



Recommendations regarding ongoing communication of treatment-related infertility risk and fertility preservation in patients with CAYA cancer 2020

General	<p>Healthcare providers should:</p> <ul style="list-style-type: none">• Be familiar with the latest evidence-based recommendations, institutional policies and professional educational resources on infertility risk and fertility preservation procedures• Maintain currency with training where appropriate (strong recommendation; very low- to moderate-quality evidence)
Provision of information about treatment-related infertility risk and fertility preservation	<p>Healthcare providers should:</p> <ul style="list-style-type: none">• Deliver clear, comprehensive and age-appropriate information in a professional, neutral and empathetic manner;• Provide up-to-date written and/or online educational resources to patients and their parents/caregivers/partner in appropriate languages and health literacy levels. (strong recommendation; very low- to moderate-quality evidence)
Communicating treatment-related infertility risk and fertility preservation	<p>Healthcare providers¹ should:</p> <ul style="list-style-type: none">• Involve patients and/or their parents/caregivers/partners• Offer a private conversation with the patient depending on age• Offer a separate conversation with parents/caregivers/partners after consent or assent of the patient• Consider the patient's age, developmental status and the family's cultural/religious beliefs• Provide emotional support to patients and their parents/caregivers/partners during counselling about treatment-related infertility risk and fertility preservation and prompt psychosocial specialist referrals (e.g. social workers and psychologists) as appropriate• Initiate counselling as early as possible after a cancer diagnosis and treatment plan are established and when a change in disease status occurs that requires treatment intensification with gonadal toxic agents/modalities• Offer counselling on an ongoing basis during treatment and throughout survivorship because the infertility risk or patient's ideas may change (strong recommendation; very low- to moderate-quality evidence) <p>Hospitals should:</p> <ul style="list-style-type: none">• Establish referral pathways for accessing fertility specialists or fertility specialist centres where appropriate (strong recommendation; very low- to moderate-quality evidence)

¹ A system should be in place to identify who is responsible for having the discussion, taking into account the provider's knowledge, patient's disease state and local access to fertility specialists.

Recommendations regarding ethical issues about treatment-related infertility risk and fertility preservation in patients with CAYA cancer patients

What are the ethical issues related to fertility preservation?

Healthcare providers should:

- Foster the autonomy of the patient
- Assess the patient's emotional, psychological and intellectual status as part of the informed consent process
- Ensure that decisions about fertility preservation are driven by patient's best interest and not by own interest and/or interest of parents/caregivers/partners
- Encourage patients to consider the risks, and the medical, social and ethical contingencies of fertility preservation procedures as well as future use of frozen tissue
- Address the uncertainty of future technologies during counselling about infertility risk and fertility preservation procedures
- Include societal and ethical values connected to social parenthood (adoption) and the potential discrimination when applying for adoption in the discussions with the patient and parents/caregivers/partners about adoption
- Include a two-stage consent process with patients and/or their families/caregivers/partners: 1) at diagnosis when the decision about harvesting and storing tissue is made and 2) after therapy at a developmentally appropriate age when the decision of whether and how to use the stored material is made
- Be aware of the importance to determine upfront with patients and their families/caregivers/partners the access of researchers to their stored gametes
- Be aware of the importance to determine upfront with patients and their families/caregivers/partners the disposition of gametes and/or preserved tissue in the event of patient's death
- Be aware of possible conflicts of interest between the needs of patients/parents/caregivers and the potential short- and long-term financial costs involved in fertility preservation procedures and storage, as well as post-treatment costs associated with pursuing family-building

(Good practice statements)

Publication

Mulder RL, Font-Gonzalez A, van Dulmen-den Broeder E, Quinn GP, Ginsberg JP, Loeffen EAH, Hudson MM, Burns KC, van Santen HM, Berger C, Diesch T, Dirksen U, Giwercman A, Gracia C, Hunter SE, Kelvin JF, Klosky JL, Laven JSE, Lockart BA, Neggers SJMM, Peate M, Phillips B, Reed DR, Tinner EME, Byrne J, Veening M, van de Berg M, Verhaak CM, Anazodo A, Rodriguez-Wallberg K, van den Heuvel-Eibrink MM, Asogwa OA, Brownsdon A, Wallace WH, Green DM, Skinner R, Haupt R, Kenney LB, Levine J, van de Wetering MD, Tissing WJE, Paul NW, Kremer LCM, Inthorn J; PanCareLIFE Consortium. Communication and ethical considerations for fertility preservation for patients with childhood, adolescent, and young adult cancer: recommendations from the PanCareLIFE Consortium and the International Late Effects of Childhood Cancer Guideline Harmonization Group. *Lancet Oncol.* 2021;22(2):e68-e80.