Developing a Community Oncofertility Program

BY FAYE FLEMMING, RN, BSN, OCN

Most academic and larger oncology facilities have fertility specialists and resources on site or easily accessible, increasing the likelihood that these programs will have a formal oncofertility program. In the community-based setting, it is more challenging to meet the fertility needs of cancer patients. While development of a quality oncofertility program will likely require time and effort, community cancer centers can and should still offer these services to their patients. In 2011 Southside Regional Medical Center won an ACCC Innovator Award for its oncofertility program. Here are innovative tools and resources developed as part of *Nicole's Oncofertility Toolkit*—named in honor of the author's niece.

Oncofertility is a somewhat new term that is used to describe cancer-related fertility issues. Unfortunately, it is a cancer care domain that is often avoided or forgotten by clinicians. However, when cancer programs do not include oncofertility in assessment and treatment planning for childbearing-age patients, they run the risk of increasing patient distress and decreasing quality of life. Instead, cancer programs should espouse the idea that oncofertility is every cancer patient's right and ensure that they offer these types of fertility-related services, including:

- Timely assessment of fertility needs and desires
- Education about fertility risks and options
- Financial and mental health counseling
- Quick referrals and care
- Ongoing and constant follow-up.

Many cancer patients experience unnecessary emotional turmoil due to a lack of attention, knowledge, support, resources, planning, and preparation related to oncofertility issues. Providers and payers share the blame. Without timely fertility support from their oncology providers, patients can quickly become depressed and helpless. No patient should be distraught because cancer programs are not meeting their fertility needs. There are many options available to cancer patients today. See page 25 for a list of these.

Oncofertility Challenges

Cancer programs developing an oncofertility program face many challenges. Time is one of the biggest hurdles. Oncofertility assessments, education, counseling, referrals, and fertility care must be completed very quickly—often *before* cancer treatment starts. Accordingly, cancer programs must include fertility-related support and care in the treatment planning process and plan of care. That said, fertility procedures, especially for women,

often require weeks to complete. Delaying the start of cancer treatment could be detrimental to patients. To ensure timely oncofertility care without unnecessary treatment delays, cancer programs should develop a formalized oncofertility process that includes continual coordination and monitoring of cancer and fertility treatment planning and care.

Fertility costs are another challenge for patients with oncofertility needs. Fertility-related care and procedures can cost thousands of dollars. Health insurance plans usually do not cover these services. Therefore, patients with oncofertility needs will likely require timely referrals to a financial specialist or resources to help:

- Assess insurance benefits
- Estimate the costs of fertility care
- Evaluate the patient's financial situation
- Connect with local and national resources
- Contact referrals
- Apply for financial assistance, disability, or other benefits
- Help the patient meet other financial needs.

Assisting patients and families with distress management during what is likely one of the most stressful times in the cancer care continuum is another challenge for providers. Patients have usually just received their diagnosis and are in the process of completing more diagnostic tests, obtaining results, and being educated on their treatment plan. Suddenly the patient is told that his or her fertility may be affected. Besides worrying about their life, health, family, work, pain, finances, and future, patients now need to worry about their fertility. To help patients and families cope with this added stress, cancer programs should ensure that distress management is a core component of their oncofertility program.

To overcome these and other challenges (see box below), successful oncofertility programs have a defined process for oncofertility care that includes up-to-date policies and procedures, tools, and resources. Further these programs ensure that staff and providers are educated about oncofertility and the oncofertility program or process.

Developing an Oncofertility Program

The first step in developing an oncofertility program is to complete a fertility-related assessment of your program, community, and patients (see page 27). As part of this assessment, answer the following questions:

- Which oncology diseases do you see and which treatment choices are available?
- What are your patient demographics?
- Are there specific cultural, community, geographic, or other needs that should be addressed?
- What fertility assessments, policies, tools, providers, and resources does your cancer program presently use?
- Which administrators, physicians, non-physicians, community agencies, or others support a formalized oncofertility program or process?

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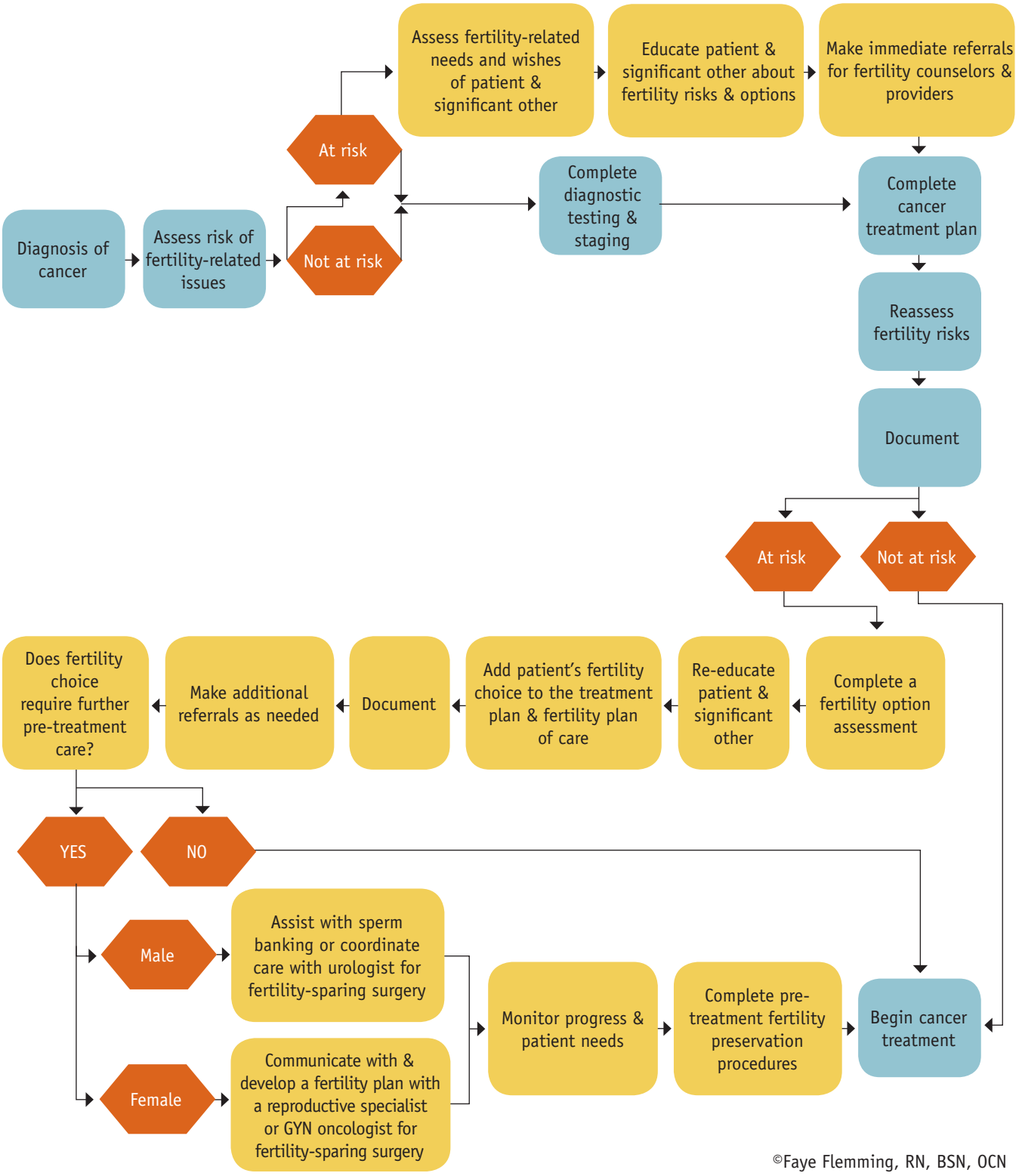
ONCOFERTILITY CHALLENGES

- Fast-growing cancers where time is of the essence for beginning treatment(s).
- Advanced cancers where patients are too ill and there are concerns about the patient's prognosis.
- Costs of fertility-related care.
- Lack of coverage by insurance:
  - Only 15 states have any type of mandatory coverage for fertility treatments (AR, CA, CT, HI, IL, LA, MD, MA, MT, NJ, NY, OH, RI, TX, WV).
  - No state mandates oncofertility preservation coverage.
- Timing of fertility care to not delay cancer treatment:
  - Timely referrals and counseling to assist patients to make informed decisions relating to fertility.
  - Timely completion of all procedures required before beginning cancer treatment.
  - Coordinating fertility care and cancer care to meet all patient needs.
- Assuring that all providers include fertility-related assessments, support, and care in their cancer treatment planning.
- Assisting patients and family with distress management during this time of additional stress.

NICOLE'S ONCOFERTILITY PRESERVATION ALGORITHM TOOL



ONCOFERTILITY TEAM ROLES

Patient
- √ Be aware of their patient rights and ask providers all the questions they have.
- √ Answer provider questions honestly, letting providers know when they do not understand.
- √ Must understand all information and options.

Significant Other
- √ Be present to offer support, discuss options with patient, ask questions, and assist with decision making.

Oncologist
- √ Be knowledgeable about the actual and/or or potential effects of recommended cancer treatments on their patient's fertility.
- √ Be knowledgeable about basic reproductive options for male and female cancer patients.
- √ Have a process in place that is used for all childbearing-age cancer patients to assure they all receive timely information, support, referrals, and follow-up for fertility-related needs.
- √ Have information and contacts for local referral sources for fertility-related needs, such as financial and psychosocial care.
- √ Develop a referral system for consults with endocrinologists and reproductive health specialists that includes sharing of information, treatment plan, timing, and monitoring of progress.
- √ Answer basic questions and provide basic information about fertility options.
- √ Obtain informed consent, which includes education about fertility-related risks for recommended treatments as early as possible in the diagnosis and treatment planning phase.

Oncology Nurse
- √ Assist oncologists and oncology team in providing education, care, assessment, distress management, referrals, support, navigation, and coordination of care.

Primary Care Physician
- √ Have a long-term relationship with the patient and generally know the patient best.
- √ Help support, educate, and guide the patient.

Social Worker & Mental Health Counselor
- √ Provide needs assessments, distress management, emotional support, counseling, psychosocial support and referrals, and mental health support and referrals.
- √ Assist with meeting cultural, ethical, and spiritual needs.

Nurse Navigator & Case Manager
- √ Provide needs assessments.
- √ Assist with access and help navigate the healthcare system and providers.
- √ Provide communication support, education, distress management, and referrals.

Financial Specialist
- √ Provide timely financial needs assessments.
- √ Assist with financial, insurance, and related support, information, and referrals.

Pastoral Care & Clergy
- √ Offer spiritual, psychosocial, and emotional support to assist patients with decision-making and support.

Pharmacist
- √ Assist with understanding cancer and fertility-related drugs.

Genetics Counselor
- √ Counsel, inform, test, and support patients that are high risk for genetic abnormalities.
- √ Counsel, inform, test, and support patients that are high risk for having offspring with possible genetic cancer risks.

Gynecologist
- √ May be the physician diagnosing female cancers.
- √ Often have a long-standing relationship with their patients.
- √ Help to prepare and guide patients in addressing fertility needs.

Oncologic Gynecologist
- √ Often the surgeon providing fertility-sparing female surgery.

Urologist
- √ May be the physician diagnosing some cancers.
- √ Help prepare and guide their patients in addressing their fertility-related issues.
- √ May be the surgeon providing fertility-sparing surgery.

Endocrinologist & Reproductive Specialist
- √ Offer expertise in fertility preservation methods.
- √ Conduct a timely consult that can help patients make better informed decisions about their future fertility.
- √ Explain options, procedures, costs, timing, success rates, and available support.
- √ Carry out any fertility-preserving procedures if chosen as the option.

Family-planning Specialist
- √ Help better educate patient and family about parenting options.

Adoption Professional
- √ Conduct timely consults that can help patients make a better informed decision about having non-biologically related offspring.
- √ Explain the criteria, timing, cost, process, and availability of adoption and answer any questions. OI

KNOW YOUR OPTIONS

Oncofertility Options for Women*

- ◯ Choose to have no children.
- ◯ Do nothing and take a chance on having children naturally after treatment is completed and the physician has given approval.
- ◯ Do nothing until after treatment is completed and then assess fertility. If patient decides she wants to have children, choose from post-treatment options.
- ◯ Radiation shielding. Use of shields for reproductive areas during radiation treatment, if this does not affect the required treatment field.
- ◯ Fertility-sparing surgery, if it will not affect outcome of cancer treatment.
- ◯ Adoption. Approximate cost: $2,500 to $50,000 or more. Cost is very dependent on the agency and country.
- ◯ Foster parenting. Approximate cost paid by agency: $500 to $900/month, depending on location and age. Note: these funds are to be used for care and supplies for the child—not compensation.
- ◯ Embryo freezing. Requires in vitro fertilization of egg and sperm and then freezing of the embryo. Approximate cost: $12,000 to $40,000 or more, plus storage fees.
- ◯ Donor egg(s). Approximate cost: $17,000 to $35,000 or more for one cycle.
- ◯ Donor embryo(s). Approximate cost: $17,000 to $25,000 or more for one cycle.
- ◯ Surrogacy. Use of another woman to implant the pregnancy into her womb and have her carry it through birth.
  - – Traditional. Uses surrogate's egg and male sperm from the couple trying to conceive. Approximate cost: $12,000 to $15,000 or more for one cycle if IVF used.
  - – Gestational. Uses embryo of cancer patient and spouse. Approximate cost: $12,000 to $15,000 or more for one cycle, plus $10,000 to $100,000 or more for compensation to the woman if she is expecting to be paid for being a surrogate.
- ◯ Experimental options. Should be done for research only:
  - – Egg freezing banking. Freeze eggs prior to fertilization. Approximate cost: $12,000 to $35,000 for one cycle, plus storage fees.
  - – Ovarian suppression. Uses gonadotropin-releasing hormone (GnRH) analogs or antagonists to suppress ovaries during chemotherapy. Approximate cost: $400 to $600/month.
  - – Ovarian tissue freezing. Freezes tissue from the ovaries and tissue is re-implanted after treatment is completed. Approximate cost: $17,000 or more, plus storage fees.

*Approximate costs are provided, but can vary greatly and/or include additional costs, such as normal pregnancy costs.

Oncofertility Options for Men*

- ◯ Choose to have no children.
- ◯ Do nothing and take a chance on having children naturally after treatment is completed and the physician has given approval.
- ◯ Do nothing until after treatment is completed and then assess fertility. If decides he wants to have children, choose from post-treatment options.
- ◯ Radiation shielding. Use of shields for reproductive areas during radiation treatment, if this does not affect the required treatment field.
- ◯ Fertility-sparing surgery, if it will not affect the cancer treatment outcome.
- ◯ Adoption. Approximate cost: $2,500 to $50,000 or more. Cost is very dependent on the agency and country.
- ◯ Foster parenting. Approximate cost paid by agency: $500 to $900/month, depending on location and age. Note: these funds are to be used for care and supplies for the child—not compensation.
- ◯ Sperm banking. Approximate cost: $675 to $2,000, plus $350 to $750/year in storage fees. (Under the "Live On" program, qualified applicants pay a total of $675 for one.)
- ◯ Donor:
  - – Sperm. Approximate cost(s): $200 to $1,500, plus artificial insemination or IVF costs.
  - – Embryo. Approximate cost(s): $12,000 to $15,000/cycle, plus pregnancy costs of between $5,000 to $10,000.
- ◯ Experimental options (should be done for research only):
  - – Testicular sperm extraction (TESE): cost varies.
  - – Epididymal sperm aspiration: cost varies. OI

U.S. Cancer Incidence Rates Age at Diagnosis 15 to 44†

AGE	COUNT
15–19 years	4,325
20–24 years	6,902
25–29 years	10,766
30–34 years	16,185
35–39 years	27,669
40–44 years	51,220
Total	**117,067**

Source: 1999–2006 (CDC WONDER online). Rates are per 100,000 and are age-adjusted to the 2000 U.S. Std. Population.
†These individuals are women and men of childbearing age.

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- Is there any opposition or unusual obstacles to developing an oncofertility program or process? If so, who, what, and why? Obstacles and opposition should be addressed prior to development of the program or process.

Once you have completed the fertility-related assessment, the next step is to develop a multidisciplinary oncofertility team. This team should consist of any local, state, and national healthcare providers, facilities, and organizations that can work together to best meet the fertility needs of your cancer patients. Choose team members that meet the specific needs of your patient population. Oncofertility team members typically include:

- Primary care physicians
- Oncology specialists
- Fertility specialists
- Gynecologists
- Urologists
- Financial specialists
- Nurses
- Social workers and/or mental health providers
- Nurse and/or lay navigators
- Case managers
- Pastoral care
- Genetics counselors
- Pharmacists
- Adoption specialists.

Once team members are identified, define the role each staff member will have in the oncofertility program or process. Communication, coordination, and care provided (the three "C's") should be addressed in every role definition. Be sure to include patient and family roles in this process. (See "Oncofertility Team Roles," page 24 for more.)

With your team in place, it is time to define your oncofertility process. Consider developing an algorithm first that will illustrate patient flow through the oncofertility program or process (see page 23). Define each step of the algorithm and all related responsibilities and resources. This process will be the center of your oncofertility program, ensuring that all of the oncofertility needs of your patients are assessed and addressed. (See patient assessment tool on page 28.) Process components should include:

- Assessment of fertility risks, desires, and needs
- Patient and staff education
- Distress management
- Referrals
- Counseling
- Informed consent
- Documentation
- Development, monitoring, and coordination of a fertility plan of care
- Follow-up and survivorship care and support
- Quality assurance and monitoring.

Additional Online Content

Nicole's Oncofertility Toolkit is available online at: *www.accc-cancer.org/oi/MJ2012*. Download the kit today and start using it at your cancer program. Questions? Email Faye Flemming at: *oncofertility@hotmail.com*.

An Oncofertility Toolkit

The last step will be to create or adapt tools and lists of resources to assist your team in meeting the oncofertility needs of your patients. These tools need to be as simple as possible and require the minimum amount of time and documentation to ensure the needed results. Develop and package these tools and resources so that providers have easy, one-stop access to everything they need to care for the fertility need of their patients.

I have created *Nicole's Oncofertility Toolkit* to assist cancer programs to more easily develop a formal oncofertility program. This toolkit is dedicated to my brave 28-year-old niece who recently suffered severely after her oncology providers failed to address her oncofertility needs. Nicole had requested fertility help from her healthcare providers from the moment she was told she had "some type of lymphoma." It was not until months later, after her family was able to help Nicole find the "right" fertility specialist and the "right" oncology provider that Nicole began to regain some of the hope and optimism she had lost. No patient should ever have to go through this level of distress. Nicole was an educated and engaged patient. What happens to the many cancer patients who do not know to ask for help or who do not have loved ones who have the skills to assist them?

If your cancer program does not already have an oncofertility program in place, I challenge you to create one for your patients. Simply put: it's the right thing to do. Together we can all make a difference and improve the lives of our oncology patients. OI

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NICOLE'S ONCOFERTILITY PROGRAM NEEDS ASSESSMENT

DOES YOUR ONCOLOGY PROGRAM HAVE A:

- ☐ Complete and timely* fertility risk assessment that is given to all patients?
- ☐ Complete and timely* fertility-related needs assessment that is given to all childbearing-age patients who will receive a treatment that has the potential to cause fertility-related issues?
- ☐ Timely* referral process for all patients with needs to:
  - ☐ Board-certified reproductive specialists
  - ☐ Certified reproduction center or clinic
  - ☐ Genetic counseling
  - ☐ Adoption professional(s)
  - ☐ Support groups
  - ☐ Fertile Hope
  - ☐ Nurse navigator
  - ☐ Spiritual counseling
  - ☐ Financial assistance
  - ☐ Other support services
- ☐ Process that includes cultural and ethical needs in your fertility assessment and planning?
- ☐ Verbal and written education about fertility-related items available to at-risk patients?
- ☐ Counseling to assist with decision making for all at-risk patients?
- ☐ Process for coordinating fertility care, communicating with other providers, identifying referral sources, and monitoring patients?
- ☐ Written informed consent, including fertility risks obtained prior to the start of any treatment?
- ☐ Process to ensure documentation of all of the above?
- ☐ Process and program(s) to ensure that patients with oncofertility needs are assisted with post-treatment care, outcomes assessment, completion of follow-up care, and to ensure that all fertility-related needs were met?
- ☐ Survivorship program that includes fertility needs?
- ☐ Quality monitoring program that includes fertility-related issues?
- ☐ Written process and/or policy to address oncofertility needs?

**"Timely" refers to completion as close to diagnosis and before start of treatment date as possible.*

NICOLE'S ONCOFERTILITY PATIENT ASSESSMENT TOOL

Ages of present children: _____ Stepchildren: _____ Adopted children: _____

Desire future children? ☐ YES ☐ NO Comment: _____

SECTION 1: Fertility Assessment (Complete if patient desires future children.)

Estimated latest recommended treatment start date: _____

Is hormonal therapy contraindicated for any reason (females)? ☐ YES ☐ NO
Would patient and family consider partially or non-genetically related children? ☐ YES ☐ NO
Would patient and family consider someone else carrying their child? ☐ YES ☐ NO
Does patient and family have insurance and fertility-related coverage? ☐ YES ☐ NO
What is the patient's and family's financial status and what resources are available to meet their fertility needs?

_____

_____

What is the patient's and family's emotional status and present distress level (use NCCN Distress Management Tool).
Score: _____ Comment: _____

What support systems are available? _____

Are there any co-existing challenges or support needs? _____

Does the patient or family have any religious, cultural, or other preferences and/or needs? ☐ YES ☐ NO
If yes, explain: _____

SECTION 2: Fertility Plan of Care & Monitoring

Preferred choice for reproductive-risk reduction: _____

Reproductive and support referrals needed: _____

Pre-treatment fertility procedures required? ☐ YES ☐ NO

All referrals completed? ☐ YES ☐ NO

All pre-treatment fertility interventions completed? ☐ YES ☐ NO

Reproductive needs met? ☐ YES ☐ NO
Outcome: _____

Ready to begin cancer treatment?
☐ YES ☐ NO