

**Conclusions of evidence for fertility preservation in CAYA cancer patients diagnosed before 25 years.**

<b>What are facilitators of and barriers to the communication of treatment-related infertility risk and fertility preservation options?</b>	
<b>Involvement of health-care providers, patients with CAYA cancer, and their families</b>	<b>Quality of evidence</b>
Some parents of male patients diagnosed at younger than 18 years want to control whether physicians discuss sperm banking with their child	⊕⊕⊕⊕ VERY LOW <sup>24</sup>
No studies investigated the involvement of female patients and parents in the communication of fertility preservation	No studies
Some male patients who were diagnosed with cancer at younger than 18 years considered medical support by doctors to be important and few male patients who were diagnosed with cancer at younger than 18 years considered nursing support to be important	⊕⊕⊕⊕ VERY LOW <sup>25</sup>
Most doctors indicated taking a leading role, whereas most nursing staff indicated taking a helping role in providing information about fertility preservation to patients and parents	⊕⊕⊕⊕ VERY LOW <sup>26</sup>
Most doctors and few nursing staff felt confident in providing up-to-date information about fertility preservation to patients and parents	⊕⊕⊕⊕ VERY LOW <sup>26</sup>
<b>Involvement of patients with CAYA cancer in the decision making</b>	<b>Quality of evidence</b>
Most adolescents and young male adults (mean age 17.2 years [3.0]) reported the decision to be a personal one and many reported being influenced by parents in the decision to sperm bank	⊕⊕⊕⊕ VERY LOW <sup>27</sup>
Decisions about fertility preservation are essentially made jointly between male patients with cancer and their parents	⊕⊕⊕⊕ LOW <sup>25,27</sup>
Most parents considered their adolescent child (ie, aged 12–18 years) to be capable of participating in the decision-making process, whereas few parents considered their children aged 7–12 years to be capable of participating in the discussion about fertility preservation	⊕⊕⊕⊕ LOW <sup>25</sup>
No studies investigated views of female patients on decision making about procedures for fertility preservation	No studies
<b>Satisfaction with the use of decision tools, educational materials, and strategies in the communication of treatment-related infertility risk and fertility preservation</b>	<b>Quality of evidence</b>
Health-care providers reported that existing educational materials about fertility preservation are sometimes scarce and the existing materials need to be improved and adapted to the patient population	⊕⊕⊕⊕ MODERATE <sup>28-34</sup>
Most parents of childhood patients (ie, aged 0–18 years) with cancer were satisfied with the design and content of a newly developed decision aid for fertility preservation	⊕⊕⊕⊕ VERY LOW <sup>37</sup>
Most health-care providers were satisfied with newly developed decision tools, educational materials, and strategies available for the patient and health-care provider	⊕⊕⊕⊕ VERY LOW <sup>26,37,39</sup>
<b>Effectiveness of decision tools, educational materials, and strategies in the communication of treatment-related infertility risk and fertility preservation</b>	<b>Quality of evidence</b>
<i>Effect of interventions for patients and families on parent and patient outcomes</i>	
Education materials (ie, information flyer) or decision aid for patients with CAYA cancer and families increased knowledge in both patients and parents	⊕⊕⊕⊕ VERY LOW <sup>36,37</sup>

Education materials (ie, information flyer) for patients with CAYA cancer and families increased patient and parents' empowerment	⊕⊕⊕⊕ VERY LOW <sup>36</sup>
A web-based decision aid for fertility preservation was not significantly associated with decision regret in parents of patients with childhood cancer (ie, aged 0–18 years)	⊕⊕⊕⊕ VERY LOW <sup>37</sup>
<i>Effect of interventions for patients and families on oncofertility clinical practice</i>	
Education materials (ie, information flyer) for patients with CAYA cancer and families was not significantly associated with use of cryopreservation	⊕⊕⊕⊕ VERY LOW <sup>35</sup>
Education materials (ie, information flyer) for patients with CAYA cancer and families improved consultation practice for fertility preservation	⊕⊕⊕⊕ VERY LOW <sup>36</sup>
<i>Effect of interventions for health-care providers, patients, and parents on health-care outcomes</i>	
A toolkit for fertility preservation for health-care providers, including educational materials, checklist, referral forms, and handouts for patients, increased paediatric oncology clinician's confidence levels	⊕⊕⊕⊕ VERY LOW <sup>26</sup>
<i>Effect of interventions for health-care providers, patients, and parents on oncofertility clinical practice</i>	
A toolkit for fertility preservation for health-care providers, including educational materials, checklist, referral forms, and handouts for patients, increased the likelihood of paediatric oncology clinicians providing verbal and written information about fertility preservation; no significant effect of the toolkit for fertility preservation on the likelihood of clinicians being involved in discussions about fertility preservation	⊕⊕⊕⊕ VERY LOW <sup>26</sup>
A bundled intervention, including educational material for clinicians and patients and a referral pathway, increased documented risk of fertility discussion, documented referral to fertility specialist, and documented outcomes for fertility preservation of patients with adolescent and young adult cancer (ie, aged 14–25 years)	⊕⊕⊕⊕ VERY LOW <sup>38</sup>
The implementation of an opt-out mechanism (where default results in an automatic consult order) increased the likelihood of completing consultation for fertility preservation among patients with CAYA cancer; no significant association between the intervention and attempts for fertility preservation after consultation in patients with CAYA cancer	⊕⊕⊕⊕ VERY LOW <sup>40</sup>
A clinical support system for decision making, including electronic clinical oncofertility pathways and handouts for patients, provided perceived benefit to oncofertility clinical practice as reported by clinicians involved in paediatric oncofertility care	⊕⊕⊕⊕ VERY LOW <sup>39</sup>
<b>Barriers to pursuing fertility preservation as reported by patients with CAYA cancer and their families</b>	<b>Quality of evidence</b>
<p>Patient-related barriers:</p> <ul style="list-style-type: none"> <li>• Patient with poor emotional or physical status, or both<sup>25,41-47</sup></li> <li>• Absence of interest<sup>44,45,48</sup></li> <li>• Scarcity of experience with, taboo related to, and embarrassing feelings with masturbation<sup>25,53</sup></li> <li>• Absence of patient self-efficacy for banking<sup>54,55*</sup></li> <li>• Young age at diagnosis<sup>40,56</sup></li> </ul> <p>Procedure-related barriers:</p> <ul style="list-style-type: none"> <li>• Experimental nature of the procedure for fertility preservation with the associated risks or complications<sup>25,42,45,46,48,50,51</sup></li> <li>• Time constrains regarding delaying treatment<sup>25,45-49</sup></li> <li>• Costs<sup>43,45,50</sup></li> </ul>	⊕⊕⊕⊕ MODERATE

<ul style="list-style-type: none"> <li>• Poor success rate of the fertility preservation procedure<sup>45,46</sup></li> </ul> <p>Parent-related barriers:</p> <ul style="list-style-type: none"> <li>• Parents have a highly stressed emotional status<sup>44,51,52</sup></li> <li>• Absence of parental or medical team recommendation, or both<sup>53,54</sup></li> <li>• Cultural or religious beliefs<sup>41,45</sup></li> </ul>	
<p>Patient-related barriers:</p> <ul style="list-style-type: none"> <li>• Insufficient information<sup>43</sup></li> </ul> <p>Parent-related barriers:</p> <ul style="list-style-type: none"> <li>• Sensitive nature of the fertility preservation conversation (parents reported barrier)<sup>24</sup></li> <li>• Absence of parental self-efficacy<sup>53</sup></li> </ul> <p>Barriers related to health-care providers and institutions:</p> <ul style="list-style-type: none"> <li>• Absence of specific consultation by fertility specialist<sup>57</sup></li> <li>• Difficulty in finding proper facilities<sup>45</sup></li> <li>• Adult treatment center vs. non-adult treatment center<sup>47</sup></li> </ul>	⊕⊕⊖⊖ LOW
<p><b>Barriers to communicating treatment-related infertility risk and fertility preservation with patients with CAYA cancer as reported by health-care providers</b></p>	<p><b>Quality of evidence</b></p>
<p>Patient-related barriers:</p> <ul style="list-style-type: none"> <li>• Patient's poor prognosis, poor health status and risks<sup>31,32,44,48,50,56,58,59,62,64,65,67</sup></li> <li>• Patient's young age<sup>31,56,58,67</sup></li> <li>• Patient's potential disinterest<sup>62,65</sup></li> <li>• Patient already having children<sup>59,62</sup></li> <li>• Positive HIV status<sup>31,32</sup></li> <li>• Patient's cultural or religious beliefs<sup>30,61</sup></li> <li>• Patient's emotional state and the perceived additional stress with fertility topic<sup>58,65</sup></li> </ul> <p>Parental-related barriers:</p> <ul style="list-style-type: none"> <li>• Parent has highly stressed emotional status<sup>33,58</sup></li> <li>• Real or perceived parental absence of interest or knowledge<sup>61,67</sup></li> <li>• Absence of parental consent<sup>44,48</sup></li> </ul> <p>Barriers related to health-care providers and institutions:</p> <ul style="list-style-type: none"> <li>• Scarcity of knowledge, training, and educational materials, or unfamiliarity with or low availability of relevant guidelines, or both<sup>30,31,33,34,59-61,64,65,67,68</sup></li> <li>• Scarcity of time and time pressure to start treatment<sup>32,44,48,52,58,59,61-64</sup></li> <li>• Little access or inadequate referral pathways with relevant facilities and specialists<sup>30,33,58,60,61,63,66,68</sup></li> <li>• Cost of procedure and storage<sup>30,31,33,44,50,56,59,65,66,68</sup></li> <li>• Experimental nature of the procedure for fertility preservation with the associated risks and complications<sup>50,56,59,64</sup></li> </ul>	⊕⊕⊕⊖ MODERATE
<p>Patient-related barriers:</p> <ul style="list-style-type: none"> <li>• No current partner<sup>59</sup></li> <li>• Difficulty of establishing sense of trust with patient<sup>30</sup></li> <li>• Patient has few language skills<sup>65</sup></li> <li>• Patient's sexual orientation<sup>31</sup></li> </ul> <p>Parental-related barriers:</p> <ul style="list-style-type: none"> <li>• Families' socioeconomic status<sup>30</sup></li> </ul> <p>Barriers related to health-care providers and institutions:</p> <ul style="list-style-type: none"> <li>• Difficulties completing consent forms<sup>61</sup></li> </ul>	⊕⊕⊖⊖ LOW

<ul style="list-style-type: none"> <li>• A problem with the cooperative system with the pediatrics department<sup>68</sup></li> <li>• Adoption system is popular, potentially discouraging discussion or promotion of fertility preservation<sup>68</sup></li> </ul>	
<b>What are ethical issues related to fertility preservation? (Ungraded)</b>	
<b>Ethical issues regarding informed consent</b>	
<ul style="list-style-type: none"> <li>• Informed consent to fertility preservation procedures in minors and young adults<sup>5,61,69,72,74-83,85-87,89,90,92-95,97,101,104,105,119-123</sup></li> <li>• Safeguarding and protecting patients' best interest when making decisions about fertility preservation<sup>74,75,79,81,84,86,87,89,90,92,93,96,98,100-102,104,105,107,119,120,124-127</sup></li> </ul>	
<b>Ethical issues regarding communication</b>	
<ul style="list-style-type: none"> <li>• Communication between health-care providers and patients and their parents, caregivers, and partners<sup>5,56,71,72,74,76-81,84,85,88-90,92,95,96,98,103-106,120,122,125-129</sup></li> </ul>	
<b>Ethical issues regarding potential risks of fertility preservation procedures</b>	
<ul style="list-style-type: none"> <li>• Harms versus benefits of procedures for fertility preservation<sup>5,51,69,71-76,78,79,82,83,87,88,90,92,93,95,97-100,102-107,119,120,122,123,125-128,130</sup></li> <li>• Experimental nature of procedures for fertility preservation<sup>69,74,75,79,86-89,101,103,105,131</sup></li> <li>• Psychological issues surrounding decisions about procedures of fertility preservation<sup>72,75,77,82,83,85-88,93,105,123,126,127</sup></li> </ul>	
<b>Ethical issues regarding storage of patient's material</b>	
<ul style="list-style-type: none"> <li>• Decisions on use and disposition of stored tissue for fertility preservation<sup>70,73,74,76,77,81-83,85,90,99,102,105,130</sup></li> <li>• Decisions on posthumous use of stored material for fertility preservation<sup>74-77,82,83,88,90,95,99,102,104-106,5,61,69,71,73,85,87,89,94,96-98,100,101,103,107</sup></li> </ul>	
<b>Ethical issues regarding access to fertility preservation procedures</b>	
<ul style="list-style-type: none"> <li>• Offering access to procedures for fertility preservation considering patient's cultural or religious background<sup>71,101,126,128</sup></li> <li>• Restoring patients' reproductive autonomy with procedures for fertility preservation<sup>69-77</sup></li> <li>• Differences in fertility preservation services across countries<sup>72,82,83,99,105-107,121,129</sup></li> </ul>	
<b>Ethical issues regarding financial costs in fertility preservation procedures</b>	
<ul style="list-style-type: none"> <li>• Expenses linked to procedures for fertility preservation, potential complications, storage of cryopreserved material, post-treatment assisted reproductive technology, adoption or surrogacy<sup>69-71,81-83,88,93,95,106,129</sup></li> </ul>	
<b>Ethical issues regarding post-treatment adoption in cancer survivors</b>	
<ul style="list-style-type: none"> <li>• Discrimination during post-treatment adoption<sup>126</sup></li> </ul>	

\*Potential overlap in patients