Inconsistencies in fertility preservation for young people with cancer in the UK

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ABSTRACT
Objective To assess the utilisation of and funding structure for fertility preservation for children diagnosed with cancer in the UK.

Design Survey of paediatric oncologists/haematologists. Questionnaires were sent electronically with reminder notifications to non-responders.

Setting UK Paediatric Oncology Principal Treatment Centres (PTCs).

Participants Paediatric oncologists/haematologists with an interest in the effects of treatment on fertility representing the 20 PTCs across the UK.

Main outcome measures Referral practices, sources and length of funding for storage of gametes or gonadal tissue for children diagnosed with cancer in the preceding 12 months.

Results Responses were received from 18 PTCs (90%) with responses to 98.3% of questions. All centres had referred patients for fertility preservation: ovarian tissue collection/storage 100% (n=18 centres), sperm banking 100% (n=17; one centre was excluded due to the age range of their patients), testicular tissue storage 83% (n=15), mature oocyte collection 35% (n=6; one centre was excluded due to the age range of their patients).

Conclusions Inconsistencies in provision of fertility preservation for children, with 10–20% of long-term survivors experiencing subfertility. In a population-based study in Scotland of all women with a cancer diagnosis under the age of 40 between 1981 and 2014, cancer survivors were approximately 38% less likely to achieve pregnancy after diagnosis compared with women in the general population. This is a major concern for many patients and their parents at diagnosis.

INTRODUCTION
The last 50 years have seen great advances in childhood cancer treatment with over 80% of patients now becoming long-term survivors. Long-term survivors may experience adverse late effects related to both the cancer and treatments received. Reproductive effects among survivors are well recognised, with 10–20% of long-term survivors experiencing subfertility.
Effects of Childhood Cancer Guideline Harmonisation Group, have been produced.\(^9\)\(\text{-}\)\(^{11}\) Several countries have published their own guidance on fertility preservation including the American Society of Clinical Oncology (ASCO),\(^{12}\)\(^\text{13}\) Children’s Cancer and Leukaemia Group,\(^{14}\) Children’s Oncology Group\(^{15}\) and the British Fertility Society (BFS).\(^{16}\)

Within the UK, paediatric cancer services are delivered through 20 specialist Principal Treatment Centres (PTCs). Current specialist clinical guidelines recommend that ovarian tissue cryopreservation is offered to girls with cancer at risk of subfertility and premature ovarian insufficiency, while testicular tissue cryopreservation may be offered to boys at high risk of gonadotoxicity, although this remains experimental.\(^{14}\)

There is an absence of standardised National Health Service (NHS) commissioned and funded fertility preservation services for children with cancer across the UK. Funding of fertility preservation for pubertal individuals is not considered to be an ad hoc basis, which includes funding from charity and research sources, although this had not been formally assessed prior to this study. Postpubertal boys are eligible for NHS-funded sperm collection and storage, although the duration of NHS-funded storage varies according to different commissioning bodies, such as individual Clinical Commissioning Groups (CCGs), with the duration of storage limited to 10 years in some areas. In postpubertal girls, storage of oocytes, embryos or ovarian tissue may be appropriate,\(^{14}\) with indefinite NHS funding available for the first two of these options.

In the absence of central NHS funding arrangements, there is the potential for inequality and significant variation in service provision across the UK for young people with cancer who may be at risk of future long-term subfertility. To understand the exact situation across the UK and to inform delivery of equitable and optimal future services, we aimed to explore current service provision and funding structures for fertility preservation in patients diagnosed with childhood cancer (<18 years of age) across the UK.

**METHODS**

**Study design**

This was a cross-sectional electronic survey of all 20 PTCs across the UK. A clinician with a specialist interest in cancer after-care (and, where available, primarily in reproductive late effects) was identified at each centre and invited via email to participate. The invited participant was asked to answer on behalf of their institution and advised to contact the researchers if another clinician was identified as more appropriate to answer on behalf of that institution. Reminder emails were sent twice to non-responders.

**Survey questions**

Participants were asked a total of 10 questions with regard to both male and female patients, with distinction between pre- and postpubertal patients. The study opened in July 2019 and closed in August 2019. Questions covered referral practices over the preceding 12 months and included sources of funding, length of time funding is available for storage of gametes or gonadal tissue and estimated numbers of referrals. Referral numbers were collected in ranges (0, 1–5, 6–10, 11–15, 16–20, 21–25, 26–50, 51–75, 76–100 and >100) rather than discrete numbers in the interest of simplification for the participant. An estimation was deemed preferable over an omitted response as it was unlikely exact data would be readily available to participants. Questions were designed to be closed, with limited space for free text in order to facilitate analysis (online supplemental file 1).

The ‘Online surveys’ platform\(^{17}\) was used to conduct the research and all responses were exported to a secure environment within the University of Leeds. No patient identifiable data were requested or collected.

**Data analysis**

Descriptive statistics were used to analyse the data. The results are reported predominantly as individual responses as a proportion of the whole to show variation across the UK. Where reporting of individual results had the potential for centres to be identified, responses were collated into four geographical groupings to protect anonymity of individual PTCs. One responding PTC does not routinely care for new patients above 13 years of age. Their data were therefore excluded from analysis with regard to questions relating to mature oocyte or sperm storage.

**Ethical approval**

The research was approved by the University of Leeds School of Medicine Research Ethics Committee on 30 May 2019 (study reference MREC18-019).

**Patient and public involvement**

This is a report of clinical activity across the UK. There was no public/patient direct involvement.

**RESULTS**

Eighteen of 20 (90%) PTCs responded with good geographical representation across the UK. Responding PTCs were assigned to one of four groups on the basis of geographical area (figure 1). Data completeness was high, with 98.3% of questions answered. The questionnaire was composed of 10 stem questions and 30 questions in total. Nine individual questions were unanswered out of the 540 (30 questions for 18 centres) questions in total. All submitted responses were valid and included in the analysis.

**Referrals of patients aged <18 years for fertility preservation**

All PTCs had referred patients for fertility preservation in the preceding 12 months (table 1). Within this time period, responding PTCs collectively estimated that 479 individual referrals for fertility preservation had been made with an estimated range of 338–620 cases (table 2). The majority of these referrals were for postpubertal boys.

**Girls**

Centres reported 95 (range 61–130) estimated referrals for prepubertal girls and 82 (range 55–110) for postpubertal girls. All centres had referred at least one case for ovarian tissue cryopreservation (collection and storage): 18/18 (100%). Fewer centres recorded at least one referral for mature oocyte storage: 6/17 (35%).

**Boys**

Centres reported 83 (range 51–115) estimated referrals for prepubertal boys and 218 (range 171–265) estimated referrals for postpubertal boys. Each centre had referred at least one case for sperm cryopreservation (17/17 (100%)) and 15/18 (83%) centres had also referred at least one boy for testicular tissue cryopreservation (The PTC that does not treat newly diagnosed patients older than 13 years was excluded from sperm cryopreservation reporting).
**Geographical variation**
Most variation by geographical region was seen for mature oocyte storage and testicular tissue storage. With regard to mature oocyte storage, 0% of centres in the Midlands and East of England, 25% in the South of England, 50% in the North of England and 60% of centres located in the Devolved Nations had referred at least one patient while, for testicular tissue storage, 75% of centres in the North of England, 80% in the South of England and Devolved Nations, and 100% of centres in the Midlands and East of England had referred one or more patients.

**Funding sources**
Wide variation was reported in funding sources by available fertility preservation technique (figure 2A, B). In several cases the participants reported being unaware of the funding source: 2/17 (12%) for both mature oocyte and sperm storage, 2/18 (11%) for ovarian tissue cryopreservation and 3/18 (17%) for testicular tissue cryopreservation. Of the centres who were aware of their regional funding source, half reported that ovarian and testicular tissue storage was funded by charitable sources.

**Girls**
Nationally, for centres reporting their funding source, mature oocyte storage was reported as health service funded (via CCGs, local commissioning groups, NHS or Health boards) in 9/15 (60%) centres, contrasting with 3/16 (19%) centres reporting health service regulated funding arrangements for ovarian tissue cryopreservation.

**Boys**
Sperm cryopreservation was reported as being NHS funded by all responding PTCs who were aware of the funding source (15/15 (100%)). A few participating centres reported the receipt of health service funding for testicular tissue storage (2/15 (13%)).

**Figure 1** Consort diagram of invited and participating centres.

**Table 1** Pattern of utilisation of fertility preservation options by Principal Treatment Centres (PTCs) over a 12-month period

<table>
<thead>
<tr>
<th>Geographical area (n=number of centres in group)</th>
<th>Sperm collection and storage (% responding centres)</th>
<th>Testicular tissue collection and storage (% responding centres)</th>
<th>Mature oocyte collection and storage (% responding centres)</th>
<th>Ovarian tissue collection and storage (% responding centres)</th>
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</thead>
<tbody>
<tr>
<td>UK (n=18)</td>
<td>17 (100)</td>
<td>15 (83)</td>
<td>6 (35)</td>
<td>18 (100)</td>
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<tr>
<td>Devolved Nations (n=5)</td>
<td>5 (100)</td>
<td>4 (80)</td>
<td>3 (60)</td>
<td>5 (100)</td>
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<tr>
<td>Midlands and East of England (n=4)</td>
<td>4 (100)</td>
<td>4 (100)</td>
<td>0 (0)</td>
<td>4 (100)</td>
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<tr>
<td>North of England (n=4)</td>
<td>4 (100)</td>
<td>3 (75)</td>
<td>2 (50)</td>
<td>4 (100)</td>
</tr>
<tr>
<td>South of England (n=4/5)*</td>
<td>4/4 (100)</td>
<td>4/5 (80)</td>
<td>1/4 (25)</td>
<td>5/5 (100)</td>
</tr>
</tbody>
</table>

*One centre was excluded for sperm and mature oocyte storage due to difference in upper age limit (13 years) of patients treated compared with other centres.
Geographical variation in funding source
Geographical variation was seen with regard to funding sources for both ovarian and testicular tissue cryopreservation. Centres located in the Devolved Nations reported no reliance on charitable sources for funding, instead reporting either health service commissioned funding, funding via research or publicly funded health service sources on a case-by-case basis. This was in contrast to centres located in England which, when aware of their funding sources, collectively reported a heavy reliance on charitable sources: 3/4 (75%) in the Midlands and East of England, 2/2 (100%) in North of England and 4/4 (100%) in South of England.

Duration of funded storage
Variation was reported in the length of time funding was available for each technique across the UK. However, the majority of respondents were uncertain of the length of funding available at the time.

Figure 2 Source of funding for fertility preservation of gametes or tissue across the United Kingdom for female patients

Figure 2b Source of funding for fertility preservation of gametes or tissue across the United Kingdom for male patients

Table 2  Principal Treatment Centre (PTC) estimated number of referrals by age over a 12-month period

<table>
<thead>
<tr>
<th>Region</th>
<th>Boys, postpubertal</th>
<th>Boys, prepubertal</th>
<th>Girls, postpubertal</th>
<th>Girls, prepubertal</th>
<th>All &lt;18-year-olds</th>
</tr>
</thead>
<tbody>
<tr>
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<td>15–25 (20)</td>
<td>5–25 (15)</td>
<td>5–25 (15)</td>
<td>10–30 (20)</td>
<td>35–105 (70)</td>
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<td>55–110 (82)</td>
<td>13–20 (17)</td>
<td>14–30 (22)</td>
<td>55–80 (68)</td>
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<tr>
<td>North of England</td>
<td>50–95 (77)</td>
<td>29–45 (37)</td>
<td>29–45 (37)</td>
<td>18–35 (26)</td>
<td>124–205 (165)</td>
</tr>
<tr>
<td>South of England</td>
<td>83–115 (89)</td>
<td>8–20 (14)</td>
<td>19–35 (37)</td>
<td>124–200 (162)</td>
<td></td>
</tr>
</tbody>
</table>

Participants were asked to provide an estimate of their centre’s number of referrals using the following predefined ranges: 0, 1–5, 6–10, 11–15, 16–20, 21–25, 26–50, 51–75, 76–100, >100.

Table 2  Principal Treatment Centre (PTC) estimated number of referrals by age over a 12-month period

Participants were asked to provide an estimate of their centre’s number of referrals using the following predefined ranges: 0, 1–5, 6–10, 11–15, 16–20, 21–25, 26–50, 51–75, 76–100, >100.

Figure 2 Source of funding for fertility preservation of gametes or tissue across the United Kingdom for female patients

Figure 2b Source of funding for fertility preservation of gametes or tissue across the United Kingdom for male patients

Figure 2  Source of funding for fertility preservation of gametes or tissue across the UK for (A) girls and (B) boys.
of storage (≥50% for each technique). Hence, it is not possible to provide detailed evaluation other than to demonstrate the wide range of responses from <3 years to indefinite. Respondents were more likely to indicate that ovarian and testicular tissue storage had indefinite funding while time limitations on sperm and oocyte storage existed.

Management following termination of routinely funded storage period
The PTCs were asked for their unit’s usual first step in management for a patient when the agreed funding plan for the stored gametes/tissue had run out. Scenarios explored included patients whose fertility (a) appeared unaffected after their treatment, (b) had been possibly affected (eg, changes in one or more semen parameters outside of the normal range) or (c) was severely affected (eg, azoospermia). For each scenario the respondent was instructed to assume that the patient wished to continue with the storage of the gametes or tissue. Over 50% reported no experience of the scenarios; however, for those who did have experience, significant variation in practice was identified (figure 3).

DISCUSSION
To the best of our knowledge, this is the first national evaluation of fertility preservation activity for young people with cancer which includes boys and girls as well as funding sources. It was performed because of concerns among professional groups of inequalities across the UK in the provision of support for young people facing cancer treatment and the potentially associated subfertility. All centres referred patients for fertility preservation, although marked variation in both services offered and funding sources across the UK have been identified. Charitable funding was used in 50% of centres for ovarian and testicular tissue storage while health service (NHS) funding was available in all PTCs for sperm cryopreservation.

Through knowledge of cancer incidence rates and activity levels at PTCs across the UK, we estimate that approximately 25% of patients were offered fertility preservation. While the data identify that referral for fertility preservation was offered in all children’s cancer centres (PTCs), it is not known whether it was offered to all eligible patients as a single referral over the 12-month period would lead to a positive indication of service utilisation. Knowledge of funding was not universal among respondents; reproductive medicine units were not invited to participate and potentially the data could have been enriched with their complementary responses and knowledge of funding sources and duration.

NHS funding was reported to be available for sperm banking, the most established fertility preservation technique, in 100% of PTCs. This is unsurprising given its long-standing history of clinical success and relative ease of collection and storage. The equivalent practice in girls for storage of gametes is mature oocyte storage. While having a long-established clinical evidence base of success,18 this procedure does not appear to have the same availability of health service funding with only 60% of centres with knowledge of funding pathways reporting health service commissioned NHS funding.

Of the almost 500 cases estimated to have been referred to undergo some form of fertility preservation technique over the 12-month period, approximately 20% are reported to be reliant on charitably-sourced funding, most markedly in England compared with the other nations of the UK. The reliance on charitable sources, particularly for ovarian and testicular tissue cryopreservation, may lead to restrictions in access. Patients may be disadvantaged in the future without robust centralised funding, with the presented data identifying that service users in England may be more susceptible to this than residents of the Devolved Nations of the UK.

The majority of consultant paediatric oncologists/haematologists responding to the survey were unaware of the duration of funding for all the available fertility preservation options undertaken at their centre. Given the variability in funding sources and often time-limited nature of the funded provision, this lack of knowledge needs to be addressed to ensure patients receive accurate counselling and are provided with the most appropriate options for ongoing storage after the duration of NHS, or other source of funding expires.

While it is beyond the scope of this paper to explore exactly why these differences exist, it is essential that they are resolved.
A combination of differing awareness of, and reliance on, NHS versus charitable funding and varying departmental practices may underpin some of these differences, and further research into the reasons for these differences is necessary alongside strategies to improve equity of access to fertility preservation.

CONCLUSION

Maintenance of adult life choices is a key marker of successful outcomes from childhood cancer and retained fertility is rated as a major priority by survivors of childhood cancer and their families.19 While it is reassuring that so many cases are being offered fertility preservation across the UK, urgent action is required to ensure that NHS funding is available for all to provide the appropriate security and hope for these individuals while permitting delivery of accepted and NHS mandated standards of care.20 21 It is essential that all young people with cancer have access to optimal and internationally recognised best practice. To support equity of access, we recommend (1) centralised funding of fertility preservation strategies mandated by current quality standards for each devolved health nation and (2) establishment of a national multidisciplinary team available to provide optimal care with the elimination of any geographical disadvantage related to place of care.

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Contributors The idea for this study came from AG, CMH and HLN. The survey was designed by HLN, with input from AG, CMH, HMP and AJF. MB, RC, VG, MK-W, SL, RTM, RS, WHS and DY assisted with data collection and analysis. All authors contributed to the final manuscript and have approved it for publication.

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Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information. All data relevant to the study are included in the article or uploaded as supplementary information.

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REFERENCES

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 Glaser, 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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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
- IUI
- 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 space for input]

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.b.i. 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 to the past for fertility preservation? Select all that apply.
3.3. If you selected Other, please specify.

3.4. 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

5 / 9
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.

<table>
<thead>
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<th></th>
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</table>
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.

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<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>
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<td>Ovarian tissue storage</td>
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5a. 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>
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<tbody>
<tr>
<td>Sperm storage</td>
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<td>Oocyte 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
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? *Required

- 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

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? *Required

- 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.

[Blank space for comments]