CANADIAN PARTNERSHIP AGAINST CANCER

Business Case for **Oncofertility Screening in the Cancer System**

MARCH 2022

Contents

List of Abbreviations

ASCO	American Society of Oncology
AYAs	Adolescents and young adults
AYANN	Adolescents and Young Adults National Network
C17	Consortium of 17 institutions across Canada focusing on pediatric oncology, hematology, and stem-cell transplant programs
CCS	Canadian Cancer Society
CFAS	Canadian Fertility & Andrology Society
CPC	Canadian Problem Checklist
CSL	Community Service Locator
FET	Frozen embryo transfer
ICSI	Intracytoplasmic sperm injection
IUI	Intrauterine insemination
IVF	In vitro fertilization
LGBTQ2+	Lesbian, gay, bisexual, transgender, queer (or sometimes questioning), and two-spirited
OPU	Oocyte pick up
P/T	Province/Territory
POGO	Pediatric Oncology Group of Ontario's
PRO	Patient Reported Outcome
SDI	Social Difficulties Index
YACC	Young Adults Cancer Canada

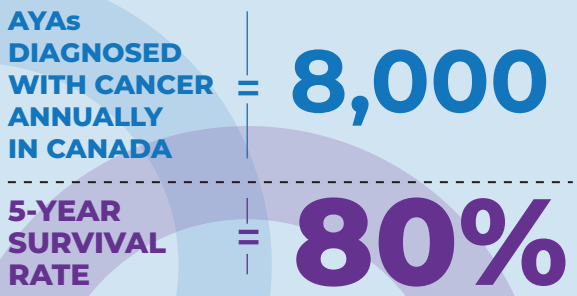
Executive Summary

In 2006, the American Society of Oncology (ASCO) published guidelines stated: "oncologists should address the possibility of infertility with patients treated during their reproductive years and be prepared to discuss possible fertility preservation options or refer appropriate and interested patients to reproductive specialists". These guidelines were then updated in 2013, and most recently in 2018. However, studies in Canada and elsewhere demonstrate that this goal is rarely achieved. Barriers include oncologists' lack of knowledge of the fertility preservation options, uncertainty as to where to refer and whose responsibility it is to inform, geographic barriers, and delays in treatment and cost.

Background

Canadian strategy for cancer control

In the summer of 2019, the Partnership launched the 2019-2029 Canadian Strategy for Cancer Control (the Strategy). The Strategy is a 10-year roadmap to improve equity in the cancer system and it has a focus on ensuring that the healthcare system is sustainable for the future. There are eight priorities highlighted in the Strategy, including three Peoples-specific priorities that were identified by First Nations, Inuit and Métis.



Priority five, action three of the Strategy specifically calls for better support of children and AYAs with cancer, given their unique challenges at key transition points, by expanding access to a wide range of integrated services. These include fertility counselling services geared toward these patients' unique needs. While none of the People-specific priorities and actions specifically call out AYAs, there are opportunities to meet the needs of First Nations, Inuit and Métis AYAs as part of the broader AYA strategy. For example, the People-specific priorities do call for culturally appropriate, self-determined care.

Over 200,000 Canadians are diagnosed with cancer annually, 8,000 of whom are adolescents and young adults (AYAs) aged 15-39, with a 5-year survival of over 80% (see Table 1). To improve the care and support of children and AYAs with cancer, emphasis needs to be on survivorship success beyond treatment, including timely access to information on the potential impacts of treatment to fertility and the fertility preservation options available to them. The World Health Organization states that individuals and couples have the right to decide the number, timing and spacing of their children.[i] One option in preventing infertility in cancer patients is through fertility preservation, which is an important part of realizing the right to have a family.

In 2019, the Canadian Partnership Against Cancer (the Partnership) working with the AYA National Network released the Canadian Framework for the Care and Support for Adolescents and Young Adults with Cancer. The vision of this national framework is that all AYAs with cancer in Canada receive optimal, developmentally appropriate care and comprehensive survivorship support that lead to improved outcomes and high quality of life. There is an opportunity to implement an accelerated action within the Canadian Framework focused on improving access to fertility information and affordable fertility preservation options by leveraging existing Partnership priority initiatives.

Table 1: New incidence cases for young adults aged 15-39, by jurisdiction† – diagnosis year 2017

Jurisdiction	Female	Male
British Columbia	550	370
Alberta	605	385
Saskatchewan	135	80
Manitoba	180	95
Ontario	2,255	1,355
Quebec	1,485	875
New Brunswick	85	50
Nova Scotia	115	75
Prince Edward Island	10	10
Newfoundland and Labrador	55	55
Northwest Territories	10	5
Yukon	10	5
Nunavut	5	5

†Data for all jurisdictions were retrieved from CANSIM table, except QC.

QC data were estimated by multiplying the projected incidence cases in CCS 2017 by the proportion of the incidence cases of all jurisdictions for young adult aged 15-39.

Data sources: Statistics Canada, CANSIM table 13-10-0111 01: https://www150.statcan.gc.ca/t1/tbl1/en/cv.action?pid=1310011101

Canadian Cancer Society, Canadian Cancer Statistics

In December 2021, the Minister serving Canadians For Women and Gender Equality and Youth stated in the Mandate Letter that work should support the Minister of Health to ensure that all Canadians have access to sexual and reproductive health services they need, no matter where they live, by reinforcing compliance under the *Canada Health Act,* developing a sexual and reproductive health rights information portal, supporting the establishment of mechanism to help families cover the costs of in vitro fertilization, and support youth-led grassroots organizations that respond to the unique sexual and reproductive health needs of young people.

High-level recommended solution

There is a need for better established guidelines and coordination through improved communication and integration across all levels of care for AYAs. Despite an increase in the availability of fertility preservation strategies, only a small fraction of newly diagnosed AYA cancer patients in Canada are being referred for fertility preservation. This is a reflection of the lack of coordination among Canadian oncofertility services and the resulting inefficiency in service delivery. Jurisdiction champions should be interdisciplinary and include oncology specialists, social workers, psychosocial workers, nurses, reproductive specialists, and patients. To support the oncofertility agenda at cancer centres, these champions will need to be supported and equipped with standardized resources, tools and knowledge about fertility risks and options with the processes part of the routine practice of the cancer care team. Education, resources and psychosocial support need to be provided to patients in the early stages of the cancer journey through timely referrals by the cancer care team, as a delay may impact the success of their treatment. This in turn will support AYA patients in making well informed decisions about fertility preservation options that are available to them.

While some progress has been made in the field of oncofertility, there is still more work to be done across Canada including more equitable availability of resources, discussion of fertility options with patients, timely referrals to fertility specialists, and established bi-directional communication between oncology specialists and fertility centres.

Work to date

- AYA partners across Canada, as represented in the AYA National Network, released the Canadian Framework for the Care and Support for AYAs with Cancer with a focused action on oncofertility.
- The Partnership's former Canadian AYA Task Force made specific recommendations around oncofertility, including the need to collect data and information to fill the information gap. As well, the Task Force curated a list of education resources for patients and healthcare providers (see Table 5, list of oncofertility resources).
- Equitable access to fertility preservation information was identified as a need among First Nations, Inuit and Métis through engagement for the refresh of the Canadian Cancer Control Strategy.

Oncofertility is a discipline at the crossroads between cancer treatment and fertility medicine.

- Ontario Health and Pediatric Oncology Group of Ontario's (POGO) oncofertility pilot initiative in London, Windsor and Ottawa (see Table 5, list of oncofertility resources).
- The IWK Health Centre (a pediatric cancer centre) in Nova Scotia developed an oncofertility guideline document for providers and a patient education brochure (see Table 5, list of oncofertility resources).
- The Canadian Cancer Society's (CCS) work in building an inventory of oncofertility resources and information in the community and training staff on the provision of oncofertility.

Canadian framework for the care and support of AYAs with cancer

In 2018, the AYAs with cancer national network was established. The network produced the Canadian Framework for the Care and Support of AYAs with Cancer, which was launched in the fall of 2019.

The Framework defines four strategic priorities to guide the evolution of AYA care. The Framework details each strategic priority and supporting platform with an associated set of actions to be considered at the individual, service and system levels. Oncofertility is called out as a priority action at all three levels under priority 1 "integrate an AYA-Centered experience throughout care and survivorship":

- Individual level: Young people are aware of potential impacts of treatment on fertility and are provided with fertility preservation options available to them. Information and resources should be tailored to the AYA's perspective and context.
- Service level: Timely provision of fertility information and referral for fertility preservation.
- System level: There is access to fertility information and affordable fertility preservation options.

What is oncofertility?

Oncofertility is a discipline at the crossroads/intersection between cancer treatment and fertility medicine. It aims to preserve the fertility of cancer patients who are at risk of becoming infertile due to chemotherapy or radiotherapy treatment. Hence patients need to be informed of the risk of infertility due to cancer treatment and their options for fertility preservation, which optimally should occur prior to the start of treatment.

Evidence

Guidelines

American Society of Oncology Guidelines

The American Society of Oncology (ASCO) published initial guidelines on oncofertility in 2006, with several iterations thereafter including the most recent guidelines published in 2018.[ii] Current guidelines recommend that clinicians address the possibility of infertility as early as possible before treatment starts with the patient and/or with the patient/guardians of pediatric patients. Also, they should be making referrals to an appropriate specialist for patients who are interested in seeking out fertility preservation. Whether a patient is a candidate for or chooses to pursue fertility preservation, having this discussion may be associated with reduced distress and improved quality of life.

Canadian Fertility & Andrology Society Guidelines

The Canadian Fertility & Andrology Society (CFAS) released clinical practice guidelines around providing immediate referral to reproductive endocrinologists and infertility specialists after a diagnosis of cancer, to provide patients with counseling regarding their fertility and fertility preservation management options.[iii]

Literature

Despite the ASCO and CFAS guidelines. studies in Canada and elsewhere demonstrate that the recommendations are rarely achieved. Research suggests that most of these conversations are not happening, and especially not before cancer treatment. Also, very few of these conversations, when they do happen, result in referrals to fertility clinics, and referrals are not always timely. Patients want to know their risks of infertility and options for fertility preservation even if they do not have viable options. It can be devastating

to find out after their cancer treatment has resulted in infertility. Barriers include oncologists' lack of knowledge of the fertility preservation options, uncertainty as to where to refer and whose responsibility it is to inform, geographic barriers, and delays in treatment and cost.[iv]

Studies have shown fertility counseling and referral were more common in the academic (such as teaching hospitals) rather than the private clinic setting. Academic institutions might facilitate a more rapid collaboration between oncologists and reproductive specialists. Also, clinics in which clinical trials were offered had higher rates of discussions regarding fertility risks. Jurisdictions with fertility preservation coverage had increased rates of fertility discussion and referral.[v]

In Canada, fertility services are only offered through private clinics. In 2011, two surveys were sent to fertility clinics across Canada asking for numbers of cancer patients referred.[vi] Most fertility clinics get very few referrals for cancer patients, suggesting that the majority are not being referred for counselling. These surveys also found that men with cancer were more often referred to fertility clinics than women. This may be due to the lower cost and increased familiarity with, ease, and accessibility of sperm banking for men. In comparison, women may not be offered referral for fertility preservation because egg harvesting can only be completed at specialized in vitro fertilization (IVF) clinics that are not universally available. Procedures such as egg harvesting are also more intensive procedures to perform in a potentially unwell patient. Egg harvesting can take upwards of two weeks, which may delay the start of treatment, and comes with a significant financial burden averaging more than $10,000.[vii]

Factors affecting access to oncofertility services among underserviced populations

Evidence shows that access to health care in Canada is not equitable.[viii] Even if a health care service is available at no cost, it does not imply that it is accessible to all. The high cost of fertility preservation services is a significant barrier for many cancer patients not only in Canada but internationally.[ix] [x] While there are opportunities for more advantaged patients to get proper consultation and fertility preservation prior to cancer treatment, research shows that individuals from underserviced populations face deeper multifaceted barriers, in addition to high cost. Underserviced populations include individuals who live in poverty, First Nations, Inuit and Métis, recent immigrants, people who identify as LGBTQ2+, minority language communities, rural, remote, and Northern residents, as well as other marginalized communities.[xi] [xii]

Some of the common patient barriers to health care services include, but are not limited to, health literacy, culture, language, transportation cost, time off work for appointments, access to childcare, payment for medications/other medical treatments (for example, fertility preservation), as well as physical and mental health barriers. [xiii] [xiv] System barriers include, but are not limited to, long waits for services, lack of services in geographical locations of need, poor coordination between primary care and specialty care and between health care and community services, lack of needs-based planning to ensure that the population has necessary services, and attitudes of health care workers. [xv]

Literature shows that barriers to oncofertility services among underserviced populations are reflective of the common barriers to health care in general. These barriers include cost, availability of oncofertility service, patients' attitudes, mistrust of the medical system, health beliefs and literacy, ethnic disparities, and perceptions among healthcare providers that negatively affect the discussion of options and risks with eligible patients. [xvi] [xvii] [xviii] [xix] [xx]

Education level, which often ties in with health literacy, is significantly associated with an increased likelihood of receiving oncofertility counseling.[xxi] [xxii] For example, women with a bachelor's degree are more likely to bring up the topic of cancer treatment
fertility risks compared to women with less education. This barrier is consistent with timely access to cervical and breast cancer care, where women with lower education levels are more likely to experience delays in cancer diagnosis and treatment. Letourneau and colleagues also observed

that White patients were more likely than non-White patients to seek fertility preservation. Voigt and collages also showed in their study that following a cancer diagnosis, Hispanic and Black women were less likely to utilize oncofertility services compared to Asian and White patients.[xxiii] In men, utilization of oncofertility services was influenced by socioeconomic status, rather than race or ethnicity. [xxiv]

Factors affecting access to oncofertility services among First Nations, Inuit, and Métis

Barriers to health care faced by First Nations, Inuit, and Métis are more complex compared to barriers faced by other Canadians due to the history of colonialism.[xxv] Some of the historical factors that impact how First Nations, Inuit and Métis experience the health care system include residential schools, forced relocation, involuntary adoption (Sixties Scoop), coerced sterilization, religious conversion, as well as inferior treatment provided in Indian hospitals.[xxvi] [xxvii] These traumatic historical experiences interconnect with other barriers, such as geography, education attainment, employment, income, racism, social exclusion, inadequate health human resources, and lack of culturally relevant education for healthcare providers.[xxviii] [xxix] All these factors manifest negative health outcomes and the vicious cycle of health inequity in First Nations, Inuit and Métis communities.

The current evidence landscape lacks a proper description of specific barriers to oncofertility services among First Nations, Inuit and Métis in Canada. However, several critical factors should be considered, in addition to the barriers discussed earlier. The history of coerced sterilization underscores the injustices faced by First Nations, Inuit and Métis and results in mistrust in gynecological procedures and the health care system in general. The latest incidences of coerced sterilization occurred as early as 2019 and the full scale of this issue continues to be unknown due to lack of investigation.[xxx] [xxxi] Boyer and colleagues emphasized that those women who were forced to undergo a tubal ligation go to great lengths to avoid health care. For example, evidence shows that many First Nations, Inuit and Métis women lack preventive care, such as cervical cancer screening through Pap tests, "I don't go to the doctor, especially a gynecologist...the fear is so – I don't know if I can overcome it." [xxxii] Cervical cancer morbidity among First Nations, Inuit and Métis women is three times higher compared to non-Indigenous women in Canada.[xxxiii] Given this vulnerability and continuous fear of coerced sterilization, any conversations with First Nations, Inuit and Métis women around fertility preservation should be informed by the historical and patient-specific context to develop trusting and safe relationships. This issue further ties with the concept of informed consent.

Barriers to health care faced by First Nations, Inuit, and Métis are more complex

Seeking input from First Nations, Inuit and Métis to inform the oncofertility screening prompt

The Partnership initiated a multipronged virtual engagement process, to seek input from a cross-section of First Nations, Inuit and Métis patients, family members and caregivers on both the benefit and wording of an oncofertility screening prompt. These participants spoke to wider issues related to cancer and fertility, including the impact of colonialism and trauma and access to fertility preservation. Participants suggested that an oncofertility screening prompt should be part of the first meeting at the cancer centre, when treatment protocol(s) are discussed. One participant spoke to the particular importance of biological children to First Nations in the context of historical population loss. Another participant recommended the prompt be shared with caregivers to help facilitate conversations between young patients and their parents/caregivers as very often the family and caregivers are not recognized in the journey, but they are very much a part of the cancer journey with the patient.

It was acknowledged that if the oncofertility screening prompt is to be asked, there needs to be resources available to ensure the wishes of patients can actually be realized, otherwise, you might cause more stress for cancer patients. Also, there was concern that only a few fertility clinics are available in the northern regions and if they have a backlog of appointments, it may not be feasible to get a fertility consultation in the timeline with cancer treatment. Also, it was said that the further north you go the more cultural differences one may encounter and hence may alter the availability of fertility supports and services.

For status First Nations and registered Inuit, Non-Insured Health Benefits (NIHB) program may be part of the solution. The issue of paying for additional fertility supports under the limits of existing programs, and scarce funding was raised by First Nations, Inuit and Métis. For example, if the patient wants to answer yes to the oncofertility screening prompt, what services are available to them, and at what cost and who will cover these costs? It was pointed out that it took a long time to get the NIHB program to cover basic costs for transportation, meals, accommodation for women to come for mammogram screening to tertiary centers.

Also, there needs to be partnerships with Elders and Spiritual Healers to develop and offer the right supports for Indigenous and diverse groups.

Achieving equity in oncofertility care

The latest evidence suggests that to address health equity, universal access to health care services should be supplemented with a targeted approach, with an intensity and scale that is proportional to the level of disadvantage. [xxxiv] [xxxv] This blended approach is called targeted universalism is also known as proportional universalism – the term, coined in the United Kingdom. [xxxvi]While advocating for oncofertility services to be covered by public health may reduce inequity that cancer patients face, more research is also required.[xxxvii] [xxxviii] It is recommended that clinical guidelines and resources for cancer patients and healthcare providers need to be better integrated into existing cancer networks that serve minority and underserviced patient populations.[xxxix]

General barriers to oncofertility services

Cancer and its treatments have demonstrated negative impact on fertility. Despite the accessibility of fertility preservation strategies, most newly diagnosed cancer patients of reproductive age are not referred to a fertility centre. Below is a table highlighting the barriers to oncofertility services based on the literature.

Table 2. General Barriers to Oncofertility Services[xl]

Factors	Women	Men
Structural factors	• Time - delays in cancer treatment while fertility preservation procedures are completed are not always feasible	• Educational material not consistently provided to patient • Lack of training and resources to support providers
System factors	• Lack of communication between oncology and fertility centres • Lack of coordination and disconect between oncology and fertility preservation • Low prioritization of oncology referrals by fertility centres • Lack of interdisciplinary co-ordination in patient care • Referrals not completed in timely manner; should be started early in the cancer journey before treatment planning	• Lack of interdisciplinary co-ordination in patient care • Referrals not completed in timely manner; should be started early in the cancer journey before treatment planning • Lack of communication between oncology and fertility centres
Clinician factors	• Insufficient knowledge regarding oncofertility and referral procedures (including surgeons and GPs) • Health care providers not initiating fertility discussions • Fertility preservation material not accessible or available	• Lack of support by provider to patients • Inconsistent knowledge of cancer-related fertility matters • Lack of knowledge for dealing with fertility discussion in adolescents • Lack of experience in reproductive medicine dealing with cancer patients (low volume)
Patient factors	• Lack of awareness of range of procedures; belief in need of partner for fertility preservation • Lack of awareness of impact of treatment on fertility • Psychological stress (treatment delay, mental/physical demands of procedure) • Requirement of sperm donor for embryo cryopreservation	• Lack of awareness of impact of treatment on fertility • Lack of awareness of importance of banking sperm before start of treatment

Legal and ethical factors		• Inconsistent consent procedures for adolescents • Lack of guidelines for adolescent sperm banking
Costs and resources	• Cost to the patient of private services, medical procedure, medication (cryopreservation) • Variation in availability of services • Lack of appropriate educational materials regarding different options available (cryopreservation) • Lack of access to educational materials before appointment to discuss treatment	
Drug / Treatment Factors	• Cancer treatments have been found to impact fertility by reducing these 'finite' ovarian stores • Anticancer drugs destroy the oocyte by either interfering in cell proliferation processes, or by acting on non-proliferating cells • Type and dose impact the variability of the effect of chemotherapy • Alkylating agents tend to have the most detrimental effects on fertility • Radiotherapy may also cause damage to the uterine vasculature, endometrium, hormone production	• Cause destruction of spermatogonal germ cells. • Chemotherapy also causes harmful changes such as fibrosis and hyalinization in interstitial gonadal tissue. • Type and dose impact the variability of the effect of chemotherapy • Alkylating agents tend to have most detrimental effects on fertility • Radiation also causes damage to the male gonads, especially the germinal epithelium

Affordability of fertility services continues to be a struggle for cancer patients

Lengthy referral processes may be a limiting factor in accessing optimal services which can reduce the effectiveness of fertility procedures, leading to lower success rates. These delays can be minimized with well-established relationships between cancer care teams and fertility specialists, and prompt disclosure of information and resources available to patients. Also, creating a more financially accessible fertility program will support family-building for those who would not otherwise have the opportunity.

The geographic location of fertility services poses a challenge for many cancer patients, even in provinces with a large number of clinics, patients may not have a clinic close to where they are being treated for cancer and may not be able to travel long distances. For example, Prince Edward Island and Newfoundland and Labrador have no IVF clinics. Patients in these provinces need to travel out of province to undertake fertility preservation, which causes substantial delays in their cancer treatment, not to mention expenditures. Accessibility continues to be a growing concern for patients seeking fertility preservation services across Canada.

Data

Maintaining options regarding future fertility is a high priority issue for AYAs. Oncofertility has been highlighted in several Partnership reports.
In 2017, the Adolescents and Young Adults with Cancer System Performance Report was the first to focus on AYAs with cancer in Canada. It reported that "many AYAs with cancer receive treatments that are toxic to their ovaries and testes, which may lead to future problems with fertility. Fertility preservation, however, is often not addressed and may be too costly for AYAs who have yet to enter the workforce." Also, while fertility preservation is an option for the AYA population, the number of fertility clinics in Canada is limited.

In 2018, Living with Cancer: A Report on the Patient Experience was published. It featured an exclusive view of the Canadian cancer care system from the patient perspective, and it illustrated the experience of over 500 AYAs living with and beyond cancer (using data from the 'Transitions Study').

In the report, "8/10 patients [shared that they] had physical challenges after their treatment ended. Increased fatigue and changes in sexual function and fertility were their biggest concerns."

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Data are not routinely available currently on how well informed AYAs are on fertility issues (e.g., risk of infertility, fertility preservation options), on how many AYAs are referred to a fertility specialist or on how many AYAs actually see a fertility specialist.
The literature suggests that the majority of cancer patients are not referred for fertility counselling, although maintaining options for future fertility is a high priority for AYAs. Insights from Young Adults Cancer Canada (YACC) Prime study data, released in 2020 suggests that "....only half of patients discussed fertility with their medical team, and only 13 per cent went through any type of fertility preserving procedure."[xli]

Costing data

Affordability of fertility services continues to be a struggle for cancer patients and affordability of services varies among provinces. It was recommended that better financial coverage in health insurance is needed particularly for cancer patients who are medically directed to undergo fertility preservation procedures.

The Partnership convened a Cost Working Group (a sub-group of the AYA Task Force) who were tasked with developing a comprehensive report on costs for fertility preservation services for AYA cancer patients across the country. This report was developed in May 2017 and included an overview of the cost of services in clinics in individual provinces, including fertility preservation procedures and items for reimbursable services and also of funding support for oncofertility services. The costing data will provide a resource for shaping future policies and practices for fertility clinics across Canada.

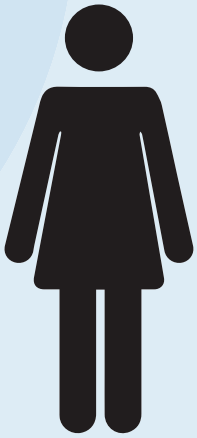
THE AVERAGE COSTS IN CANADA FOR MALES TYPICALLY INCLUDE:

$290
for sperm collection

$2140
for surgical sperm collection

$318/year
for storage

IN COMPARISON, THE AVERAGE COSTS IN CANADA FOR FEMALE PROCEDURES ARE:



$6300
for egg retrieval

$950
for freezing

$318/year
for storage

Drug costs vary, ranging from $800 to $8000, and may be covered through assistance from organizations such as Fertile Future (Power of Hope), private insurance, or compassionate programs offered by pharmaceutical companies.

Information was gathered from publicly posted pricing and through a survey sent to allied health professionals working in the field of human reproductive technologies across Canada. See Tables 3 and 4 below for a summary of this information.

Table 3: Fertility Preservation Costs (in Canadian $) for Men

Time Frame	Procedure	Range	Canadian Average
Immediate	Sperm Banking (ejaculated sample)	270-525	370
	Sperm Banking (surgically retrieved sample)	1188-1775	1415
Ongoing	Annual Storage Fee	208-400	283
Future	Sperm processing for Intra Uterine Insemination (IUI)	248-500	484
	Monitoring cost for female	1500-1775	1625
	Cost of Future IVF with ICSI	7450-8450	7962

Table 4: Fertility Preservation Cost (in Canadian $) for Women

Time Frame	Procedure	Range	Canadian Average
Immediate	Oocyte pick up (OPU) and egg freezing	6250-9060	7022
	Oocyte pick up (OPU) and embryo production	7125-9873	7697
	Embryo Freezing for future	650-875	792
Ongoing	Egg or Embryo Annual Storage Fee	200-367	274
Future	Egg thaw + ICSI to create embryos	2825-3688	3137
	Embryo Thaw and Frozen Embryo Transfer (FET)	1325-2026	1588

Due to the nature of fertility preservation options, the cost to invest in fertility preservation is very different for young women and men (see Tables 3 & 4 above). For example, a young man faced with a cancer diagnosis can produce and bank a sperm sample immediately. Once complete, sperm banking does not interfere with cancer treatment. On the other hand, a young woman diagnosed with cancer with the desire to preserve her fertility through the collection of eggs for freezing and/or embryo production and freezing requires time to coordinate her cycle for the most optimal opportunity to harvest her eggs. In addition, there is a requirement of follicle stimulating drugs to promote the growth and maturation of follicles and oocytes. This often leads to a discussion around balancing a delay in cancer treatment to allow the required time for fertility preservation. Expensive follicle stimulating medications combined with the costly procedure fees for oocyte retrieval and egg/embryo freezing make female fertility preservation options more time consuming and costly compared to those for men.

Funding models

The costs of fertility preservation are often not covered by insurance, especially given that insurance usually does not cover experimental therapies. Some jurisdictions have comprehensive fertility coveage because of mandates on insurance, and some have recently begun mandating coverage of fertility preservation (Figure 1. Fertility Preservation Services Coverage in Canada). Currently, every province and territory cover the cost of fertility consultation and recommended follow-up tests but there is variability of IVF coverage across Canada.
The provinces of Ontario and Quebec publicly fund IVF treatments with restrictions. Manitoba and New Brunswick have implemented a fertility treatment tax credit to help cover some costs of IVF treatments. The tax credit in Manitoba covers 40% of treatment costs related to infertility, including IVF, to a maximum of $8000 per year. Also, it is important to note that the NIHB for registered First Nations and recognized Inuit, does not cover the costs of fertility medications.

Fertility Preservation Services Coverage in Canada

LEGEND

\# - Total Fertility Preservation Clinics
■ - Fertility Preservation Clinics

FEDERAL COVERAGE

▸ Federal Income Tax (Medical Expense Tax Credit):
  · Medical expenses* paid for by the patient, their spouse or common-law partner and certain related persons (any dependents who are listed on your income tax forms)

*Canada Revenue Agency states that fertility procedures, medications and travel costs qualify as medical expenses as they relate to the medical condition of infertility under section 118.2 of the Income Tax Act

▸ Non-Insured Health Benefits (NIHB):
  · For registered First Nations and recognized Inuit, the NIHB does not cover the costs of fertility medications

GENERAL NOTES

▸ Every province and territory will cover the cost of consulting a doctor about fertility problems

▸ Some funding from charities may offset costs of fertility treatments e.g. Fertile Future

▸ Funding may be dependant on third party insurance for coverage of fertility treatments

▸ Jurisdictions with limited fertility services will incur extra travel expenses for the patient who must travel to receive services out of province/territory. Some fertility clinics may charge an additional non-resident fee.

Reference 1
Reference 2
Reference 3
Reference 4
Reference 5

YUKON

COVERAGE
▸ None

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 0

ADDITIONAL INFORMATION
▸ Residents access fertility services in British Columbia.

NORTHWEST TERRITORIES

COVERAGE
▸ None

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 0

ADDITIONAL INFORMATION
▸ Residents access fertility services in Alberta.

NUNA

COVER
▸ None

 # OF FI CLINIC
▸ Total

ADDITI
▸ Resid Ontario

BRITISH COLUMBIA

COVERAGE
▸ None

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 6
▸ All 6 clinics offer sperm preservation.
▸ 4 clinics offer IVF.

ADDITIONAL INFORMATION
▸ Most fertility blood tests are covered with British Columbia Medical Services Plan.
▸ The anti-Müllerian hormone blood test costs 70 dollars.

ALBERTA

COVERAGE
▸ None

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 4
▸ 3 clinics offer sperm preservation and IVF (Regional Fertility & Women's Endocrinology Clinic in Edmonton does not do sperm or egg banking)

ADDITIONAL INFORMATION
▸ Most fertility blood tests are covered with Alberta Health Care Insurance Plan.

SASKATCHEWAN

COVERAGE
▸ None

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 1
▸ Clinic offers sperm preservation and IVF

ADDITIONAL INFORMATION
▸ Saskatchewan Health covers prep work for IVF, including blood work and ultrasounds.

MANITOBA[1]

COVERAGE
▸ Partial — 'Fertility Treatment Tax Credit'

COVERAGE INFORMATION
▸ A Tax Credit of 40% of the cost of fertility treatme of $8,000 refund per year (40% of $20,000) is provi
▸ The tax credit applies to IVF, fertility preservation, drugs (among other services):
  · Treatments and related medications must be pr Manitoba licensed medical practitioner or infert clinic
  · The patient must be a resident of Manitoba.

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 1
▸ Clinic offers sperm preservation and IVF

ADDITIONAL INFORMATION
▸ The Tax Credit does not cover associated travel co
▸ The Tax Credit is payable to the patient regardless pay income taxes. However, in order to receive the c or their spouse or common-law partner must file ar return.

AVUT

RAGE

ERTILITY PRESERVATION
S*
Clinics = 0

IONAL INFORMATION
ents access fertility services in
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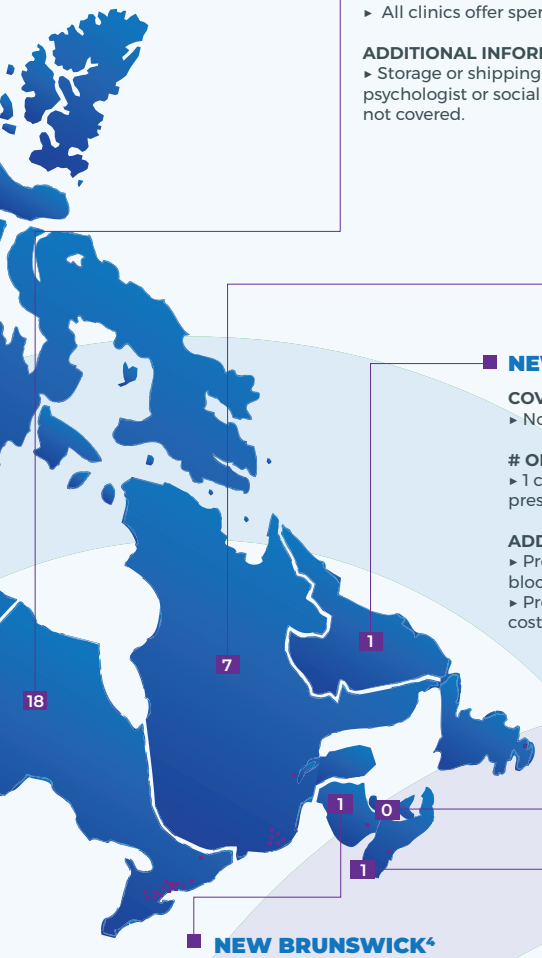

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ONTARIO[2]

COVERAGE
▸ Yes — 'Ontario's Fertility Program'

COVERAGE INFORMATION
▸ To qualify:
- Have a medical reason for fertility preservation
- Be an Ontario resident with a valid OHIP card
- Be under the age of 43 years old

▸ Coverage includes once per lifetime IVF and fertility preservation.
▸ Egg retrieval and freezing of one batch/sample of eggs or sperm.

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 18
▸ All clinics offer sperm preservation and IVF.

ADDITIONAL INFORMATION
▸ Storage or shipping of eggs/sperm/embryos, counselling by a psychologist or social worker and any drugs or medications are not covered.

QUÉBEC[3]

COVERAGE
▸ Yes — 'Assisted Procreation Services'

COVERAGE INFORMATION
▸ Funding for cancer patients through The Régie de l'assurance maladie du Québec (RAMQ) covers all costs associated with IVF for egg and embryo preservation, including storage.
▸ Sperm preservation and storage are also covered.
▸ In such cases (for cancer patients), the following services are covered by insurance:
- Ovarian stimulation or ovulation induction
- Procedures to retrieve eggs and ovarian tissue
- Procedures to collect sperm or testicular tissue
- Freezing and storage of sperm, ovarian or testicular tissue or embryos for a period of 5 years

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 7
▸ All clinics offer sperm preservation and IVF.

ADDITIONAL INFORMATION
▸ RAMQ covers the cost of storage for 5 years.
▸ Beyond 5 years it is the responsibility of the patient.

PRINCE EDWARD ISLAND[5]

COVERAGE
▸ Partial — 'Fertility Support Program'

COVERAGE INFORMATION
▸ The program provides a minimum of $5,000 and up to $10,000 annually, based on family income, for eligible expenses associated with IVF including associated medications at out-of-province clinics.
▸ An individual can access maximum annual funding for up to three years.
▸ Eligibility criteria include family income and to be a permanent resident of PEI with a Health Card. Storage fees for IVF and sperm preservation are not covered.

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 0

ADDITIONAL INFORMATION
▸ Province covers prep work for IVF, including blood work and ultrasounds.

NEWFOUNDLAND & LABRADOR

COVERAGE
▸ None

 # OF FERTILITY PRESERVATION CLINICS*
▸ 1 clinic - St. John's Clinic offers sperm preservation but not IVF treatment

ADDITIONAL INFORMATION
▸ Province covers prep work for IVF, including blood work and ultrasounds.
▸ Province does not cover associated travel costs.

NOVA SCOTIA

COVERAGE
▸ Partial — 1. 'Hematology/Oncology Fertility Support Fund' and 2. 'Nova Scotia Fertility and Surrogacy Rebate'

COVERAGE INFORMATION
1. 'Hematology/Oncology Fertility Support Fund'
▸ Eligibility to receive funds will be determined by the Pediatric Oncologist and the Social Worker in the Division of Pediatric Hematology/ Oncology based on assessment procedures and on the patients treatment modality .
▸ Following the proper criteria and assessment procedures, ma y approve funds up to a maximum of $375 per male and $5,360 per female. The source of funds are from the Hematology/Oncology Trust Fund, up to a maximum of $10,000/year.
2. 'Nova Scotia Fertility and Surrogacy Rebate'
▸ A Tax Credit of 40% of the cost of fertility treatment, to a maximum of $8,000 refund per year (40% of $20,000) is provided to residents.
▸ Services to be provided by a NS-licensed medical practitioner or infertility treatment clinic and for surrogacy-related medical expenses.
▸ No limit on the number of treatments that an individual can claim (maximum annual claim is $20,000 in eligible costs)

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 1
▸ Clinic offers sperm preservation and IVF.

ADDITIONAL INFORMATION
▸ Yearly storage fees and fertilization procedures be yond initial oocyte collection and preservation or sperm preservation are not covered.
▸ Many patients are referred to this fertility clinic from PEI and NL.

NEW BRUNSWICK[4]

COVERAGE
▸ Partial — 'The Special Assistance Fund for Infertility'

COVERAGE INFORMATION
▸ To qualify for the one time maximum grant of $5,000, applicants must:
- Be a New Brunswick resident with a valid Medicare card
- Have been diagnosed by a physician with fertility problems and have received infertility treatment after April 1, 2014

▸ The fund allows individuals to claim 50% of eligible incurred costs of IVF and related pharmaceutical products, up to a maximum of $5,000.
▸ Grant does not include coverage for sperm preservation.

 # OF FERTILITY PRESERVATION CLINICS*
▸ Total Clinics = 1
▸ Clinic offers sperm preservation and IVF

ADDITIONAL INFORMATION
▸ The fertility assistance program is separate from Medicare, which does not cover anything related to fertility treatments.
▸ Province does not cover associated travel costs.

Recommended solutions

Currently there is no standardized support through government and other programs for fertility services in Canada. In addition, there are significant differences in costs for male and female patients. With a steep cost for female procedures, it is understandable that female patients often choose to not actively seek referrals for fertility preservation due to immediate costs ranging from $10,000-$15,000. Some provinces have implemented tax credits for cancer patients utilizing fertility services as a potential solution. Unfortunately, this solution has been ineffective for reaching the AYA population since some do not meet the criteria for a tax credit due to low levels of income. Financial barriers such as the immediate costs, ongoing costs of storage of samples and cost for future treatment to complete fertility goals continue to greatly influence AYA decisions to undergo fertility preservation procedures.

Alternative cost approaches include implementing a flexible deferred patient payment plan and providing some level of government subsidies for oncofertility services. Unfortunately, governments often debate whether fertility services in general fall under the public funding umbrella, without considering oncofertility separately.

Oncofertility Ad-Hoc Working Group Meeting

On March 6, 2020, the Partnership hosted an Oncofertility Pre-Treatment Screening Ad Hoc Working Group meeting with a multi-disciplinary group of partners including patient and family advisors, fertility specialists, AYA oncology specialists, metrics and measurement specialists, and partners who are currently implementing screening tools in the cancer system. The focus of this meeting was to explore the development of an oncofertility pre-treatment screening prompt to be embedded in existing jurisdictional Patient Reported Outcome (PRO) initiatives, as well as to consider all the things that need to be in place to support fertility preservation for AYAs.

As a result of this meeting, it was agreed that an oncofertility prompt could be offered to all cancer patients in their reproductive years and at pre-treatment/consultation visit at the cancer center- as the optional timing but also throughout a patient's in-cancer centre treatment journey.

The participants also took some time to identify the different components that would be important to have in place to support implementation of an oncofertility screening prompt in the cancer centre. This includes if a patient indicates yes, they would like to speak with someone and learn more about fertility risk – there needs to be established processes to addressing their needs, some of which fall within and outside of the cancer centre, hence establishing relationships with fertility centres will be essential. There was also some discussion on the possible public policy approaches that could be used to improve equitable access to fertility preservation services for cancer patients. It was recommended that the Partnership work with partners to scope the problem.

Key takeaways:

- The need to establish clinic-specific oncofertility pathways, which will involve bidirectional relationships between the oncology system and fertility system. This will hopefully facilitate timely referrals to fertility specialists.
- The need for tools/resources to improve the ability of providers and the system to respond to patients' needs and ensure patients make informed decisions prior to treatment.
- Stakeholder engagement: Promoting inclusivty throughout the strategy to ensure underserviced and marginalized patients receive equitable access.
- And lastly, the need to influence public policy to address inequities that exist in access.

Validation of the oncofertility screening prompt

Approach

The Partnership's Person-Centred Perspective team in collaboration with the Patient and Public Engagement team engaged with patient and family advisors on the draft oncofertility screening prompt to be incorporated into existing PRO screening questionnaires that are administered to cancer patients at cancer centres across Canada. The objective was to seek feedback on both the value of adding this prompt, and their ideas on the wording of the prompt to ensure it resonates with all cancer patients and brings awareness to the fertility impacts associated with cancer treatment.

Overall, including the prompt may help patients link to and seek proactive strategies to better preserve their future fertility options.

This engagement built on an earlier workshop with patients and experts (see 'Oncofertility Ad-Hoc Working Group Meeting' above) and sought input from a cross-section of patients including: 1) AYA and pediatric patients affected by oncofertility issues now/or in the future 2) patients from a variety of underserved, Indigenous, and culturally diverse groups, and 3) cancer patients across cancer types, both English and French speaking.

The prompt is: Some cancer treatments could negatively impact fertility or reproductive health and the ability to have biological children now and in the future. I would like to speak to a healthcare professional about this.

"Some cancer treatments could negatively impact fertility or reproductive health and the ability to have biological children now and in the future. **I would like to speak to a healthcare professional about this.**"

Oncofertility Initiative Scope of Work

Background on implementation

The objective of this project is to improve the patient experience through integration of an oncofertility screening module into the existing PRO sequence. This will help cancer patients to access appropriate and timely fertility preservation information and referrals to fertility specialists and services if desired. The project objective will be accomplished through targeted education, identification of appropriate patients through integration of an oncofertility screening prompt, and the development and implementation of standardized clinic- and community-specific fertility referral pathways. Due to the complexity of implementing an oncofertility screening prompt with appropriate referrals and services, new and existing partners from fertility and oncology will need to be engaged. A focus on equity will be embedded throughout this work, with a particular focus on meeting the needs of First Nations, Inuit and Métis.

Project scope and objectives of implementation

The scope of this project is to leverage and expand the Partnership's funded PRO initiatives implementing screening tools in the cancer sytem, by adding an oncofertility screening module to prompt a discussion on fertility risk which may lead to referrals to fertility counselling and fertility preservation as needed.

Main objectives:

1. Current state analysis of local jurisdictional resources and practices, access to fertility referrals/ services including infrastructure that currently exists to support appropriate access and referrals for the defined patient population; environmental scan to review existing patient and provider education/resource materials and tools.
2. Incorporate and implement the Oncofertility screening prompt into current PROs/processes.
3. Oncofertility Education including an oncology education and awareness plan.
4. Develop and implement a sustainable referral pathway between pediatric and adult oncology.
5. Develop, promote and share education resources and implement referral pathways that are inclusive and culturally responsive for underserved and Indigenous populations. Part of adapting fertility pathways and education materials for underserved populations will be to identify barriers to oncofertility resources and services among these populations.
6. Stakeholder Engagement with inclusion of undeserved and Indigenous populations.
7. Performance Measurement and Evaluation, including measuring baseline performance (e.g., number of patients screened with the oncofertility prompt, number of referrals to fertility clinics) and post-intervention re-measurement.
8. Sustainability plan to ensure new processes are embedded into sustainable practices.

All components must be incorporated into projects in order to be eligible for funding. As aforementioned an equity lens needs to be embedded throughout this work. This includes people who are underserviced by the healthcare system as specifically called out in the Canadian Strategy for Cancer Control:

- First Nations, Inuit and Métis
- Recent immigrants
- People with lower income
- people who identify as LGBTQ2+
- Minority language communities
- Rural, remote and northern residents

Jurisdictions to identify sub-populations from the Strategy's underserviced groups and adapt the fertility pathways and related education to meet the needs of these selected underserviced populations, including additional considerations for out of province/territory patients.

Incorporate an oncofertility screening prompt

Key Activities:

- Leverage the existing **PRO initiatives/tools** by introducing and implementing a screening prompt before treatment (and other meaningful timepoints) that leads to more cancer patients receiving information about the risk of infertility and more people receiving fertility counselling that supports person-centred care.
- Existing modifiable tools in the PRO sequence such as, the Canadian Problem Checklist (CPC), Distress Thermometer, or the Social Difficulties Index (SDI) can be leveraged.

This component of the project includes incorporating a way to identify cancer patients that would like to discuss potential fertility risks with their cancer clinician and make necessary referrals to appropriate fertility specialists as needed. To identify patients who might benefit from a fertility discussion, an oncofertility screening prompt can be used prior to initiation of treatment. It is recommended that this prompt be asked of all cancer patients during their reproductive years and throughout a patient's in-cancer centre treatment journey.

The oncofertility screening prompt to be utilized is: Some cancer treatments could negatively impact fertility or reproductive health and the ability to have biological children now and in the future. I would like to speak to a healthcare professional about this.

Cancer clinicians should discuss the possible effects of cancer treatment on patient's fertility before the start of treatment. Cancer clinicians should give patients an opportunity to discuss their fertility by offering a referral to a fertility specialist who can discuss fertility preservation strategies with them (see 'Oncofertility Pathways' below). This screening prompt helps to increase awareness of and responses to infertility that patients can experience as a result of their cancer treatments. Overall, including the prompt may help patients link to and seek proactive strategies to better preserve their future fertility options.

Oncofertility pathways

Key Activities:

- With a focus on equity, each cancer centre should map out and implement a clear referral pathway to communicate effectively with fertility preservation services to ensure that a consultation and possible procedure(s) can be organized in a timely manner, if appropriate, before the start of cancer treatment. The pathway should comply with the American Society of Clinical Oncology guidelines.

"Some cancer treatments could negatively impact fertility or reproductive health and the ability to have biological children now and in the future. **I would like to speak to a healthcare professional about this."**

- Investigate barriers/facilitators that limit/enable access to oncofertility services, including out of province/ territory patients and underserved populations. There should also be the development of a culturally safe oncofertility pathway for First Nations, Inuit and Métis and an accessible pathway for all cancer patients (including underserviced groups). For example, new models of care should be considered such as virtual counselling appointments for rural and remote cancer patients as a way of facilitating appointments more conveniently.

The success of timely referrals to fertility preservation requires a coordinated effort between two separate disciplines – oncology and fertility. The benefits to a clinical oncofertility pathway include awareness of the impact of cancer treatment on fertility and reproductive health, early access to fertility information and referrals to fertility and reproductive health services, increase in fertility preservation, increase in quality of life, and decrease in post-cancer treatment distress.

Jurisdictions should conduct a current state analysis of existing cancer centres' counselling and fertility resources and an inventory of external fertility resources and services in order for local referral pathways to be modified or developed at each cancer centre. This analysis should include a focus on equity, including identification of gaps or challenges specific populations may face along the referral pathway. Successful pathways will support access and services for all patients.

The Partnership has developed an example of a model of care fertility pathway that partners can adapt to jurisdictional/cancer centre context (see example of pathway below).

Figure 2. Example of an Oncofertility Referral Pathway
The purpose of this pathway is to optimize communication and referrals to fertility resources, specialists and preservation services for cancer patients. Pathways should be integrated into standard practice in cancer centres. It is important to consider what information/resources are needed, who will provide them, and where the patient should be appropriately referred. Below is an example of a model of care.

Other important considerations include an equity lens and patients treated at pediatric cancer centres.

CANCER CENTRE

CANCER TREATMENT

INITIAL CONSULTATION/PRE-TREATMENT VISIT

- Ideal timing: Oncofertility screening question
- Risk of infertility and availability of fertility specialists discussed. Discussion to be documented.
- Referrals to fertility specialists is made, if desired. Urgent referrals should be considered for cancer patients who need to initiate treatment < 7 days.

CANCER TREATMENT

- Oncofertility screening question
- Reassess fertility and reproductive health needs. Referrals to fertility specialists is made, if desired.
- Question should be reintroduced when switching a treatment regimen with new side effects and when different healthcare providers are involved.

FERTILITY CLINIC

- In-depth consultation/counselling regarding fertility risk and fertility preservation options. To determine timing, interest and eligibility.

Patient undergoes fertility preservation procedures (if eligible)

Patient not eligible or not interested in fertility preservation

CANCER CENTRE: TREATMENT

CANCER CENTRE: TREATMENT COMPLETION

CANCER CENTRE: ONGOING FOLLOW-UP

- Oncofertility screening question

PRIMARY CARE/ COMMUNITY CARE

SURVIVORSHIP / PALLIATIVE AND END-OF-LIFE CARE

COORDINATION OF CARE

- Nurses
- Patient Navigators (e.g., Indigenous, AYA)
- Psychosocial Health Providers (e.g., mental health, peer-to-peer support)
- Financial Counselors
- Social Workers
- Genetic and/or Family Counsellors and Planners
- Elders and Spirtual Healers
- Other Oncofertility Medical Providers

- Facilitates appropriate referrals (should be offered irrespective if patient undergoes further fertility counselling or preservation)
- Provides up-to-date, age appropriate, and culturally safe information and resources on fertility risks, options and reproductive health (see Notes)
- Provides financial resources
- Referrals to peer support groups
- Virtual models of care considered for consultations with fertility specialists as a way of facilitating rural/remote patient appointments more conveniently

ONGOING FOLLOW-UP

- Some cancer patients may receive treatment in a jurisdiction outside from their home province/territory, and they may have their follow-up care provided in their home province/territory.
- Consideration needs to be given to the resources and supports that these patients will require, and the consistency in information,

Primary Care Notes:

Patient and provider education and awareness resources/materials* (print and web-based materials)

- Are the materials appropriate for:
  - General population,
  - French Canadians,
  - First Nations, Inuit and Métis,
  - Recent immigrants,
  - People with lower income,
  - People with literacy barriers**,
  - People who identify as LGBTQ2+,
  - Minority language communities,
  - Rural, remote, northern residents
- Are there appropriate supports in place for:
  - General population,
  - French Canadians,
  - First Nations, Inuit and Métis,
  - Recent immigrants,
  - People with lower income,
  - People with literacy barriers**,
  - People who identify as LGBTQ2+,
  - Minority language communities,
  - Rural, remote, northern residents
- Ensure materials and resources provide similar information for patients who will travel out of their home province/territory for care (i.e. patients are receiving the same information in their home jurisdiction as in the jurisdiction where they are being treated)
- Are any patients being missed because they get diagnosed, or began treatment, at a pediatric center?

*Canadian Cancer Society: Community Services Locator (CSL) will have oncofertility resources available as well as materials identified by the Adolescents and Young Adults National Network - Education & Capacity Building Working Group (see Business Case)

**literacy barriers include: reading/writing literacy (information should be provided for literacy at a grade 6 level at the highest), financial literacy, technology/computer literacy, etc.

Primary Care/Community Care Notes:

Patient and provider education and awareness resources/materials* (print and web-based materials)

- Are the materials appropriate for:
  - General population,
  - French Canadians,
  - First Nations, Inuit and Métis,
  - Recent immigrants,
  - People with lower income,
  - People with literacy barriers**,
  - People who identify as LGBTQ2+,
  - Minority language communities,
  - Rural, remote, northern residents
- Patient access to psychosocial supports and reproductive health specialists for post-treatment concerns, problems (special consideration may need to be given for patients treated out of their home province/territory
- Can they access these supports in their home province/territory?
- Can they access these resources virtually? etc.)
- Are there appropriate supports in place for:
  - General population,
  - French Canadians,
  - First Nations, Inuit and Métis,
  - Recent immigrants,
  - People with lower income,
  - People with literacy barriers**,
  - People who identify as LGBTQ2+,
  - Minority language communities,
  - Rural, remote, northern residents

*Canadian Cancer Society: Community Services Locator (CSL) will have oncofertility resources available as well as materials identified by the Adolescents and Young Adults National Network - Education & Capacity Building Working Group (see Business Case)

**literacy barriers include: reading/writing literacy (information should be provided for literacy at a grade 6 level at the highest), financial literacy, technology/computer literacy, etc.

Cancer Centre Notes:

Patient and provider education and awareness resources/materials* (print and web-based materials)

- Including resources to facilitate conversations with patients for oncologists, nurses, etc. (non-fertility specialists)
- Patient access to psychosocial supports, financial supports (including travel and accommodation supports); patient access to navigators (or other coordination of care supports)
- Can these supports be accessed virtually?
- Can referrals and appointments be coordinated to prevent multiple travels?

- Are the materials appropriate for:
  - General population,
  - French Canadians,
  - First Nations, Inuit and Métis,
  - Recent immigrants,
  - People with lower income,
  - People with literacy barriers**,
  - People who identify as LGBTQ2+,
  - Minority language communities,
  - Rural, remote, northern residents

- Are there appropriate supports in place for:
  - General population,
  - French Canadians,
  - First Nations, Inuit and Métis,
  - Recent immigrants,
  - People with lower income,
  - People with literacy barriers**,
  - People who identify as LGBTQ2+,
  - Minority language communities,
  - Rural, remote, northern residents

- Ensure materials and resources provide similar information for patients who will travel out of their home province/territory for care (i.e. patients are receiving the same information in their home jurisdiction as in the jurisdiction where they are being treated) consider funding and costs for fertility counselling and preservation services for patients who travel out of their home province/territory for care (i.e. does a patient's home jurisdiction provide funding for these services?
- Can the patient access this funding from their home jurisdiction while receiving care in a different jurisdiction? is a patient eligible for funding provided in the jurisdiction they are receiving care in if these services are not available in their home jurisdiction? etc.)
- Are any patients being missed because they are being treated, or began treatment, at a pediatric center?

*Canadian Cancer Society: Community Services Locator (CSL) will have oncofertility resources available as well as materials identified by the Adolescents and Young Adults National Network - Education & Capacity Building Working Group (see Business Case)

**literacy barriers include: reading/writing literacy (information should be provided for literacy at a grade 6 level at the highest), financial literacy, technology/computer literacy, etc.

Notes to consider when mapping out the fertility pathways:

- Counseling regarding fertility preservation options is the first step in assisting families in navigating options for fertility preservation. This counseling is best undertaken as early as possible after a cancer diagnosis is made and before the initiation of any cancer treatment. Even when fertility preservation is not possible because of the need for treatment or other determinants, counseling regarding the risks to fertility inherent in the various treatment options will allow patients and their families to cope with the effects of cancer treatment.
- Patients should be offered psychological support and counselling to help them deal with decisions on fertility preservation.
- Urgency for fertility consultation referrals especially for hematological cancers where there is an urgency to start treatment should be considered.
- Virtual models should be considered for consultations with fertility specialists as a way of facilitating rural/remote patient appointments more conveniently.

Public policy

Part of adapting fertility pathways and education materials for underserved populations will be to identify barriers to oncofertility resources and services among these populations including affordability of these services.

Implementing a provincial/territorial strategy to increase affordability of fertility preservation services to cancer patients through public health funding is crucial to breaking down the common barriers that cancer patients encounter.

The Partnership has developed a public policy map by jurisdiction to provide information regarding the availability of public funding for fertility preservation services in Canada (see Figure 1, page 15). Which Canadian jurisdictions fund fertility preservation? What are the eligibility criteria for public access to fertility preservation treatment? This information has been validated by our jurisdictional partners. In the future, we hope to work with governments and Assistant/Deputy Ministers on the funding landscape with the goal to advocate with our partners for funding of fertility services to reduce inequities. The goal will be to improve coverage of provincial health plans to fund oncofertility treatments for equal access to all Canadians. Financial barriers such as the immediate costs, ongoing costs of storage of samples and cost for future treatment to complete fertility goals continue to greatly influence AYA decisions to undergo fertility preservation procedures.

Literature has shown that jurisdictions with fertility preservation coverage had increased rates of fertility discussion and referral. Therefore, we encourage advocacy efforts to ensure similar coverage in other jurisdictions to improve patient access to fertility services.[xlii]

Oncofertility education

Key Activities:

- Educational materials should be developed (or leveraged and/or adapted*) and made available for healthcare providers and patients to facilitate discussions about oncofertility.
- Oncofertility education including an oncology education and awareness plan should be developed. Multiple methods of raising awareness and education may be required such as rounds and institutional communication.
- Education materials should be developed with a focus on equity and should be culturally appropriate, so they are accessible to all cancer patients (including First Nations, Inuit and Métis and underserviced groups). It is important that the resources and education enable culturally appropriate and safe conversations and interactions between the healthcare providers and patients. Cultural competency training of healthcare professionals could be one way to support responding to these needs.
- Fertility preservation information and educational materials should be readily accessible and widely available to patients and healthcare providers.

Education for patients: Awareness and uptake of resources is needed for informed decision-making by patients. Cancer patients are often not informed about fertility risks and preservation options when treatment is being planned.

Education for healthcare providers: Physicians' expertise impacts a patient's decision in fertility preservation. It is important for physicians and other healthcare providers to know the importance of patient awareness and fertility risks, and have knowledge about local fertility centres, provide referral, and to allow time for patients to access fertility preservation services.

Also, the Partnership is working with the CCS to curate an inventory of oncofertility resources in the community into their Community Service Locator (CSL) which can also be leveraged in this project.

*Note, the Partnership has a roster of existing resources identified by the Education & Capacity Building Working Group (a subset of the AYA National Network). Many of the tools were created for patients and family members with a few available for healthcare providers. The Partnership has made the list of resources available for consideration to minimize duplication (see Table 5).

Education materials should be developed with a focus on equity and should be culturally appropriate so they are accessible to all cancer patients.

Table 5. List of Oncofertility Resources

Provider	Description	Link
Canadian Cancer Society	Oncofertility resources to be entered into their Community Service Locator (CSL) through to March 31, 2022	https://csl.cancer.ca/en
ASCO University	CME	https://elearning.asco.org/catalog?text=fertility
Fertile Future		http://fertilefuture.ca/programs/power-of-hope/ https://fertilefuture.ca/wp-content/uploads/2017/12/CancerFertility-Brochure-R5.pdf
Unity Health (St. Michael's)	Begin Exploring Fertility Options, Risks and Expectations (BEFORE) DECISION AID	https://rethinkbreastcancer.com/beforeDA https://fertilityaid.rethinkbreastcancer.com/SM_BEFORE_decisionAid_V9.pdf
BC Cancer	Young Adults with Cancer Website	http://www.bccancer.bc.ca/our-services/services/library/recommended-websites/living-with-cancer-websites/young-adults-with-cancer-websites
Cancer.net Videos	Bills and Medical Expenses	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/bills-and-medical-expenses
	Work	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/work
	Body Changes	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/body-changes
	Dating and Sexuality	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/dating-and-sexuality
	Diet and Exercise	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/diet-and-exercise
	Family and Friends	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/family-and-friends
	Fear of Dying	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/fear-dying
	Health Insurance	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/health-insurance
	Fear of Recurrence	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/fear-recurrence
	School	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/school
	Managing Pain	https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/managing-pain

Princess Margaret	Fertility Preservation for Men	https://www.uhn.ca/PrincessMargaret/Clinics/Adolescent_Young_Adult_Oncology/Documents/Fertility_Preservation_for_Men_Starting_Cancer_Treatment.pdf
	Fertility Preservation for Women	https://www.uhn.ca/PrincessMargaret/Clinics/Adolescent_Young_Adult_Oncology/Documents/Fertility_Preservation_for_Women_Starting_Cancer_Treatment.pdf
Livestrong	Fertility	https://www.livestrong.org/we-can-help/livestrong-fertility
My Oncofertility	Oncofertility	https://www.savemyfertility.org/
NCI	AYA Page	https://www.cancer.gov/types/aya
Princess Margaret Cancer Centre	AYA Fertility	https://www.uhn.ca/PrincessMargaret/Clinics/Adolescent_Young_Adult_Oncology/Pages/fertility.aspx
Sick Kids	Egg Preservation	https://www.youtube.com/watch?v=wB9lfKlYReY&feature=youtu.be
Sick Kids	Sperm Preservation	http://www.sickkids.ca/PDFs/Urology/Fertility/64244-Final%20Sperm%20Banking%20Pamphlet.pdf

Stakeholder engagement

Key Activities:

- Engage stakeholders, including local champions in cancer centres, to raise awareness of, provide accurate information about, and encourage their peers to identify patients at risk and promote oncofertility referrals.
- Convene a multi-disciplinary (oncology/fertility, adult/pediatric, patient representatives, underserved and Indigenous representatives, gynecology and reproductive medicine, urology, and general practitioner oncology) team.
- Engage stakeholders to understand inequities in access to or provision of oncofertility care.
- Collaboration with multi-disciplinary stakeholders will be integral to service planning and to improve access to fertility information, counselling, and fertility preservation services.

Stakeholders may include:

- Care providers in oncology (pediatric and adult)
- Patients, families, and caregivers
- First Nation, Inuit and Métis organizations, governments and communities*****
- Underserviced groups*****
- Fertility specialists
- Nurses
- Social workers
- Patient Navigators
- Educators
- Supportive care
- Policy Specialists
- P/T Governments
- Senior Leadership
- Cancer Centre leads
- Regional health authorities

*****There needs to be respectful engagement with First Nations, Inuit and Métis organizations, governments, and communities to understand the cultural needs of Indigenous patients and families and to develop and implement culturally sensitive and safe oncofertility pathways and that is responsive to their needs. As well, members of underserviced communities must be engaged to inform the development and implementation of equitable pathways.

Performance measurement and evaluation

- Funded initiatives will be required to work with the Partnership to co-develop a performance measurement strategy that (1) outlines the outputs and outcomes of the funded work, and associated performance indicators, and that (2) aligns with and supports the Partnership's overall work more broadly. The Partnership will also request indicator data both quantitative and qualitative performance assessments to support organizational activities related to performance measurement and evaluation.
- Such indicators may include reach, adoption, education/training, coordination, and utilization of services as well as intermediate and long-term outcomes.

Anticipated project outcomes

- Priority Outcome: People with cancer, their families and caregivers have improved access to information and support.
- Initiative-level Outcome: Increased system capacity to address the barriers in cancer care, specifically in oncofertility for young people with cancer in Canada.
- Project-level Outcomes:
  - Patients have access and awareness of potential impacts of treatment on fertility and improved access to timely fertility information, fertility-related supports.
  - Health Care Providers have increased access and awareness of fertility-related supports to provide patients with timely information before treatment and referrals (if desired).
  - Fertility pathways and education resources are adapted with an equity lens of local relevance to meet the needs of underserved, out of province and First Nations, Inuit, and Métis patients.

Output/Process Indicators

Awareness – Health care providers are more knowledgeable about oncofertility and referral procedures.

Reach – All cancer patients in their reproductive years benefit from a fertility discussion through the oncofertility screening prompt.

- # of patients screened using the oncofertility screening prompt

Adoption – Health care providers effectively use oncofertility screening (as part of PROs) in routine clinical practice.

Education/training – Standardized training and resources are available to support providers and education materials are consistently provided to patients.

- # of staff trained, # of education sessions on oncofertility

Coordination – Referrals are completed in a timely manner and should be started early in the cancer journey before treatment. There is improved communication between oncology and fertility centres.

- # of patients who had fertility preservation discussions with an oncologist/health care provider prior to treatment
- # of patients referred for fertility consultation
- # of patients referred for psychosocial, financial and other fertility-related supports as a result of the fertility pathway

Access – Patients have local access to fertility consultations and fertility preservation services.

Utilization – Patients are utilizing fertility consultation and preservation services within the jurisdiction.

- # of patients who received a fertility consultation prior to treatment
- # of patients who utilized fertility preservation services

Outcome Indicators

Intermediate outcomes

- Patient experience/satisfaction with the oncofertility screening process

Long-term outcomes

- Standardized use of PROs in the cancer population
- Proportion of AYA survivors who have live births

Sustainability

A sustainability plan should ensure that the resource team is well positioned to continue this work, considerations include:

- Strong support from senior leadership and champions well positioned to sustain efforts
- Funding models are pursed to ensure continuous training and education
- Funding may be requested to sustain dedicated resources
- Process measures are being monitored to ensure continuous quality of the program
- Communication strategies are in place to ensure awareness continues
- Sustained reporting system to monitor and track referrals

Appendix

AYA Task force & AYA National Network

Back in 2008, the Partnership and C17 network of pediatric centres across Canada had established the Canadian Task Force on AYAs with cancer. This Task Force had initiated the work on oncofertility and had invested a great deal of energy and consideration into oncofertility, including considering various types and examples of resources.

Between 2008 and 2016 the Canadian Task Force for AYAs with Cancer raised awareness about the differences between AYAs and both younger and older persons with cancer and worked to mitigate the disparities of care received by AYAs with cancer related to the separation of adult and pediatric cancer services in Canada. In 2018, the Partnership launched the AYA National Network which includes representatives from each provincial cancer agency, provincial/territorial ministries of health, AYAs and their family members, and national stakeholder groups, who have provided the mechanism to implement recommendations that have been generated by the Task Force.

Through the work of the Task Force, an Oncofertility Stakeholder Workshop held in 2016 gathered AYA survivors, clinicians, researchers, policymakers, and representatives of nongovernmental organizations from across Canada to discuss the development of pan-Canadian oncofertility best practices and a framework for an oncofertility action plan to address barriers to best care and future options for fertility preservation.

Recommendations related to oncofertility champions were discussed including:

- A group of champions should include an oncologist, a social worker or nurse, a patient, and a fertility specialist.
- Champions will need the support of administrative and managerial staff to formally acknowledge and advocate for the role of champion.
- Champions will have to be equipped with standardized tools and knowledge about fertility preservation to support the oncofertility agenda in cancer centres.

Canadian Oncofertility Charter was created to assist champions and anyone else interested in improving access to oncofertility services for AYAs (see Table 1).

- A framework to develop a customizable oncofertility toolkit was established to target barriers to fertility preservation referrals before the start of cancer treatment in AYA patients. Each barrier is addressed with a selection of existing tools identified by a national working group. Further funding for the creation and implementation of new standardized tools is needed to address current gaps in the Canadian oncofertility landscape and to disseminate the tools across Canada.
- The oncofertility working group conducted a survey of all private fertility centres in Canada to report on costs and services provided, subsidies available, and other sources of financial assistance for patients. (see costing data above)

Table 1. Canadian Oncofertility Charter: a 10-point plan for AYAs, January 2018

1. Cancer clinicians should discuss the possible effects of cancer treatment on a patient's fertility, including that of children, before the start of any treatment, irrespective of the patient's prognosis.
2. Identification of appropriate patients can be facilitated by the appointment of oncofertility "champions" in cancer centres.
3. Cancer clinicians should give patients an opportunity to discuss their future fertility by offering a referral to a fertility specialist (reproductive endocrinologist, andrologist, or gynecologist) who can discuss fertility preservation strategies as well as fertility and reproductive health follow-up after cancer treatment.
4. Educational toolkits should be developed and available for clinicians and patients to facilitate these interactions.
5. Cancer centres should have a clear and timely referral pathway between the centres and fertility preservation services to ensure that a fertility preservation consultation and a suitable procedure can be organized in a timely manner when it is deemed appropriate to do so, before the start of cancer treatment.
6. A national oncofertility database should be established to enable the development and implementation of standardized referral pathways and identification of suitable facilities for the provision of oncofertility services and to provide a resource for education, research and advocacy.
7. Oncofertility care should be incorporated into the training curriculum for cancer and fertility health professionals of all disciplines at both undergraduate and postgraduate levels to ensure that oncofertility care becomes standard practice in Canada.
8. A national initiative should aim to secure equity of access to public and philanthropic funding support of fertility preservation procedures for cancer patients of reproductive age.
9. Fertility preservation strategies and storage of gonadal tissue (including sperm and oocytes) and embryos should be affordable and equitable for all cancer patients of relevant age, independent of ethnicity, sexual orientation, place of residence or socioeconomic factors.
10. Fertility-related psychosocial support should be available to all appropriate patients during and after cancer therapy, regardless of whether they choose to pursue fertility preservation strategies. Information should also be provided about contraception and safe sexual practices during treatment.

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