Fertility preservation for cancer patients:

Quality of life in survivorship

Policy Paper

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Introduction

Fertility preservation is an important consideration for adult, childhood and adolescent cancer patients. In Ireland, survivorship rates of people diagnosed with cancer aged 15-44 are generally high.[1] The UK's National Institute for Health and Care Excellence (NICE) suggests that approximately 15% of people undergoing cancer treatment will have fertility problems.[2] Fertility preservation can provide cancer patients at risk of infertility due to treatment with an opportunity to start a family. The ability to have a child is an important aspect of good quality of life in cancer survivorship for many.

In preparing this policy paper, we consulted the academic and grey literature, spoke with a small number of healthcare professionals (oncologists and fertility specialists) and representatives of child and adolescent cancer groups for background information. Onco-fertility[3] is still a relatively new and emerging practice.[4] The purpose of this policy paper is to bring attention to policies and practices in fertility preservation for cancer patients, and discuss it as a key component for quality of life in survivorship. The policy paper provides an overview of the current situation in Ireland, and makes a list of recommendations.

What is fertility preservation?

Fertility preservation is the process in which a person at risk of losing their fertility can freeze their eggs, sperm or embryos through a process known as cryopreservation. It is also possible to freeze ovarian tissue and testicular tissue, though the latter is considered experimental.[5] Fertility preservation generally occurs before cancer treatment takes place; however, it can also happen after treatment where fertility has not been lost but there is a risk that a person's fertility will decline. The term "onco-fertility preservation" refers to fertility preservation/treatment, and its study, specifically for cancer patients.

How can cancer treatment affect fertility?

Some cancer treatments can have a negative impact on a person's fertility. Some chemotherapy treatments, as well as radiation treatment conducted near reproductive organs, can raise the risk of a person losing their fertility.

Quality of life

Fertility preservation is recognised as a key component of quality of life in survivorship.[6] Fertility problems following cancer treatment are recognised as having a negative impact on quality of life beyond cancer.[7] However, in Ireland fertility services have been cited as an infrequently delivered service.[8] For cancer survivors, there is a link between their 'unfulfilled desire [for a child] and interrupted fertility' and 'poorer mental health outcomes in survivorship.'[9] Loss of fertility can have

[1] Survivorship after 10 years is 78.8% for females (aged 15-44) and 75.5% for males – NCRI, no date
[2] NICE. 2014.
[3] Study of and treatment of fertility specifically relating to cancer patients.
[4] Woodruff, 2015.
[5] Practice Committee of the American Society for Reproductive Medicine. 2019.
[6] Angarita et al., 2016; O'Connor et al., 2019; Anazodo et al., 2019a; Feichtinger &Rodriguez-Wallberg, 2016.
[7] Hegarty et al., 2018; Anazodo et al., 2019a; Rodriguez-Wallberg & Oktay, 2010
[8] Hegarty et al., 2018
[9] Logan & Anazodo, 2019.

adverse impacts on a person's confidence.[10] As such, the decision to undergo fertility preservation treatment is a psychological question as well as medical one.[11]

Fertility preservation policy and guidelines

Ireland: legislation and policy for fertility preservation

In Ireland, there is currently no comprehensive legislation governing assisted human reproduction.[12] The General Scheme of the Assisted Human Reproduction (AHR) Bill 2017 is a draft of proposed legislation to regulate assisted human reproduction.[13] This draft legislation deals more with fertility treatment than preservation. However, related to preservation, the Bill outlines that the storage of gametes cannot exceed 10 years and storage of embryos cannot exceed 5 years, without permission from the Regulatory Authority. The underpinning evidence to this decision is currently unclear; however, the 10 year limit mirrors the statutory storage time outlined in the UK's Human Fertilisation and Embryology Authority (HFEA) Code of Practice.[14] A 2019 Oireachtas Joint Committee on Health report acknowledges that survivors of childhood cancer may not be ready to start a family 10 years after fertility preservation has taken place and will likely need different consideration.[15] In December 2019, the Minister for Health announced a Model of Care for Infertility to cover primary, secondary and tertiary levels, although it is unclear if this will include provision for fertility preservation for cancer patients.[16]

The 2020 Programme for Government outlines commitments to passing the AHR Bill and implementing a publicly funded fertility treatment.[17]

International standards, guidance and recommendations

In Ireland there are currently no national guidelines specific to fertility preservation in the general population or to cancer patients. However, the Irish Medical Council has developed some ethical and professional standards which include provisions for assisted human reproduction, which do not include fertility preservation.[18] In a 2019 report released by the National Cancer Control Programme (NCCP), some cancer survivors called for standardised approaches towards providing information on fertility.[19]

Internationally, a number of guidelines have emerged outlining approaches to counselling cancer patients on fertility preservation and referral to these services. The table overleaf provides an overview of some of these guidelines from the UK, European level and USA.

[10] O'Connor et al., 2019.
[11] Logan & Anazodo, 2019.
[12] Joint Committee on Health, 2019.
[13] Department of Health & Healthy Ireland, 2017.
[14] Human Fertilisation & Embryology Authority, 2018.
[15] Joint Committee on Health, 2019.
[16] Department of Health. 2019.
[17] Fianna Fáil, Fine Gael, Green Party. 2020.
[18] Medical Council, 2019.
[19] Mullen & Hanan, 2018.

Irish Medical Council[20] ***Ireland***	• AHR should be conducted by qualified professionals. • Wording suggests that accredited clinics self-regulate, e.g. work in line with international best practice (no supporting detail), do regular clinic audits, etc.
Human Fertility and Embryology Authority (HFEA)[21] ***UK***	• The Human Fertility and Embryology Authority (HFEA) released Guidance Note 17 on the "Storage of gametes and embryos." The HFEA guidance is accompanied by an overview of the prevailing legislation in the UK, and outlines safety provisions for the storage of gametes and embryos.
National Institute for Health and Care Excellence (NICE) ***UK***	• NICE recommends that:[22] ○ no lower age limit on fertility preservation should apply. ○ information on cancer, treatment and its impact on fertility, and cryopreservation is provided at diagnosis. ○ practitioners take a range of factors into account, including the diagnosis, treatment plan, anticipated outcome, prognosis. ○ female adults and adolescents are offered oocyte and embryo cryopreservation if there is sufficient time before treatment, they are well enough, and their condition is unlikely to deteriorate because of treatment. ○ male adults and adolescents at risk of infertility are offered cryopreservation of their sperm and continue to freeze sperm for longer than 10 years if a high risk of infertility remains. ○ cancer patients are informed that the regular requirements for fertility treatment do not apply for cryopreservation; but the criteria will apply when using the stored samples in the public NHS setting.[23]
European Society for Medical Oncology (ESMO) [24] ***Europe***	• For males: ○ ESMO clinical practice guidelines suggest that males undergoing cancer treatment which could impact on their fertility should have sperm banking planned before treatment with a recommendation to preserve between 1 and 3 samples. ○ age is not a criterion on which to base fertility preservation; rather it is based on desire for future family. • For females: ○ ESMO also recommends that young women who would like to have children should receive information/counselling on fertility preservation options soon after diagnosis and before treatment commences to facilitate fertility preservation. ○ oocyte or embryo cryopreservation is the main method.

[20] Medical Council, 2019.
[21] Human Fertilisation & Embryology Authority, 2018.
[22] National Institute for Health and Care Excellence. No date.
[23] National Collaborating Centre for Women's and Children's Health, 2020
[24] Peccatori et al., 2013

European Society of Human Reproduction and Embryology (ESHRE) ***Europe***	• Ovarian Stimulation for IVF/ICSI.[25] ○ for cancer patients, ovarian stimulation is an important option. For people with an oestrogen sensitive disease, e.g. breast cancer, anti-oestrogen therapy should be considered for ovarian stimulation. GnRH antagonist protocol recommended for women seeking fertility preservation for medical reasons. • Recommendations for female fertility preservation, including people living with cancer, are due in 2020.

American Society of Clinical Oncology[26] ***USA***	• Healthcare professionals should address the risk of infertility at the earliest possible stage, and refer patients who are interested to fertility preservation services.
	• For adult males:
	  ○ sperm cryopreservation is recommended for those who want to preserve fertility; advice should be given on the risks of damage in sperm when collected after treatment commences.
	• For adult females:
	  ○ embryo cryopreservation, and cryopreservation of oocytes are options. Ovarian tissue cryopreservation does not require ovarian stimulation.
	  ○ ovarian transposition and conservative gynaecologic surgery can be used to preserve fertility, where appropriate.
	• Pre-pubertal children:
	  ○ ovarian or testicular cryopreservation.
	• Post-pubertal children:
	  ○ established methods of fertility preservation.

Practices in fertility preservation

Fertility preservation counselling and provision of information

Effectively communicating information on fertility preservation

The psychological impact of a cancer diagnosis and associated decisions can induce stress in patients. Nonetheless, it is generally recommended, based on various guidelines and from experts, that fertility/infertility should be discussed following a cancer diagnosis[27] with access to appropriate counselling. Access to information as early as possible can be important towards achieving good outcomes.[28] Counselling can be a collaborative process between oncology and fertility teams, and be part of a general model of care.

Counselling by their oncologist and/or fertility specialist has been found to decrease regret amongst women following a cancer diagnosis.[29] Information on fertility preservation for CAYA cancer patients should be presented openly, honestly, based on the profile of the patient and be age appropriate.[30]

[25] ESHRE Reproductive Endocrinology Guideline Group, 2019.
[26] Oktay et al., 2018.
[27] Lambertini et al. 2016.
[28] Adams et al., 2013.
[29] Chan et al., 2017; Deshpande et al., 2015.
[30] Anazodo et al., 2019b.

Factors influencing fertility discussion

Access to fertility preservation services can depend on several factors, including the age, type of cancer, prognosis, and general health of the individual.[31] Healthcare professionals may not counsel or make a referral to fertility preservation services due to:

- Time pressures regarding the need for urgent treatment following a cancer diagnosis;[32]
- Poor prognosis and the type of cancer;[33]
- Lack of information on fertility preservation options, and lack of skills or training to discuss fertility preservation;[34]
- Lack of comfort providing information outside of specialty/expertise; [35]
- Cost.[36]

While fertility preservation may be perceived as an issue affecting women, oncologists tend to report knowledge of sperm preservation over other fertility preserving procedures[37] (e.g. egg freezing). However, it is not entirely clear if being male or female has an impact on whether or not a person receives fertility counselling, and why. One systematic review found male patients were more likely than females to be provided with information on fertility and fertility preservation options, and to be more satisfied with discussions on fertility in some cases. [38] The same review highlighted a study in which women who have children were less likely than women without children to hear information about fertility preservation.[39] A recent evaluation using data from the US demonstrated that women were more likely to be counselled on fertility than men.[40] **Understanding factors as to why and how fertility counselling takes place prior to cancer treatment in the Irish context is vital towards ensuring standardised practice.**

Children, adolescents and young adults

CAYA cancer patients and survivors can experience a loss of fertility due to cancer treatment. For adult survivors of childhood cancer, loss of fertility is a common outcome.[41]

In spite of these outcomes, CAYA and their parents/guardians generally report a lack of information on risks to fertility.[42] CAYA-specific factors which determine whether or not healthcare professionals discuss fertility preservation for CAYA include:

- availability of educational materials to underpin the discussion;
- discomfort in discussing the topic with CAYA and their parents for fear it might be inappropriate;[43]

[31] Vindrola-Padros, C., et al
[32] Angarita et al., 2016; Collins et al., 2011; Pandey et al., 2020.
[33] Collins et al. 2011; Adams et al. 2013.
[34] Pandey et al., 2020; Anazodo et al., 2019b.
[35] Anazodo et al., 2019b; Patel et al., 2020.
[36] Pandey et al., 2020
[37] Adams et al., 2013; Hartigan et al., 2020
[38] Anazodo et al., 2019a.
[39] Ibid
[40] Patel et al., 2020.
[41] Hudson, M. M., 2016.
[42] Keegan et al., 2012.; Barrett et al., 2018.
[43] Vindrola-Padros, C., et al., 2017.

- ethical dilemmas surrounding the need to include parents in the conversation for young adults were also factors.[44]

While, information is one aspect, access to fertility preservation services is another. Referral pathways can be limited given that many fertility services are designed for adults, adding further difficulty for CAYA.[45]

Adult survivors of childhood cancer who did not have the opportunity to preserve their fertility prior to treatment, may not have lost fertility. However, some women may later experience fertility problems as a result of childhood treatment before they are ready to start a family, as egg reserves decline. As such, fertility preservation is still an option in adulthood (post-cancer treatment) for some survivors of childhood cancer.

As a child's cancer diagnosis is a devastating one, fertility preservation may not be an immediate concern for parents/guardians; however, planning for survivorship should be an integral part of a person's care and treatment plan. Healthcare professionals likely need some guidance in facilitating discussions around fertility, and simple information should be provided to parents/guardians and CAYA in a format to suit their age. As such, once the information is provided and understood, parents/guardians and CAYA can make informed decisions, balancing the benefits and the risks.

CAYA and their parents/guardians should have access to information and fertility preservation services.

Current Practice – Fertility preservation for children:
Oxford Children and Young Adult Fertility Preservation Service

In the UK, the Oxford Children and Young Adult Fertility Preservation Service was established in 2013 to support children and adolescents at risk of fertility loss. The service is run through the Oxford University Hospitals NHS Foundation Trust and the University of Oxford, and is licenced by the Human Tissue Authority and Human Fertilisation and Embryology Authority.

The service provides advice, and has developed resources for children and their families. These resources explain that cancer treatment can affect fertility, and detail the process of fertility preservation.[46] The service provides ovarian tissue and immature testicular tissue cryopreservation (freezing).

The service has been extended to accommodate children from Ireland who have needed to access the service.[47]

Decision aids

Following a cancer diagnosis, people must make many decisions on their treatment, and come to terms with the psychological effects of a cancer diagnosis. Some patients also report a lack of information or decisional conflict on fertility preservation following a cancer diagnosis.[48] The decision

[44] Vindrola-Padros, C., et al., 2017.
[45] Anazodo et al., 2019b.
[46] Lakhoo et al., 2019; Future Fertility Trust: http://www.futurefertilitytrustuk.org/get-help/information-leaflets/;
[47] Lakhoo et al., 2019; Kelleher, 2019.
[48] Barrett et al., 2018; Peate et al., 2012.

to seek fertility preservation services can be a difficult one for those who have future fertility plans, particularly for women and CAYA (and parents of young cancer patients) who may have to undergo ovarian stimulation therapies to harvest and preserve mature eggs.

Evidence-based decision aids are methods which are designed to support cancer patients and/or parents/guardians to decide on options for fertility preservation.[49] Decision aids come in a variety of formats including online and hard-copy booklets, as computerised educational tools, or decision trees.[50] Decision aids tend to provide information to support decision-making in line with a patient's, or their parent's/guardian's, values and preferences.[51] Decision aids can enhance a patients' knowledge of fertility to help them in their decision-making, reducing regret.[52] However, not all decision aids are of similar quality,[53] therefore due consideration should be given to ensure the tool is appropriate to each patient and the setting.

Practice in Ireland

There is no official guidance outlining the need to discuss fertility preservation with people upon diagnosis of cancer as part of a cancer patient's care and treatment pathway. This is not to say that conversations on fertility do not happen; rather, it is not clear that information or fertility counselling is provided to everyone.

Adults

Fertility preservation for the general population is not available through the Irish public health service; however, there is a free service for cancer patients through Rotunda IVF, The National Fertility Centre in Dublin, funded by the HSE.[54] Following a referral, a person can be seen at the fertility clinic within 24-48 hours of their cancer diagnosis to ensure that there are no unnecessary delays to cancer treatment. Following a consultation/counselling, a person can choose to freeze their sperm, eggs or embryos. These samples will be stored, free of charge, for 10 years. Generally, the National Fertility Centre treats 2-4 males and 2-3 females per week for onco-fertility preservation. The Waterstone Clinic in Cork provides fertility sparing services to male cancer patients free of charge, while storage comes with a fee. It is not clear if other fertility centres provide fertility preservation services to adult cancer patients free of charge.

Children and adolescents

Access to information and to services is more limited for parents/guardians and their children. There is a lack of standardisation in knowledge and awareness in planning for future fertility for children and adolescent cancer patients, as well as a lack of a clear pathway for fertility preservation. In a survey of healthcare professionals working in paediatric and adolescent oncology in Ireland, many showed an awareness of ovarian tissue cryopreservation, sperm freezing and of oocyte vitrification.[55] However, fewer healthcare professionals stated they had knowledge of ovarian tissue cryopreservation and of oocyte vitrification compared to those who were knowledgeable or very knowledgeable about sperm

[49] Anazodo et al., 2019b.
[50] Wang et al., 2018.
[51] Peate et al., 2012.
[52] Ibid
[53] Speller et al., 2019
[54] The National Fertility Centre – Rotunda IVF: https://www.rotundaivf.ie/
[55] Hartigan et al., 2020

freezing.[56] Of the surveyed healthcare professionals, 43% often discuss the impact of cancer treatment on fertility, while a third of respondents never discuss this topic.[57] Important to note is that adult female survivors of a childhood cancer want to know more about fertility.[58]

In 2018, Merrion Fertility Clinic at the National Maternity Hospital, in conjunction with Children's Health Ireland at Crumlin, Dublin introduced sperm and oocyte freezing services prior to cancer treatment for post-pubertal adolescents. Freezing and subsequent storage of sperm and oocytes (to the age of 21) was funded by Merrion Fertility Clinic. In some instances, Irish residents have been able to avail of ovarian tissue cryopreservation in the UK.

Following cancer treatment, if fertility has not been lost, some young female adult survivors of childhood cancer may wish to preserve their fertility in case there is a decline in fertility at a later date. Young male adult survivors who have not lost fertility post-cancer treatment do not tend to encounter the same issue. Post-cancer treatment fertility preservation is not free of charge to cancer survivors, and generally this is catered for by private providers if appropriate.

Conclusions and recommendations

The World Health Organization (WHO) recognises infertility as a global public health issue.[59] Over a 20-year period (1994-2014) the proportion of people surviving cancer after 10 years has been growing steadily.[60] Cancer treatment can risk future fertility, for many the ability to start a family can impact quality of life. But it is possible to mitigate against the risks to fertility.

In Ireland, there is no formal protocol or guidance for a healthcare professional to speak to cancer patients or their parents/guardians about fertility. Although, these conversations take place in some cases, it is not clear that this process is uniform. This is particularly important where a patient has no awareness of risks to fertility to initiate such a conversation.

The study of fertility treatment is still evolving, and while patterns emerge around the delivery of fertility preservation for cancer patients, there is more to learn. For instance, it is essential to develop an understanding of who is impacted by loss of fertility after cancer treatment, the possibilities to undergo fertility preservation after cancer treatment, and how to discuss and support CAYA and their loved ones in making decisions appropriate to their needs. As AHR legislation has not yet been finalised, there is an opportunity to take stock of the current practices in fertility preservation, pathways to treatment, access to post-treatment preservation, and the specific ways in which children, young people and adults experience the process.

Current understanding and lessons from onco-fertility preservation can lead us to some simple action-oriented solutions, such as helping doctors to grow the skills and knowledge around fertility preservation to discuss with their patients as well as to refer them to essential services. In Ireland, there is an opportunity to ensure that any future practice in onco-fertility preservation is patient-centred. This could ensure that the cancer treatment pathway takes medical and psychological approaches towards planning for quality of life in survivorship, including future fertility.

[56] Ibid
[57] Ibid
[58] Ibid
[59] WHO, no date.
[60] NCRI, no date.

The Irish Cancer Society proposes a set of initial recommendations to address existing gaps in information and services.

Irish Cancer Society

The Irish Cancer Society acknowledges its role in advocating for quality of life in survivorship and contributing to realistic and workable solutions for fertility preservation. As part of this, the Irish Cancer Society will:

- Facilitate conversations with a range of stakeholders (particularly cancer survivors) to learn more about the needs of cancer patients and fertility preservation.

Government and Department of Health

- The AHR Bill should take the specific needs of cancer patients and survivors into account, with particular attention to the time limits of storage of gametes and embryos as recommended in the Joint Committee on Health's report on Pre-Legislative Scrutiny for the AHR Bill.[61]
    - The Government and Department of Health should consult the Irish Cancer Society and other representative bodies to make the AHR Bill more suited to the needs of cancer patients in preserving fertility and accessing fertility treatments.
- Extend publicly funded fertility preservation services to children and adolescent cancer patients, as well as access to fertility preservation post-treatment for those who require it.
- Integrate fertility preservation into the Model of Care for Infertility.

National Cancer Control Programme

- The NCCP should lead the process to develop, or endorse, existing, evidence-based guidelines for healthcare professionals. The guidelines should outline the procedure for counselling on, referral to and the provision of fertility preservation services, with specific reference to cancer patients. The guidelines should make reference to both adult, and childhood and adolescent cancer patients.
    - The NCCP should invite input from patients/patient groups, oncology teams, fertility providers and civil society in pursuit of developing these guidelines.
- Guidelines for oncology staff: At a minimum, these guidelines should include a requirement for an oncologist to discuss fertility preservation with cancer patients, or the parents/guardians of paediatric or adolescent cancer patients.
- Guidelines for fertility specialists: The guidelines should recognise the role that fertility specialists have in the integrated care plans of some cancer patients, including children. The guidelines should indicate the model of care under which cancer patients (adults and children) should be treated.
- Further research should be undertaken to enhance understanding of fertility preservation in Ireland and guide policy and practice.
    - Research should focus on gathering data on the number of people receiving information on fertility preservation (pre- or post-treatment), the number of people referred for fertility preservation procedures, the number of people who subsequently use their frozen gametes or embryos, etc.

[61] Joint Committee on Health, 2019.

- Research should also explore the general awareness of healthcare professionals of fertility preservation services as well as their training needs to provide information and make referrals to these services.
- Finally, it is important to understand the underpinning infrastructural elements of fertility preservation such as a needs assessment for the future of the fertility preservation services, including capacity, resourcing as well as the appropriateness and/or feasibility of offering the service at a regional level.

National Cancer Control Programme/Health Service Executive

- Develop clearer information and resources for decision-making rooted in principles of patient consent/assent, as well as referral pathways for CAYA to fertility preservation.
- Ensure that there is adequate and accessible information on fertility preservation for cancer patients, including:
  - discussion guides for healthcare professionals to discuss potential risks to fertility cancer patients, from a young age to childbearing age;
  - booklets in plain English to support and facilitate conversations between healthcare professionals and cancer patients on fertility and cancer. The information should include the potential risks of cancer treatment on fertility, the potential risks to health outcomes if cancer treatment is delayed, as well as information about fertility treatment (e.g. general cost, success rate of treatment, etc.).

Health Service Executive

- Although assisted human reproduction is not yet offered in the public health system in Ireland, the HSE should dedicate an information page on its website on the impact of cancer treatment on fertility, and fertility preservation. This communication should provide neutral, and fact-based information.

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