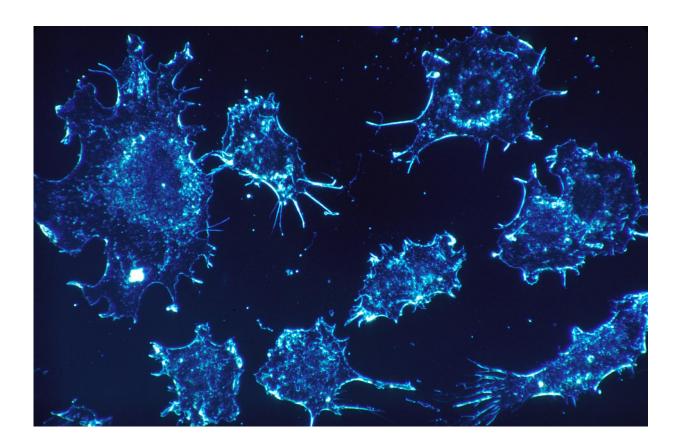


## UK kids with cancer face funding lottery for fertility preservation services

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Children and young people with cancer in the UK face something of a funding lottery for services to preserve their fertility, with specialist treatment centers heavily reliant on charities to stump up the cash needed, particularly in England, finds the first study of its kind,



published online in the Archives of Disease in Childhood.

This is despite clear international consensus that these services be provided to those at risk of losing their fertility as a result of cancer treatment, note the researchers, who call for centralized NHS <u>funding</u> to ensure equitable provision.

The treatment of childhood cancer has greatly improved over the past 50 years, with more than 80% of patients surviving their disease for many decades. But between 1 in 5 and 1 in 10 long-term survivors of childhood cancer will experience fertility problems.

Anecdotal evidence suggests wide variation in the provision and availability of NHS funding across the UK for these services, prompting concerns among professional groups about inequitable access.

Between July and August 2019, the study authors therefore surveyed all 20 specialist children's cancer treatment services across the UK on current provision and funding arrangements for fertility preservation in <u>cancer patients</u> under the age of 18.

Current clinical guidelines recommend that freezing/storage of ovarian tissue/eggs and testicular tissue/sperm is offered to children and teens whose future fertility is likely to be impaired as a consequence of their disease and treatment.

Each center was asked 30 questions, covering referral practice over the preceding 12 months, sources of funding, and length of time funding was available for egg and sperm storage. Eighteen (90%) centers responded from across the UK.

Every center had referred patients for fertility preservation in the preceding 12 months, corresponding to a total of 479 individual



referrals, with an estimated range of 338-620 cases.

All 18 centers had referred patients for ovarian tissue collection/storage; 17 had referred for sperm banking (one center was excluded due to the age range of their patients); 15 (83%) had referred for testicular tissue storage; and 6 (35%) had done so for mature egg collection (one center was excluded due to the age range of their patients).

Most regional variation was seen for mature egg and testicular tissue storage. Not one of the centers in the Midlands and East of England had referred a patient for mature egg storage, while only 1 in 4 in the South of England, half in the North of England, and 6 out of 10 of centers located in the Devolved Nations, had done so.

Some 3 out of 4 centers in the North of England, 8 out of 10 in the South of England and Devolved Nations, and all the centers in the Midlands and East of England had referred one or more patients for testicular tissue storage.

This reported variation may simply reflect the type of clinical cases treated during the study period, note the study authors.

Those centers that were aware of their funding source said that sperm freezing was funded by the NHS. But only 9 centers reported the same for mature egg storage.

And half said that ovarian and testicular tissue storage was funded by charitable sources; centers in England were much more likely to report this than centers in the rest of the UK.

Among all the cases estimated to have been referred for some form of fertility preservation during the preceding 12 months, around 1 in 5 (20%) reportedly relied on funding from charitable sources.



The length of time funding was available for each technique also varied, with respondents citing a period of under 5 years to 'indefinite'. But few respondents were certain of the exact length of time.

"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," write the study authors.

Based on their knowledge of incidence rates of childhood cancer and specialist center activity, they estimate that the reported responses from the 18 centers covers practice for 92% of newly diagnosed cases of cancer in the UK under the age of 18.

"With approximately 1800 new cases of cancer diagnosed each year in the UK in those aged under 18 years of age, these results estimate that approximately 25% of patients were offered <u>fertility preservation</u> [in 2019]," they suggest.

"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," they insist.

"It is essential that all <u>young people</u> with <u>cancer</u> have access to optimal and internationally recognized best practice."

**More information:** *Archives of Disease in Childhood* (2021). <u>adc.bmj.com/lookup/doi/10.1136 ... dischild-2021-321873</u>

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