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How do men in the United Kingdom decide to dispose of banked sperm following cancer treatment?

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Running title: Disposal of banked sperm by cancer survivors

Key words: Cancer, Semen cryopreservation, Male infertility, Psychology

## Abstract

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Current policy in the UK recommends that men bank sperm prior to cancer treatment, but very few return to use it for reproductive purposes or agree to elective disposal even when their fertility recovers and their families are complete. We assessed the demographic, medical and psychological variables that influence the decision to dispose by contacting men ( $n = 499$ ) who banked sperm more than five years previously and asked them to complete questionnaires about their views on sperm banking, fertility and disposal. From 193 responses (38.7% response rate) 19 men (9.8%) requested disposal within four months of completing the questionnaire. Compared with men who wanted their sperm to remain in storage, they were significantly more confident that their fertility had recovered (OR = 1.78, 95% CI = 1.05-3.03,  $p = 0.034$ ), saw fertility monitoring (semen analysis) as less important (OR = 0.61, 95% CI = 0.39-0.94,  $p = 0.026$ ), held more positive attitudes to disposal (OR = 5.71, 95% CI = 2.89-11.27,  $p < 0.001$ ), were more likely to have experienced adverse treatment side effects (OR = 4.37, CI = 1.61-11.85,  $p = 0.004$ ) and had less desire for children in the future (OR = 0.41, 95% CI = 0.26-0.64,  $p < .001$ ). Information about men's reasons to dispose of banked sperm may be helpful in devising new strategies to encourage men to engage with sperm banking clinics and make timely decisions about the fate of their samples.

## Introduction

51  
52 Sperm banking is routinely recommended for post-pubertal males prior to anti-neoplastic treatment  
53 (National Collaborating Centre for Women's and Children's Health, 2004; European Society for Human  
54 Reproduction and Embryology, 2004; Lee *et al.*, 2006; Royal College of Physicians, 2007; National  
55 Institute for Health and Clinical Excellence, 2013; Loren *et al.*, 2013). In the UK, sperm may be stored  
56 for up to 55 years (Human Fertilisation and Embryology Authority, 2009) and audits and reviews are  
57 needed to comply with legislative requirements. The low rates of use (Lass *et al.*, 2001) or disposal  
58 (Hallak *et al.*, 1998) mean that sperm banks are increasing in size and therefore compliance with these  
59 legal requirements is becoming time-consuming and expensive. Therefore, an understanding of how  
60 men make decisions about disposal is needed to contribute to more appropriate and cost effective use  
61 of sperm banks.

62  
63 Previous work suggests that disposal rates range from 8.7% (Meseguer *et al.*, 2006) to 23.8%  
64 (Blackhall *et al.*, 2002). Across nine studies, most disposals followed the man's death and few 'elective  
65 disposals' were reported (see Pacey and Eiser, 2011). Hallak *et al.*, (1998) reported that most men who  
66 chose to dispose did so because their fertility improved. In an interview study (Eiser *et al.*, 2011), men  
67 described complex and unresolved views about banked sperm. Many saw banked sperm as  
68 psychological protection against fertility decline if they relapsed, although others saw psychological  
69 benefits to disposal in that it allowed them to put the cancer experience behind them and 'move on'.

70  
71 In a cohort of men who banked sperm at least five years previously (Pacey *et al.*, 2012), we reported  
72 that the men's experience of adverse side effects, their initial experience of banking sperm and attitudes  
73 to disposal contributed to whether or not they attended for fertility monitoring. Using the same cohort of  
74 men, we now report the (i) frequency of elective disposal of banked sperm, and (ii) demographic,  
75 medical and psychological variables contributing towards this decision.

## Method

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### *Recruitment and Measures*

We contacted a cohort of 499 men between April 2008 and December 2010 who had banked sperm more than five years previously, prior to gonadotoxic treatment for cancer as described in Pacey *et al.*, (2012) and approved the by Trent Research Ethics Committee (Ref: 07/H0405/61). Briefly, the eligibility criteria included age (18-55 years), no known mental health problems, and sufficient English language ability to provide written informed consent and complete questionnaires. The men were recruited from sperm banks in Sheffield Teaching Hospitals NHS Foundation Trust (Jessop Wing, Tree Root Walk, Sheffield) and Nottingham University Hospitals NHS Trust (Queen's Medical Centre, Derby Road, Nottingham). In both hospitals, the subjects were written to and regularly informed about the need to attend follow-up and check any changes to their fertility and were given the opportunity to update their consent. In both centres, long-term storage was free of charge with the cost being covered by the National Health Service.

The men completed specially developed questionnaires to determine: (a) Experience of banking sperm (e.g., "I had the right amount of support from others in making this choice," and "I am pleased I decided to bank"); (b) Information about Fertility (number of samples they recalled banking, quality of banked samples ("did not have any sperm to bank" , "good enough for fertility treatment" or "don't know"), usefulness of knowing the quality of banked sperm (rated on a five point scale from "definitely very useful" to "definitely not very useful"), and current use of contraception (rely on partner, trying for a child, not in a relationship, fertility too low)); (c) Views about follow up (e.g., "I don't want to know if my fertility has recovered or not", "I am certain my fertility has already or will recover"); d) Attitudes to disposal (e.g., "If tests show my fertility has recovered, I would agree to disposal"); and (e) Children and Parenting (e.g., "How much has your experience of cancer affected your wish to have children in future?," "I worry that children born from banked sperm will have health problems"). Current late effects and perceived vulnerability were assessed using a standardized measure (Absolom *et al.*, 2006). Responses were made on 5-point Likert rating scales with appropriate end-points or multiple choice options.

Relevant medical and demographic information was extracted from medical records held by the sperm bank.

### *Analysis*

All continuous variables were standardised prior to analysis. We used independent samples t-tests and chi-square analyses to examine differences on all variables between those who decided to dispose of their samples and those who wanted them to remain in storage.

## Results

110 *Frequency of elective disposal*

111 A total of 193 men returned completed questionnaires (38.7% response rate) as summarized in Figure 1.  
112 Of those men who responded, samples had been banked for  $9.18 \pm 3.70$  years (range = 4.94-26.21) and  
113 their current age was  $35.08 \pm 7.08$  years (range = 21.58 – 54.34) (mean $\pm$ SD). One third (35.7%) had  
114 never attended for semen analysis [as reported in Pacey et al. 2012] and in addition, over the study  
115 period, 34 men (17.6%) disposed of their sample. However, the men joined the study over an extended  
116 period of time and the duration of follow-up differed between patients (range 4 – 43 months). We  
117 therefore modelled the men's decisions about banking to meet minimum follow-up possible (4 months  
118 after completing questionnaires) and nineteen men (9.8%) requested disposal within this 4-month  
119 window.

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121 *Demographic, medical and psychological variables predicting the decision to dispose of banked sperm*

122 Preliminary analyses of the information in medical records held in the sperm bank, indicated that there  
123 were no significant differences between men who agreed to disposal and those who did not, in terms of  
124 diagnosis, treatment, co-morbid conditions, participation in a clinical trial, relapse, reported late effects, or  
125 the number of ejaculates banked, the number of years that banked sperm was held in storage, pre-freeze  
126 motile concentration of the first banked sample, or number of attendances for fertility monitoring since  
127 banking. Importantly, there was no difference in post-treatment motile concentration between the  
128 disposers (mean =  $15.87 \pm 14.75 \times 10^6$  per ml) and those who continued storage (mean =  $17.72 \pm 26.52$   
129  $\times 10^6$  per ml). However, disposers were more likely to have experienced adverse treatment side-effects  
130 (OR=4.37, CI=1.61-11.85, p=0.004).

131

132 Men who agreed to disposal were significantly older (mean  $\pm$  SD:  $38.81 \pm 6.13$  versus  $34.64 \pm 7.07$ ) than  
133 those who retained the sperm in storage (OR for 1 year increase=1.09, 95% CI=1.02-1.17, p=0.017),  
134 more likely to have left full-time education under 18 years of age (OR=3.23, 95% CI=1.03-10.11,  
135 p=0.045) and to live with a partner (OR=4.47, 95% CI=1.00-20.01, p=0.050) and had significantly more  
136 children ( $1.42 \pm 1.30$  versus  $0.75 \pm 1.17$ ) than men who did not agree to disposal (OR for an additional  
137 child=1.45, 95% CI=1.05-2.01, p=0.019). There were no differences in employment (working or not;  
138 OR=0.99, CI=0.31-3.15, p=0.980) or distance from home to the sperm bank (OR for 1 mile  
139 increase=0.99, CI=0.96-1.01, p=0.165).

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141 The men who requested disposal were significantly more confident that their fertility had recovered  
142 (OR=1.78, 95% CI=1.05-3.03, p=0.034), saw fertility monitoring (semen analysis) as less important  
143 (OR=0.61, 95% CI=0.39-0.94, p=0.026), held more positive attitudes to disposal (OR=5.71, 95%

144 CI=2.89- 11.27,  $p<0.001$ ) and had less desire for children in the future (OR=0.41, 95% CI=0.26-0.64,  
145  $p<0.001$ ) than men who wanted their sperm to remain in storage.

146

## 147 Discussion

148 This study was initiated in response to an urgent practical question regarding extended and unnecessary  
149 storage. Our data support previous findings that disposal rates are low: of 193 men, 19 (9.8%) requested  
150 elective disposal of banked samples within four months of completing questionnaires, lower than  
151 previously reported (18.6% across 9 studies summarised in Pacey and Eiser, 2011). However, previous  
152 studies were usually longer-term audits where disposal rates are reported over a substantially longer  
153 period of time (e.g. 22 years: Kelleher et al., 2001). Our disposal rate may well be higher in the longer-  
154 term, and indeed over the course of the study we found that 34 men (17.6%) requested disposal.  
155 However, the shorter follow-up is more meaningful in order relate decisions about disposal to  
156 questionnaire responses.

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158

159 Given the low rates of disposal, we attempted to identify variables that distinguished between those who  
160 did, and did not, dispose of samples in the study period. These included being older, leaving full-time  
161 education before reaching 18 years of age, having more children and living with a partner, suggesting  
162 some relationship between the decision to dispose and family structure. Men who leave full-time  
163 education under the age of 18 generally start families sooner than those who enter a period of further  
164 education and training (Eggebeen, 2002). Other variables significantly associated with disposal included  
165 whether the treatment side-effects were recorded in medical notes, and self-rated confidence in fertility  
166 recovery, lower importance of fertility monitoring (semen analysis), desire for children in the future, and  
167 attitudes to disposal. Hallak *et al.*, (1998) also found that the decision about disposal was not related to  
168 age, number of specimens stored and time between diagnosis and treatment but did depend on the type  
169 of treatment. Both Hallak et al. (1998) and Meseguer *et al.* (2006) concluded that aside from death, most  
170 reasons for elective disposal included recovered fertility and no desire for further children. However, in  
171 the context of our study it is interesting to speculate if our questionnaire itself may have acted as an  
172 intervention by prompting men to consider disposal when they otherwise would not have done so. This  
173 effect has been noted before in the context of blood donation (Godin et al., 2008) where the receipt and  
174 completion of a questionnaire among registered donors increased their participation rates in comparison  
175 to a control group. This is an area for further investigation.

176 Limitations of the study include the poor response rate (38.7%) but this may reflect the general difficulties  
177 encountered when trying to recruit men to research fertility (Stewart et al., 2009) or other fertility related

178 follow-up (Chawla et al., 2004). We have only limited information about non-responders, although we  
179 have recently published a summary of interviews with six men who had held their sperm in storage for  
180 almost 10 years and who had never returned to the sperm bank (Eiser et al., 2014). This suggests that  
181 men's reasons for not responding are a complex interplay between past, present and future perspectives  
182 including fears of being told fertility has not recovered and being pressured to dispose of banked sperm.  
183 Responses to questionnaires relied on recall of events many years previously and may reflect some  
184 recall bias. Our results are limited to views of men following cancer treatment and may differ for those  
185 who bank sperm for other reasons. Our decision to focus on men who bank sperm following cancer  
186 treatment were justified because referrals to sperm banks following cancer diagnosis are more prevalent  
187 than for other causes (Pacey, 2009). We investigated a finite range of variables that might contribute to  
188 men's decisions and other variables may be worthy of investigation in the future. For example, decisions  
189 may well be influenced by cost where charges are collected for storage and concerns about the possible  
190 teratogenic nature of the treatment which could affect the health of any children born. For some, this  
191 may be a justifiable concern, but for others sensitive counselling may be needed to ensure that rational  
192 decisions are made.

193  
194 Information and counselling may assist men in making timely decisions (Pacey and Eiser, 2011). On-line  
195 information currently available about sperm banking typically requires more sophisticated reading skills  
196 than generally held the public (Merrick *et al.*, 2012). Health professionals should provide easy to  
197 understand information throughout cancer treatment, and not just on diagnosis. Men consistently  
198 describe how they rely on medical staff and family to help them make decisions to bank when diagnosed  
199 with cancer (Pacey *et al.*, 2013). Health Professionals need to take into account men's sources of  
200 support and the wider issues that contribute to views about disposal. We suggest that men's attitudes to  
201 disposal are underpinned by a complex series of variables concerning their experience and particularly  
202 the side effects of treatment, views about fertility, domestic arrangements, and desire for future children.  
203 In order to answer questions about the viability of sperm banks (Lass et al., 2001), it is vital to increase  
204 our understanding of why men bank sperm, their reasons for using banked samples for reproduction and  
205 the rationale for retaining samples in storage even when they do not anticipate using them in the future.

206  
207 Given that banked sperm can be stored for up to 55 years in the UK (Human Fertilisation and  
208 Embryology Authority, 2009), it is important that those responsible for day-to-day management of sperm  
209 banks are aware of the complexity of these issues. Storage of sperm allows men to achieve optimal  
210 quality of life after cancer treatment but there are implications for health care resources. Men need to  
211 understand from diagnosis that sperm quality will change in the years following treatment. They should

212 therefore, be encouraged to engage with the sperm banking service during treatment and beyond, in  
213 order to make timely decisions about disposal of stored samples if they are no longer needed for assisted  
214 conception.

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#### **Acknowledgements**

217 The authors would like to thank Debbie Saxton (Sheffield) and Tracey Kohut (Nottingham) for their help  
218 with the recruitment procedures. This paper was supported by funding from Cancer Research-UK to CW, AAP  
219 and RR (C481/A8141). The views expressed are those of the authors.

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#### **Declaration of interest**

222 The authors report no declarations of interest. The authors alone are responsible for the content and writing of the  
223 paper.

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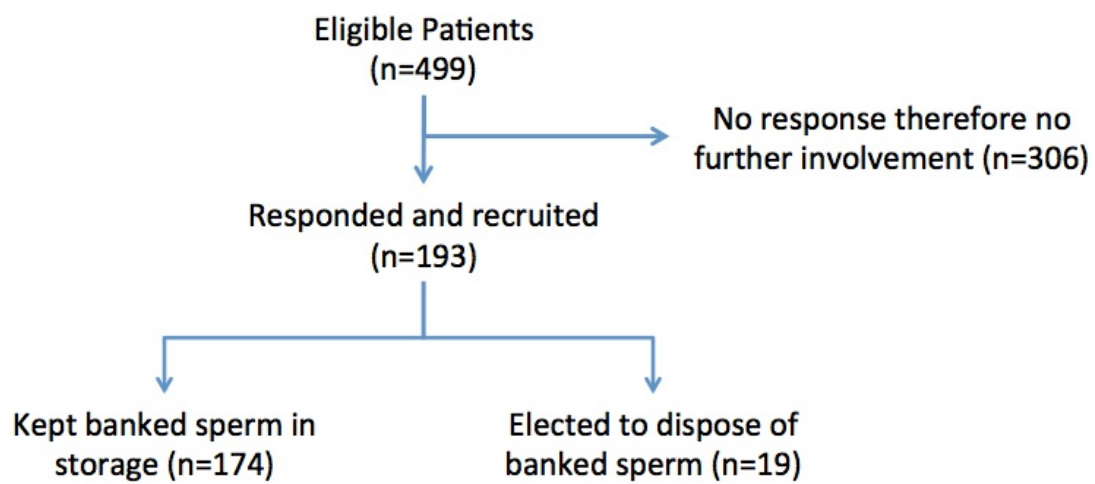
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303 Figure 1: Summary of recruitment and the disposal of banked sperm by participants