TITLE: Pilot Study of a Decision Aid Intervention for Family-building After Cancer

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1.0 SPECIFIC STUDY AIMS

Many young adult female (YA-F) cancer survivors (18-39 years old) who received gonadotoxic therapy will experience fertility problems when trying to build a family. After cancer, having a child will often require assisted reproductive technology (ART), surrogacy, or adoption. However, there are significant informational, psychosocial, and financial barriers to ART and adoption. Lack of awareness, unrealistic expectations, distress, and avoidance or postponement of fertility care put YA-Fs at-risk for being unable to have a child when they are ready or experiencing greater difficulty, distress, and higher costs during the process.

The overall goal of this work is to pilot test a single-arm intervention of a decision aid tool (interactive website identified as the "Roadmap to Parenthood") to assist young adult female cancer survivors in making decisions and preparing for family-building after cancer.

Study Objective 1:	Examine feasibility and acceptability of a decision aid intervention in a single-arm pilot trial.
Study Objective 2:	Obtain preliminary effect sizes of the decision aid intervention using a pre-post test design.

2.0 BACKGROUND AND RATIONALE

While cancer treatments are lifesaving, they come at a cost. Many young adult female (YA-F) cancer survivors have received gonadotoxic therapy and are at-risk for premature ovarian failure or unable to carry a pregnancy. As a result, family-building after cancer often requires assisted reproductive technology (ART), surrogacy, adoption, or other solutions. As many as 74% of YA-F survivors hope to have children someday and fertility is ranked as the second-most distressing survivorship issue after fears about recurrence.[1,2] Pre-treatment counseling on infertility risks and fertility preservation (such as egg or embryo freezing) is an established part of care for reproductive-aged patients,[3,4] but only 15% of YA-Fs receive follow-up fertility counseling after treatment is completed, even after "high-risk" regimens such as alkylating chemotherapy.[5] Furthermore, there is limited evidence on the gonadotoxic effects of novel therapies to guide providers in counseling their patients. Most survivors are unsure of their reproductive potential and distressed about their chances for achieving parenthood.[6,7] Without proper follow-up, YA-Fs are at-risk for experiencing unexpected premature ovarian failure, thereby eliminating chances for having a biologically-related child, and/or facing greater challenges with ART, surrogacy, or adoption including medical, emotional, legal, and financial complications.

To address this unmet need, Benedict and colleagues developed an interactive, web-based decision aid and planning tool ("Roadmap to Parenthood") for family-building after cancer (NCI-funded). To our knowledge, this is the first evidence-based resource to help YA-Fs become informed, cope with distress, and guide self-management toward "next steps" for fertility care and family-building preparation. The tool was designed to help YA-Fs learn about options for family-building, identify personal priorities and goals (values-clarification), and initiate self-management around "next steps." It was developed based on extensive pilot work[12] and theory,[15,16] following healthcare decision aid guidelines[17,18] and patient-centered design principles (NCI R03CA212924, K07CA229186).

This work was based on several prior studies led by the PI:

1. **YA-Fs' uncertainty and unmet fertility decision support needs** [7–9]

   A national sample of YA-F cancer survivors completed an online survey about pre- and post-treatment fertility experiences and decision uncertainty about family-building (N = 346). Among premenopausal YA-Fs who wanted future children, 64% worried about fertility problems, yet only 10% had undergone a fertility evaluation since their treatment ended. Sources of decisional conflict about post-treatment family-building included: feeling uninformed (87%), feeling unclear about personal values (74%), and wanting more advice/guidance (70%) and support (35%). Greater unmet needs and reproductive concerns contributed to greater decisional conflict and lower quality of life.

2. **Financial stress of family-building** [10]

   This study examined quantitative and qualitative data from 46 patient applications for family-building financial support to "The Samfund," an organization dedicated to addressing the financial effects of young adult cancer. Overall, the costs of family-building (via ART and adoption) were described as overwhelming and unexpected that far exceeded initial expectations and leading to savings depletion, loans, and "maxing out" credit cards. Cancer financial effects (eg, medical debt) further drained resources. Decisions about how to spend limited financial resources, whether to incur debt and if so, how much, were weighed against dreams of parenthood. Survivors generally felt unprepared for the financial hurdles and were simultaneously fearful of being unable to achieve parenthood and long-term implications of depleting savings and accruing debt.

3. **Preference for age-specific, technology-based support** [19]

   We conducted a qualitative study to better understand YA survivors' (N = 19) perceptions of cancer survivorship care and research, in partnership with Stupid Cancer, a young adult cancer patient organization. One of the most striking findings was that YAs commonly described feeling dissatisfied, frustrated, and angry with the lack of age-specific support resources. There was an overwhelming preference for technology-based patient support to allow for more control, flexibility, and convenience; and they wanted design features and language to be appealing to their age group. Findings have informed our study design, which includes collaboration with Patient Research Partners and patient organizations to ensure a patient-centered approach to product development is taken.

4. **YA-Fs' decision support needs, preferences, and perceived barriers**

   Dr Benedict (PI) is currently running a mixed methods study to conduct formative research about YA-F survivors' decision-making about fertility and family-building after cancer treatment (funded by the National Cancer Institute; 1R03CA212924-01). This in-depth examination aims to identify survivors' unmet needs, preferences for support services, and perceived barriers to pursuing ART or adoption. The primary aim is to collect data to inform the *content* and *delivery* of a patient decision support and planning tool. Our preliminary data analysis indicates YA-Fs (N = 116) have large knowledge deficits; difficulty coping with uncertainty, distress, and disappointment; anticipatory anxiety; and a preference for digital support platforms designed for their age (eg, non-technical language use).

Conceptual Framework

For YA-Fs who received gonadotoxic therapy, managing infertility risks, deliberating about family-building options, and preparing for barriers involves complex decision-making based on uncertainty. Uncertainty may include: **medical uncertainty** (eg, inexact estimates of fertility potential, unknown financial costs), **personal uncertainty** (eg, lack of clarity about priorities), **social uncertainty** (eg, managing relationships), and situational or systems-level uncertainty (eg, access to care).[16] As specified by Self-Regulation Theory, a system of conscious personal management that involves the process of guiding one's own thoughts, behaviors and feelings to reach goals, illness-related cognitions and emotions are central to and predictive of patients' decision-making processes and health risk management, particularly in situations of uncertainty.[20,21] Cognitive processes include beliefs about the health threat such as its causes, consequences, controllability, and overall understanding. Emotional processes include affective reactions such as worry or distress. Cognitive-emotional responses influence decision making through resulting risk perceptions, outcome beliefs, expectations, and judgments about expected consequences. YA-Fs facing potential infertility risks report avoidance of fertility information as a way to avoid distress and maintain hope.[6] While adaptive in the short-term, avoidant coping may increase their risk of missing their narrowed window of reproductive opportunity or experiencing greater barriers to family-building.

The study intervention is the Roadmap to Parenthood decision aid and planning tool (previously developed) addresses the maladaptive cognitive-emotional and behavioral responses YA-Fs' may have adopted to manage uncertainty and distress, and offer alternative planning strategies to support decision making, address barriers, and build hope that parenthood is possible. The Roadmap to Parenthood is an interactive website intended to improve decision-making regarding family-building after cancer. Effectiveness (efficacy) of Roadmap to Parenthood is measured by a number of questionnaires (surveys), also web-based. Representations of these data collection surveys are provided as appendices to this protocol document.

Summary of the premise of the study. YA-Fs report a lack of knowledge coupled with high levels of distress about their fertility and are in need of continued decision and planning support to achieve their desired family-building goals. To address this gap, the proposed study will pilot test the first theoretically driven, evidence-based decision aid and planning tool for family-building after cancer. We hypothesize the web-based tool will help YA-Fs become informed, manage negative affect, and plan financially for future costs, thereby addressing key barriers to family-building after cancer, while inspiring hope that parenthood will be achieved. Young adult cancer survivors are an underserved patient group characterized by disparities in service delivery and outcomes.[22] Developing an intervention to support post-treatment family-building will fill a critical unmet service need in AYA survivorship care.

3.0 STUDY ENROLLMENT AND PARTICIPANT ELIGIBLITY

3.1 Study Enrollment

Recruitment will primarily be conducted remotely. This study will enroll YA-F cancer survivors who have completed cancer treatment and thus may not need to return to Stanford for in-person visits. We will obtain a Waiver of Authorization for Recruitment to conduct chart reviews and telephone screens to determine eligibility.

In order to recruit eligible patients who are returning to Stanford for post-treatment survivorship care visits, we will partner with the Stanford Adolescent and Young Adult Cancer (SAYAC) program, led by Pamela Simon, who will identify and screen eligible patients and refer those who are interested. Recruitment may also occur from other clinics within the Stanford system including the Cancer Survivorship Program, Women's Cancer Center, and the Reproductive Endocrinology and Infertility center through patient referral and study advertisements. We will also partner with the Stanford Research Registry to recruit participants.

We will also recruit through collaborations with young adult cancer patient organizations. The PI (Catherine Benedict) works closely with several organizations including Stupid Cancer, of which she is a Board Member, Lacuna Loft, and The Samfund. These organizations have committed to supporting this project including through social media posts to aid recruitment. Using social media and remote recruitment and consenting procedures is advised for recruiting young adult patient populations. We will recruit participants using organization listservs and posting on social media outlets, using IRB-approved ads. Followers of these organizations will see an IRB-approved email message or social media post with a link to access study contact information and to complete a personal contact information and screener form (online version of Appendix A, Eligibility Checklist). The social media ads will instruct viewers to click on a link that will direct them to a secure, HIPPA-compliant website to provide contact information via a REDCap survey tool. For ads that we post (and not partnering organizations), we will set up all ads with security settings that do not allow participants or others from the public to post publicly on the ad. We have previously conducted recruitment in this way and been successful including when recruiting as a part of NCI-funded studies. Remote consenting procedures will be done with patients recruited through social media.

We expect to primarily conduct informed consent remotely. Remote consent via telephone will occur at the PI’s office in the Department of Psychiatry and Behavioral Sciences (401 Quarry Rd). Following recruitment conversations (in-person or telephone), consenting will include having a patient read an informed consent document and providing an electronic signature via REDCap, an online HIPPA-compliant platform. Remote consenting will include sending a participant a link to access the informed consent document online. In-person informed consent procedures will be done using a study provided tablet. Participants will be offered a paper-based copy of the informed consent document, if preferred.

The PI (Catherine Benedict) and/or a Clinical Research Assistant (TBD) will obtain informed consent for all participants.

Advertising at Stanford clinics will include posting of IRB-approved fliers in relevant locations, pending approval and agreement from clinic personnel and collaborators. Other advertisements will include social media posts in collaboration with young adult cancer patient organizations.

We will create a REDCap screening survey to guide screening procedures and assess eligibility (Appendix A) and to guide screening (Appendices C to E). The survey will include questions aligned with eligibility criteria. All patients being screened for eligibility will have a parallel REDCap screening survey completed prior to completing informed consent and completing study enrollment.

Screening data will be kept confidential and stored in HIPPA-compliant platforms according to Stanford policies.

3.2 Participant Criteria

Inclusion criteria:

- Female
- Aged 18 to 45 years old
- Understands verbal and written English
- Completed cancer treatment known to have gonadotoxic effects (eg, systemic chemotherapy, surgery affecting reproductive organs or hormone regulation, and/or pelvic radiation)
- Desires future children or uncertainty regarding family-building plans
- Access to the Internet and use of a computer, tablet, or smartphone

Exclusion criteria:

- Currently undergoing cancer treatment excluding long-term adjuvant or maintenance therapies, such as tamoxifen
- Significant physical or mental disability that prevents completion of study activities

Note: Survivors on adjuvant maintenance or endocrine treatment, such as tamoxifen, will not be excluded because clinical guidelines allow treatment delay or hiatus to accommodate fertility preservation, egg extraction for surrogacy, or pregnancy for some patients, and because patients may be interested in adopting.

3.3 Enrollment

The target sample size is 100.

4.0 MATERIAL AND METHODS

We conduct a single-arm pilot study of the Roadmap to Parenthood decision aid intervention for family-building after cancer. The Roadmap to Parenthood consists of an online decision aid tool that provides information, support, and guidance to YA-F cancer survivors making decisions about fertility and family-building options after cancer. The decision aid intervention will be presented as a webpage accessed via www.familybuildingaftercancer.com. The Roadmap to Parenthood website is a multi-page interactive resource that provides information, resources, and potential questions a participant might use to gather more information about family-building. The decision aid intervention is intended to help women investigate their options to have a child after cancer treatment and make decisions relative to their condition that are aligned with their family-building goals.

Separate from the Roadmap to Parenthood tool, participants will be asked to complete psychosocial assessment questionnaires (table of contents to the questionnaires in Appendix B) to track decisional conflict (Appendix F, the primary outcome) and cognitive-emotional and behavioral functioning (collectively, the secondary outcomes in subsequent appendices), as well as a priori covariates and process variables including sociodemographic and medical characteristics, uncertainty management preference, financial well-being, and health literacy. The questionnaires are all quantitative assessments used to assess effectiveness of the Roadmap to Parenthood intervention and include:

- Decisional Conflict Scale (DCS), Appendix F: 16-item measure, answered on a 5-point scale ranging from “strongly agree” to “strongly disagree” with higher scores indicating greater uncertainty (worse outcome).
- Unmet Fertility Information Needs, Appendix G: 5-item measure, answered with yes/no response options with higher scores indicating better perceived knowledge (better outcome).
- Illness Perceptions Questionnaire-Revised (IPQ-R), Appendix H: 28 items, answered on a 5-point scale ranging from “strongly disagree” to “strongly agree” with higher scores indicating worse outcomes.
- Reproductive Concerns After Cancer (RCAC) Scale, Appendix I: 8-item measure, answered on a 5-point scale from “strongly disagree” to “strongly agree” with higher scores indicating greater distress (worse outcome).
- Impact of Events Scale-Revised (IES-R) subscales, Appendix J: 15 items, answered on a 5-point scale ranging from “not at all” to “extremely” with higher scores indicating greater distress (worse outcome).
- PROMIS General Self-Efficacy and Self-Efficacy for Managing Emotions subscales, Appendix K: 16 items, answered on a “I am not at all confident” to “I am very confident” with higher scores indicating greater self-efficacy (better outcome).
- eHealth Impact Questionnaire (e-HIQ), Part 1 and 2, Appendix L: 26-item measure, answered on a 5-point scale with higher scores indicating a greater, more positive impact.
- COmprehensive Score for Financial Toxicity (COST), Appendix M: 10-item measure, answered on a 5-point scale ranging from “not at all” to “very much” with higher scores indicating greater financial toxicity (worse outcome).
- InCharge Financial Distress/Financial Well-being, Appendix N: 8-item measure, answered on a 10-point scale with response options varying across items (eg, “overwhelming stress” to “no stress at all” and “worry all the time” to “never worry”) with higher scores indicating better financial well-being (better outcome).
- Uncertainty Management Preferences Scale, Appendix O: 15-item measure, answered on 7-point scale from ‘strongly disagree’ to ‘strongly agree’ with higher scores indicating a stronger preference.
- Brief Health Literacy Screener, Appendix P: 3-item measure, answered on a 5-point scale ranging from “always” to “never” with higher scores indicating better health literacy (better outcome).
- Health Literacy Screening Questionnaire, Appendix Q: 8-item measure, answered on 4- and 5-point scales with response options varying across items (eg, “very bad” to “very good”; “disagree strongly” to “agree strongly”; and “never” to “always”) with higher scores indicating better health literacy (better outcome).

The questionnaires will be administered at timepoint T1 (pre-intervention baseline); at timepoint T2 (1 month, within 30 days); and timepoint T3 (2 months subsequent to the subject-specific T2 timepoint, within 60 days). Questionnaires will be administered electronically, with access granted shortly before the survey is due. These time points were chosen to allow users to review the content and have time to access medical records, finances, or insurance information, if needed, to use in interactive features and to develop their action plan. Participants will be sent reminders to complete the surveys and study staff will follow up with participants who do not complete surveys to obtain missing data.

After completing the baseline questionnaire, participants will be given a link to access the web-based decision aid and planning tool. The website utilizes a responsive design format, which will allow users to access the tool on any device or operating system (computers, laptops, tablets, or mobile phone). Access to the website will remain open for the duration of the study.

To complete Study Objective 1, feasibility and acceptability metrics will be collected. Feasibility of the decision aid intervention and study design will be evaluated with rates of eligibility, enrollment, and attrition. Reasons for refusal to participate will be tracked and evaluated. Acceptability will be evaluated using survey completion rates and web analytics to track access to website modules and exercises including time spent and click stream data.

To complete Study Objective 2, effect size estimates will be calculated for reduction of decision conflict (primary outcome; Decisional Conflict Scale [DCS][23]) and completion of an action plan module that will aim to prepare users for foreseeable barriers and suggest preparatory actions (eg, financial planning). Effect size estimates will also be calculated for secondary outcomes including unmet fertility information needs, cognitive-emotional representations of infertility or risk of infertility (ie, the Illness Perceptions Questionnaire-Revised[24] and the Reproductive Concerns after Cancer Scale[25]), distress (ie, the Impact of Events Scale-Revised[26]), and self-efficacy (PROMISE Self-Efficacy subscales[27]). Data will also be collected to track change in perceived unmet information needs about post-treatment fertility and family-building options (investigator-designed questions; alpha = .81) and cancer-specific financial stress and general financial well-being (ie, the Comprehensive Score for Financial Toxicity[28] measure and the InCharge Financial Distress/Financial Well-being scale[29]). Impact on users' confidence discussing issues with providers and motivation to take action will be described (eHealth Impact Questionnaire-Part 2)[30]. Finally, sociodemographic and medical characteristics, uncertainty management preference, and health literacy will be collected as covariates. These outcome measures were chosen based on our extensive pilot work and theoretical framework. Website access data will be tracked to assess whether participants use the tool as a one-time resource or iteratively as family-building intentions and planning strategies may change over time.

The intervention is designed for individual use. There is no group format or community component to the intervention or website; ie, it is not a group intervention and there is no opportunity for participants to interact with one another through the website or in the design of the study. This trial does not involve group- or cluster-randomization and it is not an individually randomized group-treatment trial.

Study participation will be complete within 3 months; ie, completion of baseline survey (T1), access to the web-based intervention, and completion of follow-up surveys at 1- and 3-months post-baseline (T2 and T3, respectively).

5.0 STATISTICAL CONSIDERATIONS

5.1 Measurements

The following measures will be used. Note that assessments conducted only at baseline will not be reported as ClinicalTrials.gov outcomes.

	Timepoint		
	T1: baseline; pre-intervention	**T2**: 1-month post-baseline	**T3**: 3-months post-baseline
Primary			
Decision Conflict Scale (Appendix F):[23] Validated, 16-item measure that assesses personal uncertainty in making a healthcare decision, modifiable factors contributing to uncertainty, and the quality of the decision made. It is valid, reliable, and responsive to change, and the most widely used measure of decision-making quality. Five subscales include: Informed, Values clarity, Support, Uncertainty, and Effective decision. Answers are on a 5-point scale from "Strongly agree" to "Strongly disagree." Scores are transformed to a 0 [no decisional conflict] to 100 [extremely high decisional conflict] scale such that higher scores indicate a worse outcome. Scores lower than 25 are associated with implementing decisions; whereas score exceeding 37.5 are associated with decision delay or feeling unsure about implementation.	**X**	**X**	**X**
Secondary			
Unmet fertility information needs (Appendix G): Investigator-designed questions (5 items) will assess perceived information needs about fertility and family-building topics. Participants will indicate (yes/no) whether they have as much information as they want about Risk of infertility, Risk of early menopause, Options to assess their fertility status, Options to preserve fertility, and Options for alternative family-building. Our prior use of this measure yielded adequate internal consistency ($\alpha = .81$).[7] Each item is answered 0-No or 1-Yes and total scores range from 0 to 5. Higher scores indicate better perceived knowledge (better outcome).	**X**	**X**	**X**

	Timepoint		
	T1: baseline; pre-intervention	**T2**: 1-month post-baseline	**T3**: 3-months post-baseline
Illness Perceptions Questionnaire-Revised (Appendix H):[24] Validated measure of cognitive and emotional representations of illness. Items were adapted to refer to participants' infertility risk. 5 subscales will be used (5 to 6 items each; 28 items total): Personal control, Treatment control, Illness coherence, Consequences, and Emotional representations. Items are answered on a 5-point scale from "Strongly Agree" to "Strongly Disagree," with higher scores indicating worse outcomes. Each subscale is scored separately, and averages are calculated. The IPQ-R has been validated in cancer populations.	**X**	**X**	**X**
Reproductive Concerns after Cancer Scale (Appendix I):[25] Validated, 18-item measure of AYA-F cancer survivors' fertility and health concerns with 6 subscales: Concerns about fertility potential, Partner disclosure, Becoming pregnant, Child's health, Personal health, and Acceptance. Answers are on a 5-point scale, "Strongly Disagree" to "Strongly Agree" with higher scores indicating more concern (worse outcome). Mean scores are calculated, ranging from 1 to 5.	**X**	**X**	**X**
Impact of Events Scale-Revised (Appendix J):[26] The IES-R is a validated measure of distress in reaction to negative life events and will be adapted to measure current subjective distress related to infertility risk. The Intrusive Thoughts (7 items) and Avoidance (8 items) subscales assess intrusive thoughts and effortful avoidance of reminders about a distressing event, respectively. Answers are on a 5-point scale: "Not at all" to "Extremely."	**X**	**X**	**X**
PROMIS Self-Efficacy (Appendix K):[27] The PROMIS General Self-Efficacy and Self-Efficacy for Managing Emotions subscales measure the degree to which people feel confident in managing various situations, problems, and events and confidence in managing difficult emotions. Questions will assess general self-efficacy in these domains and self-efficacy in managing fertility and family-building issues and emotions.	**X**	**X**	**X**

	Timepoint		
	T1: baseline; pre-intervention	**T2**: 1-month post-baseline	**T3**: 3-months post-baseline
eHealth Impact Questionnaire, Parts 1 and 2 (Appendix L):[30] Validated, 26-item measure of the impact and perception of using a health website, including three subscales: Confidence and Identification (9 items; eg, "*The website prepares me for what might happen to my health.*"); Information and Presentation (8 items; eg, *"The information on the website left me feeling confused."*); and Understanding and Motivation (9 items; eg, *"The website encourages me to take actions that could be beneficial to my health."*). There is a 5-point response category for all items ranging from 'Strongly disagree to Strongly agree'. Scores are summed and transformed to a 0 to 100 metric, with higher scores indicating a greater, more positive impact.		**X**	
Covariates			
COmprehensive Score for financial Toxicity (COST) (Appendix M):[28] Validated, 11-item measure of cancer-related financial effects. We have previously used this measure to assess cancer-related financial toxicity amidst family-building costs. Items are answered on a 5-point scale from 'Not at all' to 'Very much.' Scores are summed, ranging from 0 to 44, with lower scores indicating worse financial toxicity (worse outcomes).	**X**	**X**	**X**
InCharge Financial Distress/Financial Well-being scale (FDFW) (Appendix N):[29] Validated, 8-item measure of general financial well-being. It is designed to measure a latent construct representing responses to one's financial state on a continuum ranging from overwhelming financial distress/lowest level of financial well-being to no financial distress/highest level of financial well-being. For each item, responses are on a 1 to 10 scale and a total mean score is calculated, with higher scores indicating better financial well-being (better outcome). Norming data is available, and standards were established for scale scores on a continuum from 1 to 10, where 1 = overwhelming financial distress/lowest financial well-being and 10 = no financial distress/highest financial well-being. may be compared to population-level data.	**X**	**X**	**X**

	Timepoint		
	T1: baseline; pre-intervention	**T2**: 1-month post-baseline	**T3**: 3-months post-baseline
Uncertainty Management Preferences scale (UMP) (Appendix O):[31] Validated, 15-item assessment of individual's preference for managing uncertainty including 4 subscales: preference to maintain uncertainty through avoidance (4 items), preference to avoid insufficient information (3 items), preference to increase uncertainty (3 items), and preference to reduce uncertainty (5 items). The scale was developed for managing uncertainty related to cancer and was adapted to refer to uncertainty with respect to fertility and family-building. Items are answered on a 7-point scale and mean scores are calculated with higher scores indicating a stronger preference.	**X**		
Health Literacy (Appendix Q): The Health Literacy Screening Questionnaire (HL-SQ) is a brief, 8-item measure of health literacy and will be used to assess individuals' knowledge and skills to prevent disease and to promote health in everyday life.[32] The tool was developed for use with young adult populations and found to be a reliable and valid assessment of health literacy. Items are answered on 4- and 5-point scales with higher scores indicating better health literacy. This will be combined with a 3-item Brief Health Literacy Screener that has been found to be effective in detecting inadequate health literacy.[33] Items are answered on a 5-point scale ranging from 'always' to 'never' with higher scores indicating better health literacy.	**X**		
Stage of Decision Making (Appendix S): Validated, 1-item measure to assess the individual's readiness to engage in decision making, progress in making a choice, and receptivity to considering or re-considering options. Scores range from 1 to 6, indicating increasing readiness, progress, and conviction in the decision making process.	**X**	**X**	**X**
Preparation for Decision Making (Appendix T): Validated, 10-item measure that assesses a patient's perception of how useful a decision aid or other decision support intervention is in preparing the respondent to communicate with their practitioner at a consultation focused on making a health decision.		**X**	

The outcome measures do not relate to safety.

5.2 Analysis plan

For **Study Objective 1**, feasibility and acceptability will be evaluated using descriptive statistics of rates of eligibility, enrollment (≥ 80%), attrition, reasons for refusal, and completion rates of surveys. Independent means t-tests and chi-square tests will compare acceptors/decliners and completers/ non-completers. Web analytics (ie, Google analytics) will track logins and calculate web page access, time spent on modules, click stream data, and visitor segmentation. Aggregated and real-time access to this data will help us determine real-world use of the website so that we can make design adjustments as needed. Completion of the "action plan" module will be tallied (≥ 70% considered acceptable); factors predicting non-completion will be identified using tests of independent group differences. User engagement will be tracked for the entire study period to explore whether modules are used as a one-time resource or iteratively.

For **Study Objective 2**, for each outcome variable, we will examine the distributional qualities, extent of missing data, and satisfaction of assumptions of randomness (ie, MAR, MCAR). Descriptive statistics will evaluate sample characteristics. Covariates with significant relationships with the decisional conflict scale (DCS) will be included in final models. To obtain an effect size estimate of the decision aid in reducing decisional conflict, pairwise t-test will evaluate change in DCS mean scores from T1 to T2. A two-sided hypothesis test of the within-subject difference in adjusted means will test the null hypothesis (H_0: $\mu_1 = \mu_2$) at $\alpha = 0.05$. Rejection of the null hypothesis will indicate a significant within-subject DCS mean change from T1 to T2 (H_1: $\mu_1 > \mu_2$). Effect size estimates (Cohen's d) will be calculated and reported. On an exploratory level, we will examine T1 to T3 and T2 to T3 mean differences to characterize the DCS trajectory. Similar procedures will analyze changes in the IPQ-R, RCACS, PROMIS Self-Efficacy, and the IES-R as secondary outcomes, controlling for key covariates. The Stage of Decision Making Scale will be assessed, and descriptive statistics will evaluate whether use of the decision aid website impacts readiness to engage in decision making, progress in making a choice, and receptivity to considering or re-considering options between timepoints T1 and T2 and between timepoints T2 and T3. The Preparation for Decision Making Scale will be assessed, and descriptive statistics will evaluate whether use of the decision aid website impacts perception of how useful a decision aid or other decision support intervention is in preparing the respondent to communicate with their practitioner at a consultation focused on making a health decision. The eHealth Impact Questionnaire-Part 2 will be assessed and descriptive statistics will evaluate the impact of using the decision aid website across three domains: 1) confidence and identification of health concerns, 2) information and presentation of website material, and 3) understanding and motivation to manage health issues.

5.3 Sample size

The target sample size is 100.

Power Estimate: With a projected 20% attrition rate, we expect 80% power to detect an effect size of 0.3 for the T1-T2 change in DCS, with a two-sided paired t-test with a 0.05 significance level. We based this on a decision aid intervention for fertility preservation,[34] which reported 14% attrition and DCS means at baseline (M = 51.6, SD = 32.8) and 1-month post-intervention (M = 16.6, SD = 26.5). We assumed the same DCS baseline mean, but were conservative and assumed higher attrition, higher DCS mean at follow-up (M = 40, SD = 26.5), and correlation coefficient between measurements to be 0.3, so that the effect size will be 0.33; representing a moderate effect size based on Cohen's taxonomy. This also follows the DCS manual.

5.4 ClinicalTrials.gov Outcomes

Similar to endpoints, ClinicalTrials.gov outcomes are assessments that evaluate the Roadmap to Parenthood intervention. Following are the ClinicalTrials.gov outcome titles; descriptions, and timeframes.

Outcome 1 (Primary)

Title: Decisional Conflict Scale (DCS)

Description: The Decisional Conflict Scale (DCS) is a validated survey that assesses personal uncertainty in making healthcare decisions; modifiable factors contributing to uncertainty; and the quality of the decision made. It is reliable and responsive to change, and the most widely used measure of decision-making quality. The survey has 16 questions, with responses on a 5-point scale ranging from “strongly agree” (1) to “strongly disagree” (5). Total scores range from 16 to 80, with higher scores indicating greater uncertainty (worse outcome). The outcome will be reported as the mean difference from baseline to 1 and 3 months, with standard deviation.

Timeframe: 3 months

Outcome 2 (Secondary)

Title: Unmet Fertility Information

Description: This investigator-designed survey assesses perceived information needs about fertility topics such as the risk of infertility; risk of early menopause; options to assess fertility status; options to preserve fertility; and options for alternative family-building. The survey has 5 questions, each answered by a Yes / No response. Yes is scored as 1, and no is scored as 0. Total scores range from 0 to 5, with higher scores indicating greater perceived knowledge. The outcome will be reported as the mean difference from baseline to 1 and 3 months, with standard deviation.

Timeframe: 3 months

Outcome 3 (Secondary)

Title: Illness Perceptions Questionnaire-Revised (IPQ-R)

Description: The Illness Perceptions Questionnaire-Revised (IPQ-R) is a survey that assesses cognitive and emotional representations of illness and is validated in cancer populations. The survey has 28 questions, answered on a 5-point scale ranging from “strongly disagree” (1) to “strongly agree” (5). Total scores range from 28 to 140, with higher scores indicating worse outcomes. The outcome will be reported as the mean difference from baseline to 1 and 3 months, with standard deviation.

Timeframe: 3 months

Outcome 4 (Secondary)

Title: Reproductive Concerns After Cancer (RCAC) Scale

Description: The Reproductive Concerns After Cancer (RCAC) Scale is a validated survey of cancer survivors’ fertility and health concerns. The survey has 18 questions, answered on a 5-point scale ranging from (1) “strongly disagree” to (5) “strongly agree.”

Total scores range from 18 to 90, with higher scores indicating greater distress (worse outcome). The outcome will be reported as the mean difference from baseline to 1 and 3 months, with standard deviation.

Timeframe: 3 months

Outcome 5 (Secondary)

Title: Impact of Events Scale-Revised (IES-R)

Description: Impact of Events Scale-Revised (IES-R) is a validated measure of distress in reaction to negative life events that has been adapted to measure current subjective distress related to infertility risk. The survey has 15 questions, intended to collect the participant’s assessment of intrusive thoughts (7 questions) and effortful avoidance of reminders about a distressing event (8 questions). The questions are answered on a 5-point scale ranging from “not at all” (1) to “extremely” (5). Total scores range from 15 to 75, with higher scores indicating greater distress (worse outcome). The outcome will be reported as the mean difference from baseline to 1 and 3 months, with standard deviation.

Timeframe: 3 months

Outcome 6 (Secondary)

Title: PROMIS Self-Efficacy (PROMIS-SE)

Description: The PROMIS General Self-Efficacy and Self-Efficacy for Managing Emotions subscales measure the degree to which people feel confident in managing various situations, problems, and events and confidence in managing difficult emotions. Questions will assess general self-efficacy in these domains and self-efficacy in managing fertility and family-building issues and emotions. The survey has 16 questions, intended to collect the participant’s assessment of general self-efficacy (4 items), self-efficacy for managing fertility/family-building issues (4 items), self-efficacy for managing difficulty emotions (4 items), and self-efficacy for managing difficult emotions related to fertility/family-building (4 items). The questions are answered on a 5-point scale ranging from (1) “I am not at all confident” to (5) “I am very confident.” The outcome will be reported as the mean difference from baseline to 1 and 3 months, with standard deviation.

Timeframe: 3 months

6.0 DATA MANAGEMENT CONSIDERATIONS

6.1 Data management

REDCap will be used to administer online surveys to collect data. SPSS will be used to analyze data.

6.2 Confidentiality

Describe procedures for protecting the privacy interests of participants, including the confidentiality of research records and biospecimens. Describe how study data are coded and linked to participant identity in the study database (for example, is there a separate file with all identifying information or are data and identifiers kept together).

We will follow Stanford policies for maintaining and storing confidential data. All data files stored on computers, external hard disks, or USB thumbs (ie, any electronic devices that contain identifiable subject data) will be encrypted and password protected. Only the PI will have access to PHI data.

6.3 Protocol Review and Amendments

The protocol, the proposed informed consent and all forms of participant information related to the study (eg, advertisements used to recruit participants) will be reviewed and approved by the Stanford IRB and Stanford Cancer Center Scientific Review Committee (SRC). Any changes made to the protocol will be submitted as a modification and will be approved by the IRB prior to implementation. The Protocol Director will disseminate the protocol amendment information to all participating investigators.

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APPENDIX A: Participant Eligibility Checklist

A Participant Eligibility Checklist must be completed in its entirety for each subject prior to registration. The completed, signed, and dated checklist must be retained in the patient's study file and the study's Regulatory Binder.

The study coordinator, treating physician, and an independent reviewer must verify that the participant's eligibility is accurate, complete, and legible in source records. A description of the eligibility verification process should be included in the EPIC or other Electronic Medical Record progress note.

Protocol Title:	Pilot Study of a Decision Aid Intervention for Family-building After Cancer
Protocol Number:	IRB-52143
Principal Investigator:	Catherine Benedict

II. Subject Information:

Subject Name/ID:
Gender: ☐ Female

III. Study Information:

SRC-approved ☒ IRB-approved ☒

IV. Inclusion/Exclusion Criteria

Inclusion Criteria (From IRB-approved protocol)	**Yes**	**No**	**Supporting Documentation***
1. Female	☐	☐	Subject self-report
2. Age 18 to 45 years old	☐	☐	Chart review and/or subject self-report
3. Understands verbal and written English	☐	☐	Subject self-report
4. Completed cancer treatment known to have gonadotoxic effects (eg, systemic chemotherapy, surgery affecting reproductive organs or hormone regulation, and/or pelvic radiation)	☐	☐	Chart review and/or subject self-report
5. Desires future children or is uncertainty about family-building plans	☐	☐	Subject self-report
6. Access to the Internet and use of a computer, tablet, or smartphone	☐	☐	Subject self-report
Exclusion Criteria (From IRB-approved protocol)			
1. Currently undergoing cancer treatment excluding long-term adjuvant or maintenance therapies, such as tamoxifen	☐	☐	Chart review and/or subject self-report

2. Significant physical or mental disability that prevents completion of study activities	☐	☐	Subject self-report and/or screener's observation

*All subject files must include supporting documentation to confirm subject eligibility. The method of confirmation can include, but is not limited to, laboratory test results, radiology test results, subject self-report, and medical record review.

IV. Statement of Eligibility

By signing this form of this trial, I verify that this subject is [☐ **eligible** / ☐ **ineligible**] for participation in the study. This study is approved by the Stanford Cancer Institute Scientific Review Committee, the Stanford IRB, and has finalized financial and contractual agreements as required by Stanford School of Medicine's Research Management Group.

Principal Investigator Signature:	Date:
Printed Name:	

Secondary Reviewer Signature:	Date:
Printed Name:	

Study Coordinator Signature:	Date:
Printed Name:	

APPENDIX B: Patient Questionnaire Table of Contents

Questionnaires are representations of the on-line questionnaires.

Domain (Appendix location)	Assessment Tool	T1	T2	T3
Background Questionnaires (Appendices C, D, E)	Sociodemographic questions	X		
	Medical History	X		
	Reproductive History	X		
	Pre-treatment Fertility Experiences	X		
	Post-treatment Fertility Experiences	X		
Decisional Conflict (Appendix F)	Decision Conflict Scale	X	X	X
Unmet Information Needs (Appendix G)	Investigator-designed items about fertility and family-building information needs	X	X	X
Cognitive, Emotional, and Behavioral Functioning (Appendices H, I, J)	Illness Perceptions Questionnaire – Revised	X	X	X
	Reproductive Concerns after Cancer Scale	X	X	X
	Impact of Events Scale–Revised	X	X	X
Self-Efficacy (Appendix K)	PROMIS General Self-Efficacy	X	X	X
	PROMIS Self-Efficacy for Managing Emotions	X	X	X
Internet Use (Appendix L)	e-Health Impact Questionnaire			
	Part 1	X		
	Part 2		X	
Financial Stress (Appendix M, N)	COmprehensive Score for Financial Toxicity	X		
	InCharge Financial Distress/Financial Well-being Scale	X		
Uncertainty Management (Appendix O)	Uncertainty Management Preferences	X		
Health Literacy (Appendix P, Q)	Brief Health Literacy Screener	X		
	Health Literacy – Young Adult	X		
Actions & Concomitant Care (Appendix R)	Actions & Care (investigator designed)		X	X
Website Impact (Appendix S, T, U)	Stage of Decision Making	X	X	X
	Preparation for Decision Making		X	
	Family-building Website Use		X	X
Website Feedback (Appendix V)	Website feedback (investigator designed)		X	

APPENDIX C: Background Questionnaire

1. Date of Birth: __ / __ / __
2. With which of the following groups do you most identify? (Select all that apply)
   - ☐ White
   - ☐ Black
   - ☐ American Indian or Alaskan Native
   - ☐ Asian or Pacific Islander
   - ☐ Other:
   - ☐ Unknown
   - ☐ Prefer not to answer
3. Are you Hispanic/Latina?
   - ☐ No
   - ☐ Yes
   - ☐ Prefer not to answer
4. With which of the following religious groups do you most identify?
   - ☐ Christian, Catholic
   - ☐ Christian, all other denominations
   - ☐ Jewish, Orthodox
   - ☐ Jewish, Non-Orthodox
   - ☐ Muslim
   - ☐ Buddhist
   - ☐ Hindu
   - ☐ Other world religions
   - ☐ Other faiths
   - ☐ Not affiliated with a formal religion
   - ☐ Don’t Know/Refused
5. What is the highest level of education you have completed?
   - ☐ Some high school, but no degree
   - ☐ High school degree
   - ☐ Vocational training after high school, other than college
   - ☐ Some college, but no degree
   - ☐ College degree
   - ☐ Post-graduate degree
   - ☐ Prefer not to answer
6. Which of the following best describes your current student status?
   - ☐ I am a full-time student
   - ☐ I am a part-time student
   - ☐ I am not enrolled in school
   - ☐ Prefer not to answer

7. Which of the following best describes your current employment status?
    - ☐ I am employed full-time
    - ☐ I am employed part-time
    - ☐ I am not employed
    - ☐ Prefer not to answer
8. Over the past year, what is the total income of the household you live in?
    - ☐ Less than $50,000
    - ☐ $50,000 - $100,000
    - ☐ Greater than $100,000
    - ☐ Unknown
    - ☐ Prefer not to answer
9. What best describes the locality or environment in which you live?
    - ☐ Urban
    - ☐ Suburban
    - ☐ Rural
    - ☐ Prefer not to answer

APPENDIX D: Medical History

1. Have you ever been treated for a serious medical illness(s) other than cancer (eg, asthma, diabetes, hypertension, etc.)

_____ No

_____ Yes. If yes, please indicate: ____

____

____

2. Date of cancer diagnosis: ___ / ___ (MM / YY)
3. Cancer Type:
4. Cancer Stage:
5. Where did you receive most of your cancer treatment?

__ Pediatric cancer clinic

__ Adult oncology clinic

__ Specialized young adult or “teen” cancer clinic

6. Date of last cancer treatment: ____ / ____ (MM / YY)
7. ***Please circle*** which type(s) of treatment you had:

Surgery Chemotherapy Radiation Treatment Other

If other, what other type of treatment did you receive? ______________________________

____

8. Are you still on hormonal therapy?

_____ Yes; if yes, how long are you expecting to be on hormone therapy? _____________

_____ No

9. Date of last menstrual cycle: _____ / ____ /_____
10. Which of the following best describes your current menstrual periods?

__ I have regular periods (occurring about every 26 to 35 days) and I am NOT taking birth control pills or female hormones

__ I have regular periods (occurring about every 26 to 35 days) and I am taking birth control pills or female hormones

__ My periods are irregular (differing number of days between periods)

__ I have not had a period for at least 12 months.

I stopped getting my menstrual periods at age _______________

__ I am currently pregnant or my last pregnancy ended within the past 6 months.

APPENDIX E: Reproductive History

1. Do you currently have children?
   - __ Yes; if yes, how many? _____
   - __ No
2. Did you have any children **before** beginning cancer treatment?
   - __ Yes – conceived naturally; if yes, how many? ________
   - __ Yes – through fertility treatment (for example, IVF) .
   - __ Yes – adopted or fostered
   - __ No
3. Do you want to have children (or more children) at some time in the future?
   - __ Yes
   - __ No. Contact study team or Dr Benedict
   - __ Unsure
4. When would you hope to have a child in the future?
   - __ I do not want to have a child (or more children)
   - __ I am not sure if I want to have a child (or more children)
   - __ I am currently trying to get pregnant
   - __ I am currently trying to adopt or find a surrogate
   - __ Probably in the next 2 years
   - __ Probably in the next 2 to 5 years
   - __ Probably more than 5 years from now
5. Do you believe that your cancer treatment affected your fertility (your ability to conceive or have children naturally)?
   - __ I believe it definitely affected my fertility
   - __ I believe it probably affected my fertility
   - __ I do not know
   - __ I believe it probably did NOT affect my fertility
   - __ I believe it definitely did NOT affect my fertility

APPENDIX E Reproductive History

Pre-treatment Fertility Experience

Before you started cancer treatment…

6. Did your oncologist, nurse, or other healthcare professional discuss fertility with you?

__ Yes

__ No

__ I don't remember

7. Do you feel that you were well informed about the option to potentially preserve your fertility by freezing eggs or embryos before treatment?

__ I was satisfied with the amount of information

__ I was not satisfied – I did not receive enough information

__ I was not satisfied – it was not discussed at all

__ I was not interested in receiving this information, or it was not applicable to me

8. Did you meet with a fertility specialist or reproductive endocrinologist before starting treatment?

__ Yes, I met with a fertility specialist or reproductive endocrinologist (but have not pursued fertility preservation)

__ No, I did NOT meet with a fertility specialist or reproductive endocrinologist even, even though I was referred to one

__ No, I did NOT meet with a fertility specialist or reproductive endocrinologist because I did not know about this or was not referred

__ No, I did NOT meet with a fertility specialist or reproductive endocrinologist because I was not interested in fertility preservation

__ I don't remember

Did you undergo fertility preservation before starting your cancer treatment?

☐ Yes

☐ No

☐ Prefer not to answer

If Yes, what did you do? Check all that apply

☐ Egg freezing

☐ Embryo freezing

☐ Ovarian tissue freezing

☐ Ovarian transposition

☐ Ovarian suppression

☐ Other type of fertility preservation: _________

APPENDIX E, Reproductive History

Post-treatment Follow-up Care

After you finished your cancer treatment…

9. Has your oncologist or other health care professional discussed fertility with you during your follow-up care?

__ Yes, I was satisfied with the amount of information I received
__ Yes, but I was NOT satisfied with the amount of information I received
__ No, it was not discussed at all
__ No, I was not interested in receiving this information, or it was not applicable to me
__ I don't remember

10. Has your oncologist or other health care professional discussed risk for infertility or premature menopause with you during your follow-up care?

__ Yes, I was satisfied with the amount of information I received
__ Yes, but I was NOT satisfied with the amount of information I received
__ No, it was not discussed at all
__ No, I was not interested in receiving this information, or it was not applicable to me
__ I don't remember

11. Has your oncologist or other health care professional discussed fertility preservation or alternative family-building options (such as adoption) with you during your follow-up care?

__ Yes, I was satisfied with the amount of information I received
__ Yes, but I was NOT satisfied with the amount of information I received
__ No, it was not discussed at all, but I wish it had been
__ No, I was not interested in receiving this information, or it was not applicable to me
__ I don't remember

12. Have you been referred to a fertility specialist or reproductive endocrinologist since your treatment ended?

__ Yes, I was referred and I have met with a fertility specialist or reproductive endocrinologist (but have not pursued fertility preservation)
__ Yes, I was referred but I have NOT met with a fertility specialist or reproductive endocrinologist
__ No, I was not referred, but I am interested in this
__ No, I was not referred, but I pursued it on my own
__ No, I was not referred and I am NOT interested in this
__ I don't remember or am unsure.

13. Have you met with a fertility specialist or reproductive endocrinologist since your treatment ended?

    __ Yes

    __ No

A fertility evaluation is generally done by a reproductive endocrinologist, a gynecologist who specializes in fertility. Blood is drawn to measure fertility hormone levels and an ultrasound is done so the doctor can see your ovaries.

14. Have you undergone a fertility evaluation with a reproductive specialist since your cancer treatment ended?

    __ Yes → go to Question 35

    __ No → go to Question 34

    __ Unsure → go to Question 34

    __ Prefer not to answer → go to Question 34

15. Have you considered having a fertility evaluation and/or undergoing fertility preservation in the future?

    __ Yes – I have decided to do this / have done this already

    __ Yes – I am thinking about doing this

    __ No – I have not thought about doing this

    __ Prefer not to answer

16. Have you undergone fertility preservation since completing your cancer treatment?

    ☐ Yes

    ☐ No

    ☐ Prefer not to answer

    If Yes, what did you do? Check all that apply

    ☐ Egg freezing

    ☐ Embryo freezing

    ☐ Other type of fertility preservation: ____________

17. Have you been told that you will not be able to get pregnant or carry a pregnancy because of your cancer treatment?

    __ Yes

    __ No

    __ I don't remember / I'm not sure

    __ Prefer not to answer

APPENDIX F: Decision Conflict Scale

Cancer treatments sometimes impact fertility and may change the options you have for having a child.

Family-building after cancer may require assisted reproductive technology, such as in vitro fertilization (IVF), surrogacy, or adoption.

The decision of how you want to pursue family-building can be difficult to think about. There are often "pros" or positive aspects (benefits) of pursuing one option over another, as well as "cons" or negative aspects (sometimes thought of as risks or side effects).

We would like to know how you feel about the decision of whether or not to undergo fertility preservation in the future.

	Strongly disagree	**Somewhat disagree**	**Neither disagree, nor agree**	**Somewhat agree**	**Strongly agree**
1. I know which options are available to me.	☐	☐	☐	☐	☐
2. I know the benefits of each option.	☐	☐	☐	☐	☐
3. I know the risks and side effects of each option.	☐	☐	☐	☐	☐
4. I am clear about which benefits matter most to me.	☐	☐	☐	☐	☐
5. I am clear about which risks and side effects matter most to me.	☐	☐	☐	☐	☐
6. I am clear about which is more important to me (the benefits or the risks and side effects).	☐	☐	☐	☐	☐
7. I have enough support from others to make a choice.	☐	☐	☐	☐	☐
8. I am choosing without pressure from others.	☐	☐	☐	☐	☐
9. I have enough advice to make a choice.	☐	☐	☐	☐	☐
10. I am clear about the best choice for me.	☐	☐	☐	☐	☐
11. I feel sure about what to choose.	☐	☐	☐	☐	☐
12. This decision is easy for me to make.	☐	☐	☐	☐	☐
13. I feel I have made (or could make) an informed choice.	☐	☐	☐	☐	☐
My decision shows (or would show) what is important to me.	☐	☐	☐	☐	☐
14. I expect to stick with my decision. ☐ NA – I have not made a decision.	☐	☐	☐	☐	☐
15. I am satisfied with my decision. ☐ NA – I have not made a decision.	☐	☐	☐	☐	☐

Appendix G. Unmet Information Needs

Many cancer survivors want information about their fertility. Do you feel you have as much information as you want about the topics below?

	Yes	**No**	**Not Interested**	**Prefer not to answer**
1. My risk of infertility	___	___	___	___
2. My risk of early menopause	___	___	___	___
3. Options to assess my fertility status	___	___	___	___
4. Option to preserve my fertility	___	___	___	___
5. Other options to build a family if I am not fertile	___	___	___	___

APPENDIX H: Illness Perceptions Questionnaire (revised)

[questions will be adapted for YA-Fs' with a confirmed infertility diagnosis vs infertility risk]

We are interested in your own personal views of your fertility and reproductive health. Please indicate how much you agree or disagree with the following statements by ticking the appropriate box.

These questions refer to your possible risk for fertility problems, infertility, or premature menopause because of the cancer treatment you received.

This is NOT based on your individual risk and does NOT mean that you have or will have fertility problems in the future.

	Strongly Disagree	**Disagree**	**Neither Disagree or Agree**	**Agree**	**Strongly Agree**
1. My fertility is a serious problem.	☐	☐	☐	☐	☐
2. Problems related to my fertility have major consequences on my life.	☐	☐	☐	☐	☐
3. Problems with my fertility do not have much effect on my life.	☐	☐	☐	☐	☐
4. Problems with my fertility strongly affect the way others see me.	☐	☐	☐	☐	☐
5. Problems related to my fertility and/or family-building have (or will have) serious financial consequences.	☐	☐	☐	☐	☐
6. Problems related to my fertility and/or family-building cause difficulties for those who are close to me.	☐	☐	☐	☐	☐
7. There is a lot which I can do to control problems related to my fertility and/or family-building.	☐	☐	☐	☐	☐
8. What I do can determine whether my fertility and/or family-building problems get better or worse.	☐	☐	☐	☐	☐
9. Whether or not I experience problems related to my fertility and/or family-building depends on me.	☐	☐	☐	☐	☐

10. Nothing I do will affect the problems I experience (or may experience) related to my fertility and/or family-building.	☐	☐	☐	☐	☐
11. I have the power to influence any problems that I experience (or may experience) with my fertility and/or family-building.	☐	☐	☐	☐	☐
12. My actions will have no effect on my fertility and/or family-building.	☐	☐	☐	☐	☐
13. There is very little that can be done to improve my fertility and/or family-building.	☐	☐	☐	☐	☐
14. There are treatments that will be effective in curing any fertility problems that I might have now or in the future.	☐	☐	☐	☐	☐
15. The negative effects of any fertility problems I experience now or in the future can be prevented (avoided) by treatments.	☐	☐	☐	☐	☐
16. There are treatments that can address any fertility problems that I might experience.	☐	☐	☐	☐	☐
17. If I experience fertility and/or family-building problems, there is nothing that can help.	☐	☐	☐	☐	☐
18. The symptoms of fertility problems are puzzling to me.	☐	☐	☐	☐	☐
19. My fertility is a mystery to me.	☐	☐	☐	☐	☐
20. I don’t understand my fertility or the problems I might have now or in the future.	☐	☐	☐	☐	☐

21. My fertility doesn’t make any sense to me.	☐	☐	☐	☐	☐
22. There is nothing that can help my risk for experiencing fertility and/or family-building problems.	☐	☐	☐	☐	☐
23. I get depressed when I think about my fertility and/or family-building.	☐	☐	☐	☐	☐
24. When I think about my fertility I get upset.	☐	☐	☐	☐	☐
25. My fertility makes me feel angry.	☐	☐	☐	☐	☐
26. My fertility does not worry me.	☐	☐	☐	☐	☐
27. The possibility that I might have fertility and/or family-building problems makes me feel anxious.	☐	☐	☐	☐	☐
28. I feel afraid when I think about my fertility and/or family-building problems .	☐	☐	☐	☐	☐

APPENDIX I: Reproductive Concerns after Cancer (RCAC) Scale

Thinking about how you feel **right now** about having (more) biological children someday, please circle whether you strongly disagree, somewhat disagree, neither agree nor disagree, somewhat agree, or strongly agree with each statement. If you feel that a statement does not apply to you, please select "Neither Agree nor Disagree".

	Strongly disagree	**Somewhat disagree**	**Neither disagree, nor agree**	**Somewhat agree**	**Strongly agree**
1. I am afraid I won't be able to have any (more) children.	☐	☐	☐	☐	☐
2. I am worried about passing on a genetic risk for cancer to my children.	☐	☐	☐	☐	☐
3. I worry about telling my (potential) spouse/partner that I may be unable to have children.	☐	☐	☐	☐	☐
4. I am scared of not being around to take care of my children someday.	☐	☐	☐	☐	☐
5. I can accept it if I'm unable to have (more) children.	☐	☐	☐	☐	☐
6. I am overwhelmed by the thought of trying to get pregnant (again).	☐	☐	☐	☐	☐
7. I am concerned that my (potential) spouse/partner will be disappointed if I can't get pregnant.	☐	☐	☐	☐	☐
8. I am worried about my ability to get pregnant (again).	☐	☐	☐	☐	☐
9. I am worried about how my family history might affect my children's health.	☐	☐	☐	☐	☐
10. I will be happy with life whether or not I have (more) children someday.	☐	☐	☐	☐	☐

	Strongly disagree	**Somewhat disagree**	**Neither disagree, nor agree**	**Somewhat agree**	**Strongly agree**
11. Having (more) children will make me more nervous about getting cancer again.	☐	☐	☐	☐	☐
12. I worry that getting pregnant (again) would take too much time and effort.	☐	☐	☐	☐	☐
13. I am cautious about having (more) children because I might not be around to raise them.	☐	☐	☐	☐	☐
14. It is stressful to think about trying to get pregnant (again).	☐	☐	☐	☐	☐
15. I will feel content if I do not have (more) children.	☐	☐	☐	☐	☐
16. The thought of telling my (potential) spouse/partner that I may be unable to have children makes me uncomfortable.	☐	☐	☐	☐	☐
17. I am concerned that I may not be able to have (more) children.	☐	☐	☐	☐	☐
18. I am afraid my children would have a high chance of getting cancer.	☐	☐	☐	☐	☐

APPENDIX J: Impact of Events Scale (revised)*

Below is a list of difficulties people sometimes have after stressful life events. Please indicate how distressing each difficulty has been for you. Please answer in regards to your feelings DURING THE PAST SEVEN DAYS.

Please answer with respect to your fertility and possible risk for experiencing problems with family-building.

		Not at all	A little bit	Moderately	Quite a bit	Extremely
1.	Any reminder brought back feelings about it.	0	1	2	3	4
2.	I had trouble staying asleep.	0	1	2	3	4
3.	Other things kept making me think about it.	0	1	2	3	4
4.	I felt irritable and angry.	0	1	2	3	4
6.	I thought about it when I didn’t mean to.	0	1	2	3	4
9.	Pictures about it popped into my mind.	0	1	2	3	4
10.	I was jumpy and easily startled.	0	1	2	3	4
14.	I found myself acting or feeling as though I was back at that time.	0	1	2	3	4
15.	I had trouble falling asleep.	0	1	2	3	4
16.	I had waves of strong feelings about it.	0	1	2	3	4
18.	I had trouble concentrating.	0	1	2	3	4
19.	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	0	1	2	3	4
20.	I had dreams about it.	0	1	2	3	4
22.	I tried not to talk about it.	0	1	2	3	4

*Only the Intrusive Thoughts and Avoidance subscales of the IES-R are included.

APPENDIX K: PROMIS Self Efficacy

General Self Efficacy

Please respond to each item by marking one box per row.

For the next set of questions, please read each sentence and rate your level of confidence in managing various situations, problems, and events.

Rate your level of confidence.	I am not at all confident (1)	I am a little confident (2)	I am somewhat confident (3)	I am quite confident (4)	I am very confident (5)
1. I can manage to solve difficult problems if I try hard enough.	☐	☐	☐	☐	☐
2. I am confident that I could deal efficiently with unexpected events.	☐	☐	☐	☐	☐
3. If I am in trouble, I can think of a solution.	☐	☐	☐	☐	☐
4. I can handle whatever comes my way.	☐	☐	☐	☐	☐

Now, thinking about your emotions related to your fertility and family-building, please respond to each question or statement by marking one box per row.

Rate your level of confidence about your **emotions related to your fertility and family-building.**	I am not at all confident (1)	I am a little confident (2)	I am somewhat confident (3)	I am quite confident (4)	I am very confident (5)
1. I can manage to solve difficult problems related to my fertility and/or family-building.	☐	☐	☐	☐	☐
2. I am confident that I could deal efficiently with unexpected events related to my fertility and/or family-building.	☐	☐	☐	☐	☐
3. If I am in trouble, I can think of a solution.	☐	☐	☐	☐	☐
4. I can handle whatever comes my way related to	☐	☐	☐	☐	☐

my fertility and/or family-building.					

APPENDIX K: PROMIS Self Efficacy

Self-Efficacy – Managing Emotions

Please respond to each question or statement by marking one box per row.

Rate your CURRENT level of confidence….	I am not at all confident (1)	I am a little confident (2)	I am somewhat confident (3)	I am quite confident (4)	I am very confident (5)
1. I can handle negative feelings.	☐	☐	☐	☐	☐
2. I can find ways to manage stress.	☐	☐	☐	☐	☐
3. I can avoid feeling discouraged.	☐	☐	☐	☐	☐
4. I can bounce back from disappointment.	☐	☐	☐	☐	☐

Now, thinking about your emotions related to your fertility and family-building, please respond to each question or statement by marking one box per row.

Rate your level of confidence about your **emotions related to your fertility and family-building.**	I am not at all confident (1)	I am a little confident (2)	I am somewhat confident (3)	I am quite confident (4)	I am very confident (5)
1. I can handle negative feelings related to my fertility and/or family-building.	☐	☐	☐	☐	☐
2. I can find ways to manage stress related to my fertility and/or family-building.	☐	☐	☐	☐	☐
3. I can avoid feeling discouraged related to my fertility and/or family-building.	☐	☐	☐	☐	☐
4. I can bounce back from disappointment related to my fertility and/or family-building.	☐	☐	☐	☐	☐

APPENDIX L: eHealth Impact Questionnaire (**eHIQ) Part 1 and Part 2**

eHealth Impact Questionnaire, <u>Part 1 (T1 only)</u>

We would like to get an understanding of how you think and feel about receiving online health information and sharing your health experiences through online platforms.

Response options:
1= Strongly disagree
2= Disagree
3= Neither agree nor disagree
4= Agree
5= Strongly agree

Scale	Items	1 to 5
Attitudes towards online health information (5 items)	1. The internet is a reliable resource to help me understand what a doctor tells me.	
	2. The internet can help the public to know what it is like to live with a health problem.	
	3. The internet can be useful to help people decide if their symptoms are important enough to go to see a doctor.	
	4. I would use the internet if I needed help to make a decision about my health (for example, whether I should see a doctor, take medication or seek other types of treatment).	
	5. I would use the internet to check that the doctor is giving me appropriate advice.	
Attitudes towards sharing health experiences online (6 items)	6. The internet is a good way of finding other people who are experiencing similar health problems.	
	7. It can be helpful to see other people’s health-related experiences on the internet.	
	8. The internet is useful if you don’t want to tell people around you (for example, your family or people at work) how you feel.	
	9. It can be reassuring to know that I can access health-related websites at any time of the day or night.	
	10. The internet is a good way of finding other people who are facing health-related decisions I may also face.	
	11. Looking at health-related websites reassures me that I am not alone with my health concerns.	

APPENDIX L: **eHealth Impact Questionnaire, <u>Part 2 (T2 and T3 only)</u>**

Next, we'd like to ask you some questions about the decision aid and planning tool you viewed. Please answer as honestly as possible, as we would like to learn what you liked and disliked about the website and how to make it better (2 pages).

Response options:
1= Strongly disagree
2= Disagree
3= Neither agree nor disagree
4= Agree
5= Strongly agree

Scale	Items	1 to 5
Confidence and identification (9 items)	1. The website prepares me for what might happen related to my fertility and family-building.	
	2. The people who have contributed to the website understand what is important to me.	
	3. I feel I have a sense of solidarity with other people using the website.	
	4. I can identify with other people using the website.	
	5. I value the advice given on the website.	
	6. The website gives me confidence that I am able to manage what my happen related to family-building.	
	7. I feel I have a lot in common with other people using the website.	
	8. The website gives me the confidence to explain my concerns to others.	
	9. The website makes me more confident to discuss fertility and family-building issues with the people around me (for example, my family or people at work).	
Information and presentation (8 items)	10. The information on the website left me feeling confused.	
	11. The website provides a wide range of information.	
	12. The language on the website made it easy to understand.	
	13. I can easily understand the information on the website.	
	14. I trust the information on the website.	
	15. Photographs and other images were used appropriately on the website.	
	16. I found the images on the website distressing.	
	17. The website is easy to use.	

Scale	Items	1 to 5
Understanding and Motivation (9 items)	18. The website encourages me to take actions that could be beneficial to my health.	
	19. The website has a positive outlook.	
	20. The website includes useful tips on how to make life better.	
	21. I feel more inclined to look after myself after visiting the website.	
	22. I have learnt something new from the website.	
	23. I would consult the website if I had to make a decision about family-building.	
	24. On the whole, I find the website reassuring.	
	25. The website helps me to have a better understanding of my family-building options.	
	26. The website encourages me to play a more active role in my healthcare and family-building decisions.	

APPENDIX M: COmprehensive Score for financial Toxicity (COST)

Below is a list of statements that other people have said are important**. Please circle a number to indicate your response as it applies to the past 7 days.**

	Not at all	A little bit	Some-what	Quite a bit	Very much
1. I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment.	0	1	2	3	4
2. My out-of-pocket medical expenses are more than I thought they would be.	0	1	2	3	4
3. I worry about the financial problems I will have in the future as a result of my illness or treatment.	0	1	2	3	4
4. I feel I have no choice about the amount of money I spend on care.	0	1	2	3	4
5. I am frustrated that I cannot work or contribute as much as I usually do.	0	1	2	3	4
6. I am satisfied with my current financial situation.	0	1	2	3	4
7. I am able to meet my monthly expenses.	0	1	2	3	4
8. I feel financial stressed.	0	1	2	3	4
9. I am concerned about keeping my job and income, including work at home.	0	1	2	3	4
10. My cancer or treatment has reduced my satisfaction with my present financial situation.	0	1	2	3	4
11. I feel in control of my financial situation.	0	1	2	3	4

APPENDIX N: InCharge Financial Distress/Financial Well-being Scale

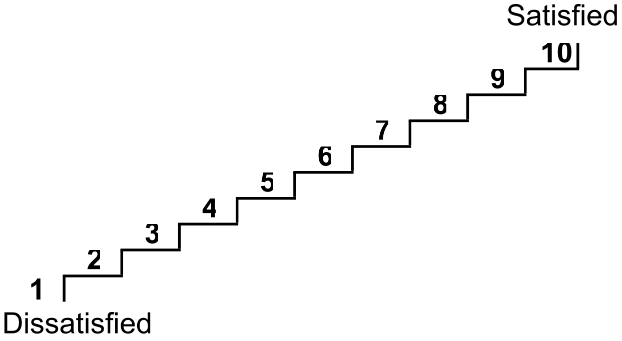
Directions: Circle or check the responses that are ***most appropriate*** for your situation.

1. What do you feel is the ***level*** of your ***financial stress today?***

1	2	3	4	5	6	7	8	9	10

Overwhelming Stress — High Stress — Low Stress — No Stress at All

2. On the stair steps below, mark (with a circle) how ***satisfied*** you are with your **present financial situation.** The "1" at the bottom of the steps represents complete dissatisfaction. The "10" at the top of the stair steps represents complete satisfaction. The more dissatisfied you are, the lower the number you should circle. The more satisfied you are, the higher the number you should circle.



3. How do you feel about your ***current financial situation?***

1	2	3	4	5	6	7	8	9	10

Feel Overwhelmed — Sometimes Feel Worried — Not Worried — Feel Comfortable

4. How often do you worry about being ***able to meet*** normal monthly living expenses?

1	2	3	4	5	6	7	8	9	10

Worry All the Time — Sometimes Worry — Rarely Worry — Never Worry

5. How confident are you that you could find the money to pay for a ***financial emergency*** that costs about **$1,000**?

1	2	3	4	5	6	7	8	9	10

No Confidence — Little Confidence — Some Confidence — High Confidence

6. How often does this happen to you? You want to go out to eat, go to a movie or do something else and ***don't go because you can't afford to***?

1	2	3	4	5	6	7	8	9	10

All the time　Sometimes　Rarely　Never

7. How frequently do you find yourself just getting by financially and living ***paycheck to paycheck***?

1	2	3	4	5	6	7	8	9	10

All the time　Sometimes　Rarely　Never

8. How ***stressed*** do you feel about your personal finances ***in general?***

1	2	3	4	5	6	7	8	9	10

Overwhelming Stress　High Stress　Low Stress　No Stress at All

APPENDIX O: Uncertainty Management Preferences

	Strongly agree	…………	…………	…………	…………	…………	Strongly disagree
Preference to maintain uncertainty through avoidance I tend to AVOID information about my fertility or any family-building problems because…	1	2	3	4	5	6	7
1. It can be depressing.	1	2	3	4	5	6	7
2. I get anxious when I think about it.	1	2	3	4	5	6	7
3. Being constantly reminded of it makes me nervous.	1	2	3	4	5	6	7
4. It can be scary to think about.	1	2	3	4	5	6	7
Preference to avoid insufficient information I tend to AVOID information about my fertility and/or family-building problems because…	1	2	3	4	5	6	7
5. There's a lot of misinformation out there, so it's difficult to know which is truthful. 6. The recommendations are always changing.	1	2	3	4	5	6	7
7. The amount of information out there can be overwhelming.	1	2	3	4	5	6	7
Preference to increase uncertainty I tend to SEEK OUT information about my fertility and/or family-building options because…	1	2	3	4	5	6	7
8. I want to get a second opinion.	1	2	3	4	5	6	7
9. New information can give me hope.	1	2	3	4	5	6	7
10. Finding new information helps me check what my doctor told me.	1	2	3	4	5	6	7
Preference to reduce uncertainty I tend to SEEK OUT information about my fertility and/or family-building options because…	1	2	3	4	5	6	7
11. It's good to be prepared.	1	2	3	4	5	6	7
12. It makes me feel equipped to handle difficult situations.	1	2	3	4	5	6	7
13. It makes me less fearful.	1	2	3	4	5	6	7
14. I try to find all kinds of information I can.	1	2	3	4	5	6	7
15. Being knowledgeable can be helpful.	1	2	3	4	5	6	7

APPENDIX P: Brief Health Literacy Screener

1. How often do you have problems learning about your medical condition because of difficulty understanding written information?

   (1) Always (2) Often (3) Sometimes (4) Occasionally (5) Never

2. How often do you feel confident filling out medical forms by yourself?

   (1) Always (2) Often (3) Sometimes (4) Occasionally (5) Never

3. How often do you have someone (like a family member, friend, hospital/clinic worker, or caregivers) help you read hospital materials?

   (1) Always (2) Often (3) Sometimes (4) Occasionally (5) Never

APPENDIX Q: Health Literacy Screening Questionnaire (HL-SQ)

How well do you understand the following information?

1. … instruction leaflets for medication?

   (1) Not at all well (2) Slightly well (3) Moderately well
   (4) Very well (5) Extremely well

__ I do not make use of this kind of information

2. … information brochures on health issues?

   (1) Not at all well (2) Slightly well (3) Moderately well
   (4) Very well (5) Extremely well

__ I do not make use of this kind of information

3. When I have questions on diseases or complaints, I know where I can find information on these issues.

   (1) Disagree strongly (2) Disagree (3) Agree (4) Agree strongly

__ I do not have experience with these issues

4. When I want to do something for my health, I know where I can find information on these issues.

   (1) Disagree strongly (2) Disagree (3) Agree (4) Agree strongly

__ I do not have experience with these issues

5. How often are you able to help your family members or a friend if they had questions concerning health issues (e.g. stress, minor sport injuries, or nutrition)?

   (1) Never (2) Seldom (3) Sometimes (4) Often (5) Always

__ There have never been any questions

6. If you have questions about health issues, how often are you able to get information and advice from others (family and friends)?

   (1) Never (2) Seldom (3) Sometimes (4) Often (5) Always

__ There have never been any questions

7. How well can you choose health advice that meets your needs?

   (1) Very bad (2) Bad (3) Moderate (4) Good (5) Very good

__ I do not make use of this kind of information

8. Regarding health information on the Internet, I'm able to determine which sources are of high quality and which of poor quality?

   (1) Disagree strongly (2) Disagree (3) Agree (4) Agree strongly

__ I do not have experience with these issues

APPENDIX R: Actions & Concomitant Care (T2 and T3 only)

These questions ask about what actions or “next steps”, if any, you have taken related to fertility and family-building.

1. To what extent did the website prompt you to consider your family-building decisions?

Not at all	**A little bit**	**A moderate amount**	**Very much**	**Extremely**

2. To what extent did the website prompt you to take “next steps” toward planning for future family-building?

Not at all	**A little bit**	**A moderate amount**	**Very much**	**Extremely**

In the past month/past two months [T2 and T3, respectively], have you…

3. Sought guidance from your oncologist or member of your cancer care team related to your fertility and family-building options, such as having an office visit (or scheduling one)?

Yes → If Yes, what did you do? ________________________________
No → If No, why not? ________________________________
N/A

4. Sought guidance from a fertility specialist related to your fertility and family-building options, such as having an office visit (or scheduling one)?

Yes → If Yes, what did you do? ________________________________
No → If No, why not? ________________________________
N/A

5. Taken steps to learn more about, or plan for, the cost of family-building options?

Yes → If Yes, what did you do? ________________________________
No → If No, why not? ________________________________
N/A

6. Connected with family, friends, or peers for help, support, or guidance related to family-building concerns?

Yes → If Yes, what did you do? ________________________________
No → If No, why not? ________________________________
N/A

7. Talked to your partner about family-building options?

Yes → If Yes, what did you do? ________________________________
No → If No, why not? ________________________________
N/A

8. Did the website prompt any other action related to your fertility and family-building? ________

APPENDIX S: Family-building Website Use (T2 and T3 only)

1. Did you access the “Roadmap to Parenthood” website (www.familybuildingaftercancer.com)?
   Yes / No

2. How many times did you access the website?
   [number drop down]

3. About how long did you spend on the website the first time you used it?
   [number drop down] minutes

4. About how much time have you spent using the website in total?
   [number drop down] minutes

APPENDIX T: Stage of Decision-making

People who are interested in having a child after cancer may consider multiple options for family-building.

At this time, would you say you:

__ haven't begun to think about the choices (1)
__ haven't begun to think about the choices, but am interested in doing so (2)
__ are considering the options now (3)
__ are close to selecting an option (4)
__ have already made a decision, but am still willing to reconsider (5)
__ have already made a decision and am unlikely to change my mind (6)

APPENDIX U: Preparation for Decision Making (T2 only)

Did you visit the Roadmap to Parenthood website? Yes/ No (if No, SKIP measure)

Did the website…	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**A great deal**
1. Help you understand that a decision needs to be made about family-building options (at some point, even if in the future)?	1	2	3	4	5
2. Prepare you to make a better decision?	1	2	3	4	5
3. Help you think about the pros and cons of each option?	1	2	3	4	5
4. Help you think about which pros and cons are most important?	1	2	3	4	5
5. Help you know that the decision depends on what matters most to you?	1	2	3	4	5
6. Help you organize your own thoughts about the decision?	1	2	3	4	5
7. Help you think about how involved you want to be in this decision?	1	2	3	4	5
8. Help you identify questions you want to ask your doctor*? *oncologist, fertility specialist, or any other doctor you would discuss fertility and family-building with	1	2	3	4	5
9. Prepare you to talk to your doctor* about what matters most to you? *oncologist, fertility specialist, or any other doctor you would discuss fertility and family-building with	1	2	3	4	5
10. Prepare you for a follow-up visit with your doctor*? *oncologist, fertility specialist, or any other doctor you would discuss fertility and family-building with	1	2	3	4	5

APPENDIX V: Website Feedback (T2 only)

1. What is your overall impression of the website?

2. What did you like best about the website?

3. What did you like least about the website?

4. Is there anything that you feel is missing or could have been done better on the website?

	Very unlikely	Unlikely	Undecided	Likely	Very Likely
5. How likely are you to recommend the website to a friend?					
6. In the future, what is the likelihood that you would use the website again?					

7. Do you have any other final comments or suggestions about the website?