Fertility Preservation Current UK Paediatric Oncology Centre Practices for Patients under 18 years old with Cancer.

Page 1: Introductory Statement

You are being invited to participate in a research study titled Fertility Preservation Current UK Paediatric Oncology Centre Practices for Patients under 18 years old with Cancer. This study is being undertaken by a team from the University of Leeds in collaboration with the Children's Cancer and Leukaemia Group Late Effects Group. The team includes: Dr H.L.Newton, Prof. A.W Glaeser, Prof. H.M Picton and Prof. R Skinner

The purpose of this research study is to assess the current practices of fertility preservation in paediatric cancer patients in the UK and will take you approximately 5 minutes to complete. Your participation in this study is entirely voluntary and if you wish your responses to be withdrawn after completion please notify Dr Hannah Newton at H.L.Newton@leeds.ac.uk as soon as possible. It may not be possible to remove your responses after presentation of the results. You do not have to answer all the questions in the study.

We believe there are no known risks associated with this research study; however, as with any online related activity the risk of a breach is always possible. To the best of our ability your participation in this study will remain confidential, and only anonymised data will be published. We will minimise any risks by anonymising the data after collection and all data will be stored within the University's IT network.
Page 2: Current Referral Practices

1. In the past 12 months; has your centre referred under 18 year old patients with cancer for any of the following fertility preservation treatments?

- [ ] Sperm storage
- [ ] Testicular tissue storage
- [ ] Oocyte storage
- [ ] Ovarian tissue storage

2. How likely are you to refer an under 18 year old patient with cancer for fertility preservation in the following scenarios. (Assume each patient has a >70% risk gonadotoxicity risk from their proposed treatment). 1 - very unlikely to refer and 10 - very likely to refer

Please don't select more than 1 answer(s) per row.

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<td>Male, post-pubertal</td>
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<td>Male, pre-pubertal</td>
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<td>Female, post-pubertal</td>
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<td>Female, pre-pubertal</td>
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Page 3: Referral Centres

3. Which reproductive medicine unit(s) have clinicians in your centre referred under 18 year old POST-pubertal male oncology patients to in the past for fertility preservation? Select all that apply.

- Never referred before
- Aberdeen Fertility Centre
- Belfast Fertility Centre
- Birmingham Women's Fertility Centre
- Cambridge IVF at the Rosie
- Care Fertility
- Create Fertility
- Edinburgh Fertility and Reproductive Endocrine Centre
- Oxford Children and Young Adult Fertility Service (John Radcliffe)
- Glasgow Royal Fertility Clinic
- IVI
- Jessop Fertility (Sheffield)
- Leeds Fertility
- Leicester Fertility Centre
- London Women's Fertility
- Newcastle Fertility Centre
- Nurture Fertility
- Queens Medical Centre (Nottingham)
- Salisbury Fertility Centre
- Southampton Fertility Unit
- Southmead Fertility Clinic (Bristol)
- St Mary's Reproductive Medicine Unit (Manchester)
- Thames Valley Fertility
- The Hewitt Fertility Centre (Liverpool)
- UCLH Reproductive Medicine Unit (London)
- University Hospitals Coventry and Warwick Centre for Reproductive Medicine
- Wales Fertility Institute
- Other

3.a. If you selected Other, please specify:

[Blank field]

3.b. Which reproductive medicine unit(s) have clinicians in your centre referred under 18 year old PRE-pubertal male oncology patients to in the past for fertility preservation? Select all that apply.

- Never referred before
- Aberdeen Fertility Centre
- Belfast Fertility Centre
- Birmingham Women's Fertility Centre
- Cambridge IVF at the Rosie
3. If you selected Other, please specify:

☐

3.c. Which reproductive medicine unit(s) have clinicians in your centre referred under 18 year old POST-pubertal female oncology patients in the past for fertility preservation? Select all that apply.

☐ Never referred before
☐ Aberdeen Fertility Centre
☐ Belfast Fertility Centre
☐ Birmingham Women's Fertility Centre
☐ Cambridge IVF at the Rosie
☐ Care Fertility
☐ Create Fertility
☐ Edinburgh Fertility and Reproductive Endocrine Centre
☐ Oxford Children and Young Adult Fertility Service (John Radcliffe)
☐ Glasgow Royal Fertility Clinic
☐ IVF
☐ Jessop Fertility (Sheffield)
☐ Leeds Fertility
☐ Leicester Fertility Centre
3.c. If you selected Other, please specify:

3.d. Which reproductive medicine unit(s) have clinicians in your centre referred under 18 year old PRE-pubertal female oncology patients to in the past for fertility preservation? Select all that apply.

- London Women's Fertility
- Newcastle Fertility Centre
- Nurture Fertility
- Queens Medical Centre (Nottingham)
- Salisbury Fertility Centre
- Southampton Fertility Unit
- Southmead Fertility Clinic (Bristol)
- St Mary's Reproductive Medicine Unit (Manchester)
- Thames Valley Fertility
- The Hewitt Fertility Centre (Liverpool)
- UCLH Reproductive Medicine Unit (London)
- University Hospitals Coventry and Warwick Centre for Reproductive Medicine
- Wales Fertility Institute
- Other

Never referred before
- Aberdeen Fertility Centre
- Belfast Fertility Centre
- Birmingham Women's Fertility Centre
- Cambridge IVF at the Rosie
- Care Fertility
- Create Fertility
- Edinburgh Fertility and Reproductive Endocrine Centre
- Oxford Children and Young Adult Fertility Service (John Radcliffe)
- Glasgow Royal Fertility Clinic
- IVI
- Jessop Fertility (Sheffield)
- Leeds Fertility
- Leicester Fertility Centre
- London Women's Fertility
- Newcastle Fertility Centre
- Nurture Fertility
- Queens Medical Centre (Nottingham)
- Salisbury Fertility Centre
- Southampton Fertility Unit
- Southmead Fertility Clinic (Bristol)
- St Mary's Reproductive Medicine Unit (Manchester)
- Thames Valley Fertility
3. If you selected Other, please specify:

4. Approximately how many under 18 year old patients with cancer has your unit referred in the last 12 months for fertility preservation?

Please don't select more than 1 answer(s) per row.

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<thead>
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<th></th>
<th>0</th>
<th>1-5</th>
<th>6-10</th>
<th>11-15</th>
<th>16-20</th>
<th>21-25</th>
<th>26-50</th>
<th>51-75</th>
<th>76-100</th>
<th>&gt;100</th>
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<tbody>
<tr>
<td>Pre-pubertal males</td>
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<td>Post-pubertal males</td>
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<td>Pre-pubertal females</td>
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## Page 4: Funding

5. What are your centre’s funding arrangements for under 18 year old patients with cancer for the following fertility preservation options?

Please don’t select more than 5 answer(s) per row.

<table>
<thead>
<tr>
<th></th>
<th>Clinical commissioning group / Local commissioning group / NHS board / Health board</th>
<th>Local cancer network funded</th>
<th>Publicly funded on individual cases by case basis</th>
<th>Charity funded</th>
<th>Private funding</th>
<th>Don’t know</th>
<th>Other</th>
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<tbody>
<tr>
<td>Sperm storage</td>
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<td>Testicular tissue storage</td>
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<td>Oocyte storage</td>
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<tr>
<td>Ovarian tissue storage</td>
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5.a. If you selected other please provide details below.


6. For how many years is funding available, from the time of storage for fertility preservation options for under 18 years old patients with cancer?

Please don’t select more than 1 answer(s) per row.

<table>
<thead>
<tr>
<th></th>
<th>&lt;5 years</th>
<th>5 years</th>
<th>6-10 years</th>
<th>&gt;10 years but age restricted</th>
<th>55 years</th>
<th>Indefinite</th>
<th>Don’t know</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sperm storage</td>
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<td>Testicular tissue storage</td>
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<td>Ovarian tissue storage</td>
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7. What would be your centre’s usual first step in management if a patient who had stored gametes or ovarian or testicular tissue prior to the age of 18 returned at the end of their agreed funding period with evidence of unaffected fertility after their treatment and wanted to continue to store their gametes/tissue? *Required

- Our centre has no experience with this scenario

7 / 9
**Question 8:** What would be your centre’s usual first step in management if a patient who had stored gametes or ovarian or testicular tissue prior to the age of 18 returned at the end of their agreed funding period with evidence of possible affect on their fertility (for example changes in 1 or more semen parameters outside of the normal range) and wanted to continue to store their gametes/tissue?  

- Our centre would ask the patient to self-fund further storage
- Our centre would complete a request for additional funding for the patient. For example through completion of an individual funding request (IFR)
- Our centre would continue to store the gametes/tissue at cost to our centre
- We would allow the sample to perish
- Our centre would not be responsible for this. In our region the reproductive medicine specialists would manage this patient
- Not applicable as our centre offers indefinite funding
- Other

**Question 9:** What would be your centre’s usual first step in management if a patient who had stored gametes or ovarian or testicular tissue prior to the age of 18 returned at the end of their agreed funding period with evidence of severely affected fertility (for example azoospermia on semen analysis) after treatment and wanted to continue to store their gametes/tissue?  

- Our centre has no experience with this scenario
- Our centre would ask the patient to self-fund further storage
- Our centre would complete a request for additional funding for the patient. For example through completion of an individual funding request (IFR)
- Our centre would continue to store the gametes/tissue at cost to our centre
- We would allow the sample to perish
- Our centre would not be responsible for this. In our region the reproductive medicine specialists would manage this patient
- Not applicable as our centre offers indefinite funding
- Other
### Page 5: Patient Information

10. How satisfied are you with the quality and accessibility of fertility preservation patient information for the under 18 age group? (0 - unaware of any specific patient information, 1 - very unsatisfied, 10 very satisfied)

Please don't select more than 1 answer(s) per row.

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<td>For parents/guardians regarding their child's options</td>
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10a. Please use the space below if you wish to comment further regarding quality and availability of patient information for under 18's in regard to fertility preservation.

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