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## FINDING OUT ABOUT SPERM BANKING

# Finding out about sperm banking: what information is available online for men diagnosed with cancer?

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### Abstract

Sperm banking is routinely offered to men where there is a risk of infertility following cancer treatment but uptake is lower than expected. Since these men may turn to the internet for information, we used the search engine www.google.com to identify the material available about sperm banking and fertility preservation options. Sixty-six resources (NHS/Private Clinic, Charity, Press Releases, General and Forums/Blogs) fulfilled the criteria for inclusion and were examined for quality including readability, layout and content. The most frequently reported information related to: (1) effects of cancer treatment on fertility (77.3%); (2) reasons to bank sperm (69.7%); and (3) fertility recovery after treatment (57.6%). Information about maintaining contact with the sperm bank (18.2%) and disposal of banked samples (10.6%) was less often included. The quality of information available on the Internet about sperm banking was variable. The readability of all resources was assessed as 'fairly difficult', i.e. reading skills required were too complex for the average member of the public to understand. Furthermore, visual presentation of material (e.g. lay out) did not facilitate easy reading. More attention should be given to information about longer-term issues, such as fertility recovery and the use or disposal of banked sperm.

**Keywords:** Sperm banking, internet information quality, male infertility, fertility preservation

### Introduction

Our focus in this paper is on the information needs of young men diagnosed with cancer whose treatment carries a risk of future infertility. As part of their cancer care, these men should be offered the opportunity to bank sperm prior to starting treatment (ESHRE, 2004; National Collaborating Centre for Women's and Children's Health, 2004; Lee et al., 2006; Royal College of Physicians, 2007). However, many men do not bank sperm prior to treatment, potentially compromising their future quality of life (Pacey & Eiser, 2011). Several explanations for this omission have been proposed as outlined below.

From the point of view of Health Care Professionals, there is little time between the diagnosis of cancer and beginning chemotherapy, during which they need to prioritise what, from a considerable amount of information about cancer and treatment, to convey to the patient. Discussions about sperm banking may be seen as less important than treatment issues (Zapalka

et al., 1999; Schover et al., 2002). Oncologists have reported several barriers to discussing fertility preservation including a lack of detailed or relevant information (Achille et al., 2006; Gilbert et al., 2011; Quinn et al., 2011), concern about treatment delays (Hobbie et al., 2009), and patients' lack of receptiveness to discussions about fertility preservation (Vadaparampil et al., 2008; Gilbert et al., 2011). Oncologists are often poorly informed about where to refer patients for sperm banking (Quinn et al., 2007; Gilbert et al., 2011) and may not be aware of progress in assisted conception whereby very poor quality samples may still be useful to bank (Zapalka et al., 1999).

Male cancer patients are provided with a great deal of information, much of which (40–80%) is forgotten immediately and half recalled incorrectly (Kessels, 2003). Men fear that sperm banking might delay life-saving treatment (Schover et al., 1999) and worry about abnormalities and teratogenic risk for children born from frozen sperm (Lass et al., 2001). Young adult

cancer patients want more information about future fertility and options for having children (Zebrack, 2008) and have reported that the process of sperm banking would be easier if more information was available (Edge et al., 2006). Given that oncologists must focus on issues about treatment, it is likely that men or their families will turn to the Internet to access more information.

In 2011, 19 million (77%) of households in the UK had an internet connection; up from 73% in 2010 (Office for National Statistics, 2011). Between 2008 and 2010, internet searches for cancer information increased three-fold (McHugh et al., 2011) and UK reports predict that by 2020, 37% of the general population will use the internet to search for health-related information (Future Foundations, 2009). In theory, the Internet provides convenience, anonymity, and comprehensive information that can be accessed whenever needed (Ziebland et al., 2004; Mayer et al., 2007). As well as patients, carers (e.g. family, friends and informal care givers) use the internet to obtain further information about diagnosis and treatment (James et al., 2007).

Organisations and charities have responded to the increasing growth in the use of the Internet by making information more readily available to the general public (McHugh et al., 2011). For the cancer patient, this means that relevant information can be accessed at all stages of diagnosis, treatment and recovery, potentially providing a useful aid to decision making. In practice, previous assessments of the quality and accessibility of online health-related information suggest a number of shortcomings (Kusec et al., 2003; Chestnutt, 2004; Boulous, 2005) and material is often written at a level too complex for the average member of the public to understand. A common method of assessing the comprehensibility of written information is readability analysis (Freda et al., 1999). Readability refers to the quality and style of writing as it relates to ease of reader comprehension and understanding (Klare, 1984). Readability formulae generate a mathematically derived rating of the grade reading level or reading ease of written materials, taking account of vocabulary, sentence structure, and word density. As sentence length decreases and words become shorter, material is rated easier to read. Readability can be enhanced by visual presentation of the material, especially the use of clear layout such as bullet points.

If men are to make truly informed decisions about sperm banking, it is important they appreciate the longer-term implications of their decisions. For those who decide not to bank, there are real possibilities that fertility will not recover enough for them to father children in the future (Pacey, 2007). For those who do decide to bank, longer-term considerations include the decision about whether to monitor fertility over time, whether to use banked sperm in assisted conception, and what to do about disposal when samples are no longer needed (Pacey & Eiser, 2011).

A recent interview study of 19 men, who had banked sperm more than 5 years previously, found that they

were ill-informed about these longer-term commitments (Eiser et al., 2011). Some were unaware that fertility could change in the years following treatment and most were reluctant to agree to disposal, even when fertility had recovered, resulting in unnecessary and expensive storage for sperm banks.

Given the evidence that men, for a number of reasons, may not be given satisfactory information about sperm banking on diagnosis, and that many report wanting more information, our aims were to simulate the internet searches that men themselves might carry out. We first describe the internet resources they might identify, secondly, any differences in the information depending on the source (e.g. Charity or NHS leaflets, blogs) and thirdly we rated the quality of the information available by assessing its readability, layout and content.

## Materials and methods

### *Search strategy*

An Internet search was conducted between 15 and 21 February 2011 to identify online resources that offered information about sperm banking and fertility preservation directed at male cancer patients. The search engine [www.google.com](http://www.google.com) was used as recent statistics have shown that Google is the most popular search engine used in the UK (Experian Hitwise, 2011). The search terms “sperm banking”, “fertility preservation AND cancer”, and “sperm cryopreservation” were entered to generate a list of sites, ranked in order of relevance to the search term. Search terms were chosen based on preliminary searches which indicated these terms gave the most relevant results.

Search results were reviewed sequentially until five lists of results (~60 unique web addresses) for each search term had been assessed (Figure 1). This cut-off was agreed since preliminary searches indicated that subsequent websites were duplicates or did not meet inclusion criteria. If a page provided a link to further information it was followed, on the assumption that a patient would do the same. However, only one link from each initial online resource was assessed.

Resources that met the following criteria included those: (1) directed at patients or carers; (2) which included information about sperm banking or fertility in men undergoing cancer treatment; and (3) written in the English language. Scholarly articles or abstracts were excluded as were those aimed solely at health care professionals, fertility preservation for women or focused on sperm donation. We also excluded websites requiring registration and log-in details. The web address, country of origin and date of publication were recorded for each online resource.

### *Coding*

A content analysis was undertaken (EW and HM) to determine the topics covered by each online resource. Coding was conducted independently and

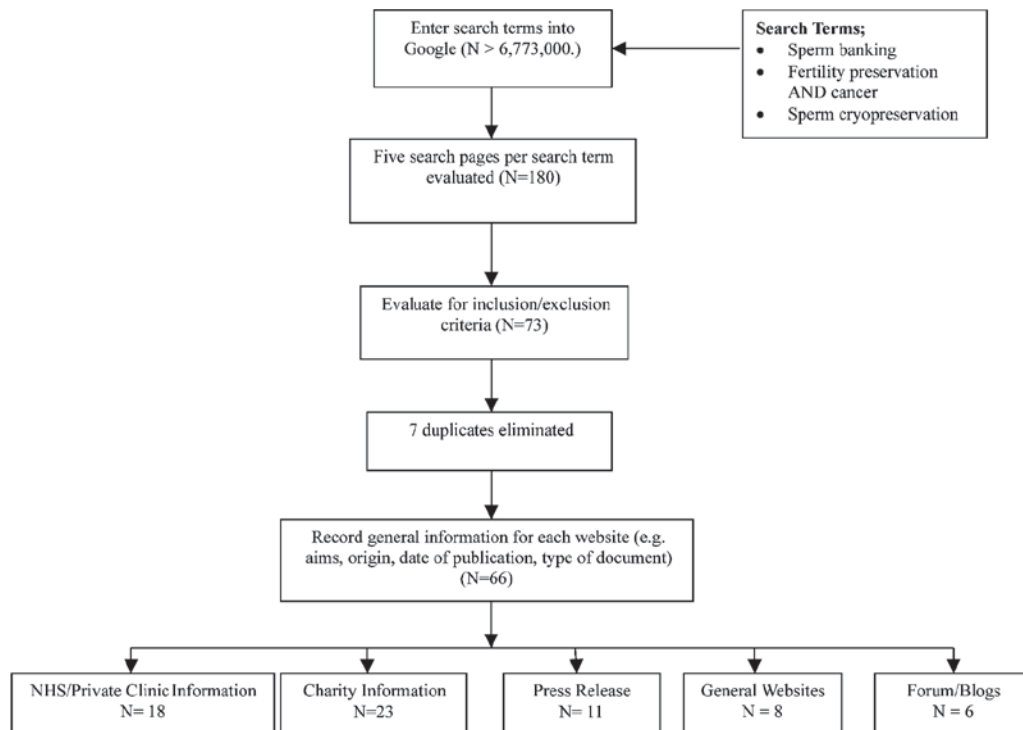


Figure 1. Summary of search strategy.

then discussed to resolve any discrepancies. Inter-rater reliability was calculated to determine consistency among raters and indicated substantial agreement ( $\kappa = 0.67$ ; Landis & Koch, 1977).

### Quality measures

A Readability Ease score (Flesch, 1948) was calculated for each online resource (based on the number of words per sentence and number of syllables per word) using the Flesch-Kincaid readability function available on Microsoft Office Word 2007. Scores are based on a scale of 0–100, with higher scores representing easier readability. Scores of 90–100 indicate material that should be understandable by an average 11-year-old, 60–70 by 13–15-year-old, and 0–30 by university graduates.

Each resource was also assessed for layout (Wilford & Hunt, 2003) by noting the presence or absence of any of the following formats: bullet pointing, subheadings, question and answer, block text, bold text or visual aids (e.g. tables, diagrams, pictures).

### Results

Of the 180 online resources identified, 73 met the inclusion criteria. Seven of these were excluded since they were duplicates, leaving 66 for further analysis. The majority of resources originated from the USA ( $n = 39$ ) or UK ( $n = 25$ ), with one from Canada and one from Australia. Information about the last update was provided by half of the resources ( $n = 33$ ). Five had been updated within 1 month of the search, seven within 6 months and 5 within a year. The date of last update for

15 of the resources was over a year before the search was conducted.

Of the 66 resources analysed, 25 aimed to provide information about sperm banking, 21 aimed to discuss fertility preservation and cancer treatment, 19 were directed at testicular cancer patients and one at prostate cancer patients. The resources were grouped into five categories: (1) NHS/Private Clinic information ( $n = 18$ ); (2) Charity information ( $n = 23$ ); (3) Press Releases ( $n = 11$ ); (4) General Websites (e.g. Wikipedia,  $n = 8$ ); and (5) Forums/Blogs ( $n = 6$ ).

### Information availability

Content analysis suggested the information available could be grouped around three common themes, each including several sub-themes, as shown in Table I. These were (1) Decision Making (the effects of treatment on fertility, reasons to bank, implications for others, availability); (2) Practicalities (procedures, legal issues, storage and risks, costs) and (3) After Cancer Treatment (fertility recovery, maintaining contact with clinics, routes to assisted conception, disposal).

Across all resources identified, the most frequently reported information related to: (1) effects of cancer treatment on fertility ( $n = 51$ , 77.3%); (2) reasons to bank sperm ( $n = 46$ , 69.7%); and (3) fertility recovery after treatment ( $n = 38$ , 57.6%). Less than half ( $n = 30$ , 45.5%) of the websites reported information about how banked sperm can be used in assisted conception if sperm quality did not recover. Information about maintaining contact with the sperm bank in the longer term was less frequently available ( $n = 12$ , 18.2%). A small number of resources gave additional information about

Table I. Content analysis: themes and sub-themes with examples.

Themes	Example
Decision making	
Effects of treatment on fertility	"There are two possible effects of chemotherapy or radiotherapy: (1) that no sperm will be present after the therapy or (2) that therapy will have the potential to affect the DNA of the sperm."
Reasons to bank	"Storing sperm prior to cancer therapy and availability of IVF technology means the vast majority of men can go on to have their own genetic children."
Implications for others	"The decision to bank your sperm is a highly personal one. If you are married or in a committed relationship, it is best if your partner is a part of your decision."
Availability	"Only half of oncologists and haematologists across the UK agreed that information on sperm banking is readily available to patients, despite national guidelines which state sperm banking should be offered."
Practicalities	
Procedures	"All samples should be produced by masturbation...There are comfortable, private rooms allocated for this purpose..."
Legal issues (Consent, viral screening, storage period)	"You'll also have to sign a consent form that states how your sperm is to be used."
Storage and risks	"Under HFEA regulations, sperm can be stored for an initial maximum period of 10 years and there must be fully informed written consents in place." "The temperatures of these vessels are continuously monitored and they are connected to alarm systems that will alert one of the staff if there is a problem with the tank."
Costs	"Some NHS cancer treatment centres offer free sperm banking service .... Prices can vary but, on average, it will cost £200-400 ..."
After cancer treatment	
Fertility recovery	"Sperm production may stop for a temporary amount of time. It may return immediately or many years after cancer treatments end."
Maintaining contact with clinic	"It is important to stay in contact with the sperm bank so that yearly storage fees are paid and your address is updated."
Routes to assisted conception	"If men want children at a later stage, the frozen semen can be thawed and used in fertility treatments."
Disposal	"If you have regained normal sperm counts and are doing well, then at that time you may make the decision to discard your stored sperm."

the availability of support groups or suggested questions to ask the doctor.

#### *Differences in information depending on resource type*

There were some differences in information depending on how the resource was classified (Figure 2). Both the NHS/Private Clinic and Charity websites were the only ones to discuss cancer treatment options and suggest questions to ask the doctor about sperm banking. These resources, along with the general ones, also contained more information about the practicalities of sperm banking, including legal issues, what happens at the sperm bank and risks to banked samples during long-term storage. Press releases tended to include information about availability of sperm banking, diagnosis and prognosis. Forums and blogs had the most limited content, restricted mostly to the costs of sperm banking and availability of support groups.

Information about longer-term issues was not well covered in any resource. Information about maintaining contact with the sperm bank (12/66, 18.2%) was not covered at all by general websites or forums/blogs and by just one press release. Only one website (www.cancerresearchuk.org) provided information on how men can monitor their fertility after treatment. Information about disposal was available in seven of the 66

resources (10.6%). This was mostly provided by NHS/Private Clinics with only one press release and one charity resource providing information on disposal. General websites and forums/blogs gave none.

#### *Quality of online information*

##### *Readability*

Information about readability and other quality ratings by resource are summarised in Table II. All the resources were scored as requiring considerable reading skills. The most difficult to read resources were the Press Releases, likely to be accessible only to those working toward an undergraduate degree. Forums and blogs were the most accessible but even these might be easily read only by those with a reading age of around 13 years (see above).

##### *Layout*

In terms of layout, just under half (n = 32, 48.5%) used clear subheadings to break up the text into separate sections, while another 14 resources (21.2%) used a question and answer format to break down the information into discrete sections. Bullet points were used to highlight important points and summarise the information provided (n = 27, 40.9%). Less than 20% of the resources (n = 13) used bold text to highlight important words/phrases, or used visual aids such as pictures, tables or

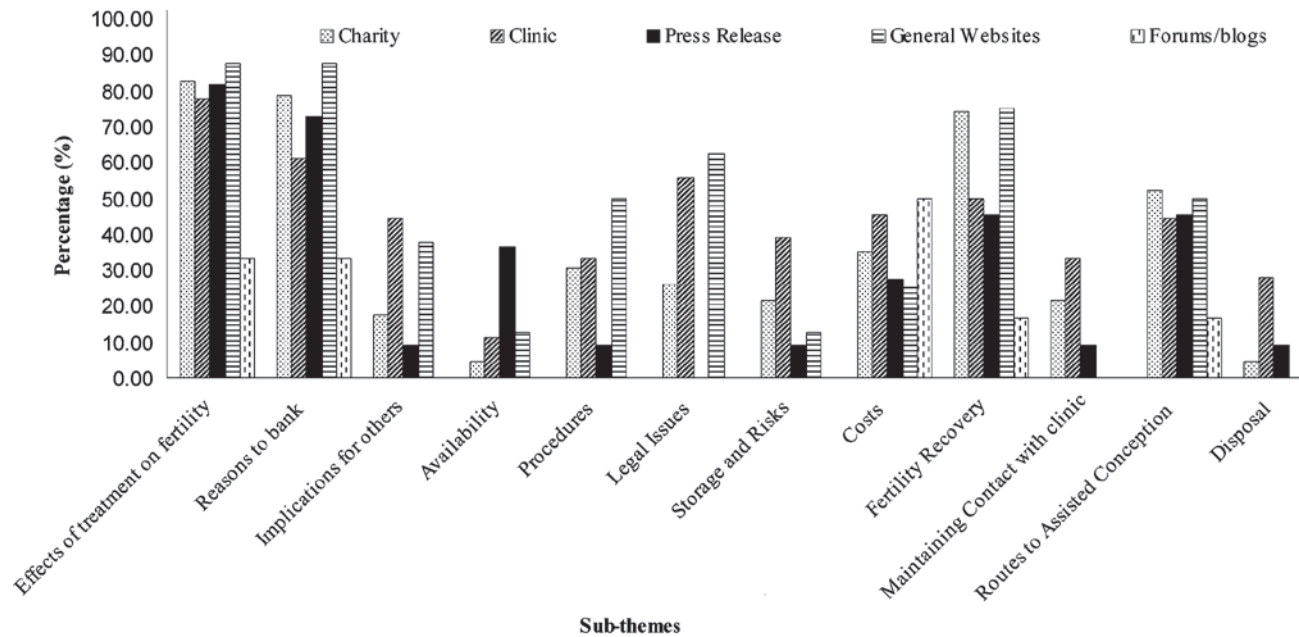


Figure 2. Comparisons of sperm banking content covered between each resource.

Table II. Quality of online information: readability, content rating and layout scores.

	Readability Mean $\pm$ SD (Range)	Layout (n)					
		Question and answer	Subheadings	Bullet points	Block text	Visual aids	Bold text
NHS/Private clinic (n = 18)	44.82 $\pm$ 14.09 (8.5–60.4)	5	3	5	1	0	3
Charity information (n = 23)	54.67 $\pm$ 13.74 (26.2–77.6)	7	20	19	5	6	1
Press release (n = 11)	38.46 $\pm$ 6.09 (31.6–49.9)	0	3	2	7	3	3
General web-pages (n = 8)	42.09 $\pm$ 13.92 (13.1–61.9)	2	4	1	2	1	6
Forums/blogs (n = 6)	56.98 $\pm$ 8.76 (48.4–72.3)	0	0	0	0	0	0
Total	47.97 $\pm$ 13.93 (8.5–77.6)	14	30	27	15	10	13

diagrams. Twenty of the resources (30.3%) were formatted in block text, with no separation of topics.

## Discussion

We began this research with the assumption that men were not well informed about sperm banking before cancer treatment. Given the pressure on oncologists to provide information about cancer and treatment rather than fertility preservation, we assumed that men would turn to the internet for further information to help them make decisions prior to beginning treatment. We conducted relatively simple searches that might reflect those conducted by a general population. At the same time, we attempted to determine how far currently available online resources provided balanced information not only about the reasons for banking but longer-term implications for monitoring fertility, use of banked samples in assisted conception and ultimately, disposal of unwanted samples.

Our initial search identified 180 online resources but only 66 provided unique and relevant information, and

only 25 of these focussed solely on sperm banking. The remainder included information about sperm banking within a wider context of information about cancer treatment and fertility preservation. The information most generally available was aimed at men considering sperm banking on diagnosis and included effects of cancer treatment on fertility, reasons to bank sperm and chances of fertility recovery after treatment. Far fewer gave information about how banked sperm might be used in assisted conception and even less about fertility monitoring or disposal.

The content and quality of information men read will depend on the online resources they access. Those who accessed press releases would be most aware of differences in availability of sperm banking depending on geography and much less aware about some of the legal issues involved in banking or the longer-term consequences. Charity and clinic websites and leaflets gave a broader range of information especially emphasising reasons to bank sperm and patterns of fertility recovery. As would be expected, forums and blogs potentially

gave the most biased information, focusing on personal experience, especially of assisted conception. None of the sources gave adequate coverage to issues of disposal.

If information is to be useful to the majority of patients it is important that readability and quality is appropriate. However, consistent with other work describing the readability of cancer information (Stinson et al., 2011), we assessed the average readability of the online resources found as 'fairly difficult'. Readability ease was associated with the resource type, with press releases being the most difficult. Information from NHS/Private Clinics and Charity websites and leaflets had the easiest reading levels. These were also more likely to make use of formatting to allow for easier browsing through relevant information. For example, the NHS/Private clinic and Charity websites and leaflets, and the general websites used either subheadings or a question and answer format to aid navigation through the relevant aspects of sperm banking.

Critically, it is the information missing from online resources that causes the most concern. While many gave information about who should bank sperm and the practicalities involved in doing so, information about what happens in the longer-term was less frequently covered. Just under half of the resources (45.5%) covered information about how samples could be used for assisted conception if sperm quality did not recover, but disposal was rarely mentioned (10.6%). Understandably, these issues may not be a concern for men who are recently diagnosed with cancer and are simply looking for practical information about sperm banking. However, they may become important at later stages after treatment where contact with healthcare professionals is less frequent.

Although there are guidelines about 'how' to write for the lay public on the Internet (Fulcher, 1997), our results suggest the quality remains lower than might be expected. There was often no clear information about who contributed to the development (e.g. oncologist, nurse, or patient), raising questions about the accuracy and impartiality of the content. While websites written by professionals have credibility, they may address questions men themselves have less well.

### *Limitations*

Limitations of this study relate first to the searches that were conducted. We used only one search engine and different results may be obtained if other search engines were also explored. Second, we only used three search terms; other search terms (e.g. sperm storage) may result in identification of different information, however we believe this does not detract from the key messages of this study. Third, we evaluated a relatively small number of online resources ( $n = 66$ ). However, we believe that our results may reflect what men themselves would find, since there is evidence that people tend to view only the first page of results listed by a search engine (Eysenbach & Köhler, 2002). Fourth, our results represent a snapshot of online

resources available at a particular time and we are aware that online content can change quickly. Fifth, there are aspects of website design that we have not attempted to evaluate or were unable to code, such as user-friendliness, accuracy of information or approval by professional organisations. We also chose to exclude scholarly articles and information aimed at health professionals that some patients may access and read.

### **Conclusion**

Previous work suggests there is a lack of relevant educational materials about sperm banking and that this hinders discussions with patients (Gilbert et al., 2011; Quinn et al., 2011). There have been a number of attempts to address this recently, including special training for oncology nurses and social workers to facilitate discussion of infertility and preservation options (Canada & Schover, 2005), development of interactive DVDs such as 'Banking on Fatherhood' (Huyghe et al., 2009), and Internet tools ([www.myoncofertility.org](http://www.myoncofertility.org)) to aid decision making (Jona & Gerber, 2010).

We have shown that men wishing to access the Internet for information about sperm banking can download a range of material in the form of press releases, forums or blogs and charity websites. Information about banking sperm on diagnosis was relatively widely available, but little was directed at longer-term issues such as monitoring fertility, use of samples in assisted conception, or disposal. Charity websites were scored as most easy to read but generally, readability was high, suggesting that much information might not be understood by all men.

The Internet is a potentially highly valuable source of information for men considering banking sperm. It can be accessed at any time and is especially valuable given that information about fertility is not readily available from oncologists (Quinn & Vadaparampil, 2009). In general, Internet users cite problems with finding the specific information they want, the time it can take and the information itself being too difficult to understand (Mayer et al., 2007). Most of these problems would seem to apply to the online resources about sperm banking we identified. Several sites had not been updated for a year or more and the level of reading skill required was perhaps higher than the level of much of the population.

It is important, however, to recognise the challenges associated with developing this information online. Information needs to be sufficiently general so as to be appropriate for all those who seek access, while at the same time, taking into account individual differences in vulnerability and the likelihood of fertility recovery. The challenge to the development of a realistic, and balanced account is to take into account the general principals involved while also acknowledging individual differences in vulnerability to the complex interplay between cancer, its treatment and likely impact on personal fertility.

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