Fertilit-*e*
Wake Forest Baptist Comprehensive Cancer Center (WFBCCC)
WFBCCC # 01717

ClinicalTrials.gov: NCT03599661

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Version Date: 06/30/2020
Amended:

Confidential

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1.0 Introduction and Background

Every year, approximately 70,000 young adults (ages 18-39) are diagnosed with cancer, which can significantly affect their health-related quality of life in multiple areas, including the potential for infertility or other reproductive challenges. Despite this, very few young adults diagnosed with cancer are actually provided fertility preservation information let alone effective strategies or tools for how to best navigate their fertility preservation options.[1] **It is critical to provide decision-making information and support about infertility risk and existing interventions to maintain reproductive potential in a delivery mode that is most congruent with this population's health communication style, such as mHealth applications.** Numerous organizations, including the American Society for Reproductive Medicine (ASRM),[2] American Society of Clinical Oncology (ASCO),[3,4] and the National Comprehensive Cancer Network (NCCN),[5] have established national guidelines to enhance provider adherence and facilitate patient and provider discussions about fertility preservation options prior to proceeding with fertility compromising treatments. These guidelines recommend that 1) all oncologists inform their patients about the impact of their cancer and/or treatment on their fertility, and 2) all patients who solicit information about fertility preservation receive it, including a referral to a reproductive specialist when appropriate. However, previous studies suggest that oncologists face many communication challenges when discussing fertility preservation with their patients. These challenges can be related to physician attributes (e.g., knowledge barriers), patient attributes (e.g., cultural or religious prohibitions for assisted reproduction), and healthcare factors (e.g., time demands).[6] In fact, a burgeoning scientific literature exists on adult oncology providers' practice patterns and barriers to discussing fertility preservation[7-16] and suggests that **oncologists rarely refer patients to fertility preservation specialists[6,10] with less than 25% being aware of or distributing written educational materials to their patients[10] and <50% following recommended ASRM/ASCO/NCCN guidelines.[6]** Similar trends hold true for the dearth of fertility preservation information and support provided to young adult cancer patients.[17] When more than one specialist is involved (commonly the case in young adult care), information on fertility preservation may be neglected as one specialist may assume another already discussed the topic with the patient.

Given these provider-centered obstacles, it is essential that patients can receive timely and accurate fertility preservation information via non-provider channels so they can be empowered to ask specific questions and be engaged to make appropriate decisions on their own behalf. mHealth interventions represent promising options for patient engagement, especially within a younger demographic such as young adults with cancer. Technology-enabled communications are increasingly utilized, accessible, and can be tailored to reflect specific values and preferences of a population. **By delivering guideline-based fertility preservation information to young adult patients using mHealth technologies, patient knowledge may be increased and sustained, and both patients and providers may be more empowered to attend to this unaddressed issue through shared decision-making.**[18]

This study will utilize advances in mHealth technologies to address knowledge deficits,

enhance self-efficacy, and promote shared decision-making about fertility options among newly diagnosed young adults with cancer and their providers. We will achieve this goal by developing an mHealth tool (Fertilit-*e*) to increase patient knowledge, thereby positively impacting self-efficacy for fertility preservation decision-making, and enhancing satisfaction with fertility preservation decisions made for this group of underserved patients. The use of mHealth interventions has grown significantly in recent years,[19,20] increasing the potential to make decision-making interventions more accessible, personally tailored, and integrated into clinical practice.

2.0 Objectives

2.1 Primary Objective

2.1.1 Adapt and optimize fertility preservation content in a tailored mHealth tool for fertility preservation decision-making. More specifically, we will adapt fertility-preservation content for tailored, rapid, and clear dissemination of information in an engaging, cross-platform, patient-friendly mHealth format. We will alpha-test this tool with an ethnically diverse sample of cross-cultural end users to collect qualitative data and evaluate usability to refine content and design. No formal hypothesis testing will be done.

2.2 Secondary Objective

2.2.1 To qualitatively evaluate comprehensibility of the mHealth tool.

2.3 Exploratory Objectives

2.3.1 To describe the characteristics of the study population in terms of health literacy, sociodemographics, technology use, and eHealth literacy.
2.3.2 To explore differences in usability by health literacy, sociodemographic characteristics, technology use, and eHealth literacy.

3.0 Study Population

Young adult patients are eligible if they: 1) are ages 18 to 39; 2) had a histologically confirmed diagnosis of cancer during ages 15 to 39, 3) will be receiving or have received treatment associated with a risk of infertility (i.e., systemic chemotherapy, pelvic radiotherapy, and/or pelvic surgery with potential impact on reproductive function), 4) considered or wish they had considered fertility preservation treatments, 5) are able to speak, read, and understand English, and 6) are able to provide electronic informed consent 7) have access to the internet 8) have access to a computer that will allow for a WebEx research interview. Young adult patients will be excluded if they: 1) had an infertility diagnosis prior to cancer diagnosis, 2) had a history of fertility preservation or fertility treatments prior to their cancer diagnosis, 3) are more than five years post-cancer-related treatments (i.e., systemic chemotherapy, pelvic radiotherapy, and/or pelvic

surgery). The electronic medical record will be queried to identify potentially eligible patients. IRB-approved study flyers may also be disseminated through email blasts or postings on websites of local cancer support agencies such as Cancer Services. Once potential participants have been identified, a study team member will contact patients by phone, email, and/or MyWakeHealth to describe the study, answer questions, confirm eligibility, and consent those who are interested.

Alpha testing will occur with 24 young adults. For this purposive sample, we will recruit equal numbers of men and women, one half (n=12) of our sample will be from racial or ethnic minority groups, and one fourth (n=6) will have low literacy (i.e., <12 years of education). We will recruit participants in three phases that correspond to three rounds of computer prototype testing (Round 1, n=6; Round 2, n=6; Round 3, n=12). We will strive for target representation of racial or ethnic minorities and low literacy participants within each phase.

4.0 Methods

4.1 Registration Procedures

All patients entered on any WFBCCC trial, whether treatment, companion, or cancer control trial, **must** be linked with a study protocol in EPIC or WISER if non Wake patient within 24 hours of Informed Consent. Patients **must** be registered prior to the initiation of the study.

We will perform the following steps in order to ensure prompt registration of our patients:

1.0 Complete the Eligibility Checklist (Appendix A)
2.0 Complete the Protocol Registration Form (Appendix B)
3.0 Alert the Cancer Center registrar by phone, *and then* send the electronic signed Informed Consent Form, Eligibility Checklist and Protocol Registration Form to the registrar, either by fax or e-mail.

Contact Information:
Protocol Registrar PHONE (336) 713-6767
Protocol Registrar FAX (336) 713-6772
Protocol Registrar E-MAIL (registra@wakehealth.edu)

*Protocol Registration is open from 8:30 AM - 4:00 PM, Monday-Friday.

4.0 Fax/e-mail ALL eligibility source documents with registration. Patients **will not** be registered without all required supporting documents.

Note: If labs were performed at an outside institution, provide a printout of the results. Ensure that the most recent lab values are sent.

To complete the registration process, the Registrar will:

- assign a patient study number
- register the patient on the study

4.2 Study Procedures

Led by Dr. Miller (Co-I) and supported by Mr. Hepler (Senior Analyst and Programmer), we will configure and enable technological specifications of the alpha version of our cross platform, web-based decision-making tool. Fertilit-*e* will leverage the technical infrastructure from Dr. Miller's validated mPath platform (1R01CA178941), and since Fertilit-*e* will be web-based and cross-platform, it will be accessible across multiple different user systems and not limited to a tablet or smartphone (e.g., Android, iPhone). Further, Informed by the Ottawa Decision Support Framework,[21,22] self-efficacy theory,[23-25] and existing fertility preservation decision-aids,[26-30] we expect Fertilit-*e* to include, but not be limited to, the following modules: (1) personal information, values, and preferences; (2) fertility risks and options; (3) personal stories; (4) financial concerns; (5) frequently asked questions; (6) additional resources; and (7) session summary. Across all modules, the goal will be to provide tailored information (by gender) about the risks of infertility and options to preserve fertility if interested.

Alpha Testing with Patients. Aim 1 qualitative activities will be supported by the Developing Shared Resource, Q-PRO (Qualitative and Patient-Reported Outcomes) of the Wake Forest Baptist Comprehensive Cancer Center (WFBCCC). Once Fertilit-*e* alpha content has been developed, we will begin pilot testing the material with consented patients (n=6). Patients will meet virtually through WebEx or individually in a private setting with a member of the research team.. Participants will review a computer prototype of Fertilit-*e* alpha content and its design elements (**see https://fertilite.phs.wakehealth.edu/**). Using an interview guide (Appendix C), a research team member will ask about issues of content, functionality, and ease of use (i.e., comprehensibility and usability). Interviews will be completed within 45-60 minutes. Alpha testing will be audio and video recorded and transcripts will be de-identified prior to subsequent qualitative coding by research team member and Dr. Canzona. All participants will complete an interviewer administered screener for health literacy[31,32] and self-report items for technology use, eHealth literacy,[33] and need for cognition.[34] Input will be used to modify Fertilit-*e* for a second round of computer prototype testing (n=6 new patients) which will follow the same process as before.

After two rounds of computer prototype testing have been completed, our

team will then review participant input and incorporate pertinent changes into a revised version of our decision aid that will be pilot tested with an additional 12 new patients who will use Fertilit-*e* on an iPad. As with earlier rounds of computer prototype testing, all participants will meet individually with a research team member in a private location. We will use the "Think Aloud" protocol to examine how individuals interact with and interpret Fertilit-*e*. A research team member will also ask each participant additional questions about the clarity of content and ease of use following an interview guide. At the end of alpha testing, participants will receive $25. Feedback will be examined systematically by the study team and Advisory Board after each round of computer prototype testing to make necessary modifications prior to pilot testing in a subsequent aim.

5.0 Outcome Measures

5.1 Primary and Secondary Outcomes

To evaluate Fertilit-*e* alpha, we will examine its comprehensibility and design through a series of think aloud interviews[35] and usability with additional open-ended questions (See Appendix C). We will complement the qualitative data by administering the System Usability Scale.[36,37] After our alpha testing, we will have an eHealth decision aid on fertility preservation (Fertilit-*e*) ready to be field tested in a sample of newly diagnosed young adults with cancer.

6.0 Analytic Plan

6.1 Analysis of Primary Outcome

Q-PRO staff will review qualitative data to provide an integrative summary and identification of key points, potential themes, and areas of further exploration. A summary report will be created using the interview recordings and interviewer field notes. The report would include a summary for each module based on the data from the Think Aloud and Interview Guide that incorporates usability for Fertilit-*e* alpha. Q-PRO will also include a section on general comments and overall recommendations. Finally, they will be maintaining a spreadsheet that includes data for the sequence of modules selected, modules skipped, and overall time spent using the app. Q-PRO will then move to standard analysis (transcription, thematic analysis, saturation, etc.) for beta testing. [38,39]

Our study team will calculate descriptive statistics for the System Usability Scale by gender and race/ethnicity.

6.2 Analysis of Secondary Outcome

Q-PRO staff will review qualitative data that incorporates and summarizes comprehensibility for Fertilit-e alpha using the same techniques and approaches as described above (Section 6.1).

6.3 Analysis of Exploratory Outcomes

We will calculate descriptive statistics (means and standard deviations, frequencies) for all sociodemographic variables, the health literacy scale,[31,32] the technology use items, the eHealth literacy scale,[33] and the Need for Cognition – short form[34] to describe the study population. This will be considered exploratory due to the small sample size and intentional selection of participant groups.

To explore differences in usability by health literacy, sociodemographic characteristics, technology use and eHealth literacy, we will use t-tests, ANOVAs, and correlations to examine the relationship between these variables and the outcome of the System Usabilty Scale score.

6.4 Sample Size and Power

The combined sample size from each round of computer prototype testing (N=24) should permit us to achieve data saturation for gender (12 men and 12 women) With 24 participants, we will also be able to estimate the usability data within ±0.4 SD for the System Usability Scale using 2-sided 95% confidence intervals (CIs).

6.5 Accrual Rate

The WFBCCC sees a high volume of young adults with cancer annually. In the last fiscal year, 901 young adults with cancer were seen and ~550 of those were post-treatment survivors. For this purposive sampling strategy, we anticipate recruiting 24 young adults within 4 months (or 6 young adults/month). Given the relatively large sample sizes of young adults at WFBCCC, we believe our proposed sample sizes and timeline are realistic goals.

6.6 Length of Study

Patients will complete their participation in 45-60 minutes. We expect the entire qualitative data collection will be completed within 4 months.

7.0 Data Management

Informed consent document	EPIC/REDCap
Protocol registration form	WISER/OnCore
Study questionnaire	REDCap

8.0 Confidentiality and Privacy

Confidentiality will be protected by collecting only information needed to assess study outcomes, minimizing to the fullest extent possible the collection of any information that could directly identify subjects, and maintaining all study information in a secure manner. To help ensure subject privacy and confidentiality, only a unique study identifier will appear on the data collection form. Any collected patient identifying information corresponding to the unique study identifier will be maintained on a linkage

file, store separately from the data. The linkage file will be kept secure, with access limited to designated study personnel. Following data collection, subject identifying information will be destroyed, consistent with data validation and study design, producing an anonymous analytical data set. Data access will be limited to study staff. Data and records will be kept locked and secured, with any computer data password protected. No reference to any individual participant will appear in reports, presentations, or publications that may arise from the study.

9.0 Data Safety and Monitoring

The principal investigator will be responsible for the overall monitoring of the data and safety of study participants. The principal investigator will be assisted by other members of the study staff.

The risks of this study are low; however, staff will be trained to handle situations with sensitivity and empathy. The study coordinator will be trained to monitor for significant patient distress or depressive symptoms and will be instructed on the appropriate courses of referral is a patient is considered to be at risk for a safety concern.

10.0 Reporting of Unanticipated Problems, Adverse Events or Deviations

Any unanticipated problems, serious and unexpected adverse events, deviations or protocol changes will be promptly reported by the principal investigator or designated member of the research team to the IRB and sponsor or appropriate government agency if appropriate.

In the rare event that a participant becomes distressed as a result of participating in this study or rather becomes more reflective and wants to talk about these issues in more depth, we will provide referrals to members of the psychosocial support team and/or other clinical staff as appropriate.

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Appendix A – Subject Eligibility Checklist

IRB Protocol No. ___ ___ ___ ___ ___ ___ ___ ___ ___ ___	**WFBCCC Protocol No** .___ ___ ___ ___ ___
Study Title: Fertilit-*e*	
Principal Investigator: John M. Salsman, Ph.D.	

Inclusion Criteria (as outlined in study protocol)	**Criteria is met**	**Criteria is NOT met**	**Source Used to Confirm * (Please document dates and lab results)**
Age 18 to 39.	☐	☐	
Histologically confirmed diagnosis of cancer during ages 15 to 39	☐	☐	
Will be receiving or have received treatment associated with a risk of infertility (i.e., chemotherapy, pelvic radiotherapy, and/or pelvic surgery with potential impact on reproductive function).	☐	☐	
Considered or wish they had considered fertility preservation treatments.	☐	☐	
Able to speak, read, and understand English.	☐	☐	
Able to provide informed consent.	☐	☐	
Have internet access	☐	☐	
Have a laptop, or desktop computer that can connect to WebEx	☐	☐	
Exclusion Criteria (as outlined in study protocol)	**Criteria NOT present**	**Criteria is present**	**Source Used to Confirm * (Please document dates and lab results)**
Infertility diagnosis prior to cancer diagnosis.	☐	☐	
History of fertility preservation or fertility treatments prior to their cancer diagnosis.	☐	☐	
Are more than five years post-cancer-related treatments (i.e., systemic chemotherapy, pelvic radiotherapy, and/or pelvic surgery)	☐	☐	

This subject is ☐ eligible / ☐ ineligible for participation in this study.

OnCore Assigned PID: ___ ___ ___ ___ ___ ___ ___ ___

Signature of research professional confirming eligibility:_____

Date: ___ ___/___ ___/___ ___

Signature of Treating Physician**: _____

Date: ___ ___/___ ___/___ ___* Examples of source documents include clinic note, pathology report, laboratory results, etc. When listing the source, specifically state which document in the medical record was used to assess eligibility. Also include the date on the document. Example: “Pathology report, 01/01/14” or “Clinic note, 01/01/14”
**Principal Investigator signature can be obtained following registration if needed

Appendix B– Reduced Review** Registration Form

DEMOGRAPHICS

Patient: Last Name: _____ First Name: _____

MRN: ___ ___ ___ ___ ___ ___ ___ ___ ZIPCODE: ___ ___ ___ ___ ___

*SEX: ☐ Male ☐ Female

*Ethnicity (choose one): ☐ Hispanic ☐Non-Hispanic

*Race (choose all that apply): ☐ WHITE ☐African American
☐ ASIAN ☐ PACIFIC ISLANDER
☐ NATIVE AMERICAN (Alaskan)

*Diagnosis: _____

DOB (mm/dd/yy): ___ ___ / ___ ___ / ___ ___ (include if no MRN is provided)

*MD Name (Last, First) : _____, _____

*Date Consent Signed: ___ ___ / ___ ___ / ___ ___

Date of Registration: (if different than consent signing) ___ ___ / ___ ___ / ___ ___

PID # (OnCore): ___ ___ ___ ___ ___ ___ ___ ___ (to be completed by registrar)

The Comprehensive Cancer Center requires that all registrations be sent to the CCCWFU Centralized Registrar the day the patient is consented; if this is not possible we require that all registration be communicated to the Centralized Registrar within 72 hours by the CRM registrar.

***Reduced Review means eligibility and other review are not performed by CRM registrar.*

For questions, the Protocol Registrar can be contact by calling 336-713-6767 between 8:30 AM and 4:00 PM, Monday – Friday.

Completed Eligibility Checklist and Protocol Registration Form must be hand delivered, faxed or e-mailed to the registrar at 336-713-6772 or registra@wakehealth.edu.

**** if not using the full wakehealth.edu outlook client (full outlook, not web outlook) save this file and attach to an email to registra@wakehealth.edu.*

Submitter of this form is responsible for insuring that all regulatory and eligibility requirements are met for this registration

APPENDIX C. Data Collection Measures

Variable/Construct	Measure	Items	Source
Health Literacy	Brief Health Literacy Screener	3	Chew et al., 2008; Wallston et al., 2014
Patient Characteristics	Sociodemographic variables	23	Standard items
Technology Use	Type, frequency, and purpose of technology use variables	11	Study team developed
eHealth Literacy	Questions about comfort with and use of eHealth information	10	Norman & Skinner, 2006
Need for Cognition	Need for Cognition Scale	18	Cacioppo et al., 1984
Comprehensibility	Interview Guide	10	Study team developed and informed by Kelly-Blake et al., 2014
Usability	Interview Guide; System Usability Scale	11; 12	study team developed; Brooke, 1996

BRIEF HEALTH LITERACY SCREENER

1. How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials? (Help Read)
   - ☐ all of the time
   - ☐ most of the time
   - ☐ some of the time
   - ☐ a little of the time
   - ☐ none of the time
   - ☐ Refused [DO NOT READ]

2. How often do you have problems learning about your medical condition because of difficulty understanding written information? (Problems Learning),
   - ☐ all of the time
   - ☐ most of the time
   - ☐ some of the time
   - ☐ a little of the time
   - ☐ none of the time
   - ☐ Refused [DO NOT READ]

3. How confident are you filling out medical forms by yourself? (Confident with Forms)
   - ☐ extremely
   - ☐ quite a bit
   - ☐ somewhat
   - ☐ a little bit
   - ☐ not at all
   - ☐ Refused [DO NOT READ]

Chew LD, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med.* 2008;23(5):561-566.

Wallston KA, Cawthon C, McNaughton CD, Rothman RL, Osborn CY, Kripalani S. Psychometric properties of the brief health literacy screen in clinical practice. *J Gen Intern Med.* 2014;29(1):119-126.

Patient Sociodemographic Variables

This set of questions is about your cancer treatment and general background. Unless otherwise stated, please select only one response for each question. All of the information you provide is confidential.

What is your current cancer treatment plan? Check all that apply

- ☐ I have not had any treatment
- ☐ I am currently receiving chemotherapy
- ☐ I am currently receiving radiation
- ☐ I have had surgery to remove or treat cancer or tumor
- ☐ I have completed treatment
- ☐ Other (please describe:_____)

What is your gender?

- ☐ Male
- ☐ Female
- ☐ Transgender

Are you of Hispanic, Latino, or Spanish origin or descent?

- ☐ Yes, Hispanic, Latino, or Spanish
- ☐ No, not Hispanic, Latino, or Spanish

What is your race? (check all that apply)

- ☐ White
- ☐ Black or African American
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ American Indian or Alaska Native
- ☐ Other

What is your residential zip code?_____

What is your present religion, if any?

- ☐ Protestant; if yes, which denomination? _____
- ☐ Roman Catholic
- ☐ Mormon
- ☐ Orthodox such as Greek or Russian Orthodox
- ☐ Jewish
- ☐ Muslim
- ☐ Buddhist
- ☐ Hindu
- ☐ Atheist
- ☐ Agnostic
- ☐ Other _____
- ☐ No particular religion

How important are your religious or spiritual beliefs to you?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

What is the highest grade or level of school that you have completed?

- ☐ 8th grade or less
- ☐ Some high school, but did not graduate
- ☐ High school graduate or GED
- ☐ Some college or 2-year degree
- ☐ 4-year college graduate
- ☐ More than 4-year college degree

What was your employment or school status <u>JUST BEFORE</u> your cancer diagnosis? (check all that apply):

- ☐ Employed full-time (including self-employed)
- ☐ Employed part-time (including self-employed)
- ☐ Full-time homemaker
- ☐ Full-time student
- ☐ On temporary medical leave/disability
- ☐ Unemployed
- ☐ Permanently unable to work

What is your employment or school status <u>NOW</u>? (check all that apply):

- ☐ Employed full-time (including self-employed)
- ☐ Employed part-time (including self-employed)
- ☐ Full-time homemaker
- ☐ Full-time student
- ☐ On temporary medical leave/disability
- ☐ Unemployed
- ☐ Permanently unable to work

What is your current marital / relationship status?

- ☐ Single / Never married
- ☐ Single/Divorced
- ☐ Single/Widowed
- ☐ Married or living with partner in committed relationship
- ☐ Married but currently separated

Who lives at home with you? (check all that apply):

- ☐ Parent(s)
- ☐ Grandparents
- ☐ Siblings
- ☐ Spouse

- ☐ Significant other/partner
- ☐ Child(ren) Number of children_____
- ☐ Friend(s)/Roommate(s)
- ☐ I live alone
- ☐ Other, please specify _____

Who is the primary income earner in your household?

- ☐ Me
- ☐ My spouse or significant other
- ☐ My child
- ☐ My parent(s)* [*If patient selects this option, please skip to "In general, would you say your health is…" item*.]
- ☐ Someone else not listed here, please specify _____
- ☐ There is no income earner in my household

How many financial dependents (i.e children or other family members) are in your household?

- ☐ None
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 or more
- ☐ Do not know

Using the categories below, please indicate the annual income of your household. Include yourself and anyone you live and share finances with.

- ☐ Less than $15,000
- ☐ $15,000 to $29,999
- ☐ $30,000 to $59,999
- ☐ $60,000 to $100,000
- ☐ More than $100,000
- ☐ Do not know

Are you currently receiving disability payments?

- ☐ No
- ☐ No, but I have applied for disability
- ☐ Yes, short term disability (i.e., pays you a portion of your income for a short period of time after you run out of sick leave; depending on your plan, it will generally pay you for between 9 and 52 weeks)
- ☐ Yes, long term disability (i.e., pays you a portion of your income after you run out of both sick leave and short term disability, Social Security Disability Insurance or Supplemental Security Income)
- ☐ Yes, I am permanently disabled

What is your current primary health insurance provider (mark one)

- ☐ Medicare
- ☐ Qualified health plan from the Health Insurance Marketplace
- ☐ Medicaid
- ☐ Private insurance (employer-provided)
- ☐ Private insurance (purchased directly)
- ☐ Veterans/Military Insurance
- ☐ I don't have any health insurance

Do you have household/family savings that can help pay medical bills?

- ☐ No
- ☐ Yes
- ☐ Don't know/ Not sure

In general, would you say your health is…

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

How many biological children do you have? _____

How do you feel about preserving your fertility right now?

- ☐ Fertility preservation is not for me. I'm here to learn about my options just in case.
- ☐ I don't think fertility preservation is right for me. I don't know if there is a good option.
- ☐ I'm not sure about what to do. I want to explore my options.
- ☐ I'm interested in fertility preservation. I want to compare my options.
- ☐ I want to preserve my fertility. I am ready to select a method.

Rate your <u>awareness</u> of treatments to protect your ability to become a parent

- ☐ Very much
- ☐ Quite a bit
- ☐ Somewhat
- ☐ A little bit
- ☐ Not at all

Rate your <u>comfort level</u> with treatments to protect your ability to become a parent

- ☐ Very much
- ☐ Quite a bit
- ☐ Somewhat
- ☐ A little bit
- ☐ Not at all

Do you, yourself, want to have a (another) baby at some time?"

- ☐ Yes
- ☐ Probably yes
- ☐ Unsure

- ☐ Probably no
- ☐ No

The next set of questions will ask you about your use of technology.

Do you have a cellphone?
- ☐ Yes – a cellphone
- ☐ Yes – a smartphone
- ☐ No

(if yes): How often do you use your phone to send or receive text messages?
- ☐ Every day or almost every day
- ☐ 3 to 5 days a week
- ☐ 1 to 2 days a week
- ☐ Once or twice a month
- ☐ Less than once a month
- ☐ Never

Have you used a computer or laptop in the last 30 days?
- ☐ Yes
- ☐ No

Do you have a computer or laptop that you could use in your home?
- ☐ Yes
- ☐ No

Do you use the internet?
- ☐ Yes
- ☐ No

(if yes): How often do you access the internet?
On a smartphone
- ☐ Every day or almost every day
- ☐ 3 to 5 days a week
- ☐ 1 to 2 days a week
- ☐ Once or twice a month
- ☐ Less than once a month
- ☐ Never

On a tablet device (like an iPad, Amazon Fire, or Galaxy Tablet)
- ☐ Every day or almost every day
- ☐ 3 to 5 days a week
- ☐ 1 to 2 days a week
- ☐ Once or twice a month
- ☐ Less than once a month
- ☐ Never

On a laptop or computer
- ☐ Every day or almost every day

- ☐ 3 to 5 days a week
- ☐ 1 to 2 days a week
- ☐ Once or twice a month
- ☐ Less than once a month
- ☐ Never

Which of the following sources did you use to get information about cancer-related infertility and treatment options to preserve fertility? (choose all that apply)

- ☐ Physicians
- ☐ Nurses
- ☐ Family and friends
- ☐ Books/magazines
- ☐ National Cancer Institute Cancer Information 800 number
- ☐ Other Cancer organization
- ☐ Internet

Which of the following statements best describes your preferred approach to making medical decisions: (please choose only <u>one</u> answer)

- ☐ I prefer to make the final decision about which treatment I will receive.
- ☐ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion
- ☐ I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
- ☐ I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.
- ☐ I prefer to leave all decisions regarding treatment to my doctor.

Which of the following best describes the role you played when the decision was made about treatment for your cancer-related infertility? (please choose only <u>one</u> answer)

- ☐ I made the final decision about which treatment I received.
- ☐ I made the final decision about my treatment after seriously considering my doctor's opinion
- ☐ My doctor and I shared responsibility for deciding which treatment was best for me.
- ☐ My doctor made the final decision about which treatment would be used, but seriously considered my opinion.
- ☐ My doctor made all treatment decisions

eHealth Literacy Scale

The following questions are about your opinion and experiences using the internet for health information. For each statement, tell me which response best reflects your opinion and experience *right now*.

1. How **useful** do you feel the Internet is in helping you in making decisions about your health?

□1	□2	□3	□4	□5
Not useful at all	Not useful	Unsure	Useful	Very Useful

2. How **important** is it for you to be able to access health resources on the Internet?

□1	□2	□3	□4	□5
Not important at all	Not important	Unsure	Important	Very important

3. I know **what** health resources are available on the Internet.

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

4. I know **where** to find helpful health resources on the Internet.

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

5. I know **how** to find helpful health resources on the Internet.

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree

5) □ Strongly Agree

6. I know **how to use** the Internet to answer my questions about health.

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

7. I know how to use **the health information** I find on the Internet to help me.

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

8. I have the skills I need to **evaluate** the health resources I find on the Internet.

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

9. I can tell **high quality** health resources from **low quality** health resources on the Internet.

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

10. I feel **confident** in using information from the Internet to make health decisions.

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

Need for Cognition Scale (from Cacioppo, Petty, & Kao, 1984)

For each of the statements below, please indicate whether or not the statement is characteristic of you or of what you believe. For example, if the statement is extremely uncharacteristic of you or of what you believe about yourself (not at all like you) please place a "1" on the line to the left of the statement. If the statement is extremely characteristic of you or of what you believe about yourself (very much like you) please place a "5" on the line to the left of the statement. You should use the following scale as you rate each of the statements below.

1	2	3	4	5
extremely uncharacteristic of me	somewhat uncharacteristic of me	uncertain	somewhat characteristic of me	extremely characteris of me

1. _____ I would prefer complex to simple problems.
2. _____ I like to have the responsibility of handling a situation that requires a lot of thinking.
3. _____ Thinking is not my idea of fun.**
4. _____ I would rather do something that requires little thought than something that is sure to challenge my thinking abilities.**
5. _____ I try to anticipate and avoid situations where there is a likely chance I will have to think in depth about something.**
6. _____ I find satisfaction in deliberating hard and for long hours.
7. _____ I only think as hard as I have to.**
8. _____ I prefer to think about small daily projects to long term ones.**
9. _____ I like tasks that require little thought once I've learned them.**
10. _____ The idea of relying on thought to make my way to the top appeals to me.
11. _____ I really enjoy a task that involves coming up with new solutions to problems.
12. _____ Learning new ways to think doesn't excite me very much.**
13. _____ I prefer my life to be filled with puzzles I must solve.
14. _____ The notion of thinking abstractly is appealing to me.

15. _____ I would prefer a task that is intellectual, difficult, and important to one that is somewhat important but does not require much thought.

16. _____ I feel relief rather than satisfaction after completing a task that requires a lot of mental effort.**

17. _____ It's enough for me that something gets the job done; I don't care how or why it works.**

18. _____ I usually end up deliberating about issues even when they do not affect me personally.

Note: **=reverse scored item.

Please see IRB for Fertilit-e Alpha Testing Interview Guide 8.27.18

System Usability Scale

For the next questions, please read each sentence and rate your level of agreement.

		Strongly disagree				***Strongly agree***
1	I think that I would like to use Fertilit-*e* frequently (when thinking about my fertility options)	1	2	3	4	5
2	I found Fertilit-*e* unnecessarily complex	1	2	3	4	5
3	I thought Fertilit-*e* was easy to use	1	2	3	4	5
4	I think that I would need the support of a technical person to be able to use Fertilit-*e*	1	2	3	4	5
5	I found the various functions in Fertilit-*e* were well integrated	1	2	3	4	5
6	I thought there was too much inconsistency in Fertilit-*e*	1	2	3	4	5
7	I would imagine that most people would learn to use Fertilit-*e* very quickly	1	2	3	4	5
8	I found Fertilit-*e* very cumbersome to use	1	2	3	4	5
9	I felt very confident using Fertilit-*e*	1	2	3	4	5
10	I needed to learn a lot of things before I could get going with Fertilit-*e*	1	2	3	4	5
11	Compared to reading a brochure, I liked using Fertilit-*e* more.	1	2	3	4	5

12. Overall, would you rate the user-friendliness of Fertilit-*e* as:

- ☐ Excellent
- ☐ Good
- ☐ OK
- ☐ Poor
- ☐ Awful

Brooke J. SUS-A quick and dirty usability scale. Usability evaluation in industry. 1996;189(194):4-7.