in oncology, particularly when time, emotional burden, and access to specialists are constrained.[48–52,71] While previous tools in cancer genetics and fertility care have improved understanding and supported shared decision-making, they have largely addressed these domains separately.[54–57,72–75] In contrast, REFLECT integrates FP, genetic risk, and future family-building considerations within a single, interactive platform. Participants emphasized the value of this combined approach, noting that it aligned with how they conceptualize reproductive decisions after cancer and addressed gaps they encountered during care. These findings extend prior work suggesting that integrating genetic and fertility content within a single platform is a critical design feature for improving patient knowledge and ensuring that AYAs feel informed about reproductive and hereditary risk options.[27,31,57]

Beyond education, participants responded positively to REFLECT's values-based decision support component, which helped clarify priorities, assess readiness for genetic and fertility-related services, and prepare questions for providers. This aligns with evidence that decision aids can reduce decisional conflict and promote informed, patient-centered care by incorporating individual values into clinical decision-making.[43–47,58,71] In AYA oncology, where decisions about FP, GT, and family building often occur under time pressure and emotional distress, such tools may be particularly valuable for supporting communication and decision-making.[38,42,68] This pilot additionally offers preliminary insight into the implementation potential of REFLECT, as iterative user-informed refinement of navigation, accessibility, and content organization highlights the importance of designing digital interventions adaptable to diverse learning preferences and real-world use contexts.[51–53]

Some limitations warrant consideration. While the sample size was consistent with qualitative user-testing approaches and sufficient to achieve thematic saturation, the sample was small and drawn from a single NCI-designated comprehensive cancer center, which may limit generalizability. Participants were predominantly White, highly educated, and had reliable access to internet-enabled devices, potentially underrepresenting individuals of underserved populations with lower digital literacy or limited technology access and limiting evaluation of the tool across varying levels of education and health literacy. The sample also included relatively older AYAs, and findings may not fully reflect the information needs, developmental considerations, or baseline genetics knowledge of younger AYA patients. Further, this pilot was conducted with AYA cancer survivors rather than patients at diagnosis, which may limit the interpretation of decision-making under conditions of heightened urgency and emotional distress, and the tool was not evaluated in contexts where fertility decision-making often occurs in the care trajectory (e.g., remission for cancers that require immediate treatment). In addition, the study focused on individual patient perspectives and did not assess the role of parents or other support persons within the context of shared decision-making. Finally, clinical and behavioral outcomes such as uptake of GC, FP referrals, or changes in decisional conflict or distress were not assessed.

Future research should extend these findings by evaluating REFLECT's effectiveness, implementation, and impact in larger and more diverse samples, including use at the time of diagnosis. REFLECT may also be relevant for AYAs who have completed family building but seek information about hereditary cancer risk or implications for existing children. Future studies should evaluate timing and clinical integration of REFLECT across different points in the cancer trajectory. Implementation in community and non-NCI settings remains to be evaluated, where access to FP and genetic services may be more limited. Future work should assess integration into diverse oncology care settings to support scalability. Larger trials are needed to assess feasibility, acceptability, usability, and fidelity at scale, as well as effects on outcomes such as knowledge, self-efficacy, distress, and informed decision-making. In addition, examining how REFLECT can be integrated into routine clinical workflows, through mechanisms such as electronic medical record prompts, referral pathways, or multidisciplinary care models, will be important for understanding its scalability and sustainability across oncology settings. Finally, the current version of REFLECT is available in English only. However, the platform supports future multilingual adaptation. The long-term goal is to make the application broadly accessible to patients.

Conclusion

This pilot provides early evidence that REFLECT is a feasible and acceptable digital health application for delivering integrated fertility and genetic education to AYA patients with cancer. By addressing gaps in knowledge and values-based decisional support, REFLECT may enable informed, patient-centered reproductive decision-making and guideline-concordant care.

Author's Contributions

S.P.D.: Contributed to study conceptualization and design, conducted data collection, data analysis/interpretation, and led manuscript writing. L.F. and P.W.L.: Contributed to study conceptualization and design, data collection, data analysis/interpretation, and critical revision of the manuscript. M.S., E.S., and T.S.: Representing NEST Genomics, collaborated to develop and refine the REFLECT platform and contributed to manuscript revision. J.M.: Contributed to clinical interpretation and critical revision. G.P.Q. and S.T.V.: Co-led this pilot and contributed to study conceptualization and design, interpretation of findings, and critical revision of the manuscript. All authors reviewed and approved the final manuscript.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

No funding was received for the study.

References

1. Greene MH, Kratz CP, Mai PL, et al. Familial testicular germ cell tumors in adults: 2010 summary of genetic risk factors and clinical phenotype. Endocr Relat Cancer 2010;17(2): R109–R121.
2. Pearlman R, Frankel WL, Swanson B, et al.; Ohio Colorectal Cancer Prevention Initiative Study Group. Prevalence and spectrum of germline cancer susceptibility gene mutations among patients with early-onset colorectal cancer. JAMA Oncol 2017;3(4):464–471.
3. Shiyanbola OO, Arao RF, Miglioretti DL, et al. Emerging trends in family history of breast cancer and associated risk. Cancer Epidemiol Biomarkers Prev 2017;26(12): 1753–1760.
4. Raghunathan NJ, Benedict C, Thom B, et al. Young adult female cancer survivors' concerns about future children's health and genetic risk. J Adolesc Young Adult Oncol 2018; 7(1):125–129.
5. Benedict C, Shuk E, Ford JS. Fertility issues in adolescent and young adult cancer survivors. J Adolesc Young Adult Oncol 2016;5(1):48–57; doi: 10.1089/jayao.2015.0024
6. Staal DP, Vlooswijk C, Mols F, et al. Diagnosed with a common cancer at an unusual age: Causal attributions of survivors of adolescent and young adult colorectal cancer. Support Care Cancer 2021;29(1):409–416. Published online.
7. Smith KR, Ellington L, Chan AY, et al. Fertility intentions following testing for a BRCA1 gene mutation. Cancer Epidemiol Biomark Prev 2004;13(5).
8. Liede A, Metcalfe K, Hanna D, et al. Evaluation of the needs of male carriers of mutations in BRCA1 or BRCA2 who have undergone genetic counseling. Am J Hum Genet 2000;67(6):1494–1504.
9. Hadley DW, Jenkins J, Dimond E, et al. Genetic counseling and testing in families with hereditary nonpolyposis colorectal cancer. Arch Intern Med 2003;163(5):573–582.
10. Pacey AA. Fertility issues in survivors from adolescent cancers. Cancer Treat Rev 2007;33(7):646–655.
11. Signorello LB, Mulvihill JJ, Green DM, et al. Congenital anomalies in the children of cancer survivors: A report from the childhood cancer survivor study. J Clin Oncol 2012; 30(3):239–245.
12. Ethics Committee of the American Society for Reproductive Medicine. Fertility preservation and reproduction in patients facing gonadotoxic therapies: An Ethics Committee opinion. Fertil Steril 2018;110(3):380–386.
13. Su HI, Lacchetti C, Letourneau J, et al. Fertility preservation in people with cancer: ASCO guideline update. J Clin Oncol 2025;43(12):1488–1515; doi: 10.1200/JCO-24-02782
14. Coccia PF, Pappo AS, Beaupin L, et al. Adolescent and young adult oncology, version 2.2018, NCCN clinical practice guidelines in oncology in. J Natl Compr Canc Netw 2018;16(1):66–97; doi: 10.6004/jnccn.2018.0001
15. Chen D, Kolbuck VD, Sutter ME, et al. Knowledge, practice behaviors, and perceived barriers to fertility care among providers of transgender healthcare. J Adolesc Health 2019;64(2):226–234; doi: 10.1016/j.jadohealth.2018.08.025
16. Chen D, Matson M, Macapagal K, et al. Attitudes toward fertility and reproductive health among transgender and gender-nonconforming adolescents. J Adolesc Health 2018; 63(1):62–68; doi: 10.1016/j.jadohealth.2017.11.306
17. Stein DM, Victorson DE, Choy JT, et al. Fertility preservation preferences and perspectives among adult male survivors of pediatric cancer and their parents. J Adolesc Young Adult Oncol 2014;3(2):75–82.
18. Nilsson J, Jervaeus A, Lampic C, et al. 'Will I be able to have a baby?'Results from online focus group discussions with childhood cancer survivors in Sweden. 2014;29(12): 2704–2711.
19. Lehmann V, Keim MC, Nahata L, et al. Fertility-related knowledge and reproductive goals in childhood cancer survivors. Hum Reprod 2017;32(11):2250–2253.
20. Armuand GM, Wettergren L, Rodriguez-Wallberg KA, Lampic C. Desire for children, difficulties achieving a pregnancy, and infertility distress 3 to 7 years after cancer diagnosis. Support Care Cancer 2014;22(10):2805–2812.
21. Gorman JR, Su HI, Roberts SC, et al. Experiencing reproductive concerns as a female cancer survivor is associated with depression. Cancer 2015;121(6):935–942.
22. Stuckey A, Febbraro T, Laprise J, et al. Adherence Patterns to National Comprehensive Cancer Network Guidelines for Referral of Women With Breast Cancer to Genetics Professionals. Am J Clin Oncol Published online April 52016; 39(4):363–367; doi: 10.1097/COC.0000000000000073
23. Brown KL, Hutchison R, Zinberg RE, McGovern MM. Referral and experience with genetic testing among women with early onset breast cancer. Genet Test 2005; 9(4):301–305.
24. O'Neill SM, Peters JA, Vogel VG, et al. Referral to cancer genetic counseling: Are there stages of readiness? Am J Med Genet C Semin Med Genet 2006;142C(4): 221–231.
25. Peters N, Domchek SM, Rose A, et al. Knowledge, attitudes, and utilization of BRCA1/2 testing among women with early-onset breast cancer. Genet Test 2005;9(1):48–53.
26. Quinn G, Vadaparampil S, Wilson C, et al. Attitudes of high-risk women toward preimplantation genetic diagnosis. Fertil Steril 2009;91(6):2361–2368.
27. Lake PW, Kasting ML, Dean M, et al. Exploring patient and provider perspectives on the intersection between

fertility, genetics, and family building. Support Care Cancer 2020;28(10):4833–4845.

28. Partridge AH, Gelber S, Peppercorn J, et al. Web-based survey of fertility issues in young women with breast cancer. J Clin Oncol 2004;22(20):4174–4183.
29. Zebrack BJ, Block R, Hayes-Lattin B, et al. Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. Cancer 2013; 119(1):201–214.
30. Mork ME, You YN, Ying J, et al. High prevalence of hereditary cancer syndromes in adolescents and young adults with colorectal cancer. J Clin Oncol 2015;33(31): 3544–3549.
31. Vetsch J, Wakefield CE, Warby M, et al. Cancer-related genetic testing and personalized medicine for adolescents: A narrative review of impact and understanding. J Adolesc Young Adult Oncol 2018;7(3):259–262.
32. Peate M, Meiser B, Hickey M, Friedlander M. The fertility-related concerns, needs and preferences of younger women with breast cancer: A systematic review. Breast Cancer Res Treat 2009;116(2):215–223.
33. Gorman JR, Bailey S, Pierce JP, Su HI. How do you feel about fertility and parenthood? The voices of young female cancer survivors. J Cancer Surviv 2012;6(2): 200–209.
34. Maio M, Carrion P, Yaremco E, Austin JC. Awareness of genetic counseling and perceptions of its purpose: A survey of the Canadian public. J Genet Couns 2013;22(6): 762–770.
35. Molster C, Charles T, Samanek A, O'Leary P. Australian study on public knowledge of human genetics and health. Public Health Genomics 2009;12(2):84–91.
36. Woodson AH. Genetic counseling considerations for men with prostate cancer. Can J Urol 2019;26(5 (Suppl 2)): 40–41.
37. Tomiak E, Samson A, Spector N, et al. Reflex testing for Lynch syndrome: If we build it, will they come? Lessons learned from the uptake of clinical genetics services by individuals with newly diagnosed colorectal cancer (CRC). Fam Cancer 2014;13(1):75–82.
38. Canzona MR, Victorson DE, Murphy K, et al. A conceptual model of fertility concerns among adolescents and young adults with cancer. Psycho-Oncology 2021 Published online.
39. Pal T, Bonner D, Cragun D, et al. BRCA sequencing and large rearrangement testing in young Black women with breast cancer. J Community Genet 2014;5(2):157–165; doi: 10.1007/s12687-013-0166-9
40. Pal T, Bonner D, Kim J, et al. Early onset breast cancer in a registry-based sample of African-american women: BRCA mutation prevalence, and other personal and system-level clinical characteristics. Breast J 2013;19(2):189–192; doi: 10.1111/tbj.12083
41. Levy DE, Byfield SD, Comstock CB, et al. Underutilization of BRCA1/2 testing to guide breast cancer treatment: Black and Hispanic women particularly at risk. Genet Med 2011; 13(4):349–355; doi: 10.1097/GIM.0b013e3182091ba4
42. Logan S, Perz J, Ussher JM, et al. Systematic review of fertility-related psychological distress in cancer patients: Informing on an improved model of care. Psychooncology 2019;28(1):22–30.
43. NCI. Theory at a Glance. National Institutes of Health; 2005.
44. Brandon TH, Meade CD, Herzog TA, et al. Efficacy and cost-effectiveness of a minimal intervention to prevent smoking relapse: Dismantling the effects of amount of content versus contact. J Consult Clin Psychol 2004;72(5):797–808; doi: 2004-19094-007%20%5Bpii%5D%2010.1037/0022-006X.72.5.797
45. Chirikos TN, Herzog TA, Meade CD, et al. Cost-effectiveness analysis of a complementary health intervention: The case of smoking relapse prevention. Int J Technol Assess Health Care 2004;20(4):475–480.
46. Jenkins A, Christensen H, Walker JG, Dear K. The effectiveness of distance interventions for increasing physical activity: A review. Am J Health Promot 2009;24(2):102–117.
47. Rawl SM, Champion VL, Scott LL, et al. A randomized trial of two print interventions to increase colon cancer screening among first-degree relatives. Patient Educ Couns 2008;71(2):215–227; doi: S0738-3991(08)00013-X%20%5Bpii%5D%2010.1016/j.pec.2008.01.013
48. Lee K, Kim S, Kim SH, et al. Digital health interventions for adult patients with cancer evaluated in randomized controlled trials: Scoping review. J Med Internet Res 2023;25: e38333.
49. Charbonneau DH, Hightower S, Katz A, et al. Smartphone apps for cancer: A content analysis of the digital health marketplace. Digit Health 2020;6:2055207620905413.
50. Ha J, Kim M, Park H. Digital health interventions for oncofertility in female patients: A systematic review. Womens Health Nurs 2025;31(2):119–129; doi: 10.4069/whn.2025.06.13
51. Mehdizadeh H, Asadi F, Mehrvar A, et al. Smartphone apps to help children and adolescents with cancer and their families: A scoping review. Acta Oncol 2019;58(7):1003–1014.
52. McCann L, McMillan KA, Pugh G. Digital interventions to support adolescents and young adults with cancer: Systematic review. JMIR Cancer 2019;5(2):e12071.
53. McGee MR, Gray P. A handheld chemotherapy symptom management system: Results from a preliminary outpatient field trial. Health Informatics J 2005;11(4):243–258.
54. Siglen E, Vetti HH, Lunde ABF, et al. Ask Rosa–The making of a digital genetic conversation tool, a chatbot, about hereditary breast and ovarian cancer. Patient Educ Couns 2022;105(6):1488–1494.
55. Rivera JNR, Snir M, Simmons E, et al. Developing and Assessing a Scalable Digital Health Tool for Pretest Genetic Education in Patients With Early-Onset Colorectal Cancer: Mixed Methods Design. JMIR Cancer 2025;11(1):e59464.
56. Micaux C, Wiklander M, Eriksson LE, et al. Efficacy of a web-based psychoeducational intervention for young adults with fertility-related distress following cancer (Fex-Can): randomized controlled trial. JMIR Cancer 2022;8(1): e33239.
57. Dong Y, Zhang C, Fang Y, et al. Exploring Strategies to Alleviate Reproductive Concerns in Cancer Survivors: A Comprehensive Scoping Review of International Research. J Adolesc Young Adult Oncol 2024 Published online.
58. Michie S, Dormandy E, Marteau TM. The multi-dimensional measure of informed choice: A validation study. Patient Educ Couns 2002;48(1):87–91.
59. Doak CC, Doak LG, Root JH. Learner verification and revision of materials. Doak CC Doak LG Root JH Teach Patients Low Lit Ski 2nd Ed Phila Pa Lippincott-Raven Publ. Published Online 1996.

60. Chavarria EA, Christy SM, Simmons VN, et al. Learner verification: A methodology to create suitable education materials. Health Lit Res Pract 2021;5(1):e49–e59.
61. Cooke L. Assessing concurrent think-aloud protocol as a usability test method: A technical communication approach. IEEE Trans Profess Commun 2010;53(3):202–215.
62. Bangor A, Kortum PT, Miller JT. An empirical evaluation of the system usability scale. Intl J Human–Computer Interact 2008;24(6):574–594.
63. Peres SC, Pham T, Phillips R. Validation of the system usability scale (SUS) SUS in the wild. In: Vol 57. SAGE Publications Sage CA: Los Angeles, CA; 2013:192–196.
64. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qual Res Psychol 2021;18(3):328–352; doi: 10.1080/14780887.2020.1769238
65. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. Soc Sci Med 2022;292:114523; doi: 10.1016/j.socscimed.2021.114523
66. VERBI Software. Published online 2021. maxqda.com.
67. 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):349–357; doi: 10.1093/intqhc/mzm042
68. Sansom-Daly UM, Wakefield CE. Distress and adjustment among adolescents and young adults with cancer: An empirical and conceptual review. Transl Pediatr 2013;2(4):167.
69. McKay GE, Zakas AL, Osman F, Parkes A. Factors affecting genetic consultation in adolescent and young adult patients with sarcoma. J Natl Compr Canc Netw 2021; 1(aop):1–8.
70. Pathak S, Vadaparampil ST, Sutter ME, et al. Evaluating fertility preservation interventions for alignment with ASCO Guidelines for reproductive aged women undergoing cancer treatment: a systematic review. Support Care Cancer 2023;31(12):689; doi: 10.1007/s00520-023-08133-3
71. Benedict C, Dauber-Decker KL, Ford JS, et al. Development of a web-based decision aid and planning tool for family building after cancer (Roadmap to Parenthood): Usability testing. JMIR Cancer 2022;8(2):e33304.
72. Bombard Y, Ginsburg GS, Sturm AC, et al. Digital health-enabled genomics: Opportunities and challenges. Am J Hum Genet 2022;109(7):1190–1198.
73. Gasteiger N, Vercell A, Khan N, et al. Digital interventions for genomics and genetics education, empowerment, and service engagement: A systematic review. J Community Genet 2023;14(3):227–240.
74. Martínez-Borba V, Lorente-Debón B, Osma J. A Systematic Review of Telemedicine Solutions to Provide Psychological Interventions for Women Receiving Fertility Treatments. Telemed E-Health 2025 Published online.
75. Robertson I, Ogundiran O, Cheong Y. Digital support tools for fertility patients–a narrative systematic review. Hum Fertil (Camb) 2023;26(1):17–26.

Address correspondence to:
Susan T. Vadaparampil, PhD, MPH
Department of Health Outcomes and Behavior
Moffitt Cancer Center
12902 Magnolia Drive
MRC-COEE, Tampa
FL 33612
USA

E-mail: susan.vadaparampil@moffitt.org