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A QUALITATIVE STUDY OF THE  
EXPERIENCES OF TEENAGERS AND YOUNG  
ADULTS WHEN FACED WITH POSSIBLE OR  
ACTUAL FERTILITY IMPAIRMENT  
FOLLOWING CANCER TREATMENT

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MARILYN CRAWSHAW

PATRICIA SLOPER

THE UNIVERSITY *of York*



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Marilyn Crawshaw  
Tricia Sloper  
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University of York  
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## CONTENTS

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Executive Summary	5
Introduction	11
Literature review on fertility issues in adolescent cancer	12
Interview Study	23
<b>Methodology</b>	<b>23</b>
<b>Sample</b>	<b>34</b>
<b>Understanding and experience of the <i>process</i> of being told about fertility matters and/or using fertility preservation services</b>	<b>39</b>
Overall experiences	39
Who and what was involved in making the decision about whether or not to store gametes?	52
The Banking Process itself	57
<b>Information, understanding and recall following diagnosis</b>	<b>71</b>
Understanding of reproductive function	71
Understanding and use of hormone replacement therapy	73
Understanding and use of contraception	74
Understanding and use of fertility analysis or its contemplation	77
Understanding of fertility treatment options	82
Satisfaction with information received	84
<b>Telling and talking about cancer-related fertility issues</b>	<b>89</b>
Telling and talking with professionals	89
Telling and talking about fertility matters with family members	109
Telling and talking with friends and others	114
Telling and talking with a (prospective or actual) romantic partner	128

<b>The impact of possible or actual cancer-related fertility impairment</b>	<b>137</b>
Impact of fertility on self	139
Impact on family and family relationships	165
Impact on friends and friendships	171
Impact on current and future romantic relationships	174
<b>Managing the experience of thinking about, or achieving, parenthood</b>	<b>181</b>
Alternative routes to parenthood	181
Becoming and being a parent	186
Conclusions	<b>192</b>
Development of Information Materials	<b>202</b>
Focus Groups	<b>203</b>
Appendix A – Reflections Sheet for Focus Group	<b>211</b>
Appendix B - Action planning for Focus Group	<b>212</b>
Appendix C - Topic guide for interviews	<b>214</b>
Appendix D – Advisory Group Members	<b>218</b>
Bibliography	<b>219</b>

## Executive Summary

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In depth interviews were conducted with thirty eight individuals diagnosed with cancer between ages 13 and 21 and aware of a risk, no matter how small, that their fertility may have been affected. Age at interview ranged from 16 to 30. Twenty one females (nine teenagers and twelve adults) and seventeen males (seven teenagers and ten adults) were drawn from a range of backgrounds regarding educational achievement, employment, family situation and ethnicity. While none had a prior major impairment, several were left with impairments following treatment.

Recruitment was primarily through three regional paediatric oncology centres in the North of England.

### At diagnosis

- There was strong support across both genders for being told at diagnosis about the potential impact of treatment on their reproductive system.
- There was strong support for sperm banking to be offered to all males regardless of their physical or emotional state.
- Those males who tried and failed to bank their sperm were nevertheless very positive about being afforded the opportunity to try.
- There were good levels of understanding and recall about fertility related information received at around diagnosis. A range of reactions were experienced ranging from lack of concern to significant distress for both the individuals affected and their parents.
- Some females would have preferred greater clarity to be offered by doctors about the link between possible interruptions to their menstrual cycle and their reproductive system. Some wanted an explanation at this stage about why egg freezing was not on offer.
- There was a range of interpretations about the level of likely risk to fertility arising from what was said (and not said) by professionals at this stage and later.
- Many respondents spoke positively about professionals who appeared to take a genuine interest in fertility matters both at this stage and later.

### Sperm banking

- Decision making about, and preparation for, fertility preservation was largely straightforward and aided by clarity of information sharing, the manner and context within which it was shared, being spoken to directly and having parents involved (provided that the young person wanted their parents present).
- There was satisfaction with decision making and preparation for banking taking place predominantly within the paediatric oncology setting with the consent and semen collection process taking place within the sperm bank.
- Some would have preferred consent to be taken in the paediatric oncology setting.
- Age and stress of coping with diagnosis did not appear to be significant to the ability to decide about sperm banking and act on that decision. Although some respondents *said* that their age and life stage made a difference, this appeared to affect what they *thought* about undertaking this task rather than their *ability* to do it.
- Paediatric oncology professionals were rated consistently highly by respondents; the picture was more variable amongst those encountered in the sperm banks. Where there were difficulties, these centred on the professionals being too formal, using too complex language, not smiling enough and not employing appropriate humour.
- The young men welcomed having a choice about whether to be accompanied to the sperm bank and by whom. Many chose to have family members present and this helped; others were accompanied by professionals or went alone.

- The journey to the sperm bank (whether on site or off site and whether accompanied or not) was experienced as stressful. Some would have preferred to produce a sample either at home or away from the sperm bank (though not on the ward).
- There was considerable confusion about the consent conditions, including about 'consent to disclosure' and whether or not other couples would be able to use the stored sperm. There was also very limited awareness that these can be revisited. Some were distressed by questions about posthumous arrangements for semen disposal.
- The need to improve the facilities in the semen collection room was identified – making it more homely, more private, ensuring that pornographic magazines were clean and unambiguously available for all ages, providing written instructions and a clear procedure for handing in the sample.
- Many took a 'matter of fact' approach to semen collection and saw it as a required part of the process towards treatment though a few found it made them feel 'smutty'. All found it embarrassing.
- There were variations in getting the results of the semen analysis; getting them quickly seemed to be particularly well received. There were good levels of knowledge about storage matters.

### **From diagnosis to present day**

- There was a more varied picture of information sharing and opportunities for discussions about fertility with professionals following diagnosis with only about half of the respondents feeling that it was sufficient.
- There was strong support from both genders and age groups for professionals to raise the subject sooner, more frequently, in a low key way and without ambiguity. This would enable those concerned to either acquire more information or to discuss concerns as and when they felt ready.
- Although most preferred their consultant to raise the subject initially, there was also support for other professionals to do so, especially psycho-social professionals.
- Some would have liked named staff on the wards to deal with sex and fertility matters or a wholly independent service delivered from elsewhere.
- The lack of relevant psycho-social services, the need for them to be offered proactively and to be home- as well as centre- based was identified at different stages and was not necessarily related to any imminent desire to become a parent.
- Preferred professional attributes included being honest, clear and unambiguous in dialogues, friendly, approachable, compassionate, competent and not embarrassed with the subject. Respondents valued professionals who were interested in fertility matters and who engendered hope in their ability to come through.
- Respondents wanted to be treated by professionals as partners and hence prioritised over their parents.
- Although there were gender differences in understanding, recall seemed broadly similar across genders.
- Males of all ages expressed no knowledge or interest in the sperm production process; females were interested in their menstrual cycle but reported poor understanding of it despite discussing it regularly with professionals and parents. This was a source of confusion and/or distress.
- Understanding of hormone replacement therapy appeared to be particularly problematic.
- Some reported increasing concerns about the impact of uncertainty about their fertility status as the uncertainty around cancer diminished.
- While both genders were faced with possible temporary fertility impairment, females were facing a possible shortening of their reproductive lifespan through a premature menopause (which was also uncertain) while males would retain lifetime fertility if function were to return. The implications were therefore very different.

- The presence of stored sperm was an important source of reassurance to males, providing that they were confident in its quality.
- The retention of hope of reproductive function or of successful fertility treatments - even where there appeared to be a strong likelihood of damage - was an important boost to coping. Those told that their fertility was permanently and irreversibly damaged were typically badly affected.
- Information levels about contraception across gender and age were limited. When combined with attitudes towards its use, sometimes influenced by possible fertility impairment, a worrying picture of risky behaviour emerged.
- Some had sought fertility related information from other sources. Several wanted more age-appropriate written and/or internet based information to be made readily and discreetly available.
- Gender differences emerged over fertility analysis. Some females became aware unexpectedly of fertility damage through gynaecological investigations; none were expecting to be called routinely for fertility testing. Most males who had banked sperm anticipated being recalled routinely and did not express any particular anxiety about this.
- The complexity of decision making about fertility was especially apparent among older respondents and those who did not have stored gametes.
- Some reported little impact after testing (including some found to be affected) though others did. Several would have welcomed access to psycho-social services but none were offered.
- Few had sufficient knowledge about fertility treatment options. Females were far more likely than males to know others in their family or social networks that had been through fertility treatments. None had yet accessed fertility treatments themselves though some anticipated needing to.
- Some in all four groups cited media coverage as a prompt for them to think about their own situation.

#### **Involvement of families**

- Families were much less likely to talk about cancer-related fertility matters than cancer matters at any stage. Sometimes the lack of discussion was because the respondent had not felt troubled; sometimes it was because the respondent feared upsetting others, or being upset themselves, by such a discussion.
- Some respondents talked to siblings and extended family members more than to parents.
- Where the respondent felt in control of the level at which their parents and family members were involved in their lives (including treatment and contact with professionals) both in the past and in the present, this was experienced positively. While a number were saddened by the strain that their cancer experience had already imposed on the whole family, some worried that they may add to this by not being able to provide grandchildren.

#### **Involvement of friends**

- Respondents across all four groups were more likely to discuss cancer-related fertility matters with friends than with family members but nevertheless reported different reactions towards, and from, friends around this area than to cancer matters.
- Discussions were often restricted to a small number of close friends and proved helpful. A small number did *not* talk with friends; that worked well when it was because the subject was of little concern but distressing when it was.
- Some found fertility matters particularly difficult to manage in their re-entry into the education-based context.
- The stigma attached to (in)fertility and the desire to appear 'normal' influenced the decision of some not to tell friends either in the early stages or over time. This appeared more difficult to sustain over time.
- Females were particularly likely to find themselves managing conversations about parenthood plans (and actual pregnancies).

- Some of both genders used humour to diffuse the awkward nature of some conversations but males reported particular difficulty in coping with 'laddish' jokes about virility and sexual prowess. This was made more stressful where friends were not aware of their possible fertility impairment.
- A small number discussed it with opposite gender friends though the majority restricted it to same gender friendships. A few females had used discussions with male friends as a 'rehearsal' for anticipated discussions with boyfriends
- Some reported changes over time with friends either becoming less interested or becoming more involved and supportive. Some females had been involved by friends in bringing up their children.
- There was mixed evidence of respondents talking about fertility within friendships made through cancer – sometimes it had not come up at all whereas for a small number, it was an important site of shared experience.
- None had yet got friends facing fertility difficulties for non cancer related reasons.

### **Involvement of romantic relationships**

- Some were in permanent romantic relationships but many were not; some had no experience in this area at all.
- Most of those closer to treatment were more concerned with the impact of body changes than of the impact of possible fertility impairment.
- Although many said that the possibility of fertility impairment did not influence their approach to relationships, including sex, there were many examples of how it had done.
- Some were anxious about finding a partner willing to enter a potentially childless relationship while others were concerned about finding a permanent partner who later came to experience distress. A few were concerned that they themselves might not feel attracted to a partner willing to contemplate a childless relationship.
- The possibility of not being able to have a child together had contributed to the ending of a small number of relationships but was never the sole cause.
- Anticipated and actual concerns about when and how to tell a romantic partner were dominant and often present from very early on in relationships.
- Many respondents feared rejection following disclosure fuelled in part by the stigma that was perceived to attach to fertility impairment and hence the feeling that they were 'damaged goods'. This was reinforced by the subject rarely being raised in other contexts.
- Respondents across all four groups were far more likely to talk to partners about their cancer experience than about cancer-related fertility matters, mirroring communication patterns with family and friends.
- Those where complete honesty was a strongly preferred feature of relationships in general were more likely to disclose early in permanent and non permanent relationships and to feel less anxious about the process.
- Some had not disclosed in order to hide their probable infertility; some felt disclosure should be restricted to 'serious' relationships and/or that it might give the wrong message if done too early.
- Those who had told a romantic partner typically found the outcome to be more positive than anticipated and led to them feeling relieved and reassured. In other words, the anticipation of disclosure appeared worse than the reality.
- However there was variance in the extent to which fertility matters had been discussed following disclosure. Some did not discuss it very often even though (or perhaps because) they found it deeply distressing.
- Uncertainty about fertility status also affected romantic relationships. Some reported the need for more information or better coping strategies in order to help a partner when the time came to disclose. Some of the older ones had wondered whether to undergo fertility analysis as part of this preparation and strategy building process.

- Some of the older group had enjoyed a number of post treatment relationships (mainly casual) but this had changed more recently and they reported a drop off in this aspect of their lives. Some had only ever had casual relationships.
- There were varying reports of the comfort and reassurance that came from being in a permanent relationship; while there were accounts of feeling that fertility impairment was now a shared 'problem' there was also evidence of ongoing loneliness surrounding it.
- Reactions were not static but changed over time and across different situations and within different romantic relationships.

### **Becoming and being a parent**

- Females were more articulate about alternatives; had thought about it more frequently and in greater depth than had males; had the subject raised with them more often than did males. Only females had received offers of surrogacy or donated gametes from family members.
- Both genders and age groups held reservations about non biological parenthood, especially through gamete donation.
- The response of romantic partners to alternative routes was seen as important though few had actual experience of this.
- For those trying to get pregnant, the strain was clear; the extent to which the emotional impact was shared by partners varied as did responses to the styles of medical intervention.
- Some parents had planned pregnancies and others not; several had believed previously that they were infertile.
- Increased levels of monitoring of the pregnancies of affected females were welcomed; most were fearful of the pregnancy triggering a recurrence of cancer.
- Others, including non-affected females, were concerned about the risk of transmission of cancer to the unborn child; this was made worse where relevant information was not provided until after the birth.
- One parent reported that the fear of his child getting cancer had grown over time.
- Several felt better able to cope than their parents if their child were to get cancer because of their own experience and resulting strengths.
- On the whole, all appeared to have adjusted well to being parents.

### **Overall**

- Coping with the impact of cancer-related fertility concerns was a dynamic process with different aspects arising at different times, in different contexts and in different life stages.
- One key aspect was the relative invisibility of fertility matters compared to cancer matters in dialogues between the individual affected and those around them – be they professionals, family members, friends or romantic partners. Survivors were coping alone with their thoughts and feelings for much of the time.
- Some respondents felt little or no associated concern but for others it was stressful and this had grown over time.
- Lack of attention from others also limited opportunities to correct misinformation, provide new or repeated information or to help build strategies for longer term coping. It also appeared to reflect and reinforce the perceived stigma that attached to (in)fertility and thus the potential for hopelessness that comes with holding a 'spoiled identity'.
- A few reported fertility concerns arising from diagnosis onwards but they more typically strengthened once treatment ended, especially where there was uncertainty about damage or definite information to indicate damage was done.
- For some, the threat to wellbeing from fertility concerns had overtaken cancer-related concerns. This did not appear to relate to gender although age and life stage did appear to be an influence.

- Threats to wellbeing from fertility concerns were formed and maintained by, among other things a strong and conscious desire to become a biological parent one day; the way that individuals (and sometimes their parents) interpreted information received from their doctors about the likely risk of damage; the presence of an 'impaired' or 'uncertain' fertile identity
- Prior to diagnosis, all appeared to have held a 'fertile' fertile identity though some had shifted to an 'impaired' or 'uncertain' fertile identity through treatment. It seemed to prove particularly difficult to shift back to a 'fertile' identity.
- Those who had given parenthood little thought had nevertheless assumed they would become parents one day so also experienced some degree of threat.
- The priority following treatment was re-entry into the social and educational trajectory being navigated prior to diagnosis and 'active recovery through striving for normality'. For those focussed on this, fertility concerns were either consciously put to one side or 'forgotten', reinforced by their potential to make survivors appear or feel 'different'.
- Normality is contextual and is variously located in gender, ethnicity, culture, sexual orientation and so on. There was evidence of this influencing some attitudes to contraception and social friendships.
- Those less focussed on 'normality' in their recovery appeared less likely to be striving for conformity to fertility related expectations and could therefore accommodate the possibility of remaining childless for the foreseeable future.
- Those who remained fearful of relapse or who were coping with significant physical impairments or health difficulties (some with associated stigma) were preoccupied with those and less affected by potential fertility impairment.
- However there were some who felt near to, or beyond, the active recovery phase and others for whom this approach was working less well who reported that fertility concerns were not resolving.
- Where recovery was starting to be affected by fertility concerns, many nevertheless spoke positively of being a cancer survivor. They felt good about themselves and their achievements and pointed to positive role models and images among cancer survivors, including some who had become parents.
- However there were many reports of more negative associations with (in)fertility and none identified positive role models or images.
- The opportunity to exercise reproductive choice about whether or not to enter the social state of parenthood is one that most young people expect to acquire as they move towards adulthood. For those being diagnosed with cancer in their teens, that opportunity is threatened and is often an unexpected consequence of cancer treatment. When placed alongside the threat to life, it may appear as of secondary concern and become invisible. However, if life is for living, then it is of little surprise that many in this study reported that it did not stay invisible to them. Perhaps it is time that those around them to also make it more visible.

## INTRODUCTION

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This study looks in depth at the experiences of young people diagnosed with cancer who find that this may result in their reproductive system becoming damaged. Being able to decide whether and when to have children is an unwritten expectation for most people growing up and little has previously been known about what happens when this is threatened. Indeed many young people are likely to have been exposed to messages urging them to delay becoming parents and to avoid engaging in unprotected sex up to this point. The news about possible cancer-related fertility impairment has the potential to send all that into reverse gear and throws up many questions. Is it distressing? What do the young people need to know about it, if anything, and when? Is it different for females and males? Does it only really start to matter when they become adults, set up a long term partnership, decide they want a family? Is it better to talk about it or not? How do families, friends, partners deal with it? How should professionals approach it and are there gaps in services that should be filled? These were some of the areas that this study was designed to address.

As there is so little research currently available on this particular aspect of the teenage and young adult cancer experience, we designed a study that would try to capture a range of thoughts, feelings and experiences and gradually build up a picture. The way that we went about this and the findings that we came up with are included in the section called 'The Interview Study'. However we also produced some information materials as part of the study and we have included a description of that work in the section called 'Development of Information Materials'. Finally, we wanted the interview study to influence the way that services are delivered and we were interested to know how some of the professionals involved reacted to our findings. We ran four focus groups towards the end of the interview study and a range of different professionals – medical, scientific and psycho-social - came along to them. We have described that part of our work in the section called 'Focus Groups'.

There is much in this study that is thought provoking; we hope that whether you are reading this because you are directly affected or because you are involved as a professional that you find it helpful.

# LITERATURE REVIEW ON FERTILITY ISSUES IN ADOLESCENT CANCER

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## **Background**

Although there is professional and academic acknowledgement that the cancer experience during the teenage and young adult years has some unique and complex aspects both medically and psycho-socially (Craft, 2003; Eiser, Greco et al 2004; Kelly, Pearce and Mulhall 2003; Kelly, Pearce and Mulhall 2004; Lewis 2005; Neville 2000, 2005; NICE, 2005; Whyte and Smith 1997; Young et al 2003), the field of teenage and young adult cancer is small across all disciplines when compared to childhood or adult cancer. Limited data about, and attention to, this group of patients have led to them being called the 'Lost Tribe' (Michelagnoli et al, 2003) and to subsequent growing pressure to acknowledge their particular needs in relation to both their medical and their social treatment (Birch, 2005; Hollis and Morgan, 2001; Whelan, 2003; Whiteson 2003, 2005).

It is perhaps a reflection of the improved life expectancy of young people diagnosed with cancer (Birch, 2005; Cancer Research UK, 2003) that increasing attention is being paid to the long term effects, including the implications of potential damage to their reproductive systems (Eiser, 1998). The early literature came almost exclusively from clinicians and scientists trying to understand better the extent and nature of any damage and these disciplines continue to provide the bulk of writing and research. Attention to psycho-social implications has followed, albeit slowly and sparsely. The psycho-social research is commonly of mixed samples of childhood and adolescent cancer patients/survivors (often with little or no information about the proportionate distribution) and this inevitably limits its usefulness. With this in mind, this review draws on that psycho-social literature in so far as it covers fertility aspects as its core focus (though necessarily draws heavily on the few published studies) or as part of a wider study. While it is acknowledged that literature relating to such matters as body image and sexuality may add understanding to fertility issues, these are not included here.

## **Physical effects of cancer-related fertility impairment**

Knowledge of the impact of cancer and its treatment on fertility for those diagnosed in their teenage years continues to evolve but is thought to be affected variously by age at treatment (risk increases with age), type of cancer, type of treatment and gender (males are more affected than females). Its impact will continue to change as treatments themselves are constantly changing. These factors bring their own challenges as those who may be affected often have to cope with a level of uncertainty which may not be wholly resolved, for some, until they try to start a family (Reid, 2000; Self 1999; Wallace and Walker, 2001; Wallace et al 2001). Even those who use fertility preservation services (predominantly males) face a level of future uncertainty as cryopreserved samples do not always survive thawing and treatments themselves remain relatively unsuccessful (CancerBACUP 2005; Davies et al 2003; Green 1997; Pacey, 2006; Picton 2006; Reid, 2000). Prior to trying to conceive, survivors may be coping with the effects of treatment on their endocrine and fertility systems, including delayed pubertal growth, osteoporosis and premature menopause

(Balen and Glaser 2006; Davies et al 2003). Various studies have found that childhood cancer survivors are less likely to become biological parents than are their peers. Although it is not known how much of this is down to matters other than physical ability to reproduce, cancer-related infertility certainly plays a part (Wallace and Brougham, 2005). Eiser (1998) has argued that this may be the most difficult area of medical information to impart, given its uncertainty.

### **Awareness of cancer-related infertility**

There is little research into young people's prior knowledge of fertility impairment as a side effect of cancer treatment but what there is suggests that it comes as a surprise for most (Crawshaw, 2006).

Some studies have found that some survivors do not recall being warned about infertility and it comes as a surprise to them later (Green et al, 2003; Schover et al, 1999; Schover et al 2002a). In a telephone interview study with 32 US childhood cancer survivors aged 19-37 (those diagnosed in their teens were not identified separately) some could not recall being given any information by their professional carers or were unclear what they had been told, others had been told that their status was uncertain and some had been told that any risk was low but nevertheless remained uncertain (Zebrack et al 2004). Some were worrying about things that they did not necessarily have to worry about while others did not know enough to protect themselves from dangerous and potential threats to their health (p695).

### **Fertility services – patients' views**

The limited research specifically with survivors of teenage cancer as well as that with childhood cancer survivors suggests that there is strong support for fertility preservation to be made available, even though there are few facilities currently available for females (Crawshaw et al, 2003; Schover et al 1999; Schover et al, 2002a; CancerBACUP 2005; Shaw et al 2005).

It has been suggested that the use of fertility preservation services among adults with fertility difficulties poses particular difficulties for certain Black and minority ethnic (BME) groups including the Muslim and Jewish communities (Culley et al, 2005; Tomlinson and Pacey 2003) although a US study of childhood cancer survivors found no significant differences for ethnicity or religion (Schover et al, 2002a).

There is a small body of research into the take-up of fertility preservation services. In a US postal survey of 201 males aged 14 to 40 at diagnosis (only 2 were under 18) less than two thirds (60%) recalled being *told* about the possibility of fertility impairment as a consequence of treatment, only half (51%) were *offered* sperm banking and less than a quarter (24%) accepted. Those who had the opportunity to discuss infertility with their oncology physician were much more likely to take up the offer to bank *and* to have greater knowledge about this aspect of their treatment (Schover et al 2002a). This reinforced findings from an earlier mixed gender postal survey of 43 men and 89 women diagnosed before age 35 (16% of whom were aged 12 to 20 at diagnosis) by some of the same research team that found similar numbers not recalling being told about the potential impact of treatment on fertility and/or banking sperm with similar low levels of information (Schover et al 1999).

A more recent study found that there was documentation of less than a third of all eligible males being offered sperm banking in one regional paediatric oncology centre between 1997 and 2001. A postal survey of 45 males aged 13 to 21 who were offered sperm banking and accepted found that two thirds banked successfully. Those who were unsuccessful were younger, more anxious and had more difficulty in discussing fertility than those who were successful. Most found the sperm bank facilities to be adequate though would have preferred to produce their sample at home or on the oncology unit. A small group found the process humiliating. Participants also reported being embarrassed when parents accompanied them to the sperm bank although content that they were present at the consultation when it was initially raised (Edge et al 2006). This reinforced findings from an earlier study based on records that concluded that being accompanied (by a family member or professional) might increase the risk of failure to produce a sample (Bahadur et al 2002). However our earlier study of teenage males and their parents' views about sperm banking found that, while the young men found the process embarrassing, the presence of parents at any stage was helpful *providing* that this was according to their wishes (Crawshaw et al 2003; Crawshaw 2006). Both our study and that of Edge et al reported the need for more written information for patients.

Data collection from more than 300 young people living with teenage cancer and their supporters attending a UK Teenage Cancer Trust conference in 2004 found that around two thirds had not received information or counselling about fertility issues though interest in these matters at the conference itself was very high (Shaw et al 2005).

There is some evidence to suggest that failure to use fertility preservation services (either because it was not offered or because the offer was turned down) is a source of later regret (Broome and Allegretti 2004; Crawshaw 2006; Marik 2004). Similar findings were reported more recently in a questionnaire-based survey with 55 male adult cancer survivors (Saito et al, 2005). The same study reported that although the take up of fertility preservation did not eliminate worries about infertility (which were substantial) the presence of cryopreserved sperm was seen to be helpful to the men's emotional coping.

The potential for positive impact on coping was also highlighted in a practice rather than research based account of the motivations behind sperm banking among adults, Pacey (an adult cancer survivor as well as a scientist working in the field of assisted conception) identified his own motivation to bank as: 'something positive to do at an otherwise emotionally negative time' (Pacey 2003, p327). He speculated that 'maybe simply knowing that their sperm is somewhere safe, irrespective of what decisions they may or may not make about fathering, is a psychological benefit to men' (p328), it may be rational (investment against risk) but may also be 'to avoid regretting it later'; it may be passive (because the doctor told me to do it) or it may represent the chance to wrest back some of the shifted 'locus of control' by squeezing some personal control out of a situation where control has gone (p328). Explanations for the motivations to bank among teenage males in the study on teenage males and sperm banking were all located, not surprisingly, in the desire to preserve reproductive choice for adult life and this was viewed very positively (Crawshaw et al 2003; Crawshaw 2006).

Finally, findings from our earlier study suggested that the professional/patient relationship in fertility preservation discussions made some difference to outcome. Shared gender was of less importance than attributes of respect, warmth, openness in information sharing, friendliness and humour (Crawshaw et al 2003).

The literature on patient experiences therefore suggests that many young people may be prepared to take steps to safeguard their fertility through fertility preservation - even where these steps have to be taken at diagnosis - if they are made aware that it may be threatened by cancer and its treatment.

### **Fertility services – professionals' views**

There is evidence of professional unease and uncertainty around fertility matters in relation to this patient group as well as growing support for fertility preservation to be made available in the light of advances in reproductive medicine (Bahadur, 2001; Cooke et al, 2003; Coulson et al 2001; Crawshaw et al, 2004; Davies et al 2003; Schover 1999; Tomlinson and Pacey 2003; Wallace & Walker 2001; Wilford and Hunt 2003). These fall into various themes including:

- The challenges of communicating with, and obtaining informed consent from, young people in shock post diagnosis
- The moral issues associated with offering a service with no guaranteed success at a time when it is not essential for current treatment
- The lack of research into the impact of sperm banking, particularly for those who are very young or very ill
- The difficulty in developing and maintaining up to date knowledge and skills where referral rates are low
- How and when to involve parents

There is also limited evidence that clinician-initiated screening for fertility preservation may take place on the grounds of medical factors (such as poor prognosis or aggressive tumours) or social characteristics (gay men and those who are HIV positive) as well as any barriers to services associated with time, cost and facilities (Schover, 2002b). Although over 90% oncologists surveyed said that sperm banking should be offered to eligible patients, less than half (48) rarely if ever did so. Additionally, more than a third said that they would not talk to teenagers about sperm banking unless they had spoken to parents first even though their study of teenagers' views (Schover et al 2002a) found that they wanted to be told on their own and then for their parents to be involved.

Several papers have indicated that professionals need better training in discussing fertility related matters at diagnosis, during acute treatment, during remission or through late effects services (Crawshaw et al, 2004; Crawshaw and Hale 2005; Edge et al 2006; Schover, 1999; Wilford and Hunt 2003; Zebrack et al 2004). Different techniques may be required across times and contexts as well as from individual to individual.

As well as training, professionals may need greater awareness and to be more fully informed (Heiney 1989; Thaler-DeMers 2001). Koeppel (1995) drew on her nursing

practice experience with adults to argue that: 'Most patients are unable to think beyond immediate survival at diagnosis; therefore, the health-care team must think ahead for patients and offer them a chance at future paternity' (p311). In a wider paper on the unique service needs of adolescents with cancer, Whelan also argued from his clinical experience that members of the multi disciplinary team (which includes psycho-social professionals such as social workers) need to work together and to be better informed '...must have an understanding of the interaction between adolescence and cancer, be familiar with the experience and implications of treatment, for instance with regard to fertility and other treatment 'costs', and work closely together, joined by an agreed philosophy of care alongside ward nurses and medical staff' (2003;2576).

In another important comment on service provision, Blacklay et al (1998) concluded that late effects services offered an important opportunity to raise fertility matters as: '...understanding the possible effects of chemotherapy on fertility may allow survivors to come to terms with their situation and limit the risk of emotional disappointment' (p341). They cited the need to pay attention to forming adult relationships; parenthood issues; concerns about passing cancer on to their children; children and loved ones getting cancer anyway; ability to carry a baby among others. This was reinforced more recently by Davies et al (2003) who drew on their experience as health professionals running such a service to report that patients rarely initiated sexual and fertility discussions '...but are relieved when given the opportunity to ask questions' (p12). Although the clinic serves childhood and adolescent cancer survivors, they found that it was during adolescence and adulthood that these matters came to the fore and reported that more than half had questions relating to treatment and/or problems with hormone replacement. Questions fell into three main categories: (1) *hypothetical questions* concerning future fertility - these frequently arose well in advance of patients actively contemplating romantic relationships or parenthood; (2) *questions about access to, cost and types of fertility treatments* - these were sometimes accompanied by a request for a fertility test; and (3) *hormone replacement difficulties* - compliance with such medication was worryingly low; questions also indicated that medication may affect sex drive and sexual function. Added to this is an identified need for professionals to address proactively the potential for obstetric complications (increased risks of miscarriage, premature labour, low birth-weight and complications associated with treatment-related cardiac conditions) in advance of a pregnancy so that an obstetric management plan can be put into place (Davies et al 2003; Byrne 1999).

However literature reviews by both Eiser (1998) and Whyte and Smith (1997) point to the dearth of research and writing about professional interventions in general following the acute phase of cancer treatment. While Eiser concluded that there is need for specialist psychological services which would include attention to sexuality and fertility concerns, Davies et al (2003) recommended the need for counselling services and Whyte and Smith remind of the need for a family centred approach. A US study found that support and follow up of childhood cancer survivors by social workers was sporadic and inconsistent. Given that the survivor group may also be geographically mobile and given the trend towards health self care, they argued the need for more targetted 'one'shot' interventions such as workshops, conferences,

survivor celebration events run or facilitated by psycho-social professionals as well as the need for more in-depth follow up for individuals (Zebrack and Chesler 2000).

There is also support for improvements from policy bodies. The UKCCSG has been recommending for some time that it is 'good practice' to offer sperm banking to young men about to undergo potentially sterilising treatments (cited in Kissen and Wallace 1995). This has been reinforced in two subsequent important publications. The multi-disciplinary working party report for the British Fertility Society concluded that this was an area that urgently required greater standardisation as well as specific improvements in practice (Cooke et al 2003). The NICE guidance for improving outcomes in children and young people with cancer recommended that such patients should be made aware of fertility risks and offered fertility preservation where appropriate (2005). However, two studies in North America suggested that professional practices and services varied widely in this area (Glaser et al, 2000; Schover et al, 2002b) and more recent UK studies indicated similar discrepancies here (Wilford and Hunt 2003; Glaser et al 2004).

### **Involvement of parents**

There was limited evidence about the ongoing involvement of parents in fertility matters. Even at later stages in the cancer journey, professionals have found some parents preferring sexuality and reproduction not to be addressed Whelan (2003). Research with teenagers suggests that they expect to be involved and want to receive full information in age appropriate ways right from the beginning and while parents were more interested in information about prognosis, teenagers wanted to know about personal bodily concerns including fertility. (Whyte and Smith 1997)

### **Impact of cancer-related fertility impairment on self**

Most of the studies reported on here refer to fertility matters as one small part of their wider findings. With that in mind, it is interesting that several authors have suggested that potential infertility carries a significant impact and one that increases as the threat to survival diminishes following the end of treatment, including when infertility is not medically predicted (Blacklay, Eiser and Ellis, 1998; Gray et al 1992 cited in Weigers et al 1998; Lozowoski, 1992; Roberts, Turney and Knowles, 1998; Self, 1999, 2006; Zebrack and Chesler 2001). In one of the few in-depth qualitative studies about the young adult cancer experience (albeit reported by parents), Grinyer describes the immediate impact on some young adults when hearing that their reproductive systems might be affected:

'Fertility was for George a bigger issue in the weeks after diagnosis than having the cancer diagnosis because I think he believed that he would survive the cancer diagnosis but he knew that he would almost certainly be rendered infertile through therapy' (Grinyer 2002, p61).

Parents reported that sexual matters and fertility were strong themes to emerge throughout treatment and afterwards (though the majority of young adults in this study had died). A small number of the young men in particular struggled with fertility-related religious and ethical concerns (Grinyer 2001, 2002).

Thaler-DeMers' study of the quality of life among adult survivors of childhood cancer reported similar findings and suggested that 'Treatment decisions made at the time impact the interpersonal relationships, sexuality and reproductive capacity of all survivors' (Thaler-DeMers, 2001, p260).

In their self report questionnaire survey of 500 Dutch mixed gender childhood cancer survivors, Langeveld et al (2003) found that the survivors were significantly more likely than the control group to worry about fertility. This was backed up by a recent CancerBACUP postal survey (2005) of 45 teenagers in which 93% said that they worried about the impact of their cancer and treatment on their fertility – the highest scoring area of concern. Drawing on her campaigning work with the Teenage Cancer Trust, UK, Whiteson (2003) cited fertility as being a significant issue for teenagers and young adults and one that involved 'ethical, psychological and social considerations' (p2691).

There are varying reports of gender differences in impact. Wasserman et al (1987 cited in Weigers et al 1998) found in interviews that female survivors were more likely to report concerns about fertility than were men. In a questionnaire based study of childhood cancer survivors and controls, worries about recurrence and worries about fertility were the two most highly ranked concerns with females more likely to worry than males; the researchers speculated that this may reflect greater cultural pressure on women to have children (Weigers et al 1998). However other studies that looked for gender differences did not find them either in relation to impact or fears of transmission (Schover et al 1999; Langeveld et al 2003).

Only a small number of studies have focussed on fertility matters per se. In a telephone interview study of 32 mixed gender childhood cancer survivors that looked at survivors' understanding of fertility, what it meant to them and how it affected their sexual behaviour, it was found that less than half (41%) were aware of their fertility status and this included ones who had 'found out' through planned or accidental pregnancies (Zebrack et al 2004). Survivors reported concerns about their reproductive capacity as well as a range of concerns about parenting that are returned to below. Their beliefs about their fertility stemmed from what they recalled (or had forgotten) from conversations with parents and/or professionals and from lack of information. This influenced their approaches to sexual behaviour and use of contraception and the researchers concluded that:

'Understanding the sources of survivors' *beliefs* about fertility, as well as *what* they know and *how much* they know, is critical as behaviours are often based upon beliefs as well as upon verifiable knowledge.....some survivors possess or recall information about infertility risks, but this information may or may not be accurate, thereby resulting in undesired outcomes like unplanned pregnancy' (Zebrack et al, 2004, p695).

In a study that focused on the reactions of 15 male childhood cancer survivors (age at diagnosis not specified) to receiving feedback as adults aged 19 to 32 about their probable fertility status, there were variations in emotional responses (Green et al 2003). At the time, some were tearful or depressed but a more common reaction was anger and resentment including irritation at not being better informed about this

possibility. Some thought that it was relatively unimportant. However, follow up suggested that many were able to adapt rapidly to the news and reactions only became more intense for a few who felt, for example, that their manhood had been compromised and that future partners might be deterred. In concluding, the researchers wondered whether the key influence on impact was the personal meaning of infertility at an individual social and cultural context and in doing so echoed the conclusions of Zebrak et al (2004) above:

‘The particular value that patients (and their families and partners) placed on fertility and parenthood determined the level of distress with which each had to contend. In essence they were not really dealing with the same stressor at all’ (Green et al, 2003:148).

Not surprisingly, there were mixed views in this study about what might be an appropriate time to raise fertility matters. The consensus was that it should *at least* coincide with emerging sexual awareness and active interest in romantic relationships (note that this cohort included childhood cancer survivors who may be being told for the first time). There was also common agreement about the ‘...importance of not restricting discussion of fertility risk and its implications to a one-off interview however felicitously timed’ (Green et al 2003 p147) but that it should be returned to on a regular basis. Many said that they would prefer to see the same doctor at follow up clinics and a few would have liked access to a specialist fertility counselling service. This echoed findings from our own earlier study in so far as there was strong support for professionals to be proactive in raising the subject on a regular basis (Crawshaw et al 2003).

### **Effect on romantic relationships**

Several studies have attempted to identify patterns in adult relationships among childhood and teenage cancer survivors that may differ from the general population.

A review of existing work concluded that childhood cancer survivors experience increased anxiety about body image and dating but also fertility and this may contribute to the lower numbers who achieve a long term adult relationship (Schover, 1999). In a later study of adult survivors of childhood, adolescent and adult cancer led by the same researcher, those who were childless reported greater difficulties in finding a mate than those who had children. (Schover et al 2002b). A postal survey of 303 childhood cancer survivors aged 14 to 29 (age at diagnosis not specified) found that some survivors were concerned about their ability to attract a life time partner as a result of their possible infertility (Zebrack and Chesler 2001).

Similar patterns are reported elsewhere. One study reported found that less than a third (32%) of childhood cancer survivors were married/living as married (lower than average), there were heightened levels of dissatisfaction with important relationships and greater fears that potential mates would reject them (Thaler-DeMers, 2001). Two large scale quantitative studies reported a lower than national average for marriage and parenthood but again neither separated out the adolescent cancer population (Rauck et al 1999; Langeveld et al 2003). Langeveld et al also found that more survivors, especially males, were still living in the parental home. They speculated that this may reflect the tendency towards heightened dependency in the

parent-child relationship during cancer treatment and the resulting possibility of it taking some while to redress the balance. This did not appear to be related to age at diagnosis.

There is only very limited data about patterns of disclosure of fertility status in romantic relationships. In Zebrack et al's 2004 US study (reported above), less than half had discussed fertility with a partner and some had experienced tension in the relationship as a result of telling. Some had not told or had delayed telling because they were not or never had been in serious enough relationships; others had experienced rejection or fear of it. Some were married and had not told.

### **Desire to be a parent and reproductive concerns**

All the teenage males in the earlier study in which the authors were involved had thought about being a father prior to becoming ill albeit in differing amounts of detail (Crawshaw 2006). Similarly, a majority (76%) of survivors in Schover et al's mixed gender and age study (1999) were interested in having children and very few (6%) reported a decreased desire for children. Many (80%) thought that their cancer experience would make them better parents and 94% felt healthy enough to make good parents. In the later (2002b) postal survey of 201 males aged 14 to 40 at diagnosis led by Schover, just over half wanted children in the future (perhaps reflecting the male only sample and the higher upper age limit), and that rose to 77% among those who were childless at diagnosis. Again, only a small number reported that cancer had decreased their desire to become a parent. However this study added more detail to survivors' attitudes to parenting. While similar numbers to the earlier study (92%) saw themselves as healthy enough to be good fathers, two thirds (66%) said that they wanted to be parents even if they died prematurely, a similar number worried about living to see their children grow up and nearly three quarters (73%) worried about leaving their partner to be a lone parent. Despite the anxieties of some about their own survival, risks to their children's health (see below) and anxieties attached to the prospect of parenting post cancer, many of the males nevertheless felt that their experience of cancer increased the value that they placed on family closeness and would make them better parents and these perhaps are the key factors that tipped the decisional balance.

Zebrack and Chesler (2001) found a similar range of fertility related concerns in their large self report questionnaire survey of childhood cancer survivors (they did not separate those diagnosed as adolescents) referred to above:

'Concerns about their own children's risk for getting cancer (2.37), getting another cancer (2.30) and the ability to have children (2.30) top the list of survivors' cancer specific worries' (p249).

A later telephone interview study with 32 childhood cancer survivors (which again did not separate adolescents) offered fuller insights into survivors' attitudes towards parenting (Zebrack et al 2004). Some were parents by the time of the study, some were having difficulty conceiving, while others had not (yet) tried. Most wanted children and believed they still had a chance (though 60% were uncertain about their fertility). A minority said they wanted to remain child free. Some had explored alternatives, primarily adoption, but generally their knowledge about alternatives was

very patchy. Some had stored sperm but not tried to use it or any other assisted conception (yet). Several were worried about their child getting cancer or passing it on genetically, including some where the evidence was to the contrary. Some referred to the costs of fertility treatment as an inhibitor. As with Schover's earlier work, they found that those who were parents said that cancer made them think differently about being a parent and some showed resilience, enhanced appreciation for life and perhaps more confidence in their skills as parents (or future parents). A number talked of parenthood making them feel 'normal' and feeling grateful as a result. Zebrack later went on to interweave his own experience as a cancer survivor and parent as well as a social worker and academic in an account that mirrors much of these findings (Zebrack 2006).

There was no research identified to indicate whether concern about a child's health risks influence actual decisions about whether or not to have children '.....although some preliminary evidence suggests that genetic risk rarely deters infertile couples [*i.e. in the wider population – my italics*] from using assisted reproductive technology' (Schover, 1999, p56). Neither is it known whether this differs where there is heightened risk of genetic transmission, though recent increases in numbers seeking pre conceptual genetic advice and a recent consultation conducted by the Human Fertilisation & Embryology Authority (HFEA, Choices and Boundaries, 2005) on whether to extend pre-implantation genetic diagnosis for certain cancers reflect the changing medical and social context.

Schover et al (2002a) found that less than a half (43%) had ever discussed the likelihood of any genetic children having increased risk of cancer with a health professional and only a quarter (26%) had discussed whether their treatment might affect any children conceived afterwards. However there appeared to be a desire to know more that came as people moved into active contemplation of trying to conceive (that may or may not be turned into direct requests for referrals) as nearly two thirds (62%) of those at this stage would have welcomed genetic counselling. In her review of existing research, Schover concluded that, for those who might find themselves unable to achieve genetic parenthood, the experience of this coming as a result of cancer brings its own unique stresses as: 'The most profound loss, though, is the loss of the dream of having one's own genetic child.....Cancer survivors may be told by health professionals, friends or family that they should be grateful to be alive. Their right to grieve over infertility may be questioned' (Schover, 1999, p55).

### **Alternative routes to parenting**

There is little or no research about how differently, if at all, cancer survivors are treated by adoption agencies and/or birth parents involved in 'choosing' adoptive parents for their child(ren) (Schover, 1999). Additionally, there is very little information about how cancer survivors view the possibility of using donated gametes (including surrogacy) and other assisted conception treatments. Schover (1999) suggests that US society looks more favourably on the use of adoption rather than 3<sup>rd</sup> party reproduction with a common argument being that it is selfish to use costly treatments when there are children needing families (p567). She speculated that spiritual issues as well as personal preference and desire for a biological child may be deciding factors and that:

'On the one hand, a brush with mortality may increase the wish to have one's own biological children. On the other hand, concern about inherited cancer syndromes or about the impact of cancer treatment on offsprings' health may make donor gametes more attractive' (Schover, 1999, p57).

Financial constraints over accessing assisted conception treatment and so on may be an additional influential factor as 'For some couples, becoming parents in the face of infertility may simply not be affordable' (Schover, 1999, p55). Given that the majority of assisted conception treatments in the UK are only available through the private health care system, this may be an influential factor here too.

However, in their 2002a study (see above), Schover et al found that whilst 20% of those surveyed were having difficulty in conceiving, less than 5% had sought fertility treatment. They further reported that the majority would prefer to have their own biological children but, if they did find themselves infertile, 61% said that they would consider adoption while only 23% would consider donor insemination.

## **Conclusion**

The literature on fertility and sexuality aspects of living with cancer diagnosed as a teenager and young adult and its effects has to be seen against the backdrop of the relative dearth of research and writing that is specific to this group. It remains a limited area of work and is typically only included within research and writing that is focussed on other aspects of the cancer experience and including those who are younger. The small number of studies that take fertility as their primary focus have, to date, been restricted to either a particular experience (for example sperm banking) or to the resulting concerns of survivors, particularly as adults, and the majority have not restricted themselves to the teenage and young adult group. All have concluded that there are significant aspects that warrant both further study and additional professional services. These include the lack of consistency in the provision of fertility preservation services; that information about cancer-related infertility at all stages can be scanty or lacking; that survivors are concerned about whether or not they will be able to have children, whether or not their children be affected by their treatment and/or will go on to have cancer themselves. There is also some evidence to suggest that some in this group have concerns about being able to attract and keep a romantic partner, especially if they tell them about their potential fertility impairment.

No studies have been identified that seek to understand the experience of moving from adolescence through to adulthood in the knowledge that fertility may have been affected.

Existing work suggests that there is growing awareness by professionals and others of the potential for concern about fertility among this group and that this concern may be present to some degree from diagnosis onwards. There are indications that adolescent and adult cancer survivors themselves are increasingly vocal about their ongoing concerns about fertility as part of their overall experience. This is no doubt affected in part by raised awareness in the public arena about infertility in general and, to a lesser degree, cancer-affected fertility.

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# INTERVIEW STUDY

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## METHODOLOGY

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### **Background**

An earlier study by the same researchers that involved two of the regional paediatric oncology sites (Leeds and Newcastle) involved in the present study had included a qualitative research element with teenage males aged under 18 at diagnosis and their parents (Crawshaw et al 2003; Crawshaw 2006). This involved interviewing a small number of young men and their parents (either separately or together according to the wishes of the young men) about their experience of decision making around sperm banking. A key aim was to test the feasibility of recruiting to, and obtaining appropriate data from, a study using such a methodology. Take up rates were high, though predominantly from one of the two sites. However the numbers eligible to be approached were lower than anticipated. The gender and age of the interviewer did not appear to be an inhibitor. Participants were drawn from a diverse group according to socio-economic circumstances, educational achievement, ethnicity and disability, were generally articulate and reflective about the subject and showed high levels of recall.

Where the findings from interviews with the young men and their parents reinforced findings from other parts of the study – namely postal surveys of practices within regional paediatric centres and assisted conception units; and qualitative interviews with a range of professional staff – some tentative conclusions were drawn. Those of particular pertinence to the current study included:

- Where choice was offered, for example around the inclusion of parents, this was valued. The lack of choice sometimes, but not always, created difficulties for the young men.
- The need for additional sources of information was identified.
- High levels of satisfaction were recorded about the fact that sperm banking had been made available.
- The consent process had the potential to cause difficulties especially questions about disposal of banked sperm in the event of death.
- There was a lack of professional attention to the aftermath of sperm banking and ongoing impact of potential fertility impairment.

### **Development of research questions**

Whilst the intention of the qualitative element of the earlier study was, in part, to test the feasibility of recruiting for face to face interview in this sensitive area of research, the task in the present study was to develop an *understanding of the experience of coping with potentially impaired fertility when moving through teenage years to adulthood following a cancer diagnosis*. Key research questions were:

- Does a diagnosis of cancer in the teenage years which is accompanied by the information that the cancer or the treatment might impair fertility have an impact on the process of growing up? And if so, what are the ways in which those involved are affected?
- Are there any aspects that appear to be related to gender?
- How far does the way in which services are currently provided help or hinder these experiences?

## **Study design and rationale**

The study was designed to gather the views through single face to face interviews of up to 40 individuals (up to 10 each of teenage females, teenage male, adult females and adult males) who met the following criteria:

- had been diagnosed with cancer as teenagers and were now either teenagers or adults (the age span being 13 and under 21 in the 'teenage' group; and 21 and over in the 'adults' group)
- had been told that their fertility may be affected
- were off major treatment regimes.

NHS MREC and R&D approvals were obtained.

Participants were recruited through three regional paediatric oncology units in the North of England (Leeds, Manchester and Newcastle) which drew on an ethnically and socio-economically mixed population.

Interviews were tape recorded (with permission), transcribed and analysed using the computer assisted package AtlasTi.

In order to be valid, methodology needs to be rigorous and to have clear rules, principles and procedures and it also needs to be 'fit for purpose' (Robson 2002). The experience from the earlier interview study and elsewhere suggested the appropriateness of a qualitative approach given its potential to add to understanding by mapping a range of experiences, meanings, interpretations and attitudes across different encounters, contexts and time (Bryman 2004; Grinyer 2001).

The need for an exploratory approach within a qualitative research methodology paradigm was located in the fact that no other research with this client group on this subject area had been identified. It was therefore of particular importance that the approach did not constrain the ability of participants to give voice to their experiences in this intimate and potentially sensitive area. A qualitative approach enables access to 'knowledge' of personal meanings, experiences and actions from within participants' social activities and socially constituted meanings. It has argued that children and young people are the best narrators about their experience of having cancer hence the decision to focus on those directly affected (Woodgate 2001).

By adopting a loose structure to interviews, it was anticipated that this would offer the flexibility to adapt to the participants' needs and allow them to retain more control over the pace and style of their participation (Gubrium and Holstein, 2002; Reinharz 1992; Schmidt 2004; Woodgate 2001).

A grounded theory approach to data collection and analysis emphasises the systematic discovery of theory *from* data in order for theories to remain grounded in observations of the social world rather than being generated in the abstract (Robson, 2002; Strauss and Corbin, 1998). This therefore appeared to be an appropriate approach to take in this study. Any issues and questions to emerge from the data during the research process itself would therefore not be derived *from* theory but developed in the hope of generating theory on which hypotheses could be developed in, or for, future studies. The task at this stage was therefore to begin to draw the map of the emotional and social experiences and interpretations of those affected onto which future researchers can fill in the contours and redraw the lines as understanding builds further.

There are debates around frequency of contact in studies that seek to get at meaning and experience. However there are also ethical concerns about extended exposure in the research process where there is no existing research from which to draw indications of possible risk to participants. This is perhaps especially so when the subject matter is sensitive (Mauthner et al 2002). Collaborating health professionals and researchers therefore agreed on single interviews. In order to further maximise the participants' control over the process, all were invited to choose a day, time and place for the interview and were free to have supporters there if they wished. The length of interviews was also free for the participant to determine though an anticipated time of 60-90 minutes was stated at recruitment in order for participants' to have some idea of the likely time commitment.

## **Sampling**

The sample design needed to obtain a cohort most likely to provide the data from which to achieve the aims of the study (Mason, 1996). The aim was therefore not to produce an empirically representative sample or to test for causality and a theoretical or purposive sampling approach was employed.

Such an approach requires that any useful theoretical constructs that may aid data analysis have to be identified and considered at the sampling stage if qualitative analysis is to go beyond simply aggregating acquired data and noting patterns to arrive at the consideration of theoretically informed social explanations arising from the data analysis. The following two key constructs were drawn on:

- (i) that the transition to adulthood may influence attitudes to, and experiences of, sexuality and fertility for teenagers diagnosed with cancer
- (ii) that gender may influence such attitudes and experiences

This did not mean that transition to adulthood and gender *would* be important variables or that fertility impairment would *necessarily* present an emotional and social challenge, but that these were anticipated to be of possible importance.

Theoretical sampling requires the researcher to be alert to the possibility that their theoretically informed design could lead to them looking only for data to support their constructs. Consideration therefore needed to be given at all stages to the possibility that there were unexpected characteristics of participants, the experience and the context that could be hidden by an exclusive focus on age and gender. In this way,

the aim was to see whether there were experiences and explanations which did not fit the tentative ideas and could not readily be explained within the developing analysis.

Finally, given the high physical and emotional demands of cancer treatment and the study's focus on the experience of coping with possible fertility impairment rather than treatment itself, it was agreed with contact consultant paediatric oncologists at each site (and approved by MREC) that individuals would not be approached during any major phase of treatment.

### **Age spread**

Attitudes to sexuality and fertility may be formed during childhood and remain fluid through adolescence and *at least* until the attainment of adulthood. This informed the decision to sample from both teenage and adult age groups. By including one group who were still in their teens and one who were aged between 21 and 30 (but diagnosed in their teens) and inviting both groups to reflect on their past experiences (retrospective exploration) and current experiences (contemporary exploration) the aim was to add to understanding of the experience over this transition to adulthood period.

The accounts that people give are, of course, dynamic and this too has to be acknowledged. They do not explain actions 'once and for all' but are 'true' for the time and place within which they are conveyed. As such, they may change situationally as well as over time. Given the range of ages of those taking part and the fact that diagnosis would potentially occur between 13 and 19, participants would also be at different time intervals away from diagnosis and treatment.

Fertility preservation is typically only available post puberty. None of the centres involved had offered sperm banking to any males younger than 13. Although there is the potential to store testicular and ovarian tissue and oocytes, this is still experimental and none of the participating units were offering this at the time of the study; it also involves a different medical and legal process. The lower age limit was therefore set at 13.

Of course it is not straightforward to determine when someone has attained adulthood and there are a variety of measures of adulthood, some of which are context-bound. The use of 21 as the age above which participants would be classified as adults was arrived at because, although 18 is the age at which young adults in England are deemed to achieve the age of legal majority and the attainment of civic responsibilities, the progress towards full physical and social adulthood is typically still underway. Additionally, the use of 18 as the dividing line between the two age-related cohorts would reduce the potential pool of recruits from those diagnosed in their late teens as some of this group would still be in active treatment and therefore not eligible for recruitment.

Although the 'adult' group had made the transition to adulthood in a different historical time to that in which the teenagers were approaching it, this was felt to be unlikely to impact significantly for the purposes of an exploratory study. The upper

age limit of 30 was arrived at in order to minimise the historical differences while still drawing on the experiences of those in peak contemplative child-rearing age groups.

## **Gender**

There are *gendered* aspects to the experiences of adolescence, adulthood, sexuality and that of fertility. There are also differences in services. For example, fertility preservation services are rarely available to teenage females given their experimental and physiologically complex nature. The implications of not having access to fertility preservation services for females were likely to be an area for exploration as were the experiences of the availability of sperm banking services – as well as any ongoing gender differences and similarities.

## **Size of sample**

Mason (2002) suggests that sample size should be sufficient to help the researcher understand the social process being studied and: ‘....generate data to explore processes, similarities and differences, to test and develop theory and explanation to account for those similarities and differences, rather than to make statistical comparisons between the units themselves within the range and to infer causality on that basis’ (p97) – a rather vague notion made even more difficult where there is little or no existing research. As the interviews were intended to help make sense of the experience of fertility impairment within the life experience and biography of each individual and to see how far this resonated or differed with others, the use of a mixed characteristic sample (age and gender) meant that the numbers within each cohort needed to be sufficient to allow for comparison by age and gender as well as allowing for whole group analysis. In the absence of any information to suggest that there should be different sizes within the sub-groups, the decision was made to recruit equal numbers to each by age and gender.

In determining any sample size, however, one also has to be alert to practical considerations. There was a finite time for recruitment and interviewing and, given the sensitivity of the subject matter, it was felt more appropriate to be raised in face to face medical appointments at the hospital rather than by letter. The approach was to be made by a senior doctor involved in their care and therefore well known to them. This therefore brought its own timescale as some eligible patients were only attending for follow up at yearly or two yearly intervals. The rate of recruitment was anticipated to be slow.

## **Involvement of parent, carers or partners**

As the primary aim of this study was more concerned with broader accounts of individual experiences across genders, the involvement of parents, partners or others in the interviews was solely at the discretion of the individuals being interviewed. Where the potential participant was aged under 16, their parent was required as a condition of the MREC approval to give their written consent to his/her participation. Understanding of the role of parents, partners, their experiences, the impact on them and the impact of them and of family dynamics on the young person’s experience remains one that warrants further research.

## **Geographical spread**

The three centres involved in the study were located in the North of England. As a large part of the treatment for childhood and teenage cancer is carried out in regional centres, their catchment areas are widespread both geographically and in terms of socio-economic class. Two of the centres also had significant ethnically diverse catchment populations.

## **Developing the information brochures**

The Information Brochures and accompanying letters were developed from those used for the earlier study. A separate brochure was produced for parents of those aged under 16.

## **Recruitment strategy**

Recruitment was through three regional paediatric oncology unit sites. Research sisters identified eligible patients and senior doctors made the actual approach. Those who agreed to consider participation (for under 16s, only with their parents' permission) were given an information brochure and an 'agreement to contact' form to complete and return to the researcher conducting the interviews (MC). A reminder letter was sent by the research sisters to all who had agreed to consider participation approximately 2-3 weeks later. In keeping with a confidential approach to recruitment, the researchers therefore only became aware of participants' identity once they provided their written willingness to take part.

By the end of 2004, 60 eligible patients had been approached of whom only 6 (10%) refused outright to consider participation. In 2005, 31 were approached of whom only 3 (10%) refused outright to consider participation. Recruitment to some categories ceased towards the end of this year. In 2006, 5 were approached of whom 2 (40%) refused outright to consider participation. Recruitment to more categories had ceased by this time.

## **Developing the informal topic guide**

*A topic guide was developed through:*

- (i) trawling the literature
- (ii) identifying key areas of experience from interviews with the teenagers in the earlier study
- (iii) identifying areas of professional concern or interest from interviews with professionals in the earlier study,
- (iv) informal dialogues with health and social care professionals in the field

The aim was not for the guide to dictate the sequence of the interviews but to facilitate a well informed attentiveness and dialogue on the interviewer's part. It is included in Appendix C.

## **Attending to power dynamics**

Given the nature of the subject matter, it was crucial that attention was paid to the potential for barriers or collusions to be set up in the interview. Participants were also unlikely to have any direct gain as a result of taking part and this too needed to be acknowledged.

Those who responded were therefore:

- Contacted quickly on receipt of their 'agreement to contact' form and offered a speedy interview date so that *they* could then determine the speed of contact rather than experience anxiety or undue rumination during any waiting period
- Offered clear and explicit information about confidentiality both at the consent stage and throughout. However there was also a need to be alert to participants' potential wish to use their contact with the researcher to lead to dialogue with their professional carers and this was facilitated where the participant requested this.
- Allowed to be interviewed in a setting of their choosing and to terminate the interview at any stage
- Offered a style of interview that aimed to encourage a more egalitarian co-operation with the discourse developing through the dialogue between researcher and participant rather than the researcher always taking the lead.

Participants were asked for permission for the interviews to be tape recorded and transcribed and all were offered a copy of their transcript. Fourteen (three teenage males, seven teenage females and four adult females took up this offer). Finally, all were offered a summary of the final report with the option of requesting the full report.

## **Consent process**

It was agreed that the researcher would take participants' consent immediately prior to interview. The rationale for this was that the researcher was better informed about the study and therefore better able to ensure that recruits were fully informed. It also reduced the potential for them to 'please' their treating doctor, better ensured their confidentiality and anonymity and separated treatment from research involvement in a study where their existing professional supporters did not 'need to know'.

## **Approach to interviewing**

As only one researcher (MC) was undertaking interviews, there was less potential for variability in approach though, conversely, less opportunity to check for interviewer bias through the scrutiny of transcripts of different interviewers. The need for close attention to the latter was paramount.

Although adopting a looser structure to interviews fitted the grounded theory approach, so was attention needed to when and how it was appropriate for the interviewer to probe beneath surface appearances in order to seek more accurate understanding of experience (Bryman 2004; Shephard 2004). However, the associated danger for some of divulging more than they wanted to because of getting 'carried away' in a face to face interview – what Shaw (2003) has called the 'risk of

unwitting disclosure' (p15) – also needed to be guarded against. One of the challenges therefore was to decide how and when to pick up on the threads of a narrative and invite deeper exploration. For example, where someone offered a full and lengthy narrative (or even a very factual one, delivered fairly mechanically), the decision had to be made by the researcher whether it would be more fruitful to work through that narrative with the participant chronologically in order to tease out, unpack and explore the threads more fully (unpacking) or to start by exploring the most recent areas and then work back. The aim always was to try to link or connect the various themes in a meaningful way (i.e. meaningful to the participant) in order to encourage full(er) reflections and details. This is the skill of keeping the narrative unfolding without imposing either one's needs/wishes as researcher. At the same time, the need to be reflexive was imperative as a way of trying to understand the impact of the encounter on researcher and vice versa. Finally, the interviewer had to be alert to the need to remain in role – MC was present as a researcher not in a therapeutic role so had to be careful not to invite the opening of issues that might remain unmet and distressing when the interview was over.

Given the sensitivity of the subject matter, the need to pay close attention to the potential for distress and/or need for therapeutic follow up through participation in the study was identified. Arrangements for a range of services to be available to any participants were made for any who needed follow up from the interviews. Finally arrangements were made about alerting relevant services, with the participant's permission, should any examples of bad practice, poor practice or abusive practice be disclosed.

### **Recruitment process and issues**

Interviews were conducted between May 2004 and July 2006 by one of the researchers (MC). Due to the slow rate of recruitment in the early stages, MREC approval was later obtained for allowing telephone interviews and written responses as well as face to face interviews. In fact, very few took up these alternative options.

Additionally, an article about the study in the Candlelighters newsletter in September 2004 prompted several responses from people interested in sharing their experiences who were not eligible to take part (because they had been diagnosed as children). All were invited to complete written responses and their information was used as background material for the study though not included in the formal analysis.

### **Written records**

Field notes were made following each interview in order to capture the emerging experience of undertaking interviews and to aid later analysis.

Although this was a qualitative study, it was anticipated that it would be helpful to log some quantitative results onto Excel in order to build a profile of those taking part according to key measurable characteristics as an aid to qualitative analysis. These included biographical information about type of cancer; age at diagnosis; length of time between symptoms starting and diagnosis; age at interview; religion; prior impairment; position in family; number of siblings; living situation at time of diagnosis and at present day; education/employment situation; highest educational level to date;

when told about fertility; choice about who present when told; length of time between being told and banking (if applicable); choice about accompaniment to sperm bank (if applicable).

### ***Transcripts***

All the participants, and hence their transcripts, were given a unique identifier. The codes were kept securely and only available to the researchers. Transcripts were checked against the original recording and amended where necessary.

### **Analysis**

Qualitative data is often poorly structured and extremely bulky. Thus, in order not to jump to unfounded conclusions, rigorous processes of data reduction and conclusion drawing needed to be employed. Analysis of the data involved breaking them down, reconstructing them, examining them for patterns and shapes, summarising them, representing what the researchers think they say and then communicating that to others. It is the constant comparison that informs the sifting into themes, concepts or similar and the search for possible relationships between them (Bryman and Burgess 1994; Miles and Huberman 1994).

Analysis will typically include 'thick and thin' findings – i.e. those which report facts and are independent of intentions or circumstances or interpretations (Denzin 1994) and those which include the context of the experience and its meaning to the participants. This study produced more of the latter though the 'story' of the process of the cancer journey in so far as it was affected by fertility matters as *recalled* by participants was an important aspect of analysis as well as their, and the researchers', interpretations of that experience.

### ***Coding***

Coding allows the researcher to sort and categorise the data and is the process of collecting responses from the transcripts into groups which are *either* like one another (e.g. coping strategies, responses of parents) *or* which refer to a particular point in the process (aspects of the time around diagnosis or fertility testing). The codes are therefore descriptors - retrieval and organisational devices that allow the range and frequency of categorised responses to be classified/identified for the whole cohort and for any sub groups (Miles and Huberman 1994). Coding is, of course, not value free. The devising and assigning of codes is influenced by the personal and social assumptions of the person undertaking this task as well as their prior reading of relevant literature and is therefore subjective. Acknowledgement of this, as well as the process increases credibility (Shaw 2003) as does the use of a second researcher coding the same data independently (Bryman 2004).

In order to start the process of content analysis of the transcripts, the first researcher read through all the transcripts and provided a cross section for the second researcher to look through. Both researchers then independently undertook a first sift through without pre-defined categories in order to try and find possible patterns, critical terms, key events or themes. Potential key themes and sub themes were identified and a preliminary coding frame agreed with the possibility of codes being

added as the analysis unfolded. Regular discussion took place between the researchers as the analysis unfolded.

### ***Use of computer assisted qualitative analysis packages***

Coding using the computer assisted qualitative analysis programme AtlasTi was then undertaken with regular reviews of the codes and of the study aims and purpose. Once this was complete, the data were analysed in detail as the search for patterns moved towards its final stages.

Qualitative research can look for three main areas and this has great potential in assisting analysis:

- *the story* - the participants' stories about the process of what happened to them – in this case, receiving a diagnosis, being told that fertility may be affected, possibly using fertility preservation services and having ongoing professional and non-professional contact around fertility issues in relation to cancer
- *the impact* – the effect that this had on them in different stages and in different situations
- *managing the experience* – how they coped and what helped or hindered that coping

Participants were also able to articulate suggestions about service improvements.

In undertaking this stage of analysis, it remained crucial to be careful to report experiences and interpretations *as expressed by the participants* and to make clear when the researchers were offering their own analysis. Qualitative research is not aiming to uncover some objective 'truth' and there is no 'right to reply' for anyone that they refer to, for example, parents or professionals. This is not about what they *actually* were told or what *actually* happened; it is about their perception of it in retrospect – and, where appropriate, the researcher(s)'s analysis of why they think this was.

### **Production of the final report**

The format and conclusions of the final report were agreed between the researchers.

### **Advisory Group**

It was decided to appoint an Advisory Group to the study in order to:

- Offer an additional perspective on the research design and process
- Provide the forum for informed discussion on issues emerging from the analysis
- Assist with the dissemination and implementation of the findings

Given the multi-disciplinary and inter-agency context for providing services in relation to cancer-related fertility, membership was drawn from medicine (paediatric oncology and reproductive medicine), nursing, reproductive science, clinical psychology and social work together with the person who had chaired the influential BFS multi-

disciplinary working party which produced 'A Strategy for fertility services for survivors of childhood cancer' (Cooke 2003) . Each were figures of some influence within their own field. The need to take account of the regulatory framework for fertility preservation services led to decision to include a representative from the Human Fertilisation and Embryology Authority. The key role of the voluntary sector was reflected in the appointment of a representative from the Teenage Cancer Trust. The researchers discussed the relative merits of establishing a separate user advisory group or incorporating their representation in the Advisory Group and decided on the latter. An adult male and female teenage cancer survivor with an interest in fertility issues were therefore appointed. Membership is included in Appendix D.

## SAMPLE

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### Recruitment

Thirty eight participants were recruited to the study between 2004 and 2006. Additionally, four adults approached the study independently to offer to participate who were not eligible because they were diagnosed as children. All agreed to provide written information about their experiences which was then used as background information to the study.

Three males and one female who agreed initially to participate then withdrew prior to interview. None offered an explanation for their withdrawal.

The majority of those being approached agreed to consider participation though there were also some reports of mixed reactions. Whilst some were very enthusiastic about taking part, others showed distress at the subject being raised and some indicated that it was too private a matter for them to discuss in a research study. The medical staff involved were surprised on occasion at the reactions of patients that they knew well.

When one looks at recruitment patterns according to *recruitment site*, there were variations in the numbers being approached and in the take up rate. Overall take up rate was reduced by the low take up rate from one recruitment site although there were also variations across all the categories within each of the centres.

**Table 1: Numbers approached and interviewed by centre and year**

	2004	2005	2006	Total approached	Overall take up rate	Total No Recruited through the centre
Centre 1	29	7	0	36	50%	18
Centre 2	20	11	3	34	35%	12
Centre 3	11	13	2	26	12%	3

There were also different patterns between the two age groups. In 2004, the take up rate among adults was low – indeed it was less than half the take up rate among teenagers even though equal numbers of adults and teenagers were approached. If recruitment had stopped at this stage, we would have been reporting difficulty in approaching adults (and indeed that was a major concern at that stage). By the end of 2005 (a full year of recruiting) that situation had reversed with the teenagers (and especially the teenage males in 2 out of the 3 centres) proving the most difficult to recruit and pulling the overall take up rate down. By the end of the recruitment phase, the overall take up rate by age and gender was as follows:

- Teenage males – 24%
- Teenage females – 36%
- Adult males – 40%
- Adult females – 40%
- Overall take up rate for teenagers – 29%

- Overall take up rate for adults – 40%
- Overall take up rate for females – 38%
- Overall take up rate for males – 31%

## **Interviews**

Single interviews lasted between 1 and 3 hours. One teenage male and teenage female had their mothers present for part of the interview; two adult males, one adult female and one teenage female had their parent or partner present for some or all of the time. Over half the interviews were conducted in the family home (21: 55%), eleven (29%) were carried out in the hospital where they were treated, four (11%) were conducted over the telephone and one was conducted elsewhere. One participated through a written submission. All of these were according to the choice of the respondent.

## **Profile of participants**

Respondents had a range of diagnoses and these have been grouped as follows:

- 14 (37%) were from the sarcoma group
- 9 (24%) were from the lymphoma and Hodgkins group
- 6 (16%) were from the leukaemia group
- 5 (13%) were from the germ cell group
- 4 (11%) were from the brain group

The breakdown by age and gender of participants was as follows:

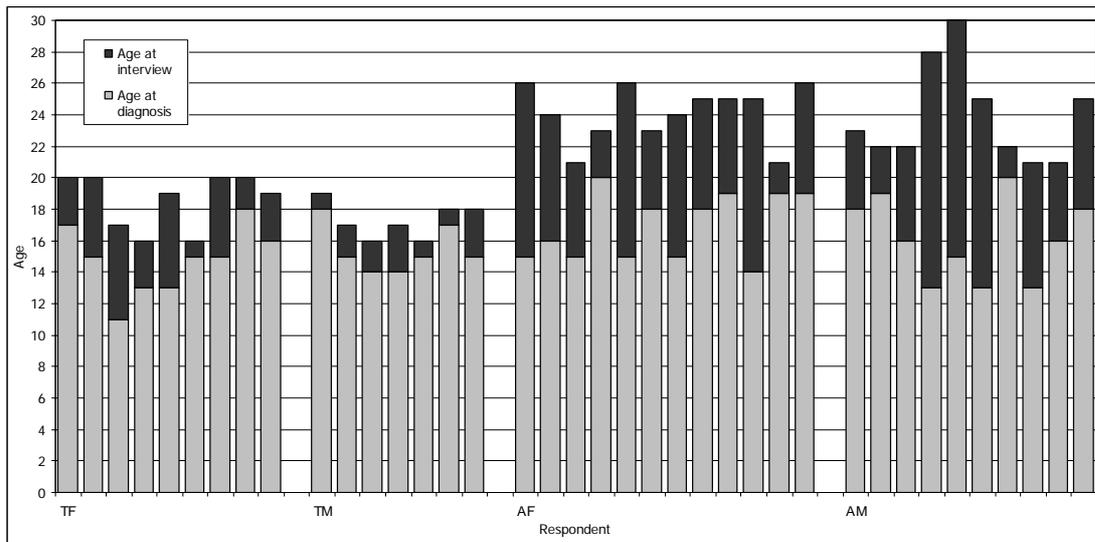
- 7 teenage males
- 9 teenage females
- 10 adult males
- 12 adult females

The overall age range at diagnosis was 11<sup>1</sup> to 20 years (median age: 15 years) and at interview was 16 to 30 years (median age: 21 years). The median age for teenagers was 15 years at diagnosis and 18 years at interview; for adults was 16 and 24 years; for females was 15 and 21 years; and for males was 15 and 21 years. The median length of time since diagnosis among teenagers was 3 years (range from 1 to 6 years) and amongst adults was 7 years (range from 2 to 15 years) (see Figure 1).

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<sup>1</sup> Included in study because re-diagnosed at 13 and told at that point about possible fertility impairment

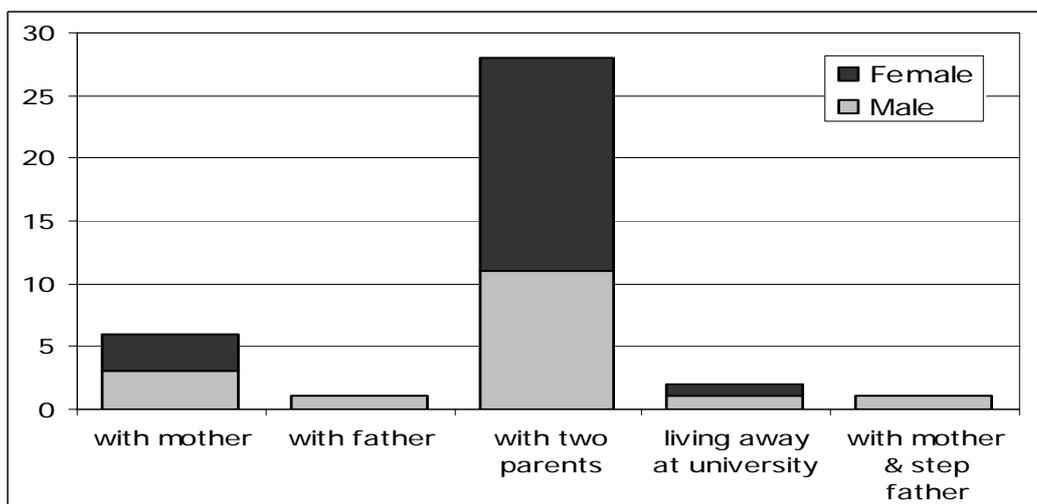
**Figure 1: Ages of respondents at diagnosis and interview by group**



Thirty four of the participants were White British, one was Hindu Asian, one was Muslim Asian and two were of white Anglo-mainland European heritage. One had a prior heart condition and two had prior minor impairments. Two identified themselves at interview as lesbian.

At diagnosis, 28 (74%) were living in a two parent household and a further two were away at university but from a two parent household, seven were in households headed by a lone parent (6 female headed and one male headed), one lived with his mother and step father (see Figure 2).

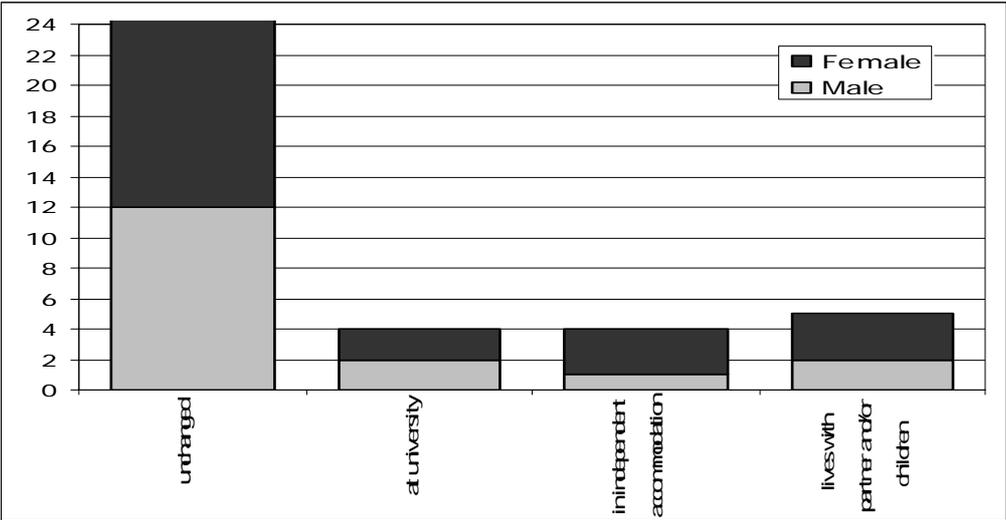
**Figure 2: Living situation at diagnosis**



Three were only children, almost half (43%) were the oldest child in the family and just over a quarter (26%) were the youngest child. The majority (79%) had one or two siblings. Two had had new siblings born between diagnosis and research interview.

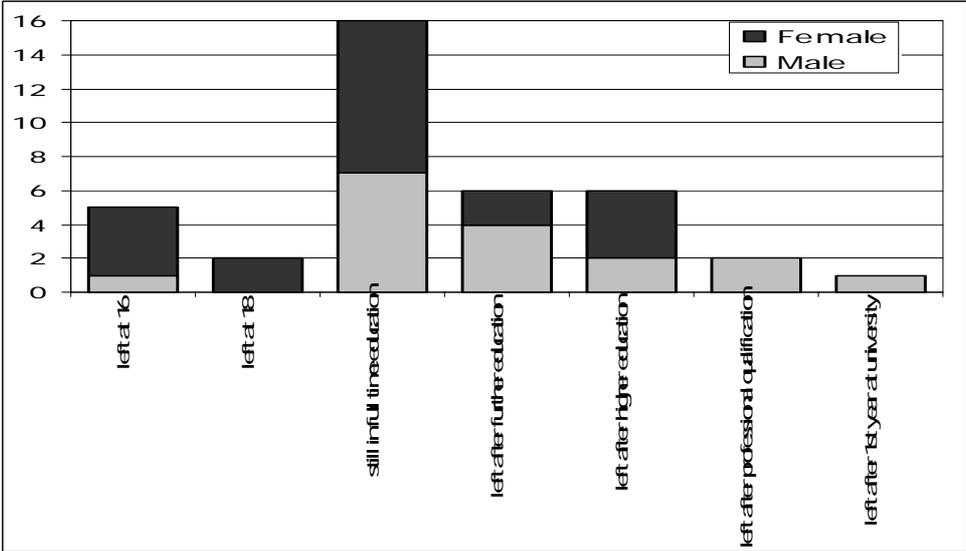
At the time of the interview, just over two thirds (66%) were still in the same living situation (though two had moved out and back again in the intervening period), four (11%) were away at university, four (11%) were in independent accommodation, and five (13%) were living with a partner and/or children (see Figure 3). Eleven (29%) described themselves as being in a permanent relationship though some were not living together.

**Figure 3: Living situation at interview**



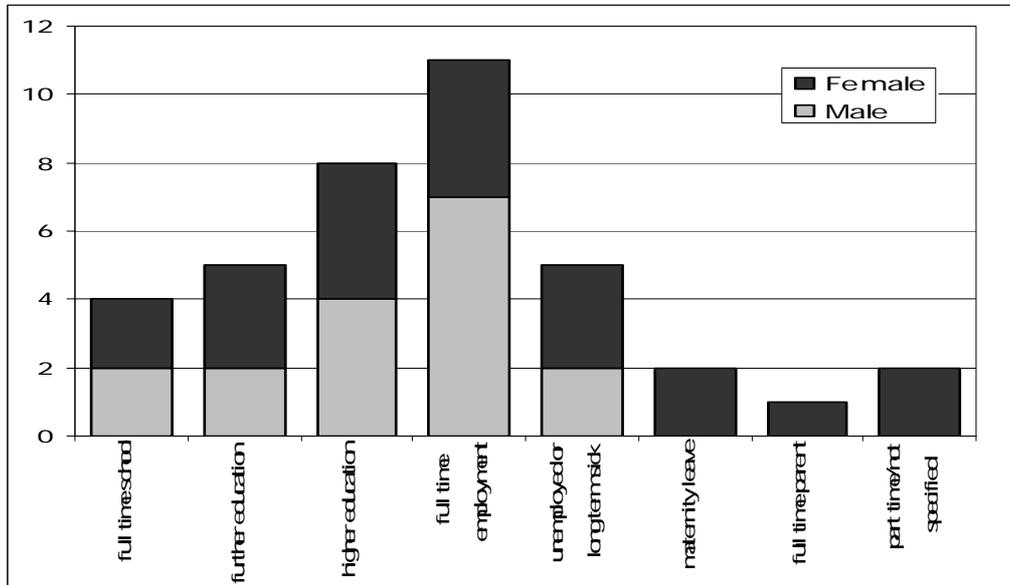
With regards to their educational profile at diagnosis, the majority were in full time education (including some in further or higher education), three (two females and one male) were in employment and one did not specify. At the time of interview, the largest group were still those in secondary or tertiary education (17:45%). Of the remainder, five (13%) had left education at age 16, two (5%) at age 18, six (16%) after completing further education courses, five (13%) after graduating from university and two after completing post-graduate training. One was getting ready to return to university after having taken some time out (see Figure 4).

**Figure 4: Highest level of education by time of interview**



In addition to the seventeen (45%) who were still in education at the time of interview, eleven (29%) were in full time employment, five (13%) were either unemployed or long term sick, two were on maternity leave and one was a full time parent and the remaining two were working part time or not specified (see Figure 5). Those in employment were in a range of jobs from unskilled, semi skilled through to professional employment.

**Figure 5: Education and employment situation at interview**



Five of the sample had become parents between diagnosis and the time of the interviews (none were parents prior to diagnosis). One adult male, one adult female and one teenage female each had one child; one adult male had two children; one adult female had one child and was pregnant with another. Two of the females with children still lived in the family home.

# UNDERSTANDING AND EXPERIENCE OF THE PROCESS OF BEING TOLD ABOUT FERTILITY MATTERS AND/OR USING FERTILITY PRESERVATION SERVICES

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## **SECTION 1: OVERALL EXPERIENCES**

The need to manage the impact of potential cancer-related fertility impairment can start from as early as the point of diagnosis. As some treatments pose a risk to fertility, some patients will be advised of this alongside other side effects and some will be offered access to fertility preservation services. This section therefore looks at the experience of these early stages. It identifies the levels of prior knowledge about cancer-related infertility and the numbers who were offered access to fertility preservation services. It goes on to explore the impact of being told about fertility matters at around the time of diagnosis and views about whether to be told and when. It then covers the level of understanding and recall of the information imparted – including interpretations of what was said - as well as factors that appeared to affect understanding and recall. With this as a backdrop, the section moves on to look at the decision making process for those who were invited to use fertility preservation services, including the role of parents and professionals in that. Next, the experience of using fertility preservation services is explored in some detail from the experience of making the journey to the sperm bank, through the consent process and the sperm procurement process to storage. This section relates solely to the experience of males as no females in this study used fertility preservation services.

### **Level of prior knowledge that fertility may be affected by cancer or treatment**

There was very little prior knowledge of this side effect. One mother and one father – both the parents of females – and one of the females who was older at diagnosis raised it at diagnosis. Another female knew about it beforehand from a television programme but did not ask about egg freezing. None of the males were aware beforehand and none of their parents raised it.

### **Those who were offered the opportunity to preserve their gametes and their response**

#### ***Males***

All the males except one were invited to bank their sperm although one agreed but did not have the service arranged. His mother was later told that his rapid deterioration made immediate entry into treatment a priority. Three of those who were invited to bank decided against.

Twelve tried to bank (six (86%) teenagers<sup>2</sup> and six (67%) adults) of whom eight were successful and four were not. Of the eight that successfully banked (ages 15 (4), 18 (2), 19 (1) & 20 (1)), four did so on two occasions and one was unsure whether he had banked once or twice.

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<sup>2</sup> As stated earlier, 'teenage' and 'adult' refers to age at interview only; all were diagnosed as teenagers

Of the four that tried but failed to bank, three failed to ejaculate (including one who failed on two occasions) and one produced an azoospermic sample.

All but one of those that failed to bank had not had *opportunity* to bank made available until they had already entered treatment (though one had been told about it at around diagnosis) with the other being overlooked until being rushed through immediately prior to commencing chemotherapy. Two of those in treatment at the time of trying to bank reported very good levels of professional support around banking. One said that great care was taken to work with him until he felt able to try with the designated nurse calling in frequently once treatment was underway. Sadly, his was the sample that proved azoospermic. Another tried to bank twice over a period of several months, again with good levels of professional support, but failed to ejaculate each time.

None in the study thought that their treatment had been unduly delayed or affected by their participation in sperm banking.

The only one who was not invited to bank has never received a satisfactory explanation about why not. He believes that he would have taken up the offer if it had been made.

### ***Females***

As one might imagine, there was more variation among the females than the males in the availability of choices in relation to fertility preservation.

Most, but not all, the females remembered being told at diagnosis that their reproductive system might be affected. Three remembered being given the opportunity to freeze their eggs. This did not appear to relate to their age at diagnosis (only two of the seven aged 18 and over at diagnosis received the offer and the third was only 15) or to the recency of diagnosis (diagnosed 3, 6 and 7 years ago). All were pleased that they had received the offer even though all declined it (see later section on decision making).

One other female said that she was offered a surgical procedure whereby her ovaries would be moved out of the line of radiation but was advised that it would not really be necessary given her age so she opted not to undergo it. Another said that her ovaries had been 'tied up' but she was not too sure what that meant.

### **What was the impact of being told about the potential impact on fertility at around diagnosis?**

The context into which news of potential cancer-related infertility is introduced is important to understand.

There are perhaps particular markers to negotiate during this life stage and these have the potential to mediate the impact of cancer-related fertility. Although it is not unusual for people of any age experiencing traumatic events to relate this to other events happening at that time (birthdays; house moves; Christmas, General Elections and so on) or trying to achieve certain milestones when in treatment, the chance of hitting on a significant stage of educational or social development is arguably greater in adolescent cancer. There was plenty of evidence of this with

many at key stages of their education (moving between schools, taking GCSEs; about to start university) or their social development:

**AM<sup>3</sup>:** I'd just started going out drinking with friends at that time, erm.. and I'd been to the first like Christmas party and that sort of thing, obviously suffered from my first hangover the next morning.

**Adult male 15:30**

About a third of respondents had moved to diagnosis within two weeks of developing symptoms and a further six did so within two months. However for almost a quarter, this process had taken up to six months and a similar number had been seeking medical advice about symptoms for longer than that including, in a few cases, over a year. Such young people and their families therefore came to the time of diagnosis with feelings of being ignored by health professionals or made to feel that they were over-reacting – in other words, not well placed to have confidence in their professional carers. There were also some gender specific experiences that had the potential to increase sensitivity to fertility issues being raised at diagnosis. At least two females were delayed in being referred on because it was assumed that their symptoms were to do with gender stereotypical behaviour – in one case that the patient's tumour was a pregnancy (despite the young woman making it clear that she was a virgin); in another that the pains caused by the growing tumour were the result of her wearing high heels (despite the fact that she explained on many occasions that she only ever wore trainers). Respondents therefore had a range of experiences that they were bringing to the point of diagnosis together with a range of symptoms in that some felt physically well while others were already very poorly.

Many had strong memories of being given the diagnosis. Most had their parents present (though some were alone) and for many, it came as a shock. The majority were told about the potential effect of treatment on their reproductive system at, or within a few days of, diagnosis.

A number talked of the impact of seeing parents, grandparents and others who were usually strong and capable being in shock and in tears at diagnosis. Some reported predominant feelings of feeling scared; others said they did not understand the seriousness of the situation at that time – especially those who did not realise at first that they had cancer because different terms were used; some reported their main reaction as being to feel protective towards loved ones, even at this early stage:

**AF:** And all I can remember is my Mam screaming and crying her eyes out and I was just like 'what are you crying for?'. I was just so straight faced, I was just 'right where do we go from here, what do we do?'. You know, my Mam just totally crumbled. All's I can hear is like her screaming and it was horrible.

**Adult female 18:23**

One of the teenage males reported that it was the sight of his family's distress that brought the seriousness of his situation home to him:

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<sup>3</sup> For all quotes, the following abbreviations are used: AM – Adult male; AF – Adult female; TM – Teenage male; TF – Teenage female. All those interviewed were teenagers at the time of their diagnosis.

**TM:** Like when I was coming home that night from [hospital] and everything like that. Me mum had been on the phone to me dad cos me dad can't drive so like every half an hour me mum's on the phone and saying we are going here and now we're doing this now. And me dad did actually come up to [hospital] and when we got back to me house I had me auntie, me uncle, me nana and granddad, me auntie and everybody round the kitchen. And when they started all grabbing hold of me and hugging me and everything cos they found out that it was a certain cancer, that's when it really did hit me in the end of it, you know.

**Teenage male 15:17**

There were differences in whether or not the diagnosis generated fears of death at diagnosis (or later). This was certainly the case for some in all four groups and this was sometimes also influenced by their parent(s)' reactions.

Seven already had direct experience of family members or family friends having cancer (and some did so afterwards) including ones who had died - some quite close to the time of their own diagnosis. That too influenced their reaction:

**TM:** As soon as I heard that I thought, right that's it now. I'm dead now, me granddad's died and me best friend's uncle died of it and everything like that so. I wasn't best pleased, I wasn't happy at that time.

**Teenage male 15:17**

Several adults in the study said that they had never seriously considered that they might die either at this stage or later:

**AF:** I really haven't ever - before they diagnosed us I knew I had cancer - and before they said it was cancer I knew I was going to be fine. And I'm not religious or anything like that, I just knew that I was going to be fine. So it really has never ever bothered us. I've always just took it as every day stuff. I laugh and I laughed all the way through. I didn't cry or anything like that. I've just been fine all the way through, so.

**Adult female 19:21**

For a small number, reactions to the diagnosis appeared to be affected significantly by the news about potential sterility. One adult male's parents, especially his father, were deeply shocked on hearing that their son's fertility may be at risk though this aspect had little lasting impact on the son. He remembered crying for a day as he refused to bank sperm and his father tried desperately to persuade him to do so. He continued to refuse and only took on a more 'laid back' approach to the rest of the medical interventions once his father accepted this following the intervention of his grandmother. However, it affected one of the teenage males in quite a different way. He felt that he was handling the diagnosis OK *until* he heard that his fertility might be affected and it was this that caused both him and his parents to break down:

**TM:** I went in there to be strong, and I thought 'right, come on, I can do this'. And then once he said that, it might affect like the way you have kids and stuff, Jesus, that were like a gunshot that. Started bawling my eyes out and then my Mum started booing and then my Dad ..... he han't cried since he wa' seven and he was close to crying, but he didn't cry, he finds it hard to cry. But .. and that's the first time he ever put like his hand on my back and said 'it'll be alright [.....]' and pulled me into his arm. And like, he's not really like

that, he's like a bit, doesn't show his feelings a reight lot. And he's done that quite a lot ever since.

**Teenage male 15:18**

Although the male who was not offered the option of sperm banking was not told about his potential infertility until three years after diagnosis, the impact on him of seeing his mother's reaction to the news at that time was also significant. He had come to think of his mother as his 'rock' through his long and complicated treatment and to see her so visibly shaken reinforced the intensity of his own reaction.

However the more common reactions to the news about possible impact on fertility were less pronounced, although many reported being surprised and embarrassed, especially males. For the males who were offered and accepted the chance to bank sperm, the focus quickly shifted to managing the *process* of that alongside getting ready for treatment and this is covered in more detail below. Thus, although there were similarities of impact across the genders in terms of seeing fertility as not being of immediate relevance, the difference at this stage was that far more of the males were required to engage actively in decision making to secure future reproductive choices.

Several of the females talked of the information having relatively little impact on them or their parents. Only one had a boyfriend closely involved at this stage and, although he asked lots of questions about it, she herself reported that 'it was no big deal really' for her. Even some of those who were disturbed by the information found that it was fairly quickly overtaken at this stage by concerns relating to other side effects and/or treatment. Those whose reactions were muted explained this as being influenced by their difficulty in separating the fact that they had no desire to have children at that age from their *potential* to want to be parents when older whilst some felt sure that their current lack of interest in parenting would never change. As so few females had any fertility preservation services open to them, the professionals placed no demands on them to take action to secure future reproductive choice and this too may have affected their reactions. It is perhaps not surprising therefore that females were more likely than males to say that the health professionals skimmed over fertility matters at this stage. It is nevertheless interesting that most assumed that this was because of their age rather than lack of fertility preservation facilities and this may well have been because such an interpretation resonated with their own reactions.

This was tempered by the site of the cancer – when the threat to the reproductive organs was greater, the more that the females appeared to experience anxiety. And for those for whom fertility *did* matter at this stage regardless, the professionals' apparent assumption that it did not was difficult to handle even at the time of diagnosis:

**TF:** There was this kind of assumption that because I was only young, I wouldn't be bothered, it would just be a, you know, whatever, leave me alone. But I was bothered.....

**Teenage female 13:19**

Nevertheless, it was true of a number of both genders that, regardless of the depth of impact, the information that fertility may be affected was something that they remembered from this time:

**AM:** [at diagnosis], it was, I remember it being important, it wasn't life ending or anything but it was, I remember it struck me as something that stands out from my treatment, there's lots I don't remember, and that I definitely do.

**Adult male 13:21**

One of the adult males summed this up by reflecting on the poignancy of being faced with a diagnosis that was life threatening and then being catapulted into making a decision about preserving the life of future progeny.

Ongoing impact on both genders will be returned to in later sections.

There were some differences in experiences of the professionals' approaches to involving parents in information sharing about fertility matters. All but five had their parents involved at some level from the start of hearing about possible fertility impairment, but few were offered a choice. Being offered a choice did not appear to relate to age – for example some aged 18 & over were offered a choice and others not while the youngest offered a choice was only 14 - or any other factor. All who were offered a choice were pleased with this. One teenage male who was told on his own also welcomed the offer from the consultant to return and discuss it with his parents present. One would have preferred her parents to be involved more.

Although only eight remembered definitely being given a choice, the absence of choice for the remainder was, on the whole, OK. Indeed, many were very positive about having their parents present and valued their support and ability to 'see' the longer term picture as part of coping both with fertility aspects and with entry into treatment and so on. Of those not offered a choice, no females in this study reported that they would have preferred to be told without their parents present though three of the males did and felt that it adversely affected the impact (see later section on decision making).

### **Timing of being asked about fertility preservation**

Not surprisingly, most of the males acknowledged that there was little choice about the timing of being invited to bank sperm – i.e. that it usually had to be before treatment started and therefore at around the time of diagnosis. For those who were successful in banking, the timing appeared to be acceptable. Only one thought that the invitation came too soon after diagnosis. However, all four who tried to bank and failed felt that they could, and should, have been given the information and hence the opportunity to bank earlier and some wondered if this would have resulted in a different outcome. In other words, the unsuccessful outcome might have influenced how they viewed the timing of the approach in retrospect. Even those who were very poorly in this group thought, looking back, that they could have 'had a go' sooner if given the opportunity:

**TM:** But I think it would have been a better idea if they'd said it first, you know, when you, before you had, before you had chemo and things, you should do it straightaway. Because they said, it were like three or four weeks

after like, while I were on chemo that she said it to me. **Interviewer:** Oh right, **TM:** And like chemo can kill it straight away can't it, and that's what, erm, that's why I were pretty.. *intake of breath*.. and I like when I went down to try, I couldn't really produce it, and that's when things were going wrong wi' chemo. It might have, I think it's done summat ....

**Teenage male 14:16**

Regardless of this, all were glad to have the chance to bank at all.

The 4 females who were asked were more likely to find the timing of the enquiry difficult. One remembered being asked if she wanted to have eggs frozen at the same consultation in which she was told that she may need a limb amputation. She thought that the two should have been delivered at separate times (though still at around diagnosis) as she found it overwhelming to try and deal with both together. Two found the timing of the offer difficult because it came alongside the need to consent to surgery that might result in the loss of their womb/ovaries. The fourth found it difficult because she had already been through a lot of treatment and was about to face radiation therapy and felt that her coping levels were fully stretched. Here again one wonders how far the outcome affected their views as at least three of the four do now appear to have impaired fertility.

### **The importance to females and males of being told about impact on fertility and/or fertility preservation at around diagnosis**

There was very strong support among both the female and male respondents for being told at or around diagnosis that their fertility might be affected.

The support from males for being told is implicit in much of what has already been said. There were very high levels of satisfaction among males with being offered fertility preservation and with the level of information provided at this early stage, not least as most felt that it was a straightforward decision to make and therefore one that did not require them to receive (and retain) detailed information. This did not vary according to length of time since diagnosis, i.e. satisfaction levels did not seem to relate to how long ago this took place and none had changed their views since. Neither did it vary according to the outcome as factors other than level of information available seemed to be more dominant in the decision to say No (see later for decision making section).

The young man whose professional carers failed to arrange for him to bank (apparently because he became too ill too quickly) held the clear view at interview that all males should have the opportunity to bank and was regretful that this had not been possible for himself. Support for the importance of being offered sperm banking at around diagnosis also came from those that refused and the one that was not offered the opportunity to bank at all. Neither the latter young man nor his parents were told that his reproductive system may have been affected by his treatment until approximately three years after diagnosis. He had therefore had to cope with feeling disadvantaged in subsequent years – lacking what he poignantly called the 'comfort zone' of sperm in the bank.

Thus although some suggestions were made by males about ways of improving the *offer* of banking (and these will be returned to later), there was high satisfaction with the *fact* that it was offered, where it was.

For the females, there may be more room for debate among professionals about whether and/or when to raise this as a potential side effect given the relative lack of fertility preservation opportunities. The strength with which the females in this study expressed their desire to know about the potential impact on fertility from the outset, regardless of whether or not they were offered fertility preservation, was clear.

One hinted at possible future litigation risks if such information was not given from the beginning – but also spoke of the crucial importance of information as a source of empowerment. Both she and others were concerned with the possible impact on themselves and on their trust in their professional carers if the information was withheld and delivered later on. Some could understand the possible motives behind withholding such information but made it clear that they were required to deal with a lot of difficult and emotionally challenging information anyway and it was better if nothing was left out.

**AF:** I would wanna know regardless. I think there would be a lot of angry and upset girls if they weren't told from day one. That yes it's not a very nice thing to hear, and yes you've got a lot going through your mind at the time and the last thing you need is to be told is there's a chance you could be infertile at the end of it ... it's better than not being told ..... And I don't think it's fair, that yes it's a big thing for you to think about and stuff, but if the boys get told why don't the girls?

**Adult female 19:25**

Some talked of the danger and damage that would be run of finding out in a later unplanned way, for example from talking to other patients, especially males who might have been offered the chance to bank their sperm.

Many felt that being told from the start would ensure that they were better informed of the breadth and depth of the challenges facing them and that they could, with the help of professional and non-professional supporters, start to prioritise and embark on developing coping strategies.

This was true even for those who coped by appearing to withdraw, but who often were in fact absorbing much of what was being said. Although one teenage female, for example, remembers her overwhelming feeling of wanting to leave everything to her parents - and if she had been asked at the time, that is what she would have opted for - she said that she knew even then that she would have regretted it if the professionals had taken her at her word.

**TF:** I just didn't want to know anything . But I think that's when they telled us that I couldn't have kids..... But like now I'm glad that they telled us then, cos I don't think I could have .. coped with it now, like getting told now, once everything's over. I'd rather get told at the start, even though like it's hard to take everything in when you first get diagnosed, like you just sit and think about everything, you know like you're glad you get told at the start rather than waiting and you're like 'why haven't you told us sooner?' you know,

so..... but I am glad that she told us in that way because it would have upset us more, cos not getting told, I just wouldn't like that.

**Teenage female 15:16**

There was unease among some females about the lack of opportunity to preserve their gametes – and of course this applied to far more of them than to the males. Many females were aware that males could bank sperm and a number felt unhappy about this disparity even though at least some of them understood the explanation for this to be biological rather than social – i.e. that the explanation did not lay in gender discrimination. Thus, there was understanding among a number that fertility preservation procedures for females were complex and might carry their own dangers, including the delay to treatment.

Nevertheless, there were indications of the potential for later regrets that comes from the lack of information sharing and opportunity to store eggs and these are returned to in later sections.

### **What was the level of understanding and recall about cancer-related fertility at around the time of diagnosis?**

The level of *understanding and recall* about cancer-related fertility at around the time of diagnosis appeared to be 'good enough' for almost all the males and perhaps the majority of females. Even those who reported little recall of *treatment* were nevertheless able to recall aspects of being given the diagnosis and/or being told about fertility, many with a good level of detail.

The level of understanding that was required differed between respondents. On the whole, males reported that the information that they required to feel confident enough to make a decision about sperm banking (a decision that was linked to information sharing) was straightforward. They understood that their treatment might affect their ability to produce sperm and that this might be temporary or, in some cases, permanent. One of the youngest at diagnosis summed up the context within which many males were processing this information and the ability to understand enough despite other pressures:

**AM:** I definitely understood. Definitely understood, yeh. I did know what was going on at the time, definitely. But like I say there's just so much to do, you're just, losing your hair. I remember my first night in there maybe three hours after I'd been told about cancer, I woke up with a dead arm. And like I must have been laying on my arm funny or something and I woke up with a dead arm and it was on me and I was like threw it and it hit the bed and I was like Oh no that's one bit gone, you know. Just the whole thing is a weird experience....

**Adult male 13:21**

Only one required more complex information because of the site of his tumour but he found it to be clearly imparted.

Some of the females too felt that the information required was straightforward providing that it was clearly explained, honest and that there were opportunities for them to ask questions. Indeed both males and females reported that, on the whole, it

was sufficient to offer 'broad brush' information at this stage with the offer for the subject to be returned to later in more detail as required by the individual patient, be that very soon or much later:

**AF:** There was nothing, I don't think there was anything that I found out later on that they hadn't gone over like the generals of in that first appointment. So you were straightaway, they just told us everything, not in detail but everything. And then as things went on they went into more into detail about things.

#### **Adult female 14:25**

However, there were some females for whom the information that needed to be conveyed was much more complex as their treatment involved their reproductive systems directly. There were differing experiences in these cases of the level of understanding that was achieved. One young woman facing surgery that might have resulted in a hysterectomy described the consultation with her surgeon in which he talked her through a pending operation with clarity of information alongside a sensitive and 'friendly' personal approach. He made it clear that she could change her mind at any time prior to the operation and approached her 'like an adult but understood that I wasn't quite mature enough to be able to make massive decisions all by myself'. This, she felt, enabled her to engage in the discussion and decision making even though she did not like 'gore and all that' *and* was resistant to listening. This also appeared to assist with her ongoing understanding of the link between the subsequent monitoring of her menstrual cycle and her reproductive capability. However another had surgery to her ovaries, felt that the accompanying information had been inadequate, confusing and poorly delivered and this impacted negatively on her (this is returned to in Part Two).

There were also some females for whom understanding and recall were more limited even when the level of information did not appear to need to be complex. This was perhaps because of incomplete, uncertain or contradictory information in the giving *or* receiving process; it did not appear to relate to educational level or academic ability. A few felt that fertility information could have been clearer *and* could usefully have included greater indication of the levels of risk involved. For example, some were told that fertility would not be affected but it quickly became obvious that it was. They had struggled to understand why this had happened. A few females remembered being told that their *periods* would be affected and might stop altogether but had not understood that this meant that their fertility may be affected until much later:

**TF:** The thing is, I don't think I was told in that way because I really have racked my brains and I can't remember being told you could not have children, it might affect you in that way. All I was told was it would be affected because of your periods, I wasn't told like, the link, I never thought about the link at all, they just never said fertility. They didn't say children, they didn't say fertility in the future they just said, well because everything in your body is shutting down, that might shut down too, and your periods'd stop, but everything else would start up again. Basically all the systems in your body, all the organs in your body are going to be affected and I think that's kind of how it was phrased. I think you needed that specific, cos it was just kind of general, that will shut down because everything else is, and they never made the distinct that shutting down is slightly more important than everything else

shutting down which will start up again and if it doesn't they'll give it a kick start.

### **Teenage female 15:20**

Some females said that they would also have found it helpful to have received an explanation at diagnosis as to why they could not freeze their eggs. One respondent suggested that it would have been better to be told that egg freezing was not possible together with an explanation – i.e. anticipating that if one later found out about the service that would be worse than receiving the explanation upfront about its absence.

One of the teenagers expanded this theme by saying that she thought that it would have been helpful for the implications also to be covered in these early stages, including the potential need for gamete donation. She felt this would have suited her coping style of assuming the worst and feeling pleased if it turned out better.

A number of the females remembered being told that male fertility was more likely to be affected than female fertility but none of the males made reference to gender-related impact.

Finally, some believed that they were told as much as the doctors themselves knew – i.e. they understood that they were dealing with uncertainty rather than withheld information.

### **So what might have affected comprehension and/or recall?**

A number of respondents referred to their age as an inhibitor for them in coping with the news and therefore understanding about possible infertility – and these were drawn from respondents' diagnosed from across the age range. In other words, it was not necessarily the youngest that cited age as an inhibiting factor.

Others said that they saw fertility as of little importance at that stage in their lives and hence gave it little thought either because they were not planning to have children in the near future or because they found it difficult to think ahead to a time when they might want children.

Some talked of the diagnosis and treatment all happening a long time ago and saw that as a reason for not remembering all the details. Interestingly, the length of time that was described as being 'a long time ago' varied from one to 15 years – i.e. memory of detail was not only affected by chronological time-span. Conversely, others could remember a lot of detail, perhaps because the intensity of the time made recall more likely. The surprise of being faced with possible fertility impairment when being given a cancer diagnosis and the embarrassment that some felt at such a sensitive matter being raised may also have contributed to either detailed recall or repression of the memory.

Only one placed his ability to understand and recall information within his general personality (so called 'trait' rather than 'state') as he saw himself as someone that was easily distracted. However he also said that he had understood as much as he felt that he needed to and had been able to make the decision to try and bank.

All were, of course, dealing with far more than being told that their fertility might be affected. Coping with the impact of the diagnosis itself alongside the need to take in a lot of information, some of it quite complex, in a short period of time was dominant for almost all of them. The volume of information and intensity of the situation meant that, for many and especially those not required to consider fertility preservation, attention to fertility was relatively scanty at first (by them as well as perhaps by professionals) and was simply logged to be returned to later, either when back in more familiar territory at home or at a later date altogether.

As already indicated, some saw cancer as life threatening and were preoccupied with that in these early stages. While many appeared to have understood enough of what they were told about the effect on their fertility, any impact for this group was typically diluted by the greater impact of the fear that they might die.

For some, the only way that they reported being able to deal with much that was going on at this time was to block it out and it is therefore all the more surprising that they remembered as much as they did. Indeed a number started the interview by saying that they remembered little and surprised themselves by how much they did in fact recall.

The patterns of involvement of parents at around diagnosis have been described above. Many valued the presence of their parents and relied on them to 'hold' and/or interpret the information that was being relayed about cancer, treatment and fertility. One young woman illustrated a familiar reaction at diagnosis of struggling to remain 'in the present' especially when sensitive subjects such as sex and fertility were raised that had not necessarily been broached much within parent-child relationships let alone with professionals – though there appeared to have been relief that her father had not been present as well!:

**TF:** My mam was trying to keep me calm as well as trying to hold her emotions back herself. .... My mam's really good like that. She can see into the future and she's very supportive of things. .... and she'll answer any queries if anyone has them. So I was pleased she was there cos she kind of explained things that the doctor necessarily wouldn't. And you're 15, you're rather embarrassed when someone talks about sex and mentions that taboo word and your mam's sitting there and you're like, 'no you didn't just say that word'. But my mam was alright about it..... I felt more like I could talk to my mam then, than I ever had done about that subject, in the past. It kind of built a bridge ..... **Interviewer:** And what would it have been like if your dad had been there do you think? **TF:** I would have pretended to be asleep. ....

**Teenage female 15:20**

The role for parents as 'holders of information', and 'translators or interpreters' both to them and to others in the informal support networks outside of the consultation room is clearly one that most parents become very skilled at very quickly and this was referred to by many. Some were even at this early stage already feeling that they were drawing closer to their parents, feeling 'all in it together' and developing shared understandings of what had been said:

**AF:** .....and they, just on their way back in the car and at home, they were talking about everything that had been raised really. But it's, you know, it's

like 'OK well it might have an effect but, you know, you could also, it [fertility] could come back as well'.

**Adult female 15:26**

Regardless of whether or not the young person appeared to be blocking out information, many commented on the importance of professionals talking to them direct rather than to their parents even (or perhaps especially) if their parents were present in the consultation. This too may have affected recall positively:

**AF:** I think it was good the way she just sort of told me instead of going round, like talking to my parents instead of speaking to me, and stuff like that. Where I think if she'd ha' told my parents that I couldn't conceive or, and not actually come to me, I think it'd have been worse than actually, cos I think you listen more to it like when a doctor or a consultant speaks to you so when she was saying it mightn't be a problem, well you think it's not going to be a problem, where if she'd have spoke to my parents I'd have been 'Well why didn't she speak to me, how come youse know and I don't', type of thing, I'd have been, thought they were hiding more things from me, where [consultant] spoke to me more than she did my parents, she made sure we were all there together, not taking my parents away and speaking to them.

**Adult female 15:24**

Indeed this was an area where some (though not all) professionals in the reproductive medicine setting scored less well with reports of some staff being more inclined to talk to the parents than the young person both at this stage and, as described later, in subsequent consultations.

Finally, where the practice was for professionals to offer only broad details about possible fertility impairment at diagnosis with the promise of returning to the subject in more depth later this may have aided the situation for those where this approach lowered anxiety about the need to understand it in depth the first time around.

### **Interpretation of what the professionals said or did not say**

There were some variations in the way that respondents, especially females, interpreted and therefore 'understood' what they had been told – or not told – at around diagnosis by professionals.

For a small number of females, the *absence* of an offer of egg freezing was the source of some later comfort in that they interpreted it as meaning that they were at little or no risk. The mother of one of the respondents who joined us for part of the interview explained that she and her daughter understood some of her peers to have been offered egg freezing and this reinforced her/their assumption that the risk to her fertility was so much lower that it was not warranted.

As reported above, one female respondent suggested that it would have been helpful for her to have some indication of risk to fertility at diagnosis. However people interpret given risk very differently both at the time and subsequently and this emerged in responses. For example, one young woman had been told that she was at high risk (75%) of infertility but thought that she might be one of the fortunate few in her risk category whereas two others who had received new types of treatment

with relatively unknown consequences for fertility assumed that they would be affected. The same was true among some of the males.

Others presented different interpretations at different parts of the interview itself. One of the adult females understood from professional advice that she was having 'milder' treatment that was not only likely to result in complete remission but also to have no effect on her fertility. However at another point in the interview, she said that the treatment was so new that she was the first to have it and the professionals did not really know what impact it would have on her fertility.

Sometimes the interpretation appeared to draw on 'accurate' information. One young woman had been provided with a written sheet for use when explaining treatment side effects to her school friends. It included the statement that her fertility would not be affected. She took that to be the case though, sadly, she has since gone through a premature menopause despite not yet reaching full adulthood.

Some appeared to accept the accuracy of information but their later behaviour still put them at risk. One young woman said that she believed her doctor's advice that she would probably be infertile (97% risk), felt that she could cope because she was prepared to consider alternative routes to parenthood, appreciated his joke about 'practice makes perfect' and associated advice that she should nevertheless use contraception – and still got pregnant accidentally!

## **SECTION 2: WHO AND WHAT WAS INVOLVED IN MAKING THE DECISION ABOUT WHETHER OR NOT TO STORE GAMETES?**

All of those who were offered fertility preservation services and associated information were offered this by doctors (usually the consultant). Nurses and doctors from the paediatric oncology centre (POC) and the sperm bank<sup>4</sup> and (in one case) social workers were also involved, as were scientists at the sperm bank. However, almost all saw the decision making as happening, on the whole, in the POC context and then carried out at the sperm bank.

As already indicated, almost all those offered fertility preservation services found it relatively straightforward to arrive at a decision even though it was made at a time of great stress, when they felt overwhelmed with information and when they were often struggling with challenging physical symptoms. In this section, I have tried to consider what helped with the decision making and what hindered. Given that far more males than females were given the opportunity to use fertility preservation services, these refer primarily, but not exclusively, to the views expressed by males.

### **The clear link to preserving reproductive choice**

The preservation of reproductive choice was the overwhelming driver for all the **males** who accepted the offer, without exception. This led to them finding the decision making about banking quite straightforward because they saw it as

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<sup>4</sup> Although all but one of the sperm banks used by young men in this study were located in an assisted conception units (ACU) we have used the term sperm bank where the context is to do with banking sperm and ACU where the context is more broadly one of reproductive medicine and/or fertility treatment.

'sensible' and requiring little thought – even though some needed their parents to help them to 'see' this (see later):

**AM:** Yeah, I didn't really think about it, to be honest. I just said yeah pretty much on the spot, so, it just seemed like commonsense to be honest. .... cos if I didn't [bank] and it came out at the end of treatment that I was infertile then, I dunno, it would be a .. bugger, really, yeah, er, cos like in later life if you ever wanted to have children, like you wouldn't have anything there, so...

**Adult male 19:22**

Although reluctant *and* being very aware of being talked *at*, one young man explained how the need to preserve reproductive choice was sufficient to overcome that:

**AM:** ..... just being told that I wan't going to have kids. So I thought it was something I didn't want to do but obviously in the back of my mind I were like, well you've got to go down and at least give it a try.....I thought, just in case like, I might want kids, I don't know. So it's like... Well, gonna go down and see if we can do it. It's always there for future use. If I can have 'em naturally when I've gone through treatment then fine. If I can't there's a back-up. But I don't know. I think when you're there and you've got everyone talking at you I think it's just something you just agree to, to be honest with you.

**Adult male 16:22**

Even those who said that they agreed predominantly because it was expected of them and felt little right and/or energy to go against this nevertheless appeared to understand and agree with the basic reasons why.

### **Age and life stage**

Many referred to their age and life stage as an inhibitor in coping with the news about possible infertility and any related decision-making but nevertheless were generally able to arrive at a decision that they thought was right for them. References to age in relation to decision making were grouped around:

- Whether or not they were too young in general to make fully informed complex decisions.
- Whether or not their age restricted their ability to think in particular about the longer term implications of possible fertility impairment.

However it is of note that only two of the four males that turned down the invitation to bank cited age as playing a part in that decision. The one whose father put him under a lot of pressure to accept thought that his age played a part in his decision. He did not see the need to preserve this potential route to parenthood as relevant at that stage in his life (though one of the other 13 year olds did) but also felt embarrassed and lacking in experience with masturbating (which could also be age related). Looking back, he could not see anything that would have enabled him to get beyond being unwilling to contemplate it. Thankfully, he did not later regret his decision (though this is undoubtedly helped by the fact that he went on to have children naturally).

One of the females also thought that her youth (15) and her embarrassment at what she perceived as the context (sex) affected her decision not to freeze her eggs (though only in part). Like many others, she was not sexually active at the time and had not thought about whether or not she ever wanted children and therefore whether she wanted or needed to retain reproductive choice. She too did not regret her decision.

The other male that turned down the offer on the grounds that it did not feel relevant at that age did go on to regret his decision. At interview, he reflected that the professionals, and perhaps his parents, could and should have worked harder to engage him in the longer term importance of the decision:

**AM:** I wish they had been more forceful, like [saying] it was essential to have it done, maybe using some shock tactics, giving me some eye-opening facts.

**Adult male 16:21**

The remainder appeared able to explain in broad terms what was happening with their body and what the issues were in relation to making the decision although, not surprisingly many continued to see their age as an influence on their overall cancer experience.

### **Influence of religious beliefs**

One of the males that turned down the offer did so on religious grounds. As a Muslim, he believed that children were a 'gift from God' and that he should not interfere with what was mapped out for him. He also said that his religion forbade him to masturbate and, even though he was aware that this prohibition could sometimes be set against on medical grounds, he did not feel that it was right to seek such permission in these circumstances. He said that he has had no regrets about his decision.

### **The need to avoid delay to treatment**

Although some of the males learnt subsequently that the delay to banking sperm was because of their need to embark urgently on treatment, the decision to avoid delay to treatment had been their consultant's rather than theirs.

The situation was different for the females offered fertility preservation as they were given the choice. The length and medical complexity of the fertility preservation process for females was clearly a major factor in their decision making. For example, the teenage female that faced a possible hysterectomy was given the choice about having an exploratory operation, being given the outcome and deciding at that point whether or not to store eggs. She decided that, on balance, the risk of delaying treatment was greater than the risk of being affected by the loss of her fertility and reasoned that she could use alternative routes to parenthood such as surrogacy or adoption if need be. She nevertheless felt it to be a very difficult decision to make (eased in the aftermath by the fact that she did not require a hysterectomy even though she does appear to have some fertility impairment). This young woman also commented positively on the fact that she knew from very early in treatment that an appointment with a fertility specialist would be available to her at a later stage of her

choosing. This proved a comfort – and enabled her to put fertility concerns to one side and concentrate on treatment.

One of the females remembered not feeling able to contemplate waiting the six weeks that she was told would be required to enable egg freezing to take place (and being advised that this could lower her chances of survival). Her age (18) and the fact that she had not thought actively about parenthood by then added to the firmness of her decision at the time which she made ‘in minutes’. However the fact that it was raised left her with some lingering doubts in the aftermath, especially as she is now having difficulty conceiving.

Finally, the one that decided against having a procedure to move her ovaries out of the line of radiation was more influenced by a desire to avoid further medical intervention than concern about any delay to treatment. She was content with that decision at the time though struggles with it now in the light of the apparent damage that has been done. She probably revisited the decision more than the others and questioned the accuracy of the professional advice given.

All four reflected that they wished that there was more time in which to make the decision and/or that they were not having to do so in such stressful circumstances – that is to say that they recognised that they and their professional carers had little room for manoeuvre. Any expressions of regret on looking back were tinged with a realistic sense of it being unlikely that they would ever have arrived at any other decision.

### **Influence of parents and close family members**

Not surprisingly, a number were taken aback at having the subject of sex and reproduction raised with their parents present. As already indicated, almost all the respondents had their parents involved at some level from the start of hearing about possible fertility impairment and being offered fertility preservation services, but this was not always their choice. The presence of choice did not have any discernible pattern by age or any other factor. However, although few remembered being given a choice (including those aged 18 and over at diagnosis) this was, on the whole, OK. Indeed, many were very positive about having their parents present and valued their support and their ability to ‘see’ the longer term picture as part of the decision making process.

There were a small number of males for whom the lack of choice proved difficult. They were clear that they would have much preferred their parents *not* to be there for the fertility discussions though for different reasons. One found his parents’ reactions difficult to cope with and there were already some hints of a low level difficult relationship that was to continue and worsen – even though not to breakdown point or anywhere near - as treatment continued. Another felt that his dad’s clear embarrassment with the subject impacted negatively on him and perhaps contributed to his eventual inability to produce a sample:

**AM:** ... when my Dad came in and asked me if I knew how [to masturbate], I was very embarrassed and I was very erm.. 'Oh God I wish it would just end and I could just carry on with whatever I was doing'. And maybe it was my Dad that sparked that feeling off as well

**Adult male 13:21**

For another, exercising the choice not to include his parent was very important to him. He felt that this enabled him to remain in control of who might get to know whether or not he became infertile – i.e. he was able to speculate about the possible need for privacy in the future and act accordingly in the present.

Of those that were happy for their parents to be there, many were aware that they too were struggling to cope with the impact of the diagnosis (as reported earlier) but welcomed their parents' – and especially their mothers' - ability to support them to consider the longer term picture in relation to reproductive choice and decision making.

**TM:** And while I was just talking to her in the car she was saying, you know [.....], you know, if you do survive all this and everything like that, at least you will have something in the future you know. Even if you can't have it, you can... there's all these tests now that you can have to have like your wife or anything pregnant, or your girlfriend and I said I know yeh. But at that time like with me head and everything like that I just didn't want to know anything.....at that time I had like severe headaches and everything like that and so me mum like talked me into going and doing it.

**Teenage male 15:17**

Mothers figured more prominently than did fathers in relation to decision making about fertility preservation, even in two parent families. However other family members also played a part and this is a side of family-based negotiations that professionals do not necessarily see. Older siblings – all of shared gender - were important for at least three respondents in these decision making phases. For example, one young woman was clear that having access to her mother *and* older sister was crucial to her ability to decide – especially as she felt they knew her so much better than did the professionals. For the young man whose father put him under extreme pressure to bank his sperm and who was supported by his mother, the crisis was only resolved through the intervention of his grandmother.

Thus, parental and family involvement seemed to be experienced more often as a help than a hindrance in the decision making process. On balance, more of the respondents were happy with the level of the involvement of their parents than not, including those who were embarrassed about the nature of the subject. Having said that, for the small number where parental presence did impact negatively, this perhaps had a disproportionately large effect.

Perhaps one of the key aspects then was the level of *control* that the young person felt that they had. Several referred positively to the approach of those professionals that facilitated them feeling as least as important as their parents in any encounter ( and more so in many) as illustrated by one of the teenage males:

**TM:** But once I got to [regional POC] it's kind of like your own decision then, you can have 'em [parents] in, you can have 'em out, some times they came in, some times they sat out. **Interviewer:** And did that work well for you, did you think that's the right way, to give you the choice? **TM:** Yeah. Cos then I told my parents after, but I didn't tell 'em, I like broke it down a bit, I kept a bit to myself and stuff.

**Teenage male 15:18**

## **Professionals' approaches**

In addition to references already made to professional approaches, some talked of the helpful way in which the offer of fertility preservation was made. For example, one adult male talked of how consultant raised it with him alone (though his parents were on hand), acknowledged that it was potentially an embarrassing subject and made it clear that he [the consultant] thought it was a good thing but that the decision rested with him as patient.

Others too referred to the value that they placed on consultants venturing their opinion whilst making it clear that the final decision rested solely with them as patient. There is, of course, a down side to this for ones like the female referred to above who accepted professional advice that her forthcoming treatment placed her at low risk and turned down the offer of a preventive intervention. Nevertheless, on the whole respondents valued being offered a clear opinion.

A few reported difficulties as a result of there being too many professionals in the room when the subject was raised or the decision discussed. Some could remember the physical situation with clarity, even to remembering several years on who was standing or sitting where. Numbers were less of an issue where it was family members present though the general sense was that it was easier to be offered access to services either alone or with only a small number of supporters present.

## **SECTION 3: THE BANKING PROCESS ITSELF**

Many males retained clear memories of the banking process remarking in particular on the journey to get there, attributes of the room where they were to produce the sample and features of the individual staff at the sperm bank. For some, this was notable as they had considerable gaps in their memory about other parts of their cancer journey.

### **Getting there**

All except one talked about the journey to the sperm bank and had clear recall of getting there even though, for some, it had been several years previously and/or they had been in acute discomfort or pain. The one who did not talk about it failed to do so as his mum joined the interview at around this stage and we did not return to the journey details.

The paediatric oncology centre made transport arrangements for some and this was valued, whether this was by taxi to another site or through staff accompanying them part of the way when in the same building. A number reported that good attention to detail in arranging the journey was paid with clear instructions about the route and staff expecting them once they arrived at their destination. In contrast, one had not only had a long journey to undertake but then they had got lost when they got there.

References to the difficulties posed by geographical distance were made by several. Whilst for some, this meant travelling across a city or even to a different town, for others it meant going to another part of the same hospital on the same site. In both situations there were some who found these journeys to be a source of stress or

anxiety. One remembered having to manage the impact of being told en route that he had cancer (he had been told that it was lymphoma and did not realise that this meant he had cancer); for another, the length of the journey (even though it was within the same building) was such that his anxiety levels rose considerably.

**AM:** Going from there all the way down there and thinking you've got that long to think about it, thinking, all the anticipation.....maybe it is something someone should think about having it a bit closer.

**Adult male 16:22**

At least five had to negotiate the journey in a wheelchair, all of whom were in the very early days of learning how to manage it. Many talked of the access difficulties, especially in manipulating awkward entrances as described graphically by this teenager:

**TM:** ..... the transport getting there was difficult like to get in and out of cos they had to get a taxi. And there are big revolving doors and umm...cos I had a leg board as well cos me leg wasn't allowed to be bent.. It was difficult to get through the revolving doors. .... it was a right sort of calamity really. And then the place I had to bank the sperm was upstairs as well so I had to squeeze into a little lift and then I was a bit of a wreck by the time I got there. .... but then I remember the nurse that was sort of in charge and helping us with the paperwork and stuff was really nice. Really helpful. And she explained like everything and any questions I had which was really good cos it set us at ease.

**Teenage male 18:19**

Another of the wheelchair users was so ill with severe headaches that he could not physically sit up at any stage of the journey. He had to lie on the back seat of the car and be tilted backwards in the wheelchair from the entrance of the hospital through to the sperm bank before transferring to the bed to produce the sample.

All were nevertheless glad that they had the chance to bank.

### **Being accompanied**

Three were accompanied by their mothers (2 teenagers, one adult), one by mother and an uncle (one teenager), 3 by fathers (all now adults), two by female nurses (both teenagers), two went unaccompanied (one adult, one teenager) and one by a social worker (one adult).

It is interesting to see that there was a complete shift from fathers to mothers or nurses (i.e. male to female) for those going through the process more recently though the numbers are, of course, too small to know whether this carries any particular significance.

The majority were given the choice as to who should go with them and expressed satisfaction with the arrangements. However, at least one who was offered a choice by the consultant did not feel that he could do other than accept his father's offer to go with him, even though he would have preferred to go alone or with a nurse. This echoes sentiments expressed elsewhere in the study about the difficulties faced by

teenagers being offered a choice (or rather, making the decision that they want to make) in the presence of their parents.

Several could not remember having a choice but were nevertheless satisfied with the arrangements. For one, this was fortuitous as he was told that he would be accompanied by a professional rather than his parents – and he, like several others, was finding it difficult to cope with his parents at times. Another valued the fact that he and his mother could talk openly on the journey without worrying about strangers (even if they were professionals) being party to their private discussion. The presence of this young man's mother at the sperm bank also resulted in him being supported to make a crucial decision to return one more time to provide another sample – and one that turned out to be much better quality (and a great comfort to him now).

Being accompanied brought its constraints, with an acute awareness of the nature of the task awaiting them at the end of the journey. However, for those who *chose* to go with relatives, or those for whom being accompanied worked well even if they did not have a choice about it, the value of this in terms of reducing stress were clear, as illustrated by this respondent (who in this case chose to be accompanied by his step father):

**AM:** I think it were better going down with him, in a way, cos he's more like my friend ..... than going down with a doctor who. ... so we were going down and we were having like a laugh and a joke. I remember that. And he were like reassuring, saying, if you can't, don't worry.....

**Interviewer:** yeh. So it was good to have the choice? And for you it worked best to have somebody that you knew? **AM:** Yeh ..... I don't think in a way... it's.. I don't think, especially being a lad, I don't think you could go down wi' your mum or a nurse, something like that. .... But if you're going down with either a friend or a parent, your dad or somebody like that you can go down if you get along and have a laugh in a way. To try and take your mind off of it... but, I think if you went down with a doctor or nurse, I think it's a bit formal so again then you wouldn't feel relaxed in a way.

**Adult male 16:22**

Even those who reported favourably on being accompanied by family members or professionals did not want them to be seated nearby when they were in the semen collection room.

### **The consent process**

Although many talked about the consent process, the level of detail that was recalled varied and tended to be lower than about other aspects of the banking process. A few would have preferred the consent process to take place on the paediatric oncology ward. Some found the consent consultation to be repetitive of what they had been told prior to going to the sperm bank and/or delivered in too much detail and complexity or with too little clarity. Although some found the approach of the staff at the sperm bank eased the consent process considerably others found that their approach contributed to making it more difficult to handle. Where it worked well, it appeared to be through a combination of manner and presentation of the information:

**AM:** I remember he was really, really nice. He was a really nice guy. Just his manner. You know, the way he talked you through it and that.. I mean it was an uncomfortable process because, you can imagine, I didn't really feel like you know.... .. he just, without making light of the subject, he just put you at ease. I think that was one of the things cos I was pretty up tight and, you know, het up about things. He was just generally very amiable. He explained things in a nice way and it wasn't like, you know, this is the way it is going to happen, bang, you know he ran through it and explained it and did I have any questions and stuff like that. ....It does make a difference, you know, the way people are.

**Adult male 18:23**

Where it proved difficult, this was often as a result of professional manner, volume of information and, for some, an inappropriate level of questioning about their current situation vis a vis romantic relationships and the extent of their desire to have children:

**AM:** I remember sat there just thinking I really don't want to be doing this. Going down, filling a load of forms in, him talking to you all about it. .... that made it even worse. Him talking to you about it all, again, through it saying 'have you got a partner yet, does she want kids' and all that. And it's like, I don't think it's really appropriate at that time for them. .... I mean, you've got people talking to you constantly anyway. And him saying, going through all that with you – 'are you thinking about having kids?' It's like I've just come down..... 'does it look like I really want to?'

**Adult male 16:22**

Others felt that the encounter had not put them in the right frame of mind for being able to produce a sample. For some, this reinforced their belief that it would have been easier for them to have gone through the consent process on the ward and then gone on to produce the sample at a time that felt right for them.

Several could remember receiving a copy of the consent form and appeared reasonably aware of its main features such as the option of extended storage and of disposal arrangements in the event of their death. While some had not been upset by the need to decide about the latter and seemed to take it in their stride (especially those who had not considered their situation to be life threatening), others had found this distressing. Some questioned the need to have this raised at this point in time:

**AM:** One of the last things you really want to hear. If you die can we pass your sperm to someone else. 'Cheers mate... I'm here. .. I'm really ill, I've got cancer and you're asking me if I die. Cheers for the reassurance'. *laughs*

**Adult male 16:22**

Several thought that they had agreed to their sperm being donated to another couple for use in creating a child if they died (this is not legally possible) and at least one had worried about that in case his sperm was 'contaminated'. Several also thought that they had agreed for it to be used for research if they were to die.

Only one could remember being asked for, and signing, 'consent to disclose' information about whether or not they had banked to staff outside the licensed centre (a legal requirement).

Very few appeared to be aware that they had the right to change their consent conditions at any stage. This included those who had since had written contact with the sperm bank over renewal of storage. In keeping with this, few seemed aware that they could put their partner's name onto the form at a later stage to facilitate posthumous use even though a number knew that posthumous use by a partner was an option.

Finally, while some spoke of there being a mass of paperwork to complete, others remembered there being very little. One or two thought that their parents had given written consent rather than them but the majority were clear that the consent had been made by them alone.

### **Physical attributes of the semen collection room**

There were a number of physical aspects of the service that were seen as a hindrance to the experience.

There were many comments about the room where the sample had to be produced. Although two thought that it was OK and much as they expected, the majority commented adversely on the size. Six of the twelve who tried to bank said that the room was too small and impersonal. One found it too hot and would have liked there to have been a fan.

Two at least had been able to hear voices outside very clearly and hence it had not felt private enough. Others were pleased to find that the room had a lock on the inside which improved their sense of privacy a little.

Some thought the room should have been less clinical and would have preferred it to contain, for example, comfortable chairs, a television, pictures on the walls, provision of food and drink (or the knowledge beforehand that they could take food and drink in with them) and so on. For one of those who failed to ejaculate, the memory of the clinical surroundings was vivid as he recalled his acute discomfort acted out by wandering around the room until finally abandoning the attempt.

Another, who was in accord with the general sentiment of wanting the room to be more pleasant, suggested particular attention should be paid to *cleanliness* because that would have made him feel less conscious that others may have used the room for similar purposes before him. He had had to use what appeared to be a consulting room with a trolley and computer in it and found this off-putting.

Another found the clinical nature of the room to be an inhibitor in part because he associated clinical with cleanliness and felt that reinforced his sense of masturbation as being inappropriate in that context.

Seven of the twelve supported the provision of pornographic magazines in the semen collection room. All thought that they were potentially useful at any age even those that did not make use of them themselves. This included two who did not have access to them when they tried the first time. One of the teenage males who failed to bank wondered whether access to magazines or a video might have helped

(although he also thought it was related to his tension at being there, the fact that he did not like the room and found it too hot, and that he was already on treatment). Another teenage male thought that their availability the second time around contributed to his higher sperm count on that occasion. However there were also hints that their presence contributed to at least three feel that they were doing something 'smutty' or 'shameful'. This was reinforced for some by the way in which they were pointed out. One was told that they were available but '...in a folder...' and another said that the fact that they were 'under wraps' made him feel that he was doing something wrong if he used them:

**AM:** And like they kind of put you in this room with appropriate magazines...'; 'and then saying 'oh if you go through that room there and I'll go out and there's some suitable reading material'; 'there you are, he shows you to the room, he tells you that there is some appropriate literature I think was your wording in there. Yeh, that's how he put it. Nice big paper brown, nice brown paper bag.. *laughs*

**Adult male 16:22**

For this male, this was compounded by the fact that the magazines were old and that they were, to him, about sex - and sex is 'one of the last things on your mind....' This was echoed by another who had also had magazines made available:

**AM:** Then there was a hardbound magazine on the side, which had been well thumbed and I didn't want to use at all and didn't use. And that made me think this is seedy, you know rather than for a purpose..... I kind of guessed that it would be in there cos it's sort of a bit of an urban myth anyway, you know, these things... everyone I tell about it says 'Oh, did they have a magazine?'. ..... it was well used and that made me feel quite ill and also it's seedy, it really is. I don't see why people should need it. It's horrible. It makes you feel dirty and I don't like that....

**Adult male 20:22**

One found the container itself very difficult to manage as it did not have a wide enough opening.

Only one reported that no-one had prepared him before he left the paediatric oncology centre by checking that he knew that he had to masturbate in order to produce a sample. When he got to the sperm bank, he was simply given a bottle and shown to a room but, again, given no instructions about what to do.

Some had concerns about the security arrangements for the sample, especially where the instructions about what to do with the sample were vague – this left them with concerns about whether it was then going to be stored securely:

**AM:** Well I said to the guy just before I went in, so he said if you just leave it on the side when you finish and I said 'why will you be waiting for me then?', and he goes 'No I can see when the door's open' and he was sort of quite off about it. And I thought 'OK yeah' and so I left it and that, yeh that seemed a bit odd (a) because he was waiting for me if he could see when the door's open, (b) because I was just leaving it on the side in a hospital with a fairly busy thoroughfare past the room, erm, and I just thought I hope they, you know, really get my details sorted there, erm. Yeah it was really odd, it

almost seemed quite rudimentary to me that they don't have a, you know, they don't even put it in a special bag marked up with your name on or anything, it just seemed a bit sort of odd

**Adult male 20:22**

Finally, although most said that they would not have wanted to produce the sample in their room on the paediatric oncology ward for reasons of privacy, there was support from the option of producing it somewhere closer to the POC, especially if the surroundings were more comfortable.

### **Getting the results**

All but one could recall having been given the results though one was hazy about the timing (which suggests that, for him, the timing was unproblematic) and another did not talk at all about getting the results.

For the one that did not recall getting any results, a number of things flowed from that including the fact that he did not know whether any of the people caring for him knew more than he did (as well as feeling embarrassed that they might know that he had masturbated and banked):

**AM:** I didn't know whether I'd given a good sample or a bad sample, no discussion was made at all over it. When I started treatment I didn't know if there was anything in my file that said whether first of all I had been for all these things. Some of the nurses might know, young impressionable, so the nurses might know, it might say what my sperm count is in that file in front of them.....

**Adult male 15:30**

Among the others, there were variations in the timing of giving results. Three got them immediately or at least the same day. This was viewed very positively as it enabled them to move forward with the reassurance of having successfully banked. Conversely, there were drawbacks for some of those that had to wait. One got the results of the first sample when going for the second appointment but then did not get the results from the second sample until he went back for a consultation after chemotherapy finished. He would have preferred to have the results sooner and commented on the reassurance that came from knowing that his first sample was of very good quality. Thus if he had not gone to bank a second time, he could well have gone into chemo without any knowledge of the results:

**AM:** They did tell me but I suppose I would probably have preferred it sooner. Yeh. It's nice to know these things. It's nice to know that there's a good sample there, because that's very reassuring actually, to think that you've got several chances there you know because they sort of divide it up, don't they, so. No I would yeah, that actually made me quite happy that you know because I knew it before I had chemo, so it made me quite happy that that was sorted.

**Adult male 20:22**

Another left the clinic without any idea of the timescale for getting the results and when they were given three weeks later it was to say that no sperm had been detected.

Most received the results direct from the sperm bank staff and this seemed to work well. However, one had been given the results by a nurse on the paediatric oncology ward who had been asked to pass on the message. Although this had been OK with him, he speculated that it might have been upsetting for some patients to hear in this way.

For those for whom completing the banking process marked a step on the way to treatment, a piece of business that was finished and done with that enabled them to keep moving forward, getting the results marked the end of this task. As such they were an important marker in a process where it frequently felt difficult to have any sense of achievement in these early stages.

### **Storage Issues**

A number of issues came up about storage:

#### ***Knowledge about storage facilities***

Although detailed knowledge seemed patchy, this did not appear to present anxieties with many feeling that they knew enough. A number were very clear about the facilities and appeared to appreciate knowing matters such as where and how their sperm was going to be stored (two were offered the chance to see the storage facility – one declined but appreciated having the opportunity, the other had a look). The majority seemed clear about the follow up process.

#### ***Charging***

A few expressed concern and a sense of unfairness that they might be charged for storage (and for any associated assisted conception treatment) in the future. Indeed one of the adults had been prompted to go for testing because the bank where his sample was stored was intending to move it to another site where storage costs would be incurred (and he would have struggled to find the costs). This also prompted him to discuss it with his then girlfriend – i.e. the timing was determined by something or someone outside of his control and perhaps reinforced the potential to *feel* that he had little control over the storage arrangements.

#### ***HIV Screening***

One of the adults raised issues to do with HIV and other screening. He had been told that he had to provide two samples because they had to go into unscreened storage where they might get contaminated. He knew that he was infection free and found this to be an additional stressor and an annoyance that he would rather have done without – especially when the rationale for it later appeared to be questioned when he learnt that both samples might be in the screened storage container anyway.

For others, this was not raised as an issue and there did not appear to be awareness that screening might have taken place (Note: mandatory HIV testing came in after the time that some of the respondents provided samples).

#### ***Follow up***

Some had already started receiving the routine letter afterwards about renewal of storage and this was well received although for at least one, it both prompted them to

think about their possible infertility and caused some anxiety in case they forgot to return it.

Several commented that the letter always included an invitation to go in for a sperm test and this too appeared to be welcome and appropriate. One adult male said that it was the letter that prompted him to think about getting tested and three of the teenagers thought that the follow up analysis referred to was a routine procedure that would happen at a certain time post treatment. None had yet reached that milestone.

It is of note that none of the males or females that did not have gametes in storage were offered fertility analysis routinely from the assisted conception centres as this was only triggered through the storage renewal process.

### **The impact of trying and failing to bank sperm**

For a small number, sperm banking was perhaps a procedure too far; something that they could barely find the spare capacity to manage. While all concerned were supportive of being asked and felt strongly that the service should be made available, failure to bank clearly left them with additional feelings to try and manage in the aftermath. There appeared to be little or no help available with this from either professional or informal carers. Some of the feelings were experienced immediately around the difficulty of making the decision to stop trying, leaving the room, facing people (those accompanying them, professionals in the sperm bank and professionals back at the POC) as well as coping with feelings of failure and disappointment. One reported how comforting it was to have his step dad outside the room waiting for him. He could not remember anyone ever raising it subsequently with him at a time when he might have been able to use help to process his feelings and try to discharge his remaining negative thoughts and feelings.

**AM:** I was disappointed, I think in a way I was disappointed in myself for not being able to and then again that was summat else on my shoulders as if to think, you know, great, you haven't been able to do it. .... I give it masses and I couldn't do it and I wanted to get out of there.

**Adult male 16:22**

The one whose need to bank had been overlooked initially and who was accompanied by an 'embarrassed' father seemed to have coped by trying to repress his feelings at failing as quickly as possible. He takes up the story:

**AM:** .... I remember it not being a nice room and I remember being very gutted when I left as well. I was quite upset but again, just feeling it was like 'just forget it, it doesn't matter'. .... I felt really bad when I left, and I think it surprised me that I couldn't manage it. And really upset me as well. And I remember, yeah, just wanting to get back to my bed, and be put on the drip.

**Adult male 13:21**

Eight years later, he still recalled it as one of the most stressful episodes of his time in hospital and, like the one above, did not remember anyone trying to raise it with him again afterwards. Even so, he valued having the opportunity to bank and thought it would have been worse not to have tried.

Both this respondent and one of the others who failed to produce a sample twice at the sperm bank were offered containers to take away and try to use back on the ward. Neither even tried to do so. One, who was only 13 at the time, remembered setting his mind against that from the start out of a mixture of embarrassment and realisation that he had so little privacy on the ward that he could be interrupted at any time. This was reinforced when it was a female nurse awaiting his return; he speculated that it might have been different if it had been a male nurse though was far from sure:

**AM:** ..... I remember coming back to my room with the vial thing they'd given me, and it was definitely a female nurse in the room and I just hid it straight away. And then I never, it's probably still down the side of the drawer or wherever I put it because I didn't want her to see I'd got it. So maybe if it was a male nurse I'd have come back and been a bit, you know, feel better...dadedada. Maybe that would have been better. Yeah, I think maybe I would have preferred a male.

**Adult male 13:21**

The other young man felt too ill to even try once back on the ward. He remained distressed about his failure to bank at the research interview as he held a strong desire to become a biological parent one day and had been told that his fertility was highly likely to have been affected by his treatment.

The ongoing impact of failing to produce a sample is returned to in Part Four.

### **What helped with managing the process of banking?**

There was consistency in the reactions among all those who had engaged in the banking process. Words such as *uncomfortable*, *het up*, *extremely strange*, *wanting to get out of there asap*, *embarrassing*, *uncomfortable*, *surreal*, *weird* were commonplace. Nevertheless, as already reported, there was strong support for the service and clear messages about what helped or got in the way of the process to augment or summarise the experiences cited already.

### ***Seeing sperm banking as part of the treatment process***

Some of those who banked remember seeing it simply as part of the process that was laid down that they had to 'take in their stride' and that approach appeared to work. Many did not think about it too deeply and saw it as something that, although unexpected, had to be done in the progress towards treatment, trying to normalise this highly abnormal event at this highly abnormal time as far as they could. Even those for whom it was particularly embarrassing were able to go with the flow, seeing it as something that had to be done as part of their process towards treatment:

**TM:** You kind of get embarrassed as well when you talk about sperm banking and stuff like that, it's like 'Jesus'. And then when you're going into the room and that, my Mum's outside room and she knows what I'm doing .. plus my Uncle [...] as well, he in't ... oh you go in there looking it and come out even like a beetroot, more looking it. But you just take it all in your stride. When you're at hospital it's like a day's work, it's what you've got to do. And I did everything to make me better.

**Teenage male 15:18**

One teenage male expressed it slightly differently as getting one thing out of the way and having a sense of achievement over that – perhaps the beginning of a sense of resilience, being an active player – reinforced by his mother’s reaction:

**TM:** So. That was one step, like part of the treatment out of the way for a bit before I started something else. **Interviewer:** And you could concentrate on getting... **TM:** Yeh, start something else now. **Interviewer:** And it would be one. I hadn't thought about that. I suppose it was one bit that would be done and dusted then. **TM:** Yeh, like me mum said if you get it all done and dusted you've got that.... a nice way of putting it yeh.

**Teenage male 15:17**

### ***Seeing sperm banking as an expression of belief that you have a future***

A few were able to see it as an expression of belief that they would survive treatment and have a future and this proved a comfort. For these, it helped when this was reinforced by professional and informal carers.

### ***A well organised service***

This of course includes various elements. It starts with the young men and their carers being ‘well enough’ informed about what would happen, including about the storage process. Good transport arrangements and instructions about how to find the venue minimised the effort required and reduced the potential for practical upset. Those who were expected and taken straight through appreciated this and conversely two who had to wait in the open waiting area found this uncomfortable and unfriendly. The unambiguous provision of clean pornographic magazines was helpful for some. The availability of clear instructions about where and how to produce the sample, what to do when finished and written instructions to back this up were also important. Where these were present, they helped considerably and vice versa.

Finally, having the opportunity to bank, or try to bank, more than once was well received. This included the one who tried and failed twice and the one who achieved a better quality sample on his second attempt. One of those who went a second time commented favourably on being able to be seen by the same staff.

### ***Contact with professionals that are sensitive to your needs***

Respondents were very clear about the crucial importance of professional responses by both the paediatric oncology and sperm banking staff. This included professionals that lowered anxiety by their manner and their way of explaining things. Key ingredients appeared to be calmness, friendliness and clarity of explanation:

**TM:** ..... I remember the nurse that was sort of in charge and helping us with the paperwork and stuff was really nice. Really helpful. And she explained like everything and any questions I had which was really good cos it set us at ease. .... She just seemed calm and relaxed and very helpful. And she smiled a lot as well which helped...

**Teenage male 18:19**

Several appreciated it when staff acknowledged that they might fail to produce a sample and reassured them that this was not out of the ordinary.

Staff in the paediatric oncology centres were rated consistently highly by respondents and this was in marked contrast to previous contact with some of the health professionals who had been involved in protracted health consultations prior to diagnosis (of which there were a number). Although there were many examples of warm and sensitive contact with staff in sperm banks, there were also examples of insensitivity or, more commonly, a formality and sense of unease or discomfort (see below).

### ***Having involved and supportive parent(s)***

As with decision making, parental involvement appears as both a help and a hindrance to managing the banking process itself. On balance, more of the respondents were happy with the level of their involvement of their parents than not, including those who were embarrassed about the nature of the subject and the need to procure the sample through masturbation.

### **What hindered with managing the process of banking?**

#### ***The rapid transition from being fit and healthy to ill, bed ridden and/or experiencing stress***

Many reported feeling that this was an extra task to undertake at a time of stress, that they did not feel like masturbating at such a time and in such a context but nevertheless were prepared to do it. There were also a number who had moved very rapidly from being apparently fit and well and perhaps experiencing fairly minor symptoms to being ill and bed ridden. The impact was both physical and emotional. For some, the stress of coping with the diagnosis or perhaps the impact of the disease (or treatment) itself proved too much to succeed in producing a sample, though none would have preferred not to have been asked. One of those who became ill very quickly described this experience:

**AM:** And it goes from you not being able to really move or do anything to being asked to do that. And then especially being told you can't have kids, so you're going down there thinking 'oh I'm never gonna have kids' and it's like the added pressure on thinking 'well I've got to do this' and then it's like, is there something that's... .....it's extra on your shoulders. Especially when you're going thinking I've got to, I've got to do this, and.. when you've like that, it's, everything there, it's just. Well I don't know about anyone else but I just couldn't do it [ejaculate] .....

**Adult male 16:22**

#### ***Having your parents knowing what you're doing***

Even though many opted to have their parents accompany them to the sperm bank and would do so again, they nevertheless talked about the difficulties of managing the fact that their parents knew that they were masturbating. Only one thought that this, together with a number of other factors, may have contributed to his failure to ejaculate. None reported any lasting negative impact on themselves or their relationships with those parents.

#### ***Insensitive professionals***

As indicated above, there were some examples where professional style proved to be insensitive and unhelpful. This appeared to be where the professionals did not

'tune in' well to the young men and often hinged around such as lack of humour, discomfort and formality as illustrated by one of the adults:

**AM:** The man then explained in very direct terms the process of what you do erm, and you know, where to leave it type thing, and it, it was all, I mean I remember sort of trying to crack a bit of a joke, and it fell on deaf ears cos they have to deal with it all the time. But, erm, it was an uncomfortable experience from the start..... I think the approach they took was because they wanted it to be a serious thing. However I think I would have preferred them to have been a bit more human and said something like, 'I know it's probably quite embarrassing, I apologise for that, but this is the way you do it', or something like that. But no, it was very regimented, these are the facts, I just think it could be nice if they are a bit, well I think they need to be friendly, if it's an embarrassing thing then you need to have somebody who you feel comfortable with and secure with - and.. I didn't really.

**Adult male 20:22**

One of those who failed to ejaculate speculated that there might have been a different outcome if the professionals' approach at the sperm bank had been different (although there were other influential factors too). He, like others, reported on the formality of the staff at the sperm bank and, in particular, their lack of humour. Several assumed that this was down to their lack of experience in talking to their age group and their familiarity with the routine making them treat it too impersonally.

## **PULLING IT ALL TOGETHER**

There are certain broad brush findings to come out of this exploration of the experiences of the process surrounding fertility matters at around diagnosis. It is clear that there was strong support for the potential impact of treatment on fertility to be stated at around the time of diagnosis. This was regardless of gender or whether or not the individual accessed fertility preservation services. Where this did not happen, it appeared to have caused difficulties, especially in the longer term.

There were good levels of understanding and recall about the information being imparted (where it had been) and a range of reactions to it from lack of concern to significant distress. This was true for family members too. It was generally agreed that information needed to be 'broad brush' only at the first time of telling though with the opportunity to ask for more detail soon after and again at intervals after that. Some females would have preferred greater clarity that references to the possibility of interrupted menstrual cycles also meant that their reproductive system was being affected. There was also some evidence of a range of interpretations about the level of likely risk to fertility arising from what was said (and not said) by professionals.

Although the impact of diagnosis and entering treatment was dominant and sometimes overwhelming, there was good evidence of the young person's ability to take in sufficient information with which to make a decision about accessing fertility preservation services. Although some *said* that they were very young to be dealing with this, they nevertheless managed. Some females not invited to preserve their eggs would have liked to have received an explanation at that stage about why this was not on offer.

Decision making was straightforward and aided by clarity of information sharing, the manner and context within which it was shared and the involvement of parents (provided that the young person wanted their parents present). Where the offer was turned down, this was often a matter for regret or occasional preoccupation in subsequent years among both males and females. Only males went ahead with accessing fertility preservation services and there was universal support among males for it to be made available. This included those who refused, those who were very ill and/or already in treatment and those who tried and failed.

Decision making and preparation for undergoing sperm banking happened predominantly within the paediatric oncology setting (and was done well) with the consent taking and semen collection process taking place within the sperm bank. The journey to the sperm bank presented challenges. The whole process was eased when the young person could exercise choice about being accompanied. Many chose to have family members present and this helped. Respondents had almost universal praise for the manner of professionals in paediatric oncology but their experiences were more mixed with sperm bank staff. Informality, friendliness, clarity of language and being spoken to directly rather than through parents were hallmarks of good professional practice. The process of consent taking was remembered in relatively little detail though some were distressed by questions about posthumous arrangements for semen disposal. There was considerable confusion about the consent conditions, including 'consent to disclosure', and very limited awareness that these can be revisited.

There were suggestions for improvements to the semen collection room. These included making it more homely, more private, ensuring that pornographic magazines were clean and unambiguously available, providing written instructions and a clear procedure for handing in the sample. A few found the process made them feel 'smutty'; all found it embarrassing. Most approached it as part of the required process towards treatment.

There were variations in getting the results; getting them quickly seemed to be particularly well received. There were good levels of knowledge about storage matters.

## INFORMATION, UNDERSTANDING AND RECALL FOLLOWING DIAGNOSIS

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It is clear from Part One that there were good levels of recall about both the information that was being conveyed and the understanding of it at around the point of diagnosis. There was also a good level of recall about the process of events at that stage, for example in relation to sperm banking. This section takes that forward by considering what respondents said of their understanding and recall of later information and events and the picture starts to become more blurred at times. The same information can be 'heard', interpreted or recalled quite differently by different people, of course, whereas some information may be incorrect, contradictory or incomplete. Some respondents acknowledged that their memories may be incomplete and that they may have been asked or told things that they do not now recall. However a number of these had also asked parents who, in each case, confirmed their recall.

Responses are considered under the following headings:

- Understanding of reproductive function
- Understanding and use of hormone replacement therapy
- Understanding and use of contraception
- Understanding and use of fertility analysis or its contemplation
- Understanding of fertility treatment options

### UNDERSTANDING OF REPRODUCTIVE FUNCTION

Most **males** in both age groups reported satisfaction with their level of understanding of reproductive function at diagnosis and this did not, on the whole, change with the passage of time. This included some of those who coped with treatment by blanking out whole sections of the experience. However, it was restricted primarily to an understanding of the possible temporary impact of treatment on the body's ability to produce live sperm and the fact that live sperm are needed in order to be fertile rather than more detailed understanding of how sperm are produced. The resulting anxiety, if there was any, was therefore associated with making the decision about whether or not to find out their fertility status.

Although levels of distress or concern *appeared* greater among those who had not banked successfully (and this will be returned to later) this appeared to be related more to uncertainty about whether function would return rather than poor understanding about the reproductive system. Only one male asked in the interview about erectile function and that was because he was having problems. No others either asked about or mentioned anything to do with reproductive functioning. For the males, the *knowledge* of possible *temporary* impairment appeared to cause little distress, again particularly among those who had banked their sperm (who were also predominantly among the younger respondents).

**TM:** .... well it kind of dun't matter really because it might be saying there when I go this time 'Oh no, you can't have kids in proper way'. But it dun't

matter cos like maybe in like a few years down line stuff might reproduce again and stuff. So it dun't really matter. There's always that chance of hope in't there? **Interviewer:** Yeah. So has somebody explained that to you that it might test now that there's nothing there but it could come back, has somebody been through it with you? **TM:** Yeah, my consultant. And like you read it in papers, like adults having kids don't you? It were in the paper a few months ago weren't it? Oh no it were in a magazine that a lad undergoing same illness I had, had a kid - no way - but I thought 'alright'. **Interviewer:** And that hope's important? **TM:** Oh definitely yeah.

**Teenage male 15:18**

The picture appeared more complex for **females** in both age groups with evidence, among many, of a closer link between poor understanding of reproductive function and the impact of potential impaired functioning. Thus the preliminary 'good enough' grasp of understanding at around diagnosis did not appear to have deepened and, if anything, may have reduced. Females were likely to talk about their confusion about the working of their reproductive system when discussing their understanding of the ongoing impact of treatment on their fertility, even when they understood any impact might only be temporary:

**AF:** ... I think she [ACU consultant] just sort of like said, I think, my eggs are ovulating and things like that, so things are working but I'm having lots of problems with my periods, so I'm just bleeding constantly, I can bleed for like twelve weeks at a time. And have a couple of days break and bleed for another ten weeks. So from that point of view I don't think I would be able to have kids at the moment anyway, because of the bleeding, until that sorts itself out. But I couldn't really tell you anything else about my chances or anything cos I don't really know myself.

**Adult female 18:23**

A number were more likely to refer to their periods - either their return to 'normal' or their irregularity - as positive or negative indicators of their response to their cancer and its treatment than as indicators of fertility. It was only when looking back that one teenager said that she realised that the questions asked of her at follow up were about reproductive function:

**TF:** Every time I went they would always say, you know, 'how are your periods?', because apparently for a lot of girls, they stop during chemotherapy anyway, but mine never did. It was often commented on oh, you know that that's a good sign, and I always used to think that a good sign meant that the chemo was doing what it was meant to, instead of interrupting everything else, it was doing what it was meant to, but looking back now I sense that maybe a good sign is that, you know, it wasn't affecting my ovaries, but I mean you don't know unless, you don't ask them...but that was the only time it was ever mentioned

**Teenage female 13:19**

A small number continued to be confused about the link between their menstrual cycle and their fertility per se. Thus, for example, some did not associate their (lack of) periods during treatment and afterwards as meaning that their fertility might be compromised and felt that this should have been made clearer by their doctors.

One of the other areas where there were gender differences in the impact of understanding of reproductive function was that eight females were coping with the knowledge that they faced a possible or an actual premature menopause whereas the males were coping with the potential interruption then *return* of fertility. Here again there were varying levels of understanding among females, perhaps because a potential loss of fertility carried greater implications than a possible delayed return of fertility. While most of those affected understood that a premature menopause would lead to a shorter reproductive life span, there was some lack of clarity about what this actually meant:

**TF:** .....one doctor said that what had happened, said it was a premature menopause, which I kind of latched on to, alarm bells went off in my head and I thought my God if I don't take the pill, I'll turn into an old woman, what's going to happen to me, but then another one, another doctor called it, you know, premature egg failure. Even now I'm sat here, I don't know what it is, I don't know if it's the same thing, or whether when they say premature menopause, it's actually like the menopause my mother's going through.

**Teenage female 13:19**

Some remembered being told that this was a possibility during treatment; others found out some time later and were surprised not to have been told earlier but were not unduly distressed; whereas for others, it had come as somewhat of a shock to be told later on and did lead to distress. For at least one, the premature menopause had already come even though not predicted medically. The ongoing impact of this is returned to in Part Four.

## **UNDERSTANDING AND USE OF HORMONE REPLACEMENT THERAPY**

A number of the females were on HRT but none of the males said that they were. Some females found some (though not all) aspects of HRT difficult to understand. In particular, these included:

- the nature of the relationship between HRT and contraception and
- the nature of any health risks that it posed.

One of the teenage females, for example, talked about the difficulties posed for her as a sexually active woman of being on HRT, not knowing whether or not she was fertile and fearing getting pregnant in case this triggered a relapse:

**TF:** But the way that my fertility stuff's affecting me is that I can't go on the pill and I don't know if I can even get pregnant anyway. But I still have to be wary, which is annoying. We still have to use protection even though I might not – there might be no chance that I can even get pregnant. So that's, that's something that's quite a big issue. It's like..... I always worry about it. .... I'm just like what if I get pregnant by accident. Even though there might never be a chance. What if I get pregnant by accident. It's like my worst fear. **Interviewer:** So you're having to hold these two things that are opposite ends of a..... **TF:** Yeh. It's like I could sleep with [fiancé], I'd sleep with him without any protection and then I'd just worry for the next three months until there wasn't a bump growing that I was pregnant. I would just be obsessed with it.

**Teenage female 18:20**

And another illustrated the confusion felt by some about the health implications of being on HRT:

**TF:** I take the pill every day religiously, and every time I open the new box, there's always the leaflet with the graph about breast cancer and things, and I look at it and think I started taking that when I was about fourteen, fifteen and I'm going to be taking it until I'm nearly fifty, you know, no one's ever said whether it puts me at any risk, it's never been brought up, and then I think to myself if there is a risk and I stop taking it what will happen to me then? I mean no one's said if you don't take the pill this is what will happen.

**Teenage female 13:19**

Some did not appear to understand (or accept) that being on HRT might be an indicator of fertility difficulties although others did.

Some struggled to remember when and why they had been put on it while others were clearer about the reasons. Only two said that they needed to be on it to reduce the risk of osteoporosis.

A number had been on 'holiday' from HRT to see whether their periods returned and understood that any failure to resume periods was an indicator that their fertility might have been affected.

## **UNDERSTANDING AND USE OF CONTRACEPTION**

It was implied by some answers that not all the respondents in the study were sexually active and a number made it clear that they were still virgins. That said, there were also some gender and age differences in references to contraception that did not appear to relate to sexual activity.

Contraception was only mentioned by one teenage male but by almost all the teenage females. However, the majority of the teenage females had been prescribed the pill post cancer to regulate their menstrual cycle or to reduce pain rather than for use as a contraceptive. The picture among adults was more balanced between the genders. As one might expect, contraception was referred to more often as a means of pregnancy avoidance than of symptom control (although a small number of adult females did use it for the latter). Only adult males talked of contraception as a means of STD avoidance and then only a small number.

While a few had contraception raised by professionals (mainly their consultant), many did not recall it being raised with them. When professionals did raise it, this was in the context of pregnancy avoidance and often involved humour, which was usually well received:

**AM:** Well I remember a doctor saying ..... just because you might not be able to have any kids doesn't mean you definitely can't have any kids and don't give you the excuse to be going spreading your seed because if you can have kids, and he didn't swear but basically you're in trouble, big trouble. .... I remember him saying that just because you might and he

like said it like MIGHT not be able to have kids, there's still a chance and if you go and do whatever, you know, you could be in trouble for it.

**Adult male 13:25**

Two of the females at least had discussed contraception with their mothers but this appeared to be as part of being sexually active rather than anything specifically to do with their cancer experience. None of the males referred to discussing it with family members.

A small number of females had deliberately sought advice from their GP rather than raising it with their oncology team. One preferred to deal with her GP over contraception as he had known her most of her life and she felt comfortable with him. Another preferred to keep her dealings with professionals over contraception separate to those over cancer – partly gender-related (she had a female GP and a male oncologist) and partly to keep the 'normal' part of health care separate from that attached to cancer:

**TF:** I've gone to my GP for all that cos ..... she's a lot easier to talk to. .... I kind of keep the two separate. That's to do with my illness and my history and this is to do with my life as far as I see it, my personal life.....I keep it separately.

**Teenage female 15:20**

However, professionals who raise it might also need to be ready for the robustness of the rebuttals that might come from some, perhaps especially when the query is rather ambiguously worded as in this case:

**TF:** He [consultant] did once say 'how's your love life?' and I said 'it's fine thanks; how's yours?' And he went 'Oh all right'.

**Teenage female 15:20**

Finally some respondents themselves raised the issue of contraception with their Consultant and included their current partner in the consultation – for some this being their first time of taking their partner to an appointment. One of the males said that he used this as a way of getting advice about whether or not his fertility had been affected.

Several respondents indicated that their approach to the use of contraception for pregnancy or STD avoidance was not actively or consciously affected by their possible infertility. These were drawn from those who were sexually active prior to cancer and those who were not and included some interesting observations, especially among the males who understood that their chances of being affected were high. For example, one adult male said that he had always used contraceptives even though he had been told that he was infertile. Whereas another said that his decision to avoid using contraceptives was also, for him, a 'normal' non cancer-related decision that was driven by being 'one of the lads': (although his partner, who took part in the interview, thought that it related to him thinking he was infertile, he was adamant that it was not). In other words, it was gender and culturally appropriate for him:

**AM:** Like me other mate, [.....], he's one of me other best mates and he was exactly the same. He was exactly the same. .... I was young wan't I? Every lad's the same..... I was like one of them - if it happens, it happens.

**Adult male 13:25**

Conversely, for others their fertility status and/or their beliefs about their fertility *did* appear to have influenced their actions.

One teenage female was advised to use contraception as she was sexually active even though she had also been told that her fertility was highly likely to have been affected. This was acceptable to her as she understood that it was better to be protected against accidental pregnancy as this could be dangerous for her so soon after treatment. This view was also reinforced by prior family and cultural messages about unplanned pregnancies.

An adult male who had been very sure that he was infertile still used contraception in all relationships until the one with his long term partner at which point he stopped using it. His partner was also the only one that he had told that he thought he was infertile. He was prompted to undergo fertility analysis shortly afterwards and learnt that he was in fact fertile and that led to him using contraception for the first time with the deliberate aim of protecting against pregnancy. Previously his reasons for using contraception were a mixture of wanting to avoid contracting a sexually transmitted disease, a desire to allay any anxiety on the part of female partners that may arise from him not using contraception and a desire to appear to be fertile and thereby maintain his privacy. Indeed this applied even on '....a couple of occasions the condom split, and I must admit at the time it went through my mind that I had nothing to worry about, and I didn't pass that information on to the woman'.

Another of the adult males similarly was quite sure that he was infertile but, at one level, acted as if he might not be when he expected an earlier girlfriend from soon after the end of treatment to use contraception. This led to the apparent confirmation of his infertility (at that time) in a disturbing way and one that threatened to invade his privacy around his fertility status. Unbeknown to him, his girlfriend had stopped using contraception in the hope of getting pregnant; when he found out and confronted her, she challenged him in return about his fertility. Interestingly, he started using condoms after this experience though said that this was mainly to avoid STD transmission (although he had not used them previously) and continued to not tell partners about his possible infertility until he entered his permanent relationship. Once in the permanent relationship, he stopped using contraception. Like the earlier adult male, there were hints of some ambivalence in his behaviour around contraceptive use in these different contexts not least as he said that he did not want children yet (if at all) and had not undergone fertility analysis.

Ambivalence in contraceptive use that stemmed from possible infertility was also evident among some of the females but it was manifest in a different way. One of the adult females expressed her ambivalence around her use of contraception in that she was using it to control symptoms but she also wanted to become pregnant so found its use distressing. In the section above, the complexity for some of understanding the impact of HRT on contraception and vice versa was voiced. The young woman

who could not go on the pill as a result of being on HRT went on to express the impact of her perceived inability to control her reproductive choices with any confidence and this, together with being out of sync with peers, was stressful:

**TF:** So that's a big issue around that. Not knowing whether I can get pregnant or not. And never being able to go on the pill cos everyone else is on the pill and it's just like..... It seems quite useful to be on that and have that peace of mind . .....And if I come off these pills [HRT] and discover that my ovary doesn't work, I have to go back on the pills, I'd still have it in the back of my mind that there's a chance that I could get pregnant and I will never take it as being able to be positive that I'm infertile. There's no way I'm ever going to be positive I'm infertile. ....

**Teenage female 18:20**

However another adult female was far less ambivalent about its use. She knew that she was some way off being able to cope with a pregnancy because of her cancer-related symptoms and impairments and the availability of a reliable contraceptive allowed her to enjoy a sex life.

And another was less ambivalent but in a rather different way. She had in the past deliberately avoided the use of contraception and had sex with multiple partners in an effort to test her fertility and become pregnant.

## **UNDERSTANDING AND USE OF FERTILITY ANALYSIS OR ITS CONTEMPLATION**

There were key differences between males and females over fertility testing in that:

- a small number of the females had been referred for help with menstrual cycle problems which resulted in them learning more about their reproductive capacity
- no females were expecting to undergo a routine analysis whereas four males were.

Only two males and two females had undergone fertility testing per se, most of whom were in their late teens or early 20s when this happened. Another two adult females were in the process of undergoing analysis at the time of the interview, one adult female had started the process but had suspended it indefinitely and another adult female and two males (one teenage, one adult) had just been referred into the process. Hence the data for those who have formally requested analysis is very limited.

Additionally, as a result of investigations for menstrual cycle related symptoms, one teenage female had been told that she was infertile and would need to use egg donation if she wanted to become a parent and an adult female had been told that she would not be able to have children naturally and would need to use IVF.

Finally, a further four respondents (one male and three females) had become aware of their fertility status as a result of pregnancies (see Part 5).

## Completed analyses

Of those who voluntarily opted for fertility analysis and had completed the process, neither of the males found it a difficult decision to make at the time. One had discussed with his partner alone whereas the other did not appear to have discussed it with anyone. The first one had been prompted by an imminent change to the venue of the sperm bank and the possibility of being charged for storage. The other did not say why he had been tested but implied that he saw it as routine. Neither remembered being offered or receiving counselling.

Both the females were younger when tested and, as with the males, the request came neither from within a symptom context nor from within an adult relationship. One of them was motivated primarily by distress, a 'need to know' and an overheard conversation between doctors and nurses in which her fertility was being discussed. However the other was more motivated by curiosity:

**AF:** I were just curious to whether I would be able to have kids or not so I went to assisted conception unit and they did some tests, and ... I think were it me left ovary? I don't think that were working, and me right one were working but it were smaller than it should be, a fair bit smaller. And I were told if I wanted to have kids then then were best time to try, but I wa' twenty and I wan't in a serious relationship or owt like that, so I wan't - time wan't right. .... So I was just being curious so I thought I'd find out.

**Adult female 18:25**

As with the males, neither remembered being offered or receiving counselling.

Only one of the males and one of the females talked in any detail about the *process* of analysis. As with the male's earlier experience of banking, he could recall certain aspects of the process – such as the journey there – with great clarity but other parts were more clouded.

The female who had been motivated by distress rather than curiosity reflected back on the process and felt that she could more usefully have been provided with counselling to slow the process down. She had pushed her consultant to refer her for testing soon after treatment ended, even though the consultant was reluctant and thought she should wait. The result was negative and she received little or no help to cope with that news either immediately or in the longer term. She reported that she found the experience devastating and described it feeling like 'a bomb being dropped' and as 'It's like my whole life was being taken away'. Several years later, she continues to struggle with it and has undergone a lot of counselling since (though is only just really trying to open up on fertility issues). More recently at a check up (at a centre near to where she is now living) she raised it again and, this time, was referred to a colleague who was able to provide her with factual information and options for treatment, names of support groups and so on which she found very helpful. Conversely, the other female had emerged from the process without any particular traumatic legacy at the time or since, even though she was found to have reduced ovarian reserve. However she continues to have cancer related physical difficulties and some ongoing treatment. Now engaged, she doubts that she can contemplate parenthood for some while yet because of her impairments and constant

pain so her views about her fertility have since become more complex for other reasons.

One of the men was found to be fertile through testing (unexpectedly for him and he has gone on to become a parent) and was delighted whereas the other male had no sperm present. He reported little effect from this news as it was what he anticipated and he located his reaction within his general approach to his cancer experience (and life) of being very laid back. He also ventured that his sperm function may still return.

Thus, the process of giving results *appeared* to be unproblematic for most of this small group even though the content was challenging.

### **Considering analysis**

As already said, four males were anticipating having routine testing and did not express any particular anxieties about this. None appeared to hold serious concerns at this stage that they might be permanently affected. One of the teenagers expressed a common understanding among them all that one needed to wait for a while after treatment and, even then, function may take a while to return so the first test result was not necessarily definitive. One of the other teenagers with stored sperm was not expecting a routine test and he expressed uncertainty about when might be the right time for him to return.

One of the adult males (who was confident that he had not been affected) had been expecting to be tested at a recent appointment but found when he got there that it was not automatically. He reflected that it would be easier in some ways if it were, as it was not an easy decision to make when one had to make it proactively. This was echoed by at least one of the females. He went on to say that he had recently heard a talk at which the speaker said that test results can also vary according to the centre where they are tested so it is always better to get tested through a sperm bank rather than one's GP – another thing to have to think about, especially when the sperm bank is geographically distant.

All of those who were expecting routine analysis had stored sperm and this expectation appeared to stem from that. All those who had stored sperm, regardless of whether they expected to receive routine testing, referred to the reassurance that came from storage.

Even some of the males who were not expecting to get an automatic call for testing because they did have sperm in storage were contemplating having one done at some stage and two, as referred to above, had recently been referred but had yet to have their first appointment. However, the approach to testing was far more variable amongst this group. The adult appeared quite relaxed about the process as he had been sexually active for a long time without using contraception and was sure that he was infertile. He saw testing as a way to tell his parents of his infertility without having to disclose his sexual activity. However for the teenager, the need for some sort of certainty was a major driver and there were indications of anxiety about the outcome. He remembers raising the subject a number of times with health professionals with no action being taken. Then, on his last visit, his consultant raised it and now he has

been referred to the sperm bank and his first appointment was due to take place shortly after the research interview.

**Interviewer:** So it's something you've been thinking about, do you talk with anybody about it? **TM:** Just mates really; that's the only people really. I mean, it's not so much a major, major issue for me to talk, I just think about it... ..I do, sometimes I talk to my mates but not that much really.....Well when you're walking around, even though I'm only eighteen, you see it like when you're at school or walking, you see little kids, it just makes you think you'd like to have that when you're older, then you start to wonder what if you can't, what if this happens or whatever, so. You can think about that as much as you want but you just need, you know, to get it sorted, and know what's going to happen and all that.

#### **Teenage male 13:25**

The adult males were more likely than the teenagers to articulate the pros and cons of finding out. However it is perhaps of note that those who expressed such uncertainty had either been unable to store their sperm or their stored sample was of poor quality – i.e. all indicated that they thought there was a high probability that they were infertile. One had raised it with his consultant and was told to wait a while but since the doctors returned to it, he himself has been delaying the referral:

**AM:** .... it is one thing over the last couple of years that has started niggling me just thinking like, do I want to know, do I, don't I? Obviously I don't at the moment but it's like I want to know just in case if I can or I can't. .. And it's like...it's one of those things if find out I can, brilliant, if I find that I can't, how is it gonna ... I don't know but it's like, just one of these things, do I, don't I?..... In a way yes, but in a way, if I can't, then where do I go from there. But then again, especially wi' girlfriends and that, it's like well always on the back of your mind. It's summat... especially difficult subject to raise. Cos obviously you don't know how long you're gonna be or what. So, in a way it would be a good way to find out, then if I can have kids, it's not a subject I would have to raise. Then if it is one that I can't have kids then it's obviously then a difficult situation to raise again, especially if they don't know my past. So it's something always there in the back of your mind subconsciously that is niggling away. But, don't know.

#### **Adult male 14:16**

Similar to the male quoted above who speculated about whether or not it would be easier if routine appointments were made, the one with stored, poor quality sperm saw merit in having the decision made for him. He said that he found it difficult to make decisions generally and so, as a self assessed passive personality, being pushed into doing things sometimes proved useful.

Although another adult male started by saying that he would probably delay testing until he was in a permanent relationship and wanting to start a family, he nevertheless illustrated a more complex decisional process that had been underway for some time. Like the adult male above, he was torn between wanting to find out and fearing that the result would remove any remaining hope that he could achieve biological fatherhood. Even though he had now overcome the hurdle of telling others, including past girlfriends, the decision was far from clear cut. He explored the emotional aspects of decision making as the rational process proved of little help:

**AM:** I think postponing dealing with something isn't denial, I think you're just putting it to a time when you can deal with it when you're at a stage that you feel you can deal with it. I don't think that's denial, that's postponing. I think denial is to always just say, you're wrong, you're wrong, you're wrong to the doctors. I mean I accept, I've always accepted what they say is a possibility, I think the denial comes when I say it's a definite, because I don't think anything is 100% definite, and I think there is always a chance, always a chance, even if it's nine hundred and ninety-nine percent certain there is a possibility and I would like to think I'd that possibility, although I know all the odds are stacked against me but, and I suppose that is the denial aspect is that I would be that .0001% but I don't know if that's denial, that's hope and optimism, isn't it.....if I didn't have the hope I'd get tested now .....

**Adult male 13:28**

Other adult males who were not contemplating testing for the foreseeable future echoed the anxiety that was voiced here about whether or not they could or should take the risk of finding out that they are infertile before they are trying actively for a family.

All three adult males also talked about the impact of gender on their approach to analysis. One wondered whether his tendency to avoid dealing with the issue was to do with his gender as well as his overall approach to life. One talked about finding out if he was a 'real man', and the third talked of the potential for the result to affect his sense of virility and male pride at a gut level even if he could cope with it intellectually.

There were similarities in the experiences of the two females who were undergoing investigations because they were actively trying to get pregnant, the two who had thought about undergoing tests for fertility though had not yet moved ahead with this and the one who had indefinitely suspended tests.

One of those considering analysis, one teenage female had been aware for some time that her fertility may have been affected. She had been on HRT and was fully aware of what her next step might be – i.e. to be referred for having a 'holiday' from the HRT to see what was happening. She talked about how valuable it was that her consultant regularly checked with her whether or not she was ready to take this next step. She also used her consultant to discuss the possible timing for this in terms of being emotionally ready; it being the 'right' time for her, free from other major pressures in her life and so on.

The difficulty of making the next step in terms of being ready for managing the consequences of analysis was illustrated by the adult female who had shied away from going any further with investigations after what seemed to be a brief foray into the process. Indeed there was the hint that her need was for emotional attention *before* continuing. She appeared deeply troubled by the information to date that she would be likely to face a premature menopause and thought that she had been referred because she got upset in her appointment with her consultant (see also Part Four):

Even those who were seeking investigations because of wanting to start a family were not necessarily finding the process easy to keep going with. One was undergoing investigations at the time of the interview but also appeared hazy about

what was happening and described other troubling symptoms that were getting her down – e.g. bleeding for weeks at a time with short breaks in between, low stamina. She knew that she had to take the initiative in arranging the next appointment and had been avoiding doing so.

However, the situation was different for another adult female who was in a similar situation but free of any ongoing cancer-related physical symptoms. She had actively welcomed earlier discussions about her options and so on but was not ready until recently to undergo testing. It was not until she was married and wanting to try for a family that she then sought further advice and investigations, feeling that she might find it easier to cope if the results were negative at this stage:

**AF:** And initially it was something that I thought about and didn't want the tests. I wasn't... ready to have a family and I felt that it would be more difficult to know that I couldn't have children than it was to not know at that point. I think for every appointment after that it's one of the things that comes up and they talk to you about and I think in the first appointment [husband] came to, it came up again and we again at that point made the decision that it's something that we'd go to the clinic when we were, when we wanted to have a family, when we'd got to the stage when it was the right time

**Adult female 14:25**

Finally, one of the adult females who had recently been referred for tests at the time of the interview born out of a desire to know rather than because of actively contemplating parenthood appeared to have as little anxiety about it as did the adult male referred for testing and the adult male and adult female who had completed analyses:

**AF:** I thought it would be interesting to know the results. I suppose it could be quite depressing if they suddenly said 'oh you've got four years', so in a way that might be better off not knowing but I think I'd be quite interested to know anyway, so. I like the scientific way for that kind of side of it anyway.

**Adult female 15:26**

## **UNDERSTANDING OF FERTILITY TREATMENT OPTIONS**

By the time of the interview, there were significantly increased levels of awareness among the females to those reported at diagnosis that egg freezing was a possible option. This perhaps reflects the increased general public coverage of this over the intervening time but also increased alertness to infertility issues among these individuals who were now perhaps more sensitised to them. Additionally, more females than males referred to having been asked subsequently by friends and others about whether or not they had used fertility preservation– perhaps again reflecting greater public awareness but also a gendered difference in raising reproductive issues with females more than males. Females were also significantly more likely than males (8 females and 2 males) to talk of knowing others in their family or wider networks who were coping with fertility difficulties, some of whom had had unsuccessful fertility treatment (none knew of anyone personally that had successful treatment). It is interesting to consider whether this reflects the actual incidence or whether gender influenced such awareness.

There were various references to the impact of media portrayal as a source of information and understanding about fertility preservation and treatment options and, for some, hope. This is likely to become even more of a factor to be taken account of in the future. It will partly depend on the level of exposure that there is in the different age or gender appropriate media contexts but in this study:

- Later interviews were taking place after the pop star Kylie Minogue had been diagnosed with breast cancer and opted to freeze her eggs. One adult female speculated that this would increase demand in the future as well as affecting those who had not had the option available to them at the time of diagnosis.
- A few of the teenage females reported being asked from time to time whether or not they had eggs frozen. With increasing awareness in the general public and/or through media coverage, some speculated that this too is something that cancer survivors may increasingly find themselves being asked about.
- A number in all four groups cited coverage of fertility and fertility treatments in the media as prompts for them to think about their own fertility afterwards as well as providing sources of information.
- For a number of the males in particular, the media coverage during the study of the man who had used his frozen sperm to father a child 21 years later was quoted as a source of information and, most importantly, hope and reassurance.

None in the study had yet used assisted conception treatments though two of those in the process of undergoing tests thought that they might go on to consider this route to parenthood shortly. A number of the females but a smaller number of the males referred to their lack of knowledge about fertility treatments.

Some of the respondents used various words or phrases in a way that was clear that they did not have a clear understanding of treatment options. Very few indicated knowledge of the low success rates or other complications such as multiple births. Some of the males with stored sperm seemed rather hazy about the number of attempts that their samples might offer them and used the research interview to ask questions, illustrating how additional knowledge might have enhanced their coping strategies and/or reduced their anxiety even further than did reassurance from banking alone:

**TM:** Like I know that I've got it in a jar or wherever it is now... I would like to know how they get it into the woman you know. Would they use like a needle or would they put her to sleep and do it some other way like that. So that maybe in time if it's still not come back, I could sit down to me wife or me girlfriend and say, explain, how they would do it so she wouldn't feel so nervous about it or things like that.

**Teenage male 15:17**

However, a small number were very clear. One of the adult females said that tests revealed that her ovaries had been 'killed' (her words) and that, while she would never be able to have children on her own, she could have IVF. She understood that this would mean using donated eggs. One of the teenage females was also clear

about the meaning of egg donation, including the effect on legal parentage. While another adult female reported that her consultant had spent a long and useful time talking with her about the impact, her options and so on soon after treatment ended and again more recently following her marriage and decision to embark on trying to get pregnant. Some knew that, even if they were to conceive naturally, the pregnancy itself may not be straightforward.

It was a different picture with the males in that there was little *evidence* of knowledge about treatment options. This may reflect the lower numbers of men who reported thinking about alternative approaches to parenthood and/or the ambivalence or hostility among men to donor insemination (DI) (see also Part Five). One of the few that talked about this, an adult, understood himself to be at very high risk of infertility and had unsuccessfully tried to bank. He seemed to take on the message of hope through treatment without necessarily having understood treatment options in any detail

Another adult male appeared so distressed about his possible infertility that he did not feel confident at raising treatment options (even though he wanted to know more) and none of the professionals had raised it with him.

Fertility treatments were also referred to in a different way across genders – as an important source of hope. It was therefore perhaps less important for this group to have *knowledge* about the treatments than it was to have *belief* in them (and other medical advances in reproductive medicine) as an alternative route to parenting:

**TF:** It is hope, isn't it .. they're forever testing new stuff. I think some of the stuff is amazing what they do these days. So I think as time goes on there is always hope somewhere. ....It's just amazing what they can do I think. I think it doesn't all have to be bad. Not in this day and age anyway.

**Teenage female 17:20**

In this context, knowledge of successful outcomes to fertility treatments gained either through media coverage or from professionals or others was an important source of hope and comfort.

## **SATISFACTION WITH INFORMATION RECEIVED**

### **Availability and quality of information**

Numbers were fairly even divided across all four groups between those who felt that the information that they had received from professionals on cancer-related fertility matters after the early stages was good enough and those who wanted more. A small number took responsibility for this personally as they said that they had not sought information.

Several of those who felt that information levels were good talked of the sense of security that came from feeling confident that they could ask anything at any time from paediatric oncology staff who were generally seen as very approachable – even though several had not actually sought information about fertility matters when they wanted it, suggesting this type of information seeking may not be as straightforward as all that.

There was general support for the subject of fertility to be raised proactively at regular intervals following treatment (though in a low key way) in order to make it clear that this was an area that professionals were willing to discuss and/or provide information on at a time that felt right for the individual. The need for clarity in this was noted by a number:

**AF:** ... everything was told straight down the line, like really clearly, but no beating about the bush... cos then there is no confusion about anything

**Adult female 19:26**

The timing and context of this is returned to in more depth in the later section on 'telling and talking with professionals' (see Part Three).

There was also acknowledgement, as there had been among those reflecting on their experience at diagnosis, that information was sometimes incomplete because the health professionals themselves were working with uncertainty and had shared as much information and advice as they could.

A few had made use of the internet to look for fertility related information and found that useful, though some had concerns about how to decide whether information thus obtained was reliable. There were similar references to information obtained through watching television programmes and documentaries. At least one reported having considered ringing a cancer telephone help line. Several referred to information received at TCT 'Find Your Sense of Tumour' conferences.

There was general support for an increase in written information though with the plea for it to be attractive and age appropriate and for it to *accompany* verbal information rather than to replace it. However some respondents said that they would be unlikely to make use of written material while others said that they preferred to use the internet instead.

Making the information easy to access also means making it visible at the same time as being discreet to gather. One young woman described having to memorise a website address that she had seen on a poster in a waiting area and one wonders how much that had limited her ability to engage fully in the consultation that followed. She explained the importance of being able to access the printed information from the web to supplement any verbal information that she had received.

A few identified a need for written or internet-based information to also be available for parents and partners both because for their own sake and to help their child or partner.

The two main areas where respondents felt that information was lacking were:

- (i) *for females* - on the workings of their reproductive systems and
- (ii) *for all groups* - on fertility treatment options.

Not surprisingly, the issue of information as a source of control, empowerment, anxiety reduction, anxiety enhancement or confusion came through.

## **Incorrect, contradictory or incomplete information**

Some felt that they had received what appeared to be *either* mixed messages from doctors *or* incorrect information *or* incomplete information. This was more likely to come from those outside of paediatric oncology than within.

**AF:** .....and I still didn't understand cos nothing had really been explained to me and I was like "yeah but I can still have kids ....?" and it was like "yeah" so I took that as yeah, so if he [surgeon] said to me 'yeah' then and then erm I kept going in for my appointments to see [paediatric oncology consultant] and it was then I realised that no, I couldn't have kids. ....I found out "no" the possibilities were quite slight of me being able to have children, because obviously my periods had stopped, like now I'm on hormone replacement, so erm because of that, obviously I realised myself no it's not just straight cut, that I can't have kids.

**Adult female 15:21**

Some of the females that reported getting incomplete information located that within the different cultures of other branches of medicine, perhaps drawing on their greater experience than males of other branches. Having been used to very open and clear communication with professionals in paediatric oncology, some reported finding information less clearly conveyed, consultations more rushed and atmospheres more formal elsewhere, including in reproductive medicine. Some used paediatric oncology doctors to then help them translate what they had been 'told' elsewhere.

**AF:** I didn't really have that relationship with the gynaecologist. It was obviously a man and I didn't feel at ease as much as I would with a woman. So I tended to shy away from questions I would have liked to have known. I sort of wanted to go in there, get my examination over with and come straight out. And anything I wanted to ask I asked [paediatric oncologist] and [...] forwarded it on, you know cos I did find it hard to talk to the gynaecologist. And I suppose with the gynaecologist you're sort of in and out, you're just a patient. Whereas with [paediatric oncologist] you can sit down and it doesn't matter if I'm in there two hours. If there is owt worrying me [...] I'll take time and explain everything fully to me. .... I just wish I had it with the gynaecologist and I think I'd know a little bit more about things, yeah.

**Adult female 18:23**

Some felt that the information offered from elsewhere was not always realistic. In paediatric oncology, they had come to value information being conveyed honestly, no matter how difficult the implications, so did not like being given false or unrealistic hope.

Parents too found this difference in information sharing difficult (as reported by respondents), not least in their role as protectors/translators and so on.

A few reported having obtained information from elsewhere that led them to realise aspects of fertility matters that they had not been told by their professional carers and thought they should have been. In particular, two of the teenagers 'learnt' through attendance at a TCT 'Find your Sense of Tumour' conference that not everyone with cancer becomes infertile while one was surprised to learn that others were more worried about fertility than she was:

**AF:** And I learnt more at that fertility talk than what I did when I had the talk here. And they didn't mention that seventy percent of the people, I think more than seventy percent are perfectly fine to go on and have children. I mean he did say at the time, you know, most, a lot of people do still have children and they're fine with it and everything like that. But you think well maybe I'm not in that group and you automatically assume that with cancer you cannot have kids straight away. You just assume, you don't think that you can have them anymore. You think it's not right and, I mean it's proven wrong at the thing [meaning TCT conference]. I mean he did say that, but maybe there needs to be a bit more emphasis on it, I think because, erm, to this day I still think I'll be one of the ones that cannot have it because of the way me body's reacted afterwards.

**Adult female 19:21**

## **PULLING IT ALL TOGETHER**

There was a more varied picture of information following diagnosis than had been the case at around the time of diagnosis itself with only about half feeling that they now had enough information. There was strong support for professionals to raise the subject sooner and more frequently. For many this was associated with the perceived role of information in reducing uncertainty as well as any dialogue offering the opportunity to discuss fears and anxieties. In particular, there appeared to be quite marked gender differences in understanding of some of the information provided although *recall* seemed broadly similar across genders. The understanding that males reported was almost exclusively to do with the likely pattern of temporary fertility impairment and the level of risk of any permanent damage (though understanding of the former was more apparent than of the latter). For females, there was evidence of poorer levels of understanding about the working of their reproductive system and the link between that and possible fertility impairment. Understanding of hormone replacement therapy appeared to be particularly problematic. These patterns did not differ by age group or educational level.

Information surrounding the use of contraception was reported as limited by both genders and age groups. When this added to attitudes surrounding its use, including the variable way in which the likelihood of fertility impairment affected contraceptive use, a worrying picture emerged.

With regard to fertility analysis, there were again differences across genders. Some females had become aware of fertility damage as a result of gynaecological investigations and none were expecting to be called routinely for fertility testing (and neither were the males who had no stored sperm). All but one of the males who had banked sperm anticipated being recalled routinely. Older respondents were more likely to talk of the complexity of such decision making; some, but not all, of the few who had been tested when younger now thought that they should have been offered counselling. A small number appeared to have little anxiety about being tested.

There was relatively little knowledge about fertility treatment options across the cohort and a firm desire to know more. A number saw them as a source of hope for the future. Females were far more likely than males to have become more aware of others in their family or social networks that had been through fertility treatments.

Some in all four groups cited media coverage as a prompt for them to think about their own situation. None had yet accessed fertility treatments though two were starting down that path.

Many of those in this study talked about their information needs around fertility as being to do solely with reproduction with only a small number linking this to sexual performance. Some had sought information from sources other than their professional supporters even though that could prove stressful at times. Several wanted more age-appropriate written and/or internet based information that was readily and discreetly available.

## TELLING AND TALKING ABOUT CANCER-RELATED FERTILITY ISSUES

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There is a commonly held assumption that it is better to talk about matters that may present emotional challenges than not. Verbal communication has at least three functions – (i) to transfer knowledge and information between parties (ii) to facilitate the development of understanding of information and (iii) to facilitate the discharge of emotions. However, little is known about whether or not verbal communication performs such functions for those dealing with cancer-related fertility issues. Indeed, little is known about the verbal communication patterns that young people adopt around this subject both during cancer treatment and following it in their journey into adulthood. Similarly, little is known about the patterns that are adopted by those around them – professionals, partners, family, friends or others. The previous sections have looked at the extent to which the respondents in this study understood what was happening to them in relation to their reproductive systems. This section builds on that by trying to capture the range of verbal communication patterns that the respondents and/or those around them used over time and in different contexts, together with their views about where these helped and hindered their ability to manage the experience. Any similarities and differences to communication patterns around cancer itself are also highlighted.

This chapter looks at this aspect through different relationships and the themes will then be explored more fully in relation to other variables in Part Four:

- telling and talking with professionals
- telling and talking with family members
- telling and talking with friends and others
- telling and talking with prospective or actual romantic partners

### TELLING AND TALKING WITH PROFESSIONALS

Respondents had contact with a range of professionals though the extent of this varied. References to the verbal communication patterns around fertility matters with different professional groups are included here in so far as they were singled out for particular mention.

#### Medical professionals

The largest single group with whom fertility matters were discussed were doctors and, in particular, consultant paediatric oncologists.

The context for consultants raising reproductive function with females was markedly different than that for males. No males said that they were asked about erectile function or any other aspect of reproductive function which is perhaps the nearest equivalent to females being asked about their periods. Most of the females recalled being asked about their menstrual cycle though, as referred to in Part Two, this was not always understood to be a query about reproductive function.

A number of those who had experience of fertility being raised explicitly and/or on a regular basis said that this was done in a relatively low key way. This approach was generally seen as appropriate in that it was then 'on the table' should they themselves want to pick up on it.

For a small number, fertility issues had been raised more proactively. For example, one of the adult females moved to the area after treatment and hence for follow up only. Her consultant raised it with her as she thought that the treatment might have had some effect. Until that time, the young woman thought about it rarely as she had been told the risk was very low and that any problems would sort themselves out. As time has gone by, it seems more likely that she is affected and this has led her to raise it herself on many occasions. She welcomed the timing and manner of it being raised.

A few of both genders raised the question of fertility themselves before such time as it was raised by professionals, suggesting that they needed to discuss it earlier than the doctors assessed it to be appropriate to raise it. Three raised it while still teenagers and pressed for a referral for investigation as they felt that they wanted to know whether or not they had been affected, albeit for different reasons – one out of curiosity and two out of a 'need to know'. All three would have welcomed it being raised with them first. One who was found to be infertile did not have it raised with her again in the years following testing but would have welcomed that (see Part Two). Another adult female raised it because she had got married and wanted to start trying to get pregnant. Although she had been asked about her menstrual cycle previously, she had not discussed fertility matters per se and would have liked to. Finally one of the mothers of a teenage female had raised the subject with the consultant as she felt that it was an important area to address (though her daughter was relatively disinterested). Both mother and daughter felt that it had not really been dealt with in sufficient detail, though this was more acceptable to the daughter than to her mum.

Many across all groups had not (yet) had fertility matters raised with them explicitly after diagnosis and treatment; for some, the first mention was when they were asked to take part in this study. Some, especially among the females, would have preferred it to have been broached in an unambiguous and low key way. This is not to say that it was unduly troubling for all of them, though it was for some. Only one (a male) said that he strongly preferred the subject to be avoided as this suited his style of coping and general approach to life. He thought that having it raised might have proved at best irrelevant and at worst disturbing.

### **Non-medical professionals**

Although the majority of the respondents' references to professionals were about consultant paediatric oncologists, there were also comments about the involvement of other professionals in the multi-disciplinary and inter-agency networks.

References to nurses were, on the whole, very positive but tended to refer to the broader cancer context, especially during the treatment phase. Although some said that they talked with ward based nurses about fertility matters as well as cancer-only issues, a number saw them as an inappropriate group for such discussions.

However some talked with MacMillan nurses, social workers and counsellors about fertility issues.

Altogether, twelve respondents referred to their contact with social workers, three with MacMillan nurses, three with counsellors (though none of these were fertility specialists), two with psychologists and one with an aromatherapist.

### **Social workers**

Many of the respondents who had social work contact did not see fertility as a subject that they would discuss with their social worker, especially where the contact was short term and centred primarily on financial and practical tasks. A few referred to the stigma attached to social work involvement as being a barrier for them and their parents to see social workers, at least initially, as sources of help rather than surveillance:

**AM:** ..... I normally associated social workers with people who were misbehaving a lot. *Laughs*. So to be given my own social worker was rather disturbing I suppose....

**Adult male 15:30**

Even where the contact was more intense, it did not necessarily come to include attention to fertility matters. In some cases, this appeared to be a missed opportunity. For example, one of the teenage males left with some cognitive impairment as well as fertility related difficulties would have welcomed more professionals raising fertility issues with them and included social workers as well as nursing staff and doctors as appropriate staff to do so.

There were a small number of respondents where the relationship with the social worker was deeper and longer lasting and did encompass fertility issues. One of the teenage males remembered positively the fact that his social worker had raised fertility issues on occasion and would welcome her doing so again. Similarly one teenage female remembered the social worker as being proactive in offering home based, long term 'counselling' (her words) in which fertility matters featured as well as other aspects of her cancer experience.

One of those whose parents had not approved of her seeing a social worker because of their stigmatised image had resorted to seeing one at hospital and, on discharge, at home 'behind their backs'. She perhaps drew on this positive experience of contact with a psycho-social professional service by then seeing a counsellor whilst at university.

Some talked about social work involvement with their family as a positive encounter in so far as the social workers aided the coping abilities of other family members. One of the teenage females felt that her mother started to feel more at ease once the social worker was involved and this had a positive knock on effect for the young person themselves. This included the social worker's willingness to discuss fertility issues.

Some reflected on the ability for the focus of the social work intervention to adapt to changing needs that presented. One teenage male who was troubled by the possibility that his treatment might have impaired his fertility reported that his social

worker was a key person in helping him return to school and work and hence back onto the road of social and emotional recovery. One of the adult females reported similarly that it was her social worker that was the most instrumental in getting her back 'on track' after treatment had ended.

### ***MacMillan Nurses***

The three teenagers who singled out MacMillan nurses saw them as particularly helpful in facilitating their emotional coping. A key feature of this appeared to be these nurses' ability to befriend the young person and to engage in discussions about 'normal' everyday matters:

**TF:** .... if [Macmillan nurse] had known about it, I would have talked to [her] more, because she's more, I don't know, she's not like a nurse, she's more like your friend. She's like 'hello darling, how are you this week?' And 'what have you done? Have you been shopping?' and she'll talk to you about everything so she like becomes your friend. And then she'd be the most likely person other than my doctor to talk to about it [fertility].

**Teenage female 18:20**

Two of those did not recall their MacMillan nurse raising fertility issues and would have liked them to.

### ***Counsellors***

As referred to elsewhere, none in this study had seen an infertility counsellor and few, if any, seemed to be aware of the existence of an infertility counselling service. However three respondents, all adult and female, had used professional counselling services at some point. Two had used the student counselling service at university and found that helpful although this was not specifically in relation to fertility matters.

One of the adult females who had struggled massively with fertility issues had had two separate periods of specialist cancer-related counselling since the end of treatment and was on the waiting list for more at the time of the interview. She reported that she had scarcely touched on fertility matters to date as they still felt so overwhelming and scary though she was hoping that she would soon be able to use counselling to tackle this.

### ***Psychologist***

Only two (both adult females) reported seeing a psychologist but the contact was brief and the context of the contact did not appear to be related to fertility issues at all.

### ***Aromatherapist/Reflexologist***

One of the adult females was very positive about the aromatherapist that she saw during treatment and with whom she discussed fertility issues:

**AF:** I've had an absolutely fantastic woman... who is an aroma therapist..... she does a lot of massage and Reiki and aromatherapy and stuff and is absolutely brilliant, they should have it everywhere. ... It sort of really helps. It's really, really good, makes you feel a lot better. And she could tell, like whenever they were doing reflexology she could tell that like I hadn't had periods in a while and stuff. It was really really good. Really good.

**Adult female 20:23**

## **Views about the ways in which fertility was discussed with professionals**

Some views were expressed about which professionals should raise fertility issues, how often and with what focus.

### ***Should it be raised at all?***

There was general agreement across all groups that professionals – especially doctors - should raise fertility matters from time to time. This was true for those who had the experience of having had it raised together with those who had not; those who were troubled by the information that their fertility may be affected and those who were not. Some said they would not raise it themselves but, as seen above, many would have liked professionals to bring it up as it would then have enabled them to talk about it or ask questions then or in the future in the knowledge that this would be acceptable:

**TF:** I wouldn't really ask for them to bring it up, but if they did, I think it would help because talking about it now [in the research interview] has helped, cos I never really thought about it until I got asked to do the interview..... but like talking about it, it's made us like, this study's like made us like think about it more and like how I'd feel. I've just like talked about it more with me friends so it has helped us.

**Teenage female 15:16**

### ***Who should raise it and how?***

If it were to be raised, all were happy for it to be raised by doctors. As indicated in the previous section, some were happy for it to be raised by nurses (especially MacMillan nurses) and social workers but others were not. Whilst relationships with Consultant Paediatric Oncologists were generally close and characterised by high levels of warmth and trust, relationships were more variable with all other professional groups. This perhaps explains the more variable support for other professionals to raise it. However it was not only the professional role that made it appropriate to be raised but also the nature of the professional-patient relationship and the particular focus of the query that informed the likelihood of any dialogue proving helpful. This went some way to explaining what enabled some to engage in discussion about fertility matters and others not.

Some talked of the importance of needing to feel secure enough in a relationship with a professional for fertility to be addressed. References to 'feeling comfortable' and 'having firm trust' – especially with consultants – were frequent. Thus, even when discussions had taken place with one professional, this did not necessarily lead to the individual concerned feeling able or willing to discuss it with other professionals as well. For example, one of the teenage males had discussed it with his social worker but would have been alarmed if others (in this case he refers to nurses) had sought to raise it:

**TM:** Depends how close you are really. [social worker] had mentioned it before and I don't mind discussing it with the likes of her cos we were very close as well. .... But if nurses had brought the subject up I would have just, er, faded away.

**Teenage male 14:17**

For a few of the males in particular, the *opportunity* to talk and be taken seriously was more important than the existence of a close prior relationship. One of the adult males related how much he had welcomed it being raised by his doctor at a 'late effects' appointment, even though it was their first encounter, because he warmed to his approach and apparent interest in fertility aspects:

**AM:** .... the last doctor I saw - a new guy, brilliant guy, got on with him fine. And his face when we were talking about it just lit up and he went 'brilliant'. .....he were really helpful actually, he were like 'if you ever need to talk about it, I'm always here, or there's a nurse here and we'll arrange everything for you.. you can come down and do it [fertility testing]'.  
**Adult male 16:22**

Some of those who said that fertility matters were not something that they could discuss with people that they did not know well nevertheless appeared able to talk at length and with some candour in the research interview. It was difficult to know how far this was related to the freedom of talking to a stranger in a single encounter or whether it related to an ability to establish a 'good enough' degree of trust and confidence very quickly.

A few of the females hinted at feeling uncomfortable in discussing 'intimate' matters such as fertility with their male doctors though only one referred to this directly. Their needs for information and a sharing of the issues had not overridden their discomfort with the subject matter in such a context. Even though one teenage female felt that she had a good relationship with her male consultant on other matters, she referred to her difficulties in talking about body functions with him and extended that to fertility.

### ***When should it be raised?***

As with views from around the time of diagnosis (see Part One) and views on appropriate levels of information (see Part Two), there was general support for fertility matters to be raised again shortly after treatment in fairly general terms and at regular intervals after that, with the patient being enabled to go into it in more depth if they so wished. The teenage males were the only group who were more passively than actively supportive of this in as much as they thought this was a good idea but had not, in the main, experienced any strong need for this for themselves.

While some across all groups wanted fairly full information early in the process, others preferred to wait. For some the trigger for wanting to access information or to talk issues through was the context rather than the stage in the process – for example a change in awareness about the implications of having impaired fertility, a move to start thinking actively about becoming a parent and so on. In other words, neither age nor stage of treatment appeared to be dominant influences. Many said that they needed to be told directly, unambiguously and on more than one occasion that information and/or the opportunity to discuss fertility issues with a professional of one's choice was available. This is not the same as saying that it should be raised vigorously or in depth but more that it should be raised in order to leave control over the degree to which the person concerned enters into discussion or information seeking as a result. A number thus talked of the importance of getting information and access to services (medical and psycho-social) *at the right time and level* to enable them to feel more in control and to develop coping strategies.

While it is tempting to assume that treatment will push fertility concerns to the margins – and this was true for the majority in this study – there were a small number who needed to talk and gain information during treatment. One teenage male raised some pressing fertility related concerns with his consultant (with his mother's support – see below) in the middle of his treatment. The relief that he felt at being told there and then that his fear that he might pass on the cancer to any child that he might have in the future was unfounded was palpable:

**TM:** I just said [name of consultant] right I'm really concerned about this now cos like if I have a kid in a couple more year, in 15 years, if when me wife has the baby is our baby gonna have cancer or like when the baby gets to my certain age, at my time, is she, he or she, gonna have cancer like I did? And he said no, no, no. It's nothing like that or everything like that. I said right good. That's another worry out of me mind and everything. **Interviewer:** How long ago was that, that you asked him? I mean, three months or a year or so. **TM:** A year ago. Like right in the middle of me treatment. At the beginning of it.

**Teenage male 15:17**

Another teenage male found that worries about fertility started to crowd in during the latter stages of treatment and became very troubling quite quickly afterwards. Unlike the young man above, he struggled to get his concerns taken seriously and reported being told on more than one occasion that these were matters to be 'dealt with later'. He and others urged greater recognition to be paid to the fact that if the patient raises it then it means that it is important to them at that point in time.

Those who had the subject of fertility raised proactively soon after treatment spoke positively about this. For example, one of the teenage females remembered her consultant raising it regularly in a low key but clear manner once the acute phase of treatment was over (as well as from time to time during treatment) and felt that to be very important. She placed this within the context of the importance of doctors making sure that patients were fully informed about potential risks. Like several others, she made it clear that there is a temptation on the part of some young people to ignore things unless the doctors made them face up to them by (gentle) challenge.

Another female was very clear from early in her treatment that she was likely to have impaired fertility. She welcomed her consultant taking the initiative and going through not only the functioning of her reproductive system but also the different scenarios that may lay ahead (including the fertility treatment options that might be available) approximately a year after treatment. He had raised it briefly from time to time beforehand but this occasion felt right for her to go through it in more detail. They then returned to it from time to time until the stage several years later when she was ready to engage with it more vigorously within the context of a marriage and decision to try for parenthood.

One teenage female also remembers it being raised by her consultant soon after the end of treatment and then on a regular basis since. She has found this to be very appropriate even though she was not sexually active and not contemplating parenthood. Questions about her periods were very clearly linked to her fertility and this was also emphasised by the offer of contraceptive advice. However it is an interesting reflection on the underlying anxiety that possible fertility impairment can

engender that she worried that the invitation to take part in the research was actually a subtle way of her consultant telling her that she was infertile:

**TF:** [paediatric oncologist] said just, you know, if you have got a boyfriend and stuff, be really careful and stuff like that, obviously, cos you're only 16..*laughs*.. He said if you do things like that but he said it looks quite good, he said, it's coming back. But I were right happy then and then when he asked me to do this [study]. I thought 'is he trying to tell me something?'

**Teenage female 13:16**

A teenager spoke of the usefulness of having information well in advance of taking any related actions in order to prepare to cope with the consequences:

**TF:** I always like to know things in advance cos then it gives you a chance to think through them and to really think about what you want and really think about the consequences of every decision that I'm going to have to make to do with it. It's very good to have everything that I need to know now rather than be thinking 'oh next time I go to see [paediatric oncologist], is [...] going to tell me a bit more about this?'. I'd rather have everything dumped on me at one point and then I can ask questions about it as the time goes on as I want to think about each thing.

**Teenage female 16:19**

Yet another reflected that it had worked well for her to get full information from the professionals and then process it at her own pace and has learnt to do so over the years.

As indicated, this is an unfolding process and the impact of professional practices around verbal communication may not become clear for some time. For example, one of the adult females who had fertility raised routinely over a period of several years reported that this enabled her to raise it herself recently after having seen a television programme that prompted some questions in her mind.

The 'little and often' approach may well have suited some of those who felt that it should have been raised earlier with them than it had been. Although for many their interest and concern was low key, they nevertheless would have preferred the chance to air questions or concerns. More than one pointed out that an external appearance of nonchalance on their part was not always an accurate representation of what was going on within. And for the ones that knew that they wanted the opportunity to receive some professional help, this approach would have given them the permission to receive it:

**AF:** I was trying to pluck up the courage to actually ask her. Because it had never been raised since and I don't know if it was because [consultant] felt awkward about raising it or, I'm not really sure, erm, but I just knew I had to ask. And I knew that I wasn't.. if I didn't ask I wasn't going to find out, so I just like wanted to know and even if [...] just said 'look there's no chance of you ever having kids' or what have you I'd rather have known, you know. So I think from that point of view I think it would be better for there to be more to offer for people who's had chemotherapy. **Interviewer:** Been easier for you if someone had been raising it? **AF:** Been raising it throughout my treatment and maybe afterwards. It would have been a lot easier for.. plus you learn

more don't you along the way you know. At least you know where you stand I suppose. **Interviewer:** So somebody bringing it up and checking out whether or not you want to know any more? So that you know that..when you're ready to.. **AF:** I mean, you can always say no can't you, you can always say 'well I'm not interested', I mean cos I can remember when I was first did ask her I felt so embarrassed asking her, I don't know why. I felt embarrassed and anxious, I felt worried, upset because I didn't know what she was going to say. And I think if it had ha' come throughout my treatment, and maybe when I'd just finished sort of, it wouldn't have been so bad. Because I'd have known rather than wait so long, and then have to ask

**Adult female 18:23**

A few reported that the subject had only been raised once the professionals had realised that they were in a romantic relationship. For some that was acceptable; indeed some prompted the discussions themselves by taking their boyfriend or girlfriend along to a consultation with them in order to discuss matters such as contraception, risk of transmission to any children and so on. For others, using the presence of a relationship as a prompt was too late.

Even among those who did not feel any need for it to be raised until it might become more pertinent for them – for example when they got their 'routine' fertility test result (teenage males), got older, entered a permanent relationship or were ready to start a family - it had not felt intrusive if it had been raised.

Raising the subject is not without risk, of course. Some talked of the importance of professionals being sensitive to the potential for distress arising from discussions about fertility. In some cases, this was about the level of detail that was conveyed and when:

**TF:** If I'd been told a lot more than I had done I'd probably think about it more and it'll eat up inside. I'd probably... I don't know how I'd be. I think every day I might wake up and I'd be like doing things and thinking I can't have a baby.

**Teenage female 15:20**

Another female was pleased that she had been advised at diagnosis that her fertility might be affected but then not given any more detail until the picture became clearer. She preferred this more cautious approach in so far as she had still never been told that she was definitely infertile though she had been given increasing amounts of information over time to indicate that her fertility was now likely to have been significantly impaired. As someone with a strong desire to become a parent, this enabled her to start to develop her coping strategies incrementally.

As reported in Part One, one of the adult males had not been told at all of any risk to his fertility until approximately three years after diagnosis. At that stage, he appears to have been told with some insensitivity that he was infertile. Coming as it did when he felt well on the way to becoming reintegrated into his friendships and school, confident that the cancer was behind him and coping primarily with age appropriate concerns about his virility (his words), he found his sexual and personal identity threatened by the information:

**AM:** .... it was such a shock out of the blue, I mean it really was, and I think at and I think that that came as such a bombshell, erm yeah, its definitely cycles I think. Shortly after treatment, it's useful to know and I think you probably have a hard time dealing with it, or I would have had a hard time dealing with it, just because of the nature of it, I've just finished everything, I don't want to deal with this. ....I should have been told earlier. I think whether I understood or not is irrelevant. .... If only to put the seed in my mind that that was something that I would have to deal with....

**Adult male 13:28**

The lack of involvement of psycho-social helping services was noticeable in these accounts. One of the adult males had fertility raised a few months off treatment and, although he remains very supportive of the fact that it was raised, it had a major impact on him perhaps indicating the need to consider what follow up information and support (professional and informal) is available at the time of raising it.

**AM:** It was a few months later and she raised it and she talked through it and it. I mean it hit, it really hit hard. You know I think that was the. ...probably more so than actually finding out I had cancer. I think that was the one thing that seemed to stick in my mind was that it was really, you know, against you. But from what I can remember she was really good about it cos you know she sat down and talked through it and did I have any questions..... I mean I remember when I first found out.. I think I must have been on the Day Unit when I was talking with [consultant] cos I remember going down to the car and just sitting in the car and just breaking-down completely and.erm.. you know... It does.... I mean I think about it all the time and it's... It is difficult to come to terms with, you know,

**Adult male 18:23**

Deciding when and how to raise it will be a matter for careful judgment as some said that professionals may need to raise it several times before the young person may feel able to engage. Getting the timing and context right is clearly important for the individual concerned.

One teenage female put the complexity of timing very clearly when she reflected on the context for her:

**TF:** I think. I mean I was 15 when I was diagnosed.... I think the fact that they never told me after I had finished chemo was good. They never mentioned it afterwards again. They kept it to before I had my first chemo. And then that gave me the time to recover, like have my treatment and give us time to recover after finishing treatment. I think maybes when your life seems to go back to normal and I say the word 'normal' very loosely, I think just to fit back into routine. Not one where you have to wake up, take tablets and waiting to take some tablets, some tablets just before your lunch. Maybes have an injection or whatever, that's, medical routine, that's what happens during treatment. perhaps even for a little while after. When I say you're back to normal life is when you are waking up in a morning and you phone your friends and you say 'oh do you want to do something?'. Spontaneity routine. .... And I think that's the time when they should really bring it up because that's the time you're in the right frame of mind, you know. Perhaps not where your life is going but you know that you've got a life to live. .... that's the time they should bring it up. I think. From various, yeh,

6 months to a year after you have finished treatment they should mention it. And I don't just mean 'do you want to know about fertility?' I think there should be something... maybe stick an extra 10 or 15 minutes on your appointment time just to go through what your options are..... and if they say 'no' then on the next appointment just mention it again just so that they know. And in after two or three times they say 'no I don't want to know' then wait for them to come to you.

**Teenage female 15:20**

## **Preferred Attributes of the professionals**

### **Age**

The **age** of professionals seemed to matter little to those in this study. Only two of the females and one male expressed a view for it to be someone older in order to reduce embarrassment and increase confidence but these views were not expressed strongly.

### **Gender**

Respondents were more likely to express a view about professional gender and then only in relation to doctors and nurses although again this was not dominant. Those that did express a view were much more likely to be female themselves and to express a preference for having a female *doctor*. One teenage male, five teenage females and three adult females preferred female doctors and most, but not all, of these currently had a female consultant though a mix of genders for other professionals. Two adult males saw some advantages to having male professionals: one preferred having a male doctor when younger but now had no preference and one thought it might have been helpful to have had a male nurse when he returned from unsuccessfully trying to bank sperm (but had no preference over subsequent contact).

However another male respondent urged caution when matching male to male as he thought that males were inclined to be less honest with other males, especially over fertility related matters as '.... the male bravado kicks in a bit more'.

The preferences for having a female doctor were primarily to do with feeling more comfortable and/or less embarrassed at talking with a woman:

**TF:** I'd rather have a female to have a male because, like, I dunno, it's just talking about that stuff with. .... plus like a woman is the same as you isn't she, so ..... Obviously like a male as a professional knows all about it, but I'd just rather have a female.

**Teenage female 15:16**

One of the adult females felt that female doctors were more intuitive in picking up on things and cited instances of that, even though with the backdrop of being satisfied on the whole with both male and female:

**AF:** Cos I mean he was good and he was nice and he was lovely, you know, he didn't say anything wrong, or you know. I think she just realised how much I was worried about it more than he did. And I think she sort of saw that, kind of, that it was something that I really really, really wanted and

he....he did realise that I wanted it but sort of, I don't know, not to the same degree.

**Adult female 20:23**

One of the teenagers was able to separate out the bits that she *did not* want a male helper for (personal care) and what she *did* want a female for (discussion about intimate matters).

However, having the gender of one's choice in a professional was not a guarantee of a good experience as one female found in her contact with reproductive medicine and a number did not find gender to be a major influential factor in helping or hindering the 'helping' relationship. Hence for many, this comment from one of the teenage males summed it up:

**TF:** No, no, it doesn't bother me. Not at all. It's just like, it's yer doctor innit - he makes you better so it dun't matter who they are really.

**Teenage female 13:16**

### **Honesty**

Perhaps the strongest support was reserved for the importance of professionals being honest, sharing information clearly and in full and approaching contact in a spirit of partnership. These attributes were seen as important mediators of the impact of fertility issues and a boost to coping. This applied to all aspects of the cancer experience not only fertility and reinforces the findings in Part One of the importance of being told about possible impact on fertility from the beginning:

**AF:** I like to be told straight as a dye and that's what she [consultant] does. She doesn't beat around the bush which is the way I like it, there's no point in stories, just come out and say it. .... and then if you're being totally honest there's less likelihood of, the patient may whoever, turn round and go I'm sorry, I don't understand. If you come out and say it in laymen's terms from day one then... there's not going to be any misunderstanding at all.

**Adult female 19:25**

The partnership approach was most clearly signalled by professionals talking directly to the young person themselves, acknowledging that they were the most important player in the room and therefore deserved to be given information:

**AF:** I think makes it easier if they speak to you like, I know you're still a child when you get take bad, but if they speak to you, so most people speak over you, but if they actually speak to you I think you find it's a lot better, than just being spoke over, cos I think then it puts your back up towards them, cos then you're like well I don't want to go cos they don't speak to me, they ignore me, type of thing.

**Adult female 15:24**

Implicit in this is that honesty from professionals contributes significantly to the development of trust and confidence. An important consequence of the build up of trust and confidence was when people felt able to ask for information as well as receive it. Several said that this was the case although there were indications, as outlined earlier, that it may be more difficult to ask questions about fertility than about some other aspects of cancer and treatment.

### ***Approachability***

As already indicated, honesty appeared to be an important ingredient in making professionals approachable. There were also frequent references to the importance of friendliness and warmth as factors in lowering barriers and encouraging confidence. Some welcomed the use of humour, especially the males. A number talked of the importance of feeling that they could approach professionals outside of set appointment times if necessary and this extended to sharing good news about non-cancer matters as well as asking health advice.

A central feature of an approachable professional, however was one that appeared to listen, take any questions seriously, allow plenty of time and offer clear communication:

**AF:** ..... speaking like so you don't have to ask what that means, doing it on a level that you understand. like instead of using like big medical terms, breaking it down so you can understand what's being said to you, instead of making you feel small because you don't understand what they're saying.

**Adult female 15:24**

Friendliness in professionals needs to be carefully managed from both sides. One of the adult males valued the relationship that he has come to have as an adult with his consultant as it enables him to explore his thoughts and feelings about how to approach addressing fertility issues in romantic relationships for example. However respondents also articulated the importance of knowing that boundaries were still in place within the professional friendship enabling sensitivity to inappropriate intrusion:

**AF:** But I should say though that [.....] and other doctors and the nurses are all willing for you to go up and talk to them all the time. They're not guarded. You don't feel like you have to protect yourself from them or anything. They're more friends than doctors but you know that there's a line there and you don't cross the line.

**Adult female 19:21**

This was sometimes about confidentiality as well. Some welcomed the fact that their paths were unlikely to cross outside of the professional encounter or, if it did, that an appropriate distance would be maintained:

**TM:** Cos it's not like I'm gonna meet them another four years down the line in the middle of the street or something and start talking about it [sperm banking and fertility] with crowds around.

**Teenage male 15:17**

However a small number also expressed concerns at not knowing how many of the professionals knew about the potential impact on their fertility and/or the fact that they had banked sperm. This left them feeling vulnerable either because of feeling embarrassed or annoyed that staff may know something that they considered to be private or because they feared that staff may then try to raise it with them at an inappropriate time.

### ***Competence***

With regard to cancer matters, there was a general sense that people felt confident that the health and social work professionals knew what they were doing. However

this was not usually the same in relation to fertility. Several said that their professional helpers did not know enough about fertility matters. Sometimes, this was an assumption – i.e. that because their doctor was an oncologist, they would not know about gynaecology for example – sometimes it was stated in the context of them being referred on for specialist medical help. In both scenarios, this was more likely to be presented as a fact than as a problem. The problem arose for those where more specialist help or information was not made available.

### ***Professional reassurance***

A similar but different set of comments were to do with the reassurance that was gained from contact with professionals.

Not surprisingly, a number of respondents reported feeling better able to cope with the impact of possible fertility impairment if they felt reassured by professional advice, information or manner (either early in the process as seen in earlier sections or in the longer term) about whatever aspect had the potential to trouble them. For some, the development of confidence in professional honesty around fertility matters led to the respondent taking their lead from their consultant about whether or not they should feel concerned about it as illustrated below:

**TF:** .... [consultant] usually tells me whether to worry or not to worry. So that's why I don't bring it up until I'm in with [consultant] cos [...]'s the doctor after all.

**Teenage female 18:20**

The implications for those who had not had access to this aspect of contact with professionals are clear.

### ***Professional discomfort or insensitivity***

Where there were accounts of professionals appearing uncomfortable or insensitive about fertility issues, these were more likely to relate to those working outside the specialist paediatric cancer services than within. For example some of the young women had experience of GPs and other health professionals assuming that their symptoms were pregnancy related prior to diagnosis, including some who were virgins. The strength of their distress from such memories was clear and appeared to affect their ongoing approach to fertility matters, perhaps compounded by the fact that the site of their cancer was in their reproductive organs or close by:

**TF:** And the fact that the doctor actually said ...I was crying and said 'can't it be something else. I would know you know'. And he said 'no I am pretty adamant you are six months pregnant'. So in a way if he hadn't ha' sent me for a scan, there wouldn't.... I wouldn't have been anywhere really would I. So it was terrible. Even one of the nurses said 'it's all in your head'. And I thought who are you to say that. So...I've got a lot of issues....

**Teenage female 17:20**

And one of the males remembered with clarity the insensitivity of someone doing a scan:

**AM:** I think actually one of the more embarrassing comments was, I had this ultrasound scan and the man who was doing the ultrasound scan was saying something like "Oh can you move your friend [meaning penis] out of the way"

and that's something that made me think 'Ooh no you shouldn't be talking like that. This is quite embarrassing for me, you know'. **Interviewer:** Because it makes it personal. **AM:** Yeah, and I almost preferred it to be talked about in a scien..... **Interviewer:** Clinically. **AM:** Yeah, clinically, so.  
**Adult male 20:22**

Some of the accounts of discomfort came from encounters with staff in reproductive medicine although it is important to remember that many others found their contact to be sensitive and helpful (see Part One for examples of this at around diagnosis). Females were more likely than males to have had such contact after the time of diagnosis but there were similarities in their accounts to those of males at sperm banking encounters. In particular, there were references to lack of warmth, lack of clarity of explanation, tendency to be more formal, be more rushed and be treated more as a 'patient' than a person.

The fact that memories of such encounters remained for some considerable time afterwards is a reflection of the potential for lasting impact, albeit at differing levels. Among the most difficult encounters was the one referred to earlier in which a young man was told that he was 'infertile' three years after diagnosis. Another was one in which a teenage female was asked a series of questions with her father present (not her choice) and this included asking about sexual activity, menstrual cycle and so on. The gynaecologist then went on to conduct a painful internal scan as she had not taken on board that the young woman was still a virgin:

**TF:** The gynaecologist we saw was an absolute nightmare. She was an awful woman. She wasn't very kind of understanding, she was quite abrupt about everything..... she got quite kind of sharp with me, said that, you know kind of saying 'come on, pull yourself together stop being such a child' ..... going to see that woman made everything ten times worse.

**Teenage female 13:19**

Whilst she was told later that his presence was 'allowed' because the professional concerned had assumed that he was her boyfriend, she argued strongly that his presence was not appropriate – and indeed neither would it have been acceptable for her boyfriend to be present without her permission.

### ***Continuity of professionals – coping with new professionals***

Not surprisingly, where people had had a change of significant professional helpers such as consultants, they did not like it. Coping with a new person was difficult and it took a while, if ever, to build up the new relationship:

**AM:** I would much rather see the same consultant every time because there's a bond there. I think certainly so important, something, when something's so, you know, a life death situation that you're in, I think the bond that you have with certain consultants is.. I'm very reluctant to leave one and meet a new one, I'm fine now I'm older, certainly as a younger, quite sensitive, you see someone for two years, then alternate and I met someone else and then gradually the first person disappeared, I met the second person.

**Adult male 13:28**

This extended to being referred on to other services for additional interventions. For example, one young woman talked of how her confidence in her consultant paediatric oncologist and her familiarity with hospital routines developed over a long time did not ease her anxiety at encountering new staff and services:

**TF:** Like when I get sent to different places I'm quite.. I don't... I'm nervous. Like she [consultant] sends me for scans and stuff like that. I find I shake. I can't control the way I feel, so...

**Teenage female 17:20**

### ***Parental and partner involvement by professionals***

The importance of professionals talking first and foremost to the patient, regardless of whether or not their parents or partners were present, was strongly advocated across all four groups (see also Part One). A number mentioned specifically the importance of receiving information at the same time, or ahead, of their parents throughout the whole process – and of being given a choice about whether or not to have parents present, particularly in relation to fertility. This was welcomed when it was present from the start or improved over time. This applied to information about non-fertility matters and fertility matters:

**AF:** .... I remember [consultant] always used to say, 'do you want me to talk to you separately or do you want your parents to come in?'. She was really professional about that, even though I was only fifteen she always asked me that, and that she always treated me like an adult, which is nice in a way, and she always used to come and say 'I want to tell you about this'. She never used to go to my parents and tell them things without me. She used to tell me first and then my parents, that was really good. Yeah, it made you feel like an adult even though I wasn't actually an adult, I was fifteen, I still felt like I was being told things, and that's the main thing because you want to be told things, you want to be told everything really. Because you might think you're fifteen and you don't have to know that but I'd rather know so.

**Adult female 15:21**

In the earlier section on parental involvement around the time of diagnosis, there were a small number of respondents who would have preferred their parents not to have been present when the subject of fertility was raised (see Part One). As time went by, increasing numbers opted to deal with this on their own and others would have done so if the choice had been offered. As in the earlier section, the need for the choice to be offered without the parents there was identified by a number. In other words, some found it difficult to exercise choice if their parents saw this as a rejection of them as illustrated by one of the teenage females:

**TF:** .... the doctor used to ... say 'is it OK if your Dad stays', and there were a couple of times when I plucked up enough courage to say well actually 'yeah would you leave' and my Dad used to go off the edge about it, and he used to get very angry and say that he cared about me and that didn't help. And that used to create problems by after a while I never used to ask him to leave, because I just didn't want all the extra trouble. So, yeh, the whole situation was a bit fraught..... I didn't feel as if I had an ally in the room almost. I felt as if I was completely on my own.

**Teenage female 13:19**

One of the adult males said that he would have welcomed the chance to have his fertility tested two or three years ago but the presence of his mother in the consultations where it was raised inhibited him from engaging in any discussion, not least as it was accompanied by questions about his sexual activity. It was only when he started attending on his own that he had been able to move forward with this.

It was easier for those where the professional took on the responsibility and asked parents to leave the room:

**TF:** .... if [consultant] like wants to talk to me summat, you know, personal, he'll say 'do you mind going while me and [.....] have a chat'. I'm like 'oh yeh fine' and they'll go. But he asks me if I want 'em to stay or not, which I think is good and he's not like telling them can you go now, you know, he asks me to make the decision, so. **Interviewer:** So it's like checking out with you what feels best for you. **TF:** Yeh and he's not saying, oh no, stay I want to talk about it in front of you, cos I know some people,. I do, I get embarrassed in front of my mum and dad, obviously. But it's just like... **Interviewer:** So it gives you permission to let them go as well. **TF:** Yeh, tell them to go away. *.laughs*

**Teenage female 14:17**

Some talked of the dilemma of wanting a parent present in order to help them remember what was being said but preferring them to be absent to enable them to talk with their doctor more freely. One teenage female had found a compromise that worked for a while as she continued to have her mother accompany her and talked with her consultant about sex and fertility when they were 'behind the curtain' during examinations and hence in a more intimate space:

**TF:** .... with my mam being in my appointments it was hard to talk to [consultant] about stuff like sexuality. And it was difficult to talk to her about something like that. We usually talk about anything like that when we're behind the curtain. Even though they could still hear it just means that they're not staring at me. It makes it easier to talk about anything.

**Teenage female 18:20**

A small number found that the focus shifted towards parents and away from them where fertility matters were involved and this was unhelpful. For example, one of the teenage females found that professionals sometimes got pulled in to talking with her mother rather than her:

**TF:** I was sixteen at the time, and I kind of felt old enough to make the decisions for myself, and especially that kind of thing you know, the conversation was very much between [nurse] and my mother. And I mean they weren't doing it on purpose or anything, but I know [nurse] said she'd had to have an internal scan, and it was horrible and my mother said: 'Oh yes, I've she'd had one before' and I felt like the child in the room.

**Teenage female 13:19**

The involvement of partners in consultations appeared to present fewer barriers. Those who had taken partners along had instigated this themselves, usually within the context of wanting to discuss sex and fertility matters or to acquaint a new partner

with the cancer treatment context. As such it appeared to have presented no concerns among those in this study as they felt in control of the involvement.

### ***Unrequited needs for professional help***

The lack of psycho-social services for helping with fertility matters has already been referred to. Some wanted existing services such as social work to be expanded and/or for staff within them to take a more active involvement in fertility issues. Others identified the need for new services. Some saw the need as being for therapeutic services whereas others identified their primary needs as being for information based services staffed by people who were both well informed and able to discuss the pros and cons of different courses of actions. The latter was especially true among those who saw counselling services as only appropriate for people with 'problems':

Several respondents also talked of unexplored and unshared worries and gaps in knowledge remaining unresolved unless they felt able to take the initiative or were reached out to by professionals:

**AM:**..... there has been occasions when I think it would be good to talk about it because like I say, you know, the problem is if you feel angry about stuff then you've got no outlet and a lot of the time you are... I think it probably would help to talk through it more and see people and like rationalise it, you know.

**Adult male 18:23**

One young man illustrated what it was like for him to be in the midst of needing someone to talk to. He had thought from diagnosis that it was certain that he would become infertile. He found that deeply troubling, especially as he had tried unsuccessfully to bank sperm, but did not feel able to ask for professional advice. When he returned to the sperm bank several months later to try to bank sperm again (again unsuccessfully), he plucked up courage to ask and gained some comfort in being told that infertility was not a foregone conclusion. By the time of the research interview several months later, he was very keen for further information and had still not felt able to raise it with his consultant, even though he got on very well with her. He has continued to have problems with erections which may well have contributed to his anxiety.

Others too illustrated the complexity of becoming engaged in professional relationships that had the potential to be therapeutic when the subject matter was so sensitive. One of the teenage females who appeared to have little close contact with any professionals hinted at her loneliness and how she might have benefited from being reached out to:

**TF:** .... I don't know how they would go about it, you know, offering the opportunity to talk to someone, but I think it would have been helpful, cos sometimes, you do, I know I'm sat here now and I can't think of anybody I know who knows that they can't have children....

**Teenage female 15:16**

One adult female suggested the need for a specific professional available on the ward that anyone could go and talk to about fertility matters during treatment or when

they returned for outpatient appointments. Another wanted a similar service but thought that it needed to be provided by someone independent of the treatment team in order to provide confidentiality or reduce embarrassment:

**AF:** It could be, OK, like if you're someone from outside the doctors, like a different face, so you could sort of like tell someone else who you're not dealing with every day, things that you wouldn't like want people to know, do you get what I'm trying to say? So you're not embarrassed or so you don't have to like look at that person all the time and think Oh I asked you that. So I think it would be better if someone outside of the doctor/nurse role would be ideal.....

**Adult female 18:23**

One of the teenage males recommended greater use being made of the internet (including chat rooms) as a source of support and a route through which to ask embarrassing questions and share problems:

**TM:** I feel that's better cos then someone like may not be confident talking face to face with someone, so it's better like emailing, maybes, talking through letters.

**Teenage male 14:17**

One of the adult females who appeared to have been increasingly troubled by her apparent infertility over time indicated a sense of ambivalence about whether or not professional help would make any difference – perhaps fuelled by a sense of hopelessness. She sighed a lot during the interview, got distressed from time to time (not surprisingly) and would undoubtedly also have needed 'reaching out to' in order to receive help.

Some who were struggling emotionally were resistant to the idea of receiving help that was offered when it was formally identified as therapeutic (such as counselling) seeing it as an indication of personal deficit or failure. Others thought that they might use it in the future but, for now, preferred to find their own way through. However, one of the adult females had been for fertility analysis and felt strongly, with hindsight, that she should have had the opportunity for implications *counselling*. She discussed it with her consultant and with the doctor at the assisted conception unit but, looking back, felt that she should have been given the opportunity (or even been required) to attend counselling as well. She was found to be infertile.

Two of the adult males would also have welcomed the offer of counselling – in their case to try and process the impact of possible infertility in general rather than to help with making a decision about analysis:

**AM:** .... I think there's a lot of stuff that you can't discuss with parents and friends and that but I think you need to sometimes need to discuss with other people. You know, like a counsellor or something like that, I don't know. Just to get some things off your chest and talk about..... I think sometimes it does help just to talk about.

**Adult male 16:22**

Some of those who would have welcomed more follow up services being made available talked of the difficulty of accessing such services if they were to be based at

the hospital treatment centre. For some this was at quite some distance from their home and accessing them would therefore involve expenditure of time, money and, for those with physical difficulties, pain and effort:

**AF:** It's hard to talk about anyway..... I just, I think if there was somewhere closer for me I would make more of an effort to sort of get things sorted out but I think just like I say having more people to talk to me about fertility would be a good idea.

**Adult female 18:23**

Those who had received follow up services at home, including counselling and support services had welcomed this.

Some thought that such services also needed to be made available for parents and partners too and that these too should be offered proactively,

**AM:** ....who does the partner go to if they have problems, maybe they don't want to discuss them in front of me because they may have issues that may be upsetting and they want to work through them but who wants to sit and say 'actually I'm thinking of leaving you because xyz unless something happens'.

**Adult male 13:28**

## **PULLING IT ALL TOGETHER ABOUT TELLING AND TALKING WITH PROFESSIONALS**

Certain key aspects were identified of particularly helpful ingredients of professional verbal communications about cancer-related fertility matters, including:

- Someone that could be relied on to be honest and tell you things straight but was also friendly and approachable
- Someone that spoke clearly, unambiguously and was not embarrassed by the subject
- Someone that you could trust, be that in a first contact or built up over time
- Someone that made you feel safe, reassured and offered hope (although not false hope)
- Someone that acknowledged what you were going through and showed compassion
- Someone that treated you as a 'partner', with respect, and saw you as the main person to relate to
- Someone that you felt knew what they were doing (i.e. competent) or would send you on to someone that knew more, if appropriate

With regard to the timing of 'telling and talking', there was a good level of support for:

- Raising it at diagnosis then returning to it again soon after in order to address any outstanding issues and then directly and unambiguously at regular intervals afterwards though in a low key way
- For it to be raised primarily by a consultant but for other professionals to be prepared to raise it and/or be on the alert to respond to it, especially where there was a close ongoing relationship and/or a therapeutic relationship.

There was a reported lack of psycho-social services available to help with fertility issues both during treatment and once treatment had ended. This was the case for respondents at different stages and was not necessarily related to any imminent desire to become a parent.

## **TELLING AND TALKING ABOUT FERTILITY MATTERS WITH FAMILY MEMBERS**

The family is an important site for forming and maintaining communication styles as well as for forming and maintaining attitudes on subjects such as fertility and sexuality. The way in which communication about fertility was managed within families and between family members was therefore an area of keen interest.

A range of communication styles seemed to operate within the families of origin of the respondents, some of which pre-dated the cancer experience and, if anything, were strengthened by it and some which appeared to be different to their usual patterns. A few but not many had changed over time. However of particular interest here is that the communication patterns for cancer in general and fertility aspects in particular appeared to differ in some families but be fairly constant for others.

### **Open communication about fertility matters**

There were examples from all four groups of families that were able to communicate openly enough about fertility related matters although this was the case in proportionately more families of females than males (especially mothers and daughters though it was difficult to know how far this was mainly about menstrual difficulties rather than fertility per se). Adult males were the least likely at the time of interview to talk to parents or family members.

A number of respondents had either a prior close relationship with parents and/or family members or one that now enabled them to talk at a level and frequency that felt right for them about fertility and related matters:

**TM:** We're quite a sort of close knit family so. It was really easy to talk to me mam and dad. We got on really well and they were supportive and there wasn't the sort of element of embarrassment that you might expect, having to tell your parents that kind of thing. So yeh it was OK I didn't have any problems with it and I still don't.

**Teenage male 18:19**

Some families were able to accommodate the 'new' need to discuss fertility related matters by shifting some considerable way from previous patterns in which the subject was never raised or was restricted to, say, discussions between siblings.

Two of the teenage males who had voiced their fears about the risk of transmitting cancer to any children they had in the future turned to their mothers initially and then went on together to seek medical advice. Some females talked to their mothers about contraception; others shared their concerns about telling prospective partners about their possible fertility impairment or fears for their chances of becoming parents.

In close family networks, there were open communication strategies involving many family members. One adult female who had to cope with a second cancer and the strong likelihood of affected fertility (which she found very difficult to cope with at times) reported that her family's response in not ignoring or minimising it helped her through. Even though the male members took a more restrained approach to support, the fact that they took an interest was nevertheless seen as very important to her:

**AF:** I always go home and tell me Mam, and generally me sister just cos they're there, what's been said. Me brother'll text us to say how did your appointment go and I'll say champion and that's pretty much all. Not because he's not interested just because he's a bloke and that's what bloke's do. Me Dad's the same when, I'll tell him how it's gone and stuff but I don't really get an opportunity to talk to him properly just cos he works so hard, erm, but then I don't know, me Mam probably tells him as well,.....I talked to me mates, I talked to me Mam, I talked to me sister and they all knew my opinion. And I suppose everyone did the right thing by not going 'don't worry about it you'll be fine'. They just kind of went 'well you've got that opinion, and it's better to look on the black side and then be told the good news...

**Adult female 19:25**

At least one parent took a pro-actively open stance around fertility issues – perhaps because one of her own siblings was coping with fertility difficulties and she herself got pregnant. She was concerned to help her daughter be prepared for possible infertility by developing coping strategies and did so from within what appeared to be a close mother-daughter relationship. This appeared to have worked well. Fertility was not deeply troubling for the young woman (though of course it may not have been even without her mother's intervention).

However one of the adult males remembered his parents each trying to raise fertility on at least one occasion but he did not want to discuss it with them and pushed them away. Along with others (see below), he felt that it should be up to the survivors to decide when it should be raised and by whom (in the family).

### **More closed communication about fertility matters**

Not all respondents found it easy (or appropriate) to talk openly with any family members about the fertility aspects of the cancer experience and vice versa. Even the presence of close relationships did not necessarily mean that fertility matters got discussed. For some, this was not troubling in that they felt that their opportunities to discuss fertility aspects were satisfactory (and conducted in the way that they chose) including, for some, outside of close family relationships. Several felt confident that they *could* discuss it within family relationships if they chose to but had not yet exercised that choice.

The family of one of the adult males adopted the approach of maintaining complete silence on fertility aspects (as he did with professionals) even though he was close to his parents otherwise. He found this worked for him:

**AM:** After that time when I said nothing [around banking], no. Nobody. It were really really good. I never got any pressure on that side. Once I said I didn't want to do it and everything had blown over, anything like going back to the sperm bank or whatever, or about kids, were never ever spoken. Maybe me mum and dad might, I don't know, they've never said. So maybe they had a discussion. ... to say we'll never mention that because he might feel bad.

**Adult male 13:25**

One of the teenage females chose to avoid fertility related discussions with her family members but for different reasons. She was close to having completed treatment and had got closer to her parents and brother since diagnosis. She now wanted to resume her moves towards independence that had been interrupted by treatment. This meant putting energy into re-establishing friendships and returning to discussing sex and fertility with them more than with her family. She, like a few others, also felt that it was perhaps more manageable to discuss with friends as she wanted to protect her parents from any more upset, including about fertility matters:

**TF:** .... I spent lots of time with them when I was bad, and now I hardly spend time, well I do spend time with them but I'd rather be out with me friends. But like they know that, they know I like to be out with me friends, but because like I'm a teenager, it doesn't mean anything else ..... Sometimes, like, I do have an odd day like getting upset but I just like to keep it to myself you know. Rather than other people getting upset. Especially me Mam and Dad. I hate like crying in front of them or anything, cos I just don't like them getting upset, so..... I just feel that I would rather talk to someone else because I don't like seeing me Mam and Dad upset, like. So I'd rather talk to someone else because it won't upset someone else you know. .... because they can go, after I've talked to them, they can like be there for us but they can also go back to their own house and just live life.

**Teenage female 15:16**

This was also true of another female who had chosen to restrict fertility discussions to those outside of her family (especially friends) because 'It's too serious for us to talk about' within it. She felt that she could turn to her family for support if she wished but, in the meanwhile, kept them at bay by saying that she had little interest in children – an approach used by some others as well who nevertheless hoped to become parents one day.

One of the teenage males who had a generally close relationship with both parents had a different reason for not discussing fertility matters with them. He did not feel that it was a topic that was appropriate to discuss with them as it did not fit their family style (though it had been OK that it was raised with them present at around diagnosis):

However there were others with a generally close relationship with at least one family member who found the more closed communication around fertility to be a matter for regret.

One of the adult females had an already close relationship with her mother in particular when she was diagnosed. They got even closer through treatment and towards the end, they shared the experience of cancer as she too got diagnosed.

But fertility was not an area that was broached in the aftermath of treatment and she talked with some regret of keeping her mother (and family) at bay by affecting disinterest or avoiding discussions about children. Similarly one of the adult males, this time from a lone parent family, who appeared close to his mother on other areas did not talk to her (or anyone else) about this. Both appeared to locate the reasons for their closed communication within themselves rather than their family's communication style.

Another female had a prior close relationship with her mother but this did not last into her adult years and she had been able to talk neither with her nor anyone else about the major impact that fertility has had on her. This has been deeply troubling for her. It was not clear whether the barriers came from her or them or from elsewhere.

Some talked of the difficulties that arose for them in what appeared to be otherwise sound relationships when parents (in these cases mothers) acted inappropriately around fertility matters, leading the respondent to try and control communication by shutting it down. Thus one teenage female opted to talk more to a few close friends and her boyfriend about fertility issues (and some other aspects of her cancer) as her mother's negativity about the future affected her so adversely. She also hoped that this would serve to protect her mother somewhat though this was a secondary reason for her approach:

**TF:** .... if someone else raises it then that starts me thinking about it and then. It's as long as it's out of my mind I'm not bothered about it. It's OK. And as long as I know that when I am ready to talk to someone I can. It's OK but I don't like other people bringing it up as much, at all. Especially not my mam. It's harder to talk to my family than it is to talk to friends..... when I think about my fertility, I don't really want to talk to my mam about it .... she doesn't look at the positive side as much, whereas my boyfriend is the most optimistic person in the world and just says 'well there's not going to be any problems, it's going be fine'. And that's what I want to hear when I'm away from the hospital, so.

**Teenage female 18:20**

In one teenage female's case, the difficulties posed by her mother wanting to talk with her about fertility caused a different set of problems. She appeared to be so concerned with making her daughter feel better that she was in danger of minimising the impact of (in)fertility with which her daughter was struggling. Female members of her extended family also used inappropriate ways of trying to help her come to terms with childlessness by downplaying its importance and stressing the importance of having a career instead, even though that was not the role model that they themselves offered:

**TF:** I remember I would go back and I would tell my Mum what had been said because obviously she wasn't there, and I would say to her and she would obviously be upset that they'd said I wouldn't be able to have children, and she would say it's not the be all and end all you know, there are more important things in life..... So we have this thing now, ... I just said I'll talk about it with whoever I need to talk about it when the time comes when I want to have children, so we just don't talk about it anymore. ....I know they're trying to make me feel better, but it just makes me feel angry..... my Mum says you shouldn't be angry about

it, you can't blame the doctors, you should just be grateful for what they have done for you and yet trying to explain that I'm not ungrateful, I'm really, really grateful, I just feel that I wasn't warned about it. .... I wasn't able to prepare for it and then when I was told, not enough was done.

**Teenage female 13:19**

For others, silence or avoidance of the subject appeared to be more a reflection of a prior (or developing) distant or uneasy relationship with parents or within families even though parents nevertheless gave them good levels of support around cancer.

One of the adult males who had failed to bank his sperm thought his previous relationship with his family had been 'good enough' though his father in particular was very reserved. He chose not to confide in them (or anyone else) at any stage - even during one particularly strong reaction to his probable infertility following the birth of a baby to a family friend when he was in his mid teens - until meeting his partner. He speculated that this reflected their family communication style as, like some others, the subject had never come up again until they were informed of his participation in the study at which point his mother urged caution about his participation:

**AM:** I remember being quite resentful of my Dad's friend [who had a baby], and quite resentful of everyone for me not having given a [sperm] sample, and very like being angry about it, but that, I don't think it lasted very long, I had a few like silly crying sessions and stuff just on my own, I've never spoken to anyone about it and erm.. well I've probably spoken to my girlfriend about it actually.. but not my parents or anyone. It was just something that I had to let go, cos you can't really talk to your friends about it.

**Adult male 13:21**

One of the adult females had never had a close relationship with her parents, saying that her parents were good at asking how she was physically but never emotionally. That had continued to present day though she did become close to an older sister to whom she confided a lot over fertility related issues.

Finally, for a few, a previously distant relationship with family members improved through the cancer experience. One teenage female had previously envied her friend's close relationship with her mother but felt that her own relationship had improved and could now cope with talking about difficult areas like fertility if she needed that.

## **PULLING IT ALL TOGETHER ABOUT TELLING AND TALKING WITH FAMILY MEMBERS**

There were notable differences as well as similarities across the cohort. Pre-existing verbal communication patterns within families were maintained or strengthened in some families but altered in others. While this built on pre-existing patterns for many families, it represented departures from the norm for a few. However, the pattern of communication about cancer matters tended to differ in most families to those around cancer-related fertility matters in that it was much more likely to be closed. Where such patterns about fertility were open, this was influenced either by pre-existing patterns of discussing such matters or by a (new) need for information or reassurance by the respondent (and this included for example sex, contraception and

fear of transmission to unborn child). Where communication patterns about fertility were closed, this was sometimes because the respondent had not felt the need to discuss it because they were not troubled by it. For others, this was because respondents feared upsetting or being upset by it being discussed with family members (especially mothers); for another group, it was because they preferred to discuss it with friends or romantic partners; finally, for some, it reflected a relatively distant relationship. Some respondents talked to siblings and members of the extended family as well as, or instead of, parents. For a small number, the lack of discussion with family members was a matter for regret as they would have preferred either to be able to broach it themselves or for others to take the initiative in doing so.

## **TELLING AND TALKING WITH FRIENDS AND OTHERS**

As with the previous section, different verbal communication patterns emerged within friendships around cancer to those around cancer-related fertility impairment. This section will therefore seek to describe what those patterns looked like and how the individuals arrived at decisions about who, what and when to tell.

### **Patterns of communication with friends and others**

Respondents divided up into 2 broad groups:

- (i) those who approached talking about their possible cancer-related fertility impairment with friends very differently than they did talking about cancer – 9 (75%) adult females, 6 (67%) teenage females, 8 (80%) adult males and 3 (43%) teenage males – i.e. 68% overall.
- (ii) those who were not aware of any particular difference in their approach to communication about both – 3 (25%) adult females, 3 (33%) teenage females, 2 (20%) adult males and 4 (57%) teenage males – i.e. 32% overall.

Not surprisingly, the volume of conversations about cancer and about cancer-related fertility was markedly different but, as in previous sections, the focus here is on the patterns of communication. The majority in all the groups except teenage males reported different patterns of approaching verbal communication with friends about cancer-related fertility than were present with cancer. While all were generally open and willing to talk about their cancer experience, this was far less true of fertility aspects – i.e. where a difference was reported, it was always to do with being more open about cancer than about cancer-related fertility. Those who reported little difference in their approach were more likely to be open than closed across both topics.

Those who were further off treatment were increasingly less likely to have regular conversations about cancer and its treatment (most, but not all, were happy to do so if it came up) while those closer to treatment were still, on the whole, having fairly regular conversations but predominantly about treatment and its more commonly understood side effects such as hair loss, weight loss and nausea. Those with visible side effects such as artificial limbs were likely to be asked about the cause of these at any stage. In all instances, these conversations were a mixture of self instigated or 'other' instigated. Of course there were variations around this with some wanting

to avoid discussions with friends about cancer at any stage, some who increasingly preferred to avoid such discussions and some having friends avoiding such conversations with them.

However where fertility issues were concerned, the picture was very different. The majority reported that, typically, fertility issues were discussed with only a small circle of others, if at all. This was caused by a mixture of the respondents' feelings about talking about fertility as opposed to cancer and the relative frequency with which it came up. The likelihood of it being discussed only with a small circle of close friends did not differ on the whole either over time, according to personality or according to the level of concern that the person affected was experiencing. For example, some of those that reported having a generally open personality adopted a more closed stance on fertility issues whereas others remained open across both areas and this did not appear to be influenced by the level of distress being experienced. Context did appear to influence patterns as the most likely place that fertility was discussed, if at all, was with a small number of close friends or a romantic partner (see later) rather than with family members. As was seen earlier, females were more likely than males to discuss it with family members (usually their mothers) though this may have been focussed on their menstrual cycle more than on fertility per se (see earlier).

The picture with teenage males with regard to relative frequency of discussing cancer and fertility with friends was different in that numbers were more evenly balanced between the two categories (though this was also the smallest group). This does not necessarily mean that this group were more open. It may reflect a broader categorisation of friends. Hence teenage males were less likely to talk about having 'close' friends and 'other' friends so may either differentiate less or may indeed have less close friendships. This makes it particularly difficult to know how far the categorisation used here accurately represents the teenage males' experience. It should be noted that both patterns were present among those who banked and those who did not bank sperm.

### **Telling and talking patterns with opposite gender friends**

While most seemed to talk only about friends of the same gender and were clear that this was primarily an area limited to same gender discussion, others did talk in cross gender friendships too. There was another dimension to cross gender friendships that two of the females mentioned. These females made use of their male friends to test out their views indirectly about whether they would contemplate having a relationship with someone who was infertile:

**AF:** ..... they [boys] don't really realize it ... but I try and ask them loads, not loads, just little things like 'do you want to have k...' if it comes into the conversation, and they'll go 'yeah I'm going to have loads of kids' you know, and you just see what the.. and usually it's really weird cos I always think girls always think about having kids but lads as well do, they always know, do you know what I mean?

**Adult female 15:21**

## Managing conversations with friends about parenthood

Some areas of discussion in friendship groups have the potential to carry particular challenges regardless of whether or not others know about potential fertility impairment. Talking about parenthood plans is just such an area but it is of interest that this was only mentioned as forming part of conversations with friends by female respondents.

Some found that others were sometimes hesitant to talk about children once they knew that the respondent might face fertility damage. One had started to take the initiative when this came up and encouraged her friends to talk openly as that is what she herself preferred.

One of the adult females (who had also been open with friends) who had the experience of a close friend getting pregnant reported that her friend was finding the sex of the unborn baby difficult to come to terms with following a scan until she realised her good fortune at being able to achieve a pregnancy in the first place. She was then able to pay attention to sharing her good fortune with the respondent and has gone on to involve her in the child's upbringing. Another spoke of having to put her own feelings of distress to one side when a close friend got pregnant in order to 'be there' for that friend.

However, one of the teenage females who had told only one friend saw fertility matters as something that she has to deal with disproportionately more than her contemporaries and this affects both her friendships and the way that her life is unfolding. She was finding it increasingly difficult to cope with conversations in which friends shared their tentative plans for being a parent, especially as they had become more frequent and as she herself has had confirmation that she is infertile:

**TF:** .... people do go 'I want three children', or 'I want a boy first', and only the other day, I was laying on one of my flatmates' bed with her and we've got an old flat, very, very cold and we'd got hot water bottles up our jumpers to keep us warm. We're both lying on a bed and she said 'just see it in a few years time, this could be us but we're pregnant'. It was just a throwaway comment, and I laughed and said 'Oh yeah' And I just thought 'no that's not going to happen'..... That is one of the biggest, you've got your head saying 'Oh for God's sake, pull yourself together. Having children isn't the most important thing and a bloke is not going to run off screaming when you tell him' but then you always have this fear that it will happen'

**Teenage female 13:19**

Some of those facing premature menopause talked about the way that such conversations with friends now prompted them to think about the fact that the clock may be ticking faster for them. Some were doing so by trying to be sensitive to their friends' needs to talk aloud about their tentative life plans then dealing with their personal distress on their own afterwards.

The fact that the males did not refer to conversations about parenthood plans with friends did not mean that they did not think about parenthood as is clear from Part Five. Perhaps it was more that their conversations, especially when younger, were

more concerned to focus on virility than parenthood as illustrated by one of the adult males when tracking the changes over time:

**AM:** Yes, I think in your teens it's not about fathering a child I think. Well, it's not even, virility is not sort of like a subject of discussion but there's something, it crops up and I think that in teens people, particularly boys are nasty to each other.....we weren't nice to each other when we were younger. And you sort of.. it's an area of weakness... it goes back, I think virility, it's one of the most important things to men at a base level you know. I think it is one of the most fundamental things that goes through you as a boy ... I think at that age, sex talk all the time you know, and I think then at that age virility and potency and everything else .... no-one distinguishes between that and say sexual prowess ....

**Adult male 13:28**

### **Verbal communication instigated by self or others**

The main finding of the presence of different verbal communication patterns applied regardless of whether such communication was instigated by the respondent or by their friends. Many respondents, especially males, said that fertility was not a subject that friends brought up much, if at all, thus mirroring the experience with family members and professionals as seen earlier. Where it was raised, it appeared to be more likely to be driven by curiosity than concern for well-being. A number of females reported being asked, for example, about whether or not they had stored their eggs and/or what they intended to do with regard to the use of fertility treatments (see Part Two).

A small number of both males and females thought that friends and others did not raise fertility with them (if they even knew) but waited to be given the 'green light'. While most in this situation found this to be helpful, a small number wanted their friends to raise it. One teenage male talked of the sense of relief that he felt when his friend raised it with him as a result of media coverage:

**TM:** ..... We were coming back from the [shopping] Centre one day and me mate had picked up this magazine from somewhere about cancer and whatever cos he was worried about me or whatever and he just read up. And he said ..... is it true that it does affect your reproductive systems and things like that? Cos I did say I mean everything like that and I said well, this and that. And he's kept it quiet and everything like that but it did help me saying that to me mate and everything. I could get it off me chest and everything. .... It did take a bit of confidence for me mate to actually come out and say that to me and everything. But it was good like to get if like off me chest and everything like that. And I said I can still do it now but I don't know if they are swimming or whatever.

**Teenage male 15:17**

One of the approaches that several males and a smaller number of females employed in talking about their cancer experience was to use humour. They often did so because of its potential to detoxify some of the difficult aspects such as hair loss, friends and relatives' tendency to imagine the worst, and loss of stamina. There were only two of the respondents – a teenage male and a teenage female - who shared fertility-related humour with friends and both found that helped. Both took a

very open stance on fertility matters as well as cancer and both reported feeling in control of the use of humour, i.e. that it was used as an aid to recovery rather than being used against them:

**TM:** .. and the thing about the fertility sort of like, all me friends know, that that was a possibility so we make jokes about it all the time. It doesn't really bother us at all. It's quite easy to live with, so that's good.... I think there is an episode of 'Only Fools and Horses' where they call Trigger a jaffa cos he's seedless. Which seems to be the running joke at the minute. But half the time I instigate it so. I don't mind at all.

**Teenage male 18:19**

However, the impact of humour about sex and fertility within friendship circles that typically drew on stereotypes ('shooting blanks' and so on) where the fact of the possibility of the cancer-related fertility impairment was not known and where the respondent did not have control over the verbal exchanges was more likely to be a source of discomfort or distress:

**AM:** ..... I knew they [friends] weren't doing it to be upsetting but secretly I actually thought 'God, if they're making these jokes, you know, there's a possibility that I can't and this is what we all think of people that can't have them'. Then that sort of was quite difficult at 16, 17, erm, you know, and I was going out with my girlfriend at school then and I suddenly thought 'Oh my god, what happens if she finds out; she's probably gonna think..'. ..... although on the outside I was probably laughing, on the inside, I was actually quite upset. I think it just sort of brought it home that actually, that would mean I was different and having already been different cos of having no hair and being in a wheelchair, I just sort of - 'not again'. I could be doing without this.

**Adult male 13:28**

For some this appeared to be underpinned by a sense of the stigma that attached to infertility and that is returned to later. For others, it appeared more to do with the seriousness attached to that state and its implications. Thus, one of the adult males who was increasingly struggling with his probable infertility had used humour a lot when talking about cancer, especially in the early days, and still does when it comes up (which is now more rarely). However he has only ever talked to his parents and one close female friend in the past about fertility and would never contemplate using jokes around this subject:

**AM:** ..... it [cancer] is something... I made a joke of it in a way. Even like when my hair were falling out and people were seeing us like. ..'Look don't use Wash and Go shampoo'. It's wicked but then I'd pull me hair out and people were going 'oh, what's wrong', 'me hair's just falling out'. It's something in a way I've just always made a laugh and a joke about. Cos that's been the easiest way to me.... it's my way of getting through it. To me it's been and gone and no point in seeing the bad things about it..... I don't think that's [fertility] something that I've told anyone. I think that's something that's my own thing. Everything else is a laugh and a joke in a way because it's... but this .. isn't. This is serious. I mean obviously it's not a laugh and a joke having cancer, but. I think that's [fertility] one of the special associations, that's not a laugh and a joke cos that's something that can affect your life.

**Adult male 16:22**

Some had the experience of being in a setting shared with friends when the subject had been introduced indirectly and not through the use of humour – usually a television programme – with differing outcomes. One of the teenage females was watching a late night television documentary about childlessness with a friend at university and became upset. However the disclosure that followed did not lead to either her or her friend returning to the subject afterwards, much to her regret:

**TF:** ... I only told them cos we were sat watching the telly one night, and we'd been out and it was the early hours of the morning and it was some documentary about people who can't have children and I got upset about it, you know and if it hadn't been for that I probably wouldn't have told them. And even then it's never been brought up, it just gets shoved under the carpet, no one wants to discuss it.

**Teenage female 13:19**

One of the adult males was older when he too was able to make positive use of television but with a better outcome – and he is someone that had been troubled a lot and had not banked. He was with a (male) friend when the subject came up on television and he took the opportunity to disclose. This was for him at a time (in his 20s) when he was already starting to think seriously about taking a 'risk' and telling some close friends. He was then able to build on that disclosure, though still with some caution, and saw it as a turning point for becoming more open and better able to cope.

### **Friendships specific to the education or employment context**

Returning to context, the other setting that affected communication patterns with friends was education and employment. Several talked about associated decisions such as whether to return to the same setting and, for education, whether to return to the same year group, which subjects to drop/retain and so on. Others had the decisions made for them. A small number kept going to school throughout treatment and a small number kept up with education outside of school and in the most difficult of circumstances. All of this affected communication patterns and many felt apprehensive about the changes.

For those still in education, most decided to return to their previous educational setting, either so that they could be back with friends or (less frequently) so that they could be in familiar surroundings with staff that would understand and support them. Where possible, they opted to return to the same year group even when this resulted in them studying for fewer subjects and/or needing additional teaching support. Those who were able to return to their own year group welcomed this. One teenage female got the chance to remain in her year group by having a mentor allocated and dropping some subjects – which meant a lot to her as she wanted to stay with her friends and used them to support her on cancer and fertility matters. She was not worried that having a mentor would mark her out as different especially as it was this that facilitated her re-entry to her prior friendship group. However one of the teenage males in a similar situation was glad when his special help ceased so that he could feel more normal, even though he was struggling academically. He too discussed both cancer and fertility matters with friends but was experiencing difficulties with the latter and was selective in what he disclosed.

Those that returned to a lower year group were more likely to report negatively on that. Some said that it impacted on their friendships and hence their patterns of disclosure. One of the adult males felt different to his new peer group, more grown up, but also perhaps lacking the maturity or perspective to enable him to recognise the impact that his tales of his cancer experience had on them. Although some *said* that they did not mind talking about fertility, the reality was that they found this difficult, on the whole, when faced with a new situation. For example, one adult female who had had to drop to a lower year at university and found it difficult to break into well-established friendship groups had not told anyone until the day of the research appointment when she disclosed to one friend.

For many who returned to their previous school, their illness had often been widely reported so there was no choice about the cancer remaining private. Some were happy with this with a small number relishing the high profile that it afforded them while others worked hard at becoming 'one of the crowd' again. However, as the fertility aspect was less widely known, the option to retain privacy about this was available and many took it. For some this was because they had not had a close prior friendship group and this continued; for others this represented a change in their pattern of verbal communication. However one female had not had the option of privacy in the wider school context as another girl in the same school had cancer at around the same time and it became known that her fertility may have been affected. This led to her fielding questions about her fertility which proved stressful at times, though helped by the fact that she understood that she is unlikely to have been affected.

A small number had chosen actively to change their educational setting in order to have some privacy and then were able to decide for themselves who to tell about their cancer history and who to tell about their potential cancer-related fertility difficulties. Those who had done this found that it worked for them. However others found it difficult if they were at the transition between educational contexts at around the time of treatment and were left with no choice but to go to a new setting afterwards.

Some found that the formal classroom space also had to be managed and that this affected relationships. A small number had chosen to talk and/or write about their cancer experience as part of presentations but none chose to include reference to fertility (including one who had banked sperm). At least one found herself having to handle a session on the reproductive system in which the teacher asked how many children everyone wanted. She described herself as a very open character and she opted to be honest in her response:

**TF:** .... here I am doing health and social care. And I was sitting doing about reproductive organs and doing about the growth of children and the teacher asked 'who here, how many children does everyone want' and I went 'I'd be lucky if I can have one'. I just want the one. And the whole class was dumb struck and I was like I shouldn't have said that, you know.

**Teenage female 15:17**

The same teenage female who had sometimes used fertility related humour with friends also reported that knowledge of both her cancer experience and her possible fertility impairment was widespread at the pub where she worked part time behind

the bar. Some of the [male] regulars joked with her about how they might help her overcome her potential fertility (sexual innuendo) and she found that worked well for her:

**TF:** And then I had like all these blokes saying 'I could get you pregnant, you know'. It's like, 'whatever'.... they say how humorous I found it. I know it's a serious subject but I can't take it seriously. I mean I'm 20 year old. What's there to take seriously?

**Teenage female 15:20**

Others too said that they had decided to be open with colleagues and friends in their workplace and, on the whole, reported this to be manageable. Some reported on positive outcomes from this, including, for a few, that future romantic relationships might arise from the workplace and their openness might avoid them having to go through the anxiety of deciding when to disclose. However, others had opted to keep either the whole experience private or only to disclose about the cancer.

### **Changes over time**

Some of the adults described how conversations with close friends developed over time to accommodate the changes that came with growing up. In some cases this led to shared strategies for managing the respondent's potential childlessness – for example through becoming more involved than otherwise in helping friends to rear their children:

**AF:** There's a very solid group of six of us including meself, and we've grown up together, I mean we've grown up in the same village, we've been together since we were little babies, a lot of us. ... They've always come in to see us and they've known what I've been going through the whole time..... and I suppose I would be the Auntie to a lot of them [their children] because we're that close, no matter what.....

**Adult female 19:21**

However it was not unusual for such references to be accompanied by the comment that others can never fully understand the impact of fertility impairment no matter how sympathetic and supportive they might be. The sense of difference was therefore lurking not far below the surface but was more likely to be voiced by the adults, especially those without children:

**AM:** .... you don't have or you're not aware of many of my friends being in a similar situation. ... a lot of my friends, although supportive, none of them really understand what I might have to go through, what I have gone through. Erm and I think...it's just so strange cos I do feel slightly, not isolated that's the wrong word, but out of my friends there's no one that's in that same position. I mean there might be, I guess, but generally speaking all the ones that weren't families seem to be having families and I think there will come a time if I'm the only person that isn't able.. certainly isn't able to on my own without some sort of treatment then I think I'll find that probably quite hard.

**Adult male 13:28**

## **Talking to others with cancer and/or fertility related problems**

Some talked about the patterns of verbal communication about fertility amongst friendships formed through sharing the cancer experience. Most in this study did not make friends with other patients because they were too ill, because their parents and family members were there and inhibited social contact, because they were in a side room, because they spend so little time in hospital and so on. Some made friendships that were not maintained for long as one or other wanted to move away from the shared history. A small number maintained longer lasting friendships and some, including a small number of the teenagers, had very active ongoing friendships that they clearly found to be very helpful and these had often been strengthened by shared attendance at conferences such as the TCT 'Find your sense of tumour' ones.

Where such friendships were established, there was varying experience of discussing fertility matters. For many, it never came up as a topic, for others it did and was fairly intense, whereas for a third group it was raised but the conversations never really developed.

Only one had experience of talking with a friend who was having possible non-cancer related fertility problems though some had talked with family members with this experience (see earlier).

A small number speculated that the time may come when they got to know others with fertility difficulties (i.e. cancer or non-cancer related) and looked forward to the potential relief of having shared experiences.

## **Factors influencing the decision about who and what to tell**

There were various factors that appeared to affect decisions about who and what to tell, some of which have been implicit in the above section.

### ***The presence of supportive friends***

A number in all four groups appeared to have a core of good friends whose support has been relatively unwavering throughout. In many cases, they did not even consider holding back on this aspect of treatment and the decision to tell appeared to provoke little anxiety. This seemed especially true for those who described themselves as having very open personalities, as coming from close knit communities or where they saw the existing culture of their friendship group as being a very open one.

One of the adult males had been very open about fertility matters as well as cancer and found the support that came from friends at the time of diagnosis and treatment (including at university) and those that he has met since to be invaluable, especially that from other males:

**AM:** And my housemates knew, as well, which was quite an important thing as well. Because I was close to them as well. They were boys; I don't know if that makes a difference. It probably does actually. .... In that they would have similar concerns if it happened to them. They could identify with it

yeah. .... I talk about it quite openly with my friends, my new friends here [current situation] who never knew I had cancer, they all know.

**Adult male 20:22**

Where friends and colleagues had taken an interest, this was generally seen as positive and encouraged respondents to share information with them, including about fertility.

One of the teenagers preferred to talk to a range of friends rather than her family about both cancer and fertility (she is the one reported above as wanting to return to developing her independence from her parents). She valued drawing from a range of friends so that no individual felt too overwhelmed by what she said, and this meant that she was open with relatively large numbers:

**TF:** But like me friends in school, like I tell them like when I'm thinking about it and that and when I'm upset and everything. I tell me friend, I just talk about it and then it's over. And then I just have a good cry and then it's over and then it doesn't come back for a while so. ...

**Teenage female 15:16**

For those who experienced friends, especially close friends, as being able to handle the information about cancer-related fertility, it appeared helpful that their friends knew. This encouraged some either to continue with being wholly open or to widen the circle that they told.

However a small number who had close friends rarely if ever talked with them about fertility matters, some because it was not an area of particular importance or concern for them and others because they simply found it too difficult a subject to discuss or know how to raise, even though troubling.

### ***The impact of adverse reactions***

There was perhaps more divergence among respondents with regard to the impact of adverse reactions by friends on the likelihood of them talking about fertility matters. A small number opted for being upfront and open in relation to both cancer and fertility when faced with difficult reactions on the part of friends and work colleagues. Conversely, others were more likely to withdraw from verbal communication when friends reacted with awkwardness, avoidance or inappropriate humour either about cancer or fertility. Some friends found it difficult to cope with them having cancer and damaged links were not always re-established. Where relationships had not recovered, respondents were unlikely to have told many, if any, friends about fertility matters:

**AF:** With my friends at home, they didn't handle me having cancer very well. They didn't have a clue what to say and it was .... I remember people in town actually crossing the street to avoid me so they didn't have to talk to me, erm, which is quite difficult, erm. Friends would avoid me cos they didn't know what to say, and I pretty much lost contact with most of my friends during the treatment. Erm, didn't really get any support from them. They couldn't handle it themselves I suppose. Erm, so I didn't speak to any friends at home about any of it [including fertility] really... .. I suppose from those experiences I just don't have friends that I talk to quite in depth about things.

**Adult female 14:25**

For some of those where friendships had been damaged, when the respondent re-entered that social space they found that they no longer embraced the norms of their previous friends. They no longer shared their priorities and found their preoccupation with 'trivial' matters difficult to cope with making it even less likely that they would ever share fertility concerns with them:

**TF:** ..... What I find with a lot of my friends is the glass is half empty a lot of the time and er, so I'm the one who turns up after they've gone out for the night and they're all sat there with their hangovers saying 'what are you moaning for, you went out there you got pissed, you've got hangovers'.. ..... It's caused problems with friends having different perspectives. .... If you think about a lot of my friends, how much time and energy when they get up in the morning they spend hours putting on their makeup and getting their hair ready.

**Teenage female 11:17**

However some were more driven by trying to temper what they said in order not to upset those around them and this too inhibited their willingness to share fertility matters.

### ***The need for self protection***

Some were limiting discussions about fertility in order to avoid getting hurt by people's lack of knowledge and potential insensitivity. Some had decided to restrict which friends they told in order to protect from hurt but also in order to feel in control of when and how it got discussed. This mirrored, for some, their approach to verbal communication with family members though was different to that with professionals whom they generally wished to raise it.

**TF:** Pretty much everyone that knows me knows what I've been through [i.e.cancer]. ..... They don't know about my fertility side. .... But serious things like my fertility or like this other lump are only people that are really close to me that I talk to. And it's only when I'm ready to talk, I don't bring it up very often. It's only if I'm thinking about it that day and it's bothered me for a few days that I'll talk to anyone about it. I try and keep it to myself quite a lot, so... I don't feel I could talk to just anyone about it. .... And like my fertility's nothing, no-one else's business. It's mine and my boyfriend and few close friends. And no-one else really needs to know about that, cos most of them aren't going to be there when it's going to be happening so. When it comes to that time I'll tell people then.

**Teenage female 18:20**

One of the teenage males had started out by being very open with friends about fertility as well as cancer in keeping with his personality but changed his approach in the light of their reactions. These differed by gender with his female friends finding it too upsetting and his male friends taking the sperm banking as a matter for joking (which he found neither helpful nor appropriate):

**TM:** My mates just laugh and say 'Ah kid. Sperm like yours, that won't be damaged' and stuff like that. *laughs*. ....It's kind of funny but at the same time it's yeah, yeah it might be damaged actually.

**Teenage male 15:18**

### ***The desire to be normal and avoid stigmatisation***

As well as taking into account the impact of potential reactions of others when deciding whether or not to talk to others about fertility issues, another factor that appeared to influence decision making was the strength of desire to be back as 'one of the crowd'.

Some who wanted to re-enter the world of 'normality' were able to do so *because* of having one or two friends that they could talk openly with about fertility matters, leaving the majority of their emotional and social space for what they saw as age-appropriate activities. However more who referred to this had taken the decision not to disclose information about their possible fertility damage and this included some who thought that the risk of damage was high.

One of the adult males spoke of pushing both cancer and fertility issues away in order to carry on as normal with friends, including when he got very distressed at the birth of a child to a family friend as reported above. The desire to be unencumbered (as he saw it) by the label of cancer survivor or infertile person appeared to guide a number of his decisions about verbal communications. However by the time of the research interview when his infertility was all but confirmed, his motivation for spending little time in verbal communications about it *appeared* to have shifted more towards finding the subject of relatively little concern.

A few of those who adopted different patterns of communication around cancer and fertility (including with friends made following cancer) spoke of wanting to be seen first and foremost as a person rather than as an abnormal object of pity.

**AF:** I find it hard to talk about, I would rather, I don't want people feeling sorry for me because I've had cancer and because I might not be able to have children. I would rather them get to know me and then if I want to tell them afterwards I would tell them. But it's not an easy topic that I find to talk about, I would rather just forget about it. .... I find it easier to talk about the cancer than I do the fertility part, it's still a bit raw, erm but I do tend to not tell people until I feel they need to know. I wouldn't like to just say Oh I've had cancer! Because I know they'd be thinking 'Oh I feel so sorry for her' and I don't want that. **Interviewer:** You don't want that, you just want to be treated for you. **AF:** I just want to be normal yeah, cos I am normal.

**Adult female 18:23**

One of the older teenagers reported that the stigma attached to infertility had influenced her decisions not to disclose to friends over the years since her treatment:

**TF:** ...although part of me didn't want to admit to it, and you know admit's maybe the wrong word, but I felt it kind of reflected on me almost and I suppose not telling people almost makes it not real. And so I mean I'm at University now, twenty next week, and even up here, I can't think, I think there's maybe one person who knows.

**Teenage female 13:19**

For some, there was a gendered dimension to this. Some of the males held back from telling friends, especially in the early years, because of the feared stigma that might result and related this to sexual identity as well. One of those who remembered references to 'shooting blanks' in school friends' jokes determined to

not let them know that this applied to him as referred to earlier. It was only when he got to his mid twenties that he was able to start telling friends but still finds jokes about his residual physical impairment acceptable – because his ability to cope is also a source of respect from others - whereas jokes about infertility are not.

**AM:** .... I can make a joke out of [cancer], people have fun, people have respect that I've come through it and have decided to still progress through school and career, and that's great and I like that.....And so I joke about it with friends and all my friends are so rude about me, anything offensive they generally are but all in good spirits and likewise you know, and it's just a bit of fun..... And likewise now if people make a joke, for example people make jokes about calling me hop a long or cripp or whatever, you know - tasteless but... if someone made a joke about infertility ..... I think 'how to make someone feel small in one easy step'.

**Adult male 13:28**

One of the males thought that he overcompensated in sexual-related activities and conversations with school friends in his drive towards normality and this had the opposite effect to that desired until he tempered his approach:

**AM:** .....perhaps I erm on occasion with the other lads was very direct when they weren't expecting me to be, about experiences or who you were with or whatever, who I was with.. ....and so that perhaps caused tension at the time between myself and my friends because they obviously didn't want to discuss things and you know part of my initial naive understanding of being infertile was not being able to get an erection. And, er, you know, that wasn't the case so, I was still able to, to have fun so to speak. And I suppose my wish at that time to point that out, be boisterous about it with friends was probably quite high.

**Adult male 15:30**

The females that talked about this were more likely to see themselves as 'damaged goods' in some way – or without all the 'right parts' – and thus shared their thoughts and feelings with very few friends.

Some respondents saw embarrassment or discomfort about the probable presence of infertility rather than shame – they are perhaps two sides of the same coin for some.

### ***The influence of shared experiences***

For the only respondent who had experience of having a friend also coping with possible fertility difficulties not as a result of cancer, this had been the prompt that led her to disclose her own situation. She then enjoyed the sharing of experiences but the conversations stopped once the other girl's periods returned a year or so later. She assumed her friend then forgot about it.

Of those who had discussed it with others who had shared the cancer experience, there appeared to be different reasons leading to disclosure. For some, it had 'just come up' in conversation on the ward; for others it was prompted after discharge when one of the group made reference to it and this opened it up for others to add their experience. Finally a small number were prompted to talk about it as a result of being invited to take part in the study.

### ***The impact of getting older***

A few talked of having a group of friends that was older than they were and speculated that this may have promoted their disclosure about fertility matters (though this was not true for all).

As already mentioned, one of the adult males moved from not telling friends when he was younger as he did not want to don the identity of a 'probably infertile' male (which he saw as negative and threatening to his masculinity and virility) to increasingly disclosing, first to friends then to girlfriends. The threat to his identity became less than his need to have the support of friends and stop having to keep the secret. He found disclosure daunting (although he had been contemplating it, the actual first time of disclosure was opportunistic rather than planned) and continues to feel nervous when telling someone new but is positive about it on the whole. He found it helpful to start slowly in telling others and process his own feelings and reactions before taking the next step. He still tries to be sensitive to other people's reactions around fertility for his own as well as for their sakes as he continues to see it as a very personal matter and often associated with virility.

A small number felt that fertility was not an appropriate subject to talk about with friends when younger (i.e. stigma was not the influence) but do so occasionally now that they are adults.

### ***The influence of the level of concern being experienced***

Implicit in some of the above is that the level of concern about fertility being experienced may play a part in influencing the decision whether or not to discuss fertility matters with friends (that is, it may prompt open or closed reactions). There is therefore one group not represented above and that is those who rarely told friends (and rarely discussed it with anyone else) *and* who did not seem to be perturbed by fertility issues.

### ***The impact on disclosure of participation in the study***

Finally, for some, disclosure and/or discussions about fertility with non cancer as well as cancer friends were prompted by the respondent's pending participation in the research study.

## **PULLING IT ALL TOGETHER ABOUT TELLING AND TALKING WITH FRIENDS AND OTHERS**

Verbal communications with friends about cancer-related fertility matters appeared to be a complex but significant area of interaction. Respondents across all four groups were more likely to discuss it with friends than with family members.

For some who enjoyed open communication with friends, this proved an important source of coping. However a small number did *not* talk with friends and that too worked well for them, especially those for whom the subject was of little concern. Others with more closed communication patterns that would have preferred them to be otherwise found that had a negative impact on them.

There were differences between the level and extent to which discussions took place about cancer as opposed to cancer-related fertility matters. Over twice as many respondents reported approaching that the latter differently with only one category

(teenage males) reporting similar approaches to both. Those reporting little difference were more likely to say that they were equally open than closed. Where discussions did happen, they were more likely to be with a small number of close friends and at the instigation of the respondent (which was preferred by most but not all).

Some found this aspect of their cancer experience particularly difficult to manage in their re-entry into the education context and the friendships there. Some reported friends, especially those who were less close, being more driven by curiosity than a wish to be supportive. The stigma attached to (in)fertility appeared to lead to some not disclosing this aspect of their cancer to anyone either in the early stages or over time. Sometimes this was driven by a desire to achieve 'normality' and hence not to be seen as different. This appeared more difficult to sustain over time.

There were also gender differences. Females were particularly likely to report having to manage conversations with friends about parenthood plans (and actual pregnancies) and, in some cases, this was where friends were not aware of their possible fertility impairment. Some of both genders used humour to diffuse the awkward nature of some conversations while males reported the difficulty in coping with 'laddish' jokes located within a virility/sexual prowess paradigm. A small number discussed it with opposite gender friends though the majority restricted it to same gender friendships. A few females had used discussions with male friends as a 'rehearsal' for anticipated discussions with boyfriends

Some reported changes over time with friends either becoming less interested or becoming more involved and supportive. Some females had been involved by friends in bringing up their children.

There was mixed evidence of respondents talking about fertility within friendships made through cancer. In some it had not come up at all whereas for a small number, it was an important site of shared experience. None had yet got friends facing fertility difficulties for non cancer related reasons.

## **TELLING AND TALKING WITH A PROSPECTIVE OR ACTUAL ROMANTIC PARTNER**

Eleven (29%) of the cohort were in a permanent relationship at the time of the interview of whom five were living together with their partner. Two were teenage females, five were adult females and four were adult males. Five (two males and three females) were parents of whom one was also a step parent (two of whom were living in the parental home and not with their partner) and one was a step parent (though the children did not live with her and her husband).

At least nine (24%) were in a non-permanent relationship at the time of interview of whom two were teenage females, one was an adult female, four were teenage males and two were adult males. The majority of the remainder appeared to have had relationships since diagnosis though were not in one currently. A small number had either not had a relationship at all or not since diagnosis.

Put another way, of the adult females, five of the twelve interviewed (42%) were in permanent relationships, one was in a non-permanent relationship and six (50%) were not in a relationship at the time of the interview. Of the adult males, four of the ten interviewed (40%) were in a permanent relationship, two were in a non-permanent relationship and four were not in a relationship. Of the teenage females, two of the nine interviewed (22%) were in permanent relationships, three were in a non-permanent relationship and four were not in a relationship. Of the teenage males, none were in permanent relationship, three of the seven interviewed (43%) were in a non-permanent relationship and two were not in a relationship.

### **Who had told a partner or thought about doing so?**

The need to decide when and how to tell a partner about one's potential fertility impairment does not apply to most adults with non cancer-related fertility difficulties as such difficulties typically come to the fore once a relationship has already been established and the decision made jointly to try for a baby (though of course it may well then be carried to any subsequent prospective or actual relationships). The numbers of people growing up with (and therefore approaching the forming of relationships with) the knowledge of potential impaired fertility are primarily restricted to those with iatrogenic infertility.

Not surprisingly the key aspect of relationships that was mentioned as the most troubling by many respondents was having to decide how and when and what to tell a boyfriend or girlfriend.

Although only one respondent had remained in the same romantic relationship throughout, several knew their boyfriend or girlfriend before they had cancer. In all these cases, the other knew about the cancer though very few were aware of the potential associated infertility. Some, especially adults, established a relationship with someone whom they did not know when they were undergoing treatment but got to know them through work or social circles before embarking on the relationship. For a few of these, cancer-related infertility had been discussed in these wider circles.

Of the eleven respondents *who were in a permanent relationship* at the time of the interview (which included all five who were parents), *all* had told their partner about their potential infertility, though in different ways and at different stages. The disclosure that came latest was where the couple had already started living together. However this female was fairly confident that her partner knew through work based conversations (they worked together and others work colleagues were aware).

Of the nine respondents *in a relationship at interview that was not permanent*, four had told their partner. With such small numbers, it is not possible to look for patterns but it was true to say that of the four that told, one was a long standing relationship but the other three were more recent. Among those that had not told, two appeared to be fairly longstanding whilst the others were more recent. There was a mix of genders in each. That is to say that, in this small group, telling did not appear to relate to length of relationship or gender.

Some, though not all, of those who were *not currently in a relationship* had had relationships previously, including since cancer. Here again, there was a mixed picture with regard to telling with some never having told anyone (including some

who had had a number of relationships), some having told all and others who had told some but not others.

Of those who were *not in a relationship* at the time of the interview, regardless of whether or not they had had relationships since cancer, the majority had contemplated this aspect of a relationship and expressed quandaries about it.

### **Deciding whether and when to tell**

Making the decision about whether or not to tell a romantic partner and when about possible cancer-related fertility appeared to be influenced by a range of factors. For some, one factor – for example a belief in complete honesty in relationship from the onset – was dominant. However for others, the factors operated in different combinations and it was the combination that tipped the balance rather than a single factor – for example, being young *and* having had only casual relationships leading to non disclosure. Some felt that the decision was made for them as, for example, the information was made public in their social circle. Fear of disclosure leading to rejection was present for many and there was a sense, for some, of the stigma attached to being infertile fuelling this fear. The complication of not knowing the full extent, if any, of fertility impairment was also a significant factor to be managed – for example, should one tell someone when the anticipated risk to fertility was only low?

For those who took a generally open stance to relationships of all sorts and who therefore talked openly about their cancer and possible infertility, this extended to romantic relationships especially where the relationships progressed beyond a very short duration. It appeared to be the least troubling for this group – who came from all four groups - and none had so far experienced rejection as a result. One of the adult females explained her reasoning (and this relationship later became permanent):

**AF:** Yeah, he knew from the beginning when we first - I mean, when we got together, you know, I told him, I thought I'm going to tell him straight from start, because if he finds out further down line, if he's like 'Oh why didn't you tell me', so I told him everything he needed to know at beginning, and to him that wasn't important, it were just, it were me who he wanted, like he said I'd rather be wi' you than have kids, it's you that's important to me so.

**Adult female 18:25**

Some of the younger ones who were a way off entering permanent relationships also went for openness and found that it worked for them; this included ones whose relationships had since ended for other reasons.

At the other end of the spectrum were the group who had not yet told anyone, several of whom appeared much more troubled at the prospect. A number of these were very sure that they were infertile so the disclosure might have to include that fact. For this group, fear of rejection and stigmatisation appeared to be significant factors, perhaps particularly those who understood themselves to be at high risk of infertility:

**AF:** I've had sort of one really serious relationship you know but erm.. but never to the stage where I've been like talking about having kids or anything

like that, so. But that does stick, and like I say I've really thought about it the last couple of years. And like it does get on my mind and I think like if I meet somebody and want to get married, that's going to be an issue. I'm going to have to tell them, 'well I might not be able to have any kids'. And what's that going to do? Wreck my whole relationship? you think about things like that and just like how its going to affect you, ripple effect you in so many different ways, so.....

**Adult female 16:24**

One of the adult males wondered if he was approaching the time for disclosure as he was in a relationship on the brink of becoming more serious. He was anxious that disclosure would lead to rejection and this was compounded, for him, by the fact that he had never felt able to discuss his situation and feelings with anyone, he had been told that his stored sperm sample was of poor quality and he knew little about fertility treatment options. He also felt at a loss as to how to approach such a conversation even though he was feeling increasingly uncomfortable at withholding this information, '.... not lying to her, but you know, just not giving her the full picture'.

Another of the adult males who was very sure that he was infertile and had not banked sperm was also very anxious at the prospect of telling a future girlfriend and had not told any so far. Indeed he had not had any long term relationships. He had been putting off going for fertility analysis and used the interview to think aloud about whether or not the 'need to tell' would be better managed by finding out:

**AM:** But then again, especially wi' girlfriends and that, it's like well always on the back of your mind. It's summat. especially difficult subject to raise. Cos obviously you don't know how long you're gonna be or what. So, in a way it would be a good way to find out, then if I can have kids, it's not a subject I would have to raise. Then if it is one that I can't have kids then it's obviously then a difficult situation to raise again, especially if they don't know my past.

**Adult male 16:22**

One of the adult females who was deeply troubled by her fertility impairment had had many relationships over the years, had never used contraception and had not told any about her probable infertility as she was using them as a way of trying to overturn the information that she was infertile. However one adult male who was also deeply troubled by his highly probable infertility and had not previously told any partners had taken a risk as he got to his mid 20s and disclosed to a friend and then, later, to two subsequent girlfriends and was positive about having done so.

Fear of rejection led to others deciding that it was better to 'get it over with' and tell a romantic partner very early in the relationship so that it would not proceed any further if the partner could not accommodate the information.

**AF:** Well it wasn't really that difficult at the time, because I told him straight away. I didn't want to hide things from him..... knowing that if he did want children, cos obviously he might not get it from me, then he could make his own mind up of what he wanted to do. So I was a bit anxious that he might leave me or you know even though it was pretty much the first couple of days of dating, erm, but he just reassured me that it was me he wanted and obviously it would be nice to have kids together but if it doesn't happen it

doesn't happen, and there's other ways of doing things, erm, so from there really..... it was like a huge weight lifted off my mind.

**Adult female 18:23**

Some were less troubled by fear of rejection than they were about how to choose the 'right' time to tell. Some worried that disclosing in the early stages of a relationship could be misconstrued by the other as suggesting a greater seriousness about the relationship than was necessarily the case but did not want to hide it either:

**TF:** I mean obviously, I'm single at the moment but if I'd suddenly announced to my ex-boyfriend, 'Oh by the way.', I think he'd have, he'd have run for the hills. I mean I'm obviously not wanting to have children just now but I don't want to be in a relationship and them not know that, because even though it doesn't make who I am, it is important, and I don't want the awkward situation where you talk about children and things and me shut down..

**Teenage female 13:19**

Some feared rejection but nevertheless waited until they were fairly sure that the relationship was becoming serious by which time telling still took a lot of courage.

This suggests that this group could accommodate the possible rejection at a later stage better than the feelings associated with early disclosure. Some in this group also talked about using other ways of trying to find out earlier on how their romantic partner might react when they were eventually told. Floating the idea to possible long term partners can therefore become an important part of deciding whether or not to remain together – as well as a source of comfort if they therefore establish that their partner might cope:

**TF:** But like me boyfriend who I've been with for quite, like a couple of year, obviously I said to him what would it be like for you if I couldn't have children, just in general conversation maybe. But with speaking to my boyfriend he is fine by that but he'd be willing to do anything he could, like treatment. Like the treatment that they do at the IVF treatment and stuff like that. So I said to him 'what would it be like if it took a lot of strain and stress just to get a child?' And he is quite supportive. So it doesn't really worry me until we actually decided.

**Teenage female 17:20**

Some felt that they needed more information about the actual impact on their fertility and/or about treatment options before they would disclose. This, they felt, would enable them to be in a better position to both inform and support their partner.

Among the ones that felt that the decision was more likely to be made for them, one of the adult females with residual physical impairments (both visible and less visible) and still on frequent checkups speculated that these factors meant that she could not avoid telling boyfriends about her cancer history and this may lead some to asking about her fertility:

**AF:** I mean I wouldn't say at the start 'I may not be able to have kids' but I would say.. I mean they would know I'd had cancer because I'm still coming up for monthly checkups. So as soon as you tell somebody you've had cancer, then if it was the other way round I would put two and two together

and think they might not be able to have kids. And I mean I suppose it would come up in conversations anyway because you would say 'oh, that kid's cute; oh yeh, I may not be able to have them, get over it' kind of thing.

**Adult female 19:21**

For some of the respondents, the presence of visible signs of treatment and/or hospital appointments or further treatment had indeed provided the trigger for disclosure. However, unlike the prediction of the adult female above, partners had not always 'put two and two together' so control over timing did remain with them.

One of the adult males had been left with little choice about 'telling' (as reported in Part Two) as the bank where his sample was stored was moving sites and he was asked to decide whether or not to maintain storage. This proved stressful, not least as it was the first time that he'd discussed it with anyone since banking his sperm.

Finally, one of the adult males had been forced into disclosure when a teenager after his then girlfriend demanded to know why she had not got pregnant when, unbeknown to him, she had not been using contraception during their year long sexually active relationship. He had not chosen to disclose in later relationships – but was more careful about the use of contraception – and only disclosed again when he entered a permanent relationship, this time in a more planned way!

### **Managing the telling**

Many of those who had disclosed talked of how they went about this, often reflecting on the need for sensitivity because of the subject matter itself. They were also aware that the information may prove difficult for a romantic partner to handle – even though they themselves might have learnt strategies for coping with emotionally laden information, partners were less likely to be experienced at this.

Two of the teenage females used their boyfriend's mother as a conduit:

**TF:** Well it were just, it just come up in conversation with his mum, cos his mum's known me since I were little cos she used to look after me. And obviously he were there and it just like come up like that and she helped me tell him in a way. .... and he were like 'oh well that dun't bother me. It dun't make you no less of a person to me'. It's just like. .he's been right good with things like that so. He's been right helpful.

**Teenage female 13:16**

Several remember experiencing heightened anxiety in the run up to disclosure. One of those who felt the decision was forced on them somewhat, remembered the time of disclosure as a time of heightened emotion – sitting on a wall outside a pub on a frosty night:

**AM:** I hadn't discussed it with anybody [at any time since banking sperm] ....nobody tried to mention it to me and so it was just something that was at the back of my mind constantly, niggling at me. And it wasn't until [girlfriend] and myself discussed it that, I don't know, it brought it to the front, and.... That was the first time and it was quite an emotional moment for me.

**Adult male 15:30**

As one of the teenage females was facing another operation as well as realising that her relationship was becoming serious, she decided that the time had come to disclose. She had already sown some seeds but then needed the prop of alcohol to actually tell him about her cancer history. Even then, she held back from telling him about fertility as well and that took a little longer.

**TF:** ....it was obvious that I'd had chemo ... cos I used to always say when I had long hair or when I was bald or make little jokes about when I was bald and there was photographs of me with like a skinhead virtually, just like no hair. So he sort of clicked that I'd had cancer and things and then I was forced into telling him cos I had to have another operation. .... After the operation I just got drunk and told him everything. .... I just told him everything I could remember on that day and it was just all a big, just blurt out of everything. And it wasn't about the fertility stuff at that point. I didn't bring that up with him until I realised how serious it was. And how important it was that he realised that there was a possibility that he might never be able to have kids with me which I thought was a bigger issue than it was. Cos I thought that it would make a difference but it doesn't, to him. He just...he doesn't mind, he knows about it and he says that if we have to adopt, we have to adopt, and we'll think about it then.

**Teenage female 18:20**

Another planned the event very carefully with the help of an older sister who also knew her boyfriend. She decided that the disclosure would come better away from the town where they both lived so undertook a lengthy journey to visit her boyfriend at his university address. He already knew she had had cancer. She was making this decision *ahead* of the relationship becoming serious and it was interesting that her boyfriend (now her husband) wondered why she had told him at the time and remembered few details of the event looking back.

**AF:** .... I was going up to stay with him, and kind of said that I had to tell him about this, and very nervous going up on the train, and I remember having to change trains part way up and nearly getting back on one in the wrong direction and turning round but ..... I didn't want to tell him over the phone. And I think I quite consciously didn't want to tell him when we were both at home as well. Erm, I think I was a little bit nervous of how he'd react. ... I didn't want everyone to know at that stage, didn't want friends to know I suppose, I suppose I was a little bit concerned that if I told him at home and he just.... **Interviewer:** He would tell others. **AF:** Yeah,.. maybe. I suppose it was easier to tell him when it was just, when he was the only person that I knew there, I think. **Interviewer:** And what did it feel like once you'd told him? **AF:** Erm. Really scary. Not knowing at all what he was thinking, erm. What he was going to think in the future. What he thought about me saying it to him then, cos like I say his initial reaction was 'what are you telling me for now?' kind of thing, 'it doesn't affect me' and ..... relieved as well though that he knew, and that I'd kind of got it over with, and kind of hoping I didn't have to tell anyone else in the future.. *laughs...*

**Adult female 14:25**

Others hoped that the need for disclosure would be avoided the more that the possibility of their fertility impairment was discussed within their wider social circles, ensuring that future partners might get to know through this route:

## **Consequences of disclosure.**

Only one reported a relationship (not a permanent one) ending as a *direct* result of telling but she has told her new partner and still believes openness to be the right approach for her. Another reported that he had told a girlfriend when he was in his late teens and she had said that she would take serious account of it if the relationship were to become any more serious – i.e. she did not know whether she could go further with a potentially childless relationship. However by far the major consequence of telling was that the romantic partner took the news well, said that (s)he was more important to them than whether or not they could have children and this reduced anxiety and/or boosted self esteem.

**AF:** ..... at the end of the day, the way I see it is if he wants to be with me he has all me packaging as well..... he was dead cool about it.

**Adult female 19:25**

Those in this position included some who were very sure they were fertile, infertile or unsure. Not all whose romantic partners reacted so positively were so accepting of it themselves but all reported finding at least some comfort in their partner's reaction.

Only two (both adult males) had a different reaction to disclosure. Both female partners expressed delight at finding out about the possible fertility impairment as neither wanted children. Both have gone on to have biological children within the relationship.

## **PULLING IT ALL TOGETHER ABOUT TELLING AND TALKING WITH ROMANTIC PARTNERS**

Deciding whether, when and how to disclose was a feature of romantic relationships across all four groups and, for many, a source of some anxiety. A number of features around telling and talking in romantic relationships emerged.

Those who held a generally open stance to relationships where complete honesty was a strongly preferred feature were more likely to disclose early on and to feel less anxious about the process. However for others, the picture was more complex. Fear of rejection following disclosure was present for many and appeared fuelled at least in part by the stigma that was perceived to attach to fertility impairment and hence to feeling that they were 'damaged goods'. This was reinforced for some by the fact that it had rarely been raised in other contexts and this contributed to them feeling that it was therefore something to be cautious of raising. This was especially pertinent as the initiative rested very firmly with them as well in this context.

The presence of uncertainty about their fertility status was also an important area of concern – many found it difficult to understand and cope with this uncertainty themselves and hence found it difficult to approach helping a partner to cope. Some felt that they needed more information themselves either about the likelihood of being affected or about treatment options so that they could be in a better position to help their partner when the time came to disclose.

Some had not told partners in the past in order to withhold the fact of their probable infertility and one had done so in the hope of being able to become pregnant. Others

had not yet told a partner because they felt that this should be restricted to 'serious' relationships only and might give the wrong message if done too early. Some had relationships with people that were already aware of their cancer history and, for a few, of their related possible fertility impairment.

All who were in permanent relationships at the time of interview had told their partners but one had not done so prior to them moving in together. There was more variation among those in non-permanent relationships. Where there was experience of having told a romantic partner at some stage, the outcome had generally been more positive than anticipated and led to them feeling relieved and reassured. In other words, the anticipation of disclosure appeared worse than the reality. Some had yet to have the experience of ever telling a romantic partner (and of course some had yet to have the experience of even having a partner).

Among those who had disclosed to partners, there was also variance in the extent to which this had continued to be an area for discussion. Some at least reported not feeling able to discuss it very often even though (or perhaps because) they found it deeply distressing.

## **PULLING IT ALL TOGETHER ON 'TELLING AND TALKING' ABOUT CANCER-RELATED FERTILITY IMPAIRMENT**

A key aspect of adapting to the knowledge that fertility may be affected that was found to be significant was the extent to which those involved had it raised with them by others (professionals, family members, friends and others) and the extent to which they themselves instigated the telling and talking. Many respondents had views about what worked best for them over time and in different contexts. It was also clear that there were major differences for many in the patterns of verbal communication in relation to fertility as opposed to cancer. This appeared to be related to a number of factors, most of which were not static. In other words, the process of managing the situation was continuous. The perceived level of threat (which was not necessarily the same as the level of threat suggested by professional carers) was an influence for some but so was the perceived impact of any disclosure (on the recipient and on the teller) and the nature of the relationships within which telling and talking might happen. Thus for some similar patterns were seen across relationships, contexts and/or time whereas for others the picture was more complex.

## THE IMPACT OF POSSIBLE OR ACTUAL CANCER-RELATED FERTILITY IMPAIRMENT

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The impact of possible fertility impairment being introduced as a factor to be considered and managed in the early stages of the cancer experience is covered in Part One. This section considers what happened after those early days and brings those reactions and experiences right up to the time of the interviews. In doing so, it builds on the data in Part Two about the role of information and levels of understanding and recall. It also offers further indications about how far the presence of 'telling and talking' that is outlined in Part Three affects, or is affected by, the impact of potential cancer-related fertility impairment.

Of course, it is not easy to separate impact from *either* coping strategies *or* those factors that appeared to increase or reduce the impact. This reflects the lived reality. Hot on the heels of an impact comes an adjustment to the reaction but it is not always clear where that distinction lies. There were therefore challenges in helping respondents to separate the impact of fertility and of cancer both during and after active treatment and on physical, social and emotional recovery – i.e. teasing out what was specific to fertility matters and what was part of a broader whole. Respondents often located the impact of fertility by describing and reflecting on the broader experience of cancer and in some ways it was artificial for them to try and effect a separation. This posed similar challenges when analysing responses. Whereas there were some aspects that were fairly obvious – for example, the predominance of the treatment experience during active treatment phases; the marked differences in the numbers of 'supporters' that were aware of fertility matters as against cancer - others aspects were less obvious – for example the impact of body image on what I have called 'fertile identity' and vice versa. The relationship between sexual identity and fertile identity (and related activity) seemed particularly elusive.

Many respondents were also moving towards a life stage where it was likely that reproductive decision making would become more salient and some considered themselves to be through that transition. They had also entered the cancer experience at different points along that continuum. Additionally, respondents came to diagnosis with a range of prior attitudes about themselves as prospective parents. While some had already incorporated a strong commitment to parenting into their self identity, others had scarcely given it a thought. Many were involved in antecedent activity through getting ready for, or gaining experience in, romantic relationships. The dynamic forces of getting older and/or becoming adult, having romantic relationships, moving out of and further away from treatment, managing changing information and advice about the level of risk to fertility, having peers becoming parents and so on had to be managed within their personal and social context in which cancer and fertility related concerns competed with other forces. However it was possible to look for statements that indicated the strength or otherwise of respondents' desires or aspirations to become parents one day to see if that added more to the picture.

Not surprisingly then, cancer itself had a major impact on many of the respondents' lives. It disrupted school or work, separated them from friends and led to major

disruptions for their nuclear family with parents often splitting their time between hospital and home and between caring for their sick child and any other children. The experience therefore impacted on the different contexts in which people found themselves. There were four key stages that respondents talked about (though not all had yet reached the 4<sup>th</sup> stage):

1. leading up to diagnosis and the impact of diagnosis itself (see Part One)
2. impact of, and coping with, treatment
3. the immediate post-treatment phase
4. the longer term

Respondents were at different stages after treatment. Some had only recently finished so were simply glad to have got their central line out, have their hair growing back and be looking forward to getting back to 'normal' while others were years off treatment. It was not unusual for those closer to treatment to talk at some length and in some detail about their treatment though all talked to some degree about the diagnosis and treatment stages, including those a long way off treatment.

What follows is therefore an attempt to try and separate these intertwined forces in order to start and answer the questions:

- What effect did the potential or actual fertility impairment appear to have on the individual over time and in different contexts?
- What did respondents think informed this?

This has been done so by paying attention to changes over time within the following contexts, noting other influences where they arose:

- Impact on self
- Impact on family
- Impact on friendships
- Impact on romantic relationships
- Impact on other relationships

Data from the narrative of the interviews were the primary source for analysis. However, respondents were also invited to give a numerical score (0 to 10) to the significance to them of facing possible fertility impairment at diagnosis and at the time of interview. The aim of this was to offer a numerical indication at these two points in time of any increase or reduction in threat experienced in order to augment the verbal descriptions. This was not a validated tool of measurement and its usefulness is therefore primarily as an opportunity for respondents to indicate their experience in an additional way. It also in fact proved an interesting additional prompt for further verbal discussion, including explanations of how respondents interpreted the question and arrived at their scoring. This data is presented here as a backdrop to what follows:

Out of the 37 responses obtained (one was not asked):

- 10 (28%) kept the same score at each time interval (of which 5 were scored at 10 and two were very low);

- 20 (54%) increased their scoring;
- 7 (19%) reduced it .

From within the four groups:

- The largest numbers of changes in scoring from within the four groups came from the teenage females of whom seven (78%) increased their score, two (22%) kept the same (one at 10 and one at 5 who was also already a parent but not with her family yet complete) and none reduced it.
- Only two (29%) of the teenage males reduced their scoring (and then only slightly) and both said it was because of the reassurance of having stored sperm; three (43%) kept the same high score each time (two had banked and found that reassuring but still kept their score high, one had not banked) and two (29%) had increased it (neither had banked).
- Of the adult females<sup>5</sup>, three (27%) reduced their score (all because they felt they had become slightly more able to cope with the consequences of potentially being infertile); three (27%) kept the same high score each time; and the largest group, five (45%), increased it (and this included one of the mothers yet to complete her family).
- Of the adult males, only two (20%) reduced their score (one reduced it because he had become a father but still not to zero even though his family was complete; the other felt that parenting had become less important to him); two (20%) retained the same score (both were low – one had a consistently low concern and the other had now become a father and completed his family); but the highest number, 6 (60%), increased their scoring

There were also differences across the cohort in how consciously and strongly the respondents had experienced the desire to be a parent by the time of diagnosis. Not surprisingly, this appeared to have an effect on the level of threat experienced for some of these (though not all) although it did *not* appear to have affected the way that they assessed the likelihood that their fertility had been affected (what we have called their 'fertile identity'). Numbers were fairly evenly divided for adults between those who remembered being clear at the time of diagnosis that they wanted children and those who had given it little thought. However the majority of the teenage males were in the former camp and the opposite was true for the teenage females. Among those who had given it little thought, most had nevertheless assumed that they would have children when they got older and might be seen as passively pro-natalist. Only a very small number had either not thought about parenting at all prior to diagnosis or had definitely not wanted children.

Taking measures at two points in time on the 0 to 10 scale has the important limitation of masking what happens in between. Variations in significance between these two points are picked up through the detailed analysis of the verbal exchanges.

## **IMPACT OF FERTILITY ON SELF**

The impact of cancer-related fertility on one's sense of self is of key importance to understand. Respondents talked about it in different ways. For some, the impact on

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<sup>5</sup> One adult female who was also a parent was not asked

their global self esteem was their key focus – how they viewed themselves in terms of their self confidence and belief in themselves. However, identity comprises many different facets and these were also reflected. Some described the ways in which one might call their social identity was affected, that is how they saw themselves and how others saw them in a social context. For some this social identity was affected by changes brought about through their cancer experience – for example residual physical impairments or ongoing health complications. The majority also talked of whether or not they saw themselves as fertile and to what degree – what I have called their ‘fertile identity’ – and what hopes and beliefs they had for themselves in relation to children. The relationship of their cancer experience and their perceived fertility to their sexual identity was also indicated by some. Underpinning this were the ways in which this was affected over time and between situations.

It is these different aspects that are now considered.

### **Global self esteem**

A large number talked of having lost their self confidence during treatment and trying to pick up the threads of their lives afterwards. For some, it had not returned to previous levels even several years on whereas others reported fairly rapid recovery to previous levels. Many reported improved self esteem and self confidence. A small number felt that their cancer experience had little lasting impact on them.

Of course there were differences between respondents in the length of time that they had been dealing with cancer as well as the severity and complications of treatment. Nevertheless, surprisingly few across all four groups saw their treatment itself as having been unduly difficult even though their accounts of it made it clear that it had been very demanding in terms of time involved and frequency of infections and complications. This included some who were recently off treatment and therefore perhaps more likely to retain strong memories. A number counted themselves as having been fortunate compared to others and this included ones whose professional helpers had made it clear that their regime had been tough. Some thought that it was harder for onlookers than it was for them. However, all of the small number who had undergone bone marrow or stem cell transplants or who had psychotic reactions reported that to be difficult to manage. With regard to this study, neither the length nor the intensity nor the complexity of treatment was cited by the respondents as having a particularly significant effect on the impact of cancer-related fertility except where physical impairments or ongoing health problems were involved (see later).

At least four had to deal with second cancers and this group were more likely to refer to the devastation that accompanied this and the negative aspects of the treatment that followed. For one, it happened while she was still very young and she went on to have lengthy, demanding and complex treatment which left some ongoing physical complications. She referred less to the impact on her self esteem than she did to the physical impact of treatments, the deaths of many of her peers going through treatment and the severe disruption to family life. Reference to self esteem and identity came when describing her eventual return to school. She commented very positively on the ‘freedom’ that her entry to a new peer group and educational context, combined with the exit from treatment, afforded her to develop an identity about

which she felt, and has continued to feel, significantly more positive about than her pre-cancer one:

**TF:** I'm a very sort of outgoing person. But yeah that's how I've chosen to be. I recreated myself basically, 'cos I got my cancer when I went from junior school to secondary school, so I missed a year even, so when I came back in year eight I could be whoever I wanted to be, which was a lovely freedom, it really was so. **Interviewer:** It's had a positive side effect then? **TF:** Yeah, a lot of people say 'Oh! you had cancer, Oh! my god that must have been horrible', but no I do see it as a positive effect. I do say I wouldn't change having cancer.

**Teenage female 11:17**

The priorities in this 'new' life did not include parenthood, at least not in the foreseeable future. She reported feeling 'different' to most of her peers and did not share their everyday preoccupations with clothes, make up, going out and boyfriends. Neither did she spend much time thinking a long way ahead and hence gave little thought to parenting except as a possible desired goal one day - especially as there had been times when she had not expected to make it this far:

**TF:** Yeah, Mum is going sort of 'Either way, you might not have children' and I'm like sitting there 'I'm leaving home in a year, bigger problem' *laughter*.. .....I'm going to go travelling .... finish my A levels, last year, last year of school, scary. .... Lots to do this year. I'm setting up schemes in school. A mentoring scheme. And a Learning Cycle which is like helping children with learning disabilities...and I've got schoolwork, and got a job so.... ...I lie in bed going...can't sleep...It's really exciting, I'm just glad to be here at the end of the day so....

**Teenage female 13:17**

For another, the second diagnosis came soon after the first round of treatment ended. It knocked his confidence and led to a very demanding treatment regime which caused him to fear for his life at times. He was still having frequent check ups at the time of interview. Being able to have children was a very important matter for him and he had very clear ideas about the preferred sex and gender of his future family but, at this stage, he was trying to rebuild his confidence by concentrating on tackling the cancer and its aftermath. Like others who had banked sperm, this was aided by the reassurance of having 'tadpoles' to use if necessary:

**TM:** So it's kind of like, that's the thing that I try to put in the back of my mind, about kids. Just like, when time comes for it, I'll try it and if it don't work I've always got my tadpoles in hospital haven't?!

**Teenage male 15:18**

For the remaining two, both females, the second diagnosis came at a stage when they saw themselves as more grown up with one well into the transition to adulthood at age 18 and the other as having pretty much achieved it at age 22/23. Both found the impact of the second diagnosis was made worse by increased fears for their fertility. Although both had been aware of the danger to their fertility the first time round and both had held strong and conscious desires to be mothers since childhood, neither had felt seriously threatened by this. This was in part because both had understood the risk to be small at that stage. The younger one was requiring further

treatment to her reproductive organs with the attendant heightened risk; the other felt more aware of the threat even though there was nothing in the advice from the doctors to say that it had increased. Both felt that this contributed to a negative impact on their sense of self at this time:

**AF:** And the second time around, I suppose I was older as well and I was thinking about, I was twenty-two twenty three, so I was thinking about a family, having a family and things.....

**Adult female 19:25**

Returning to the main cohort, most of those who were closer to treatment were more likely to relate the impact on their self esteem to physical symptoms such as nausea and fatigue, managing infections, dealing with hospital and treatment regimes and coping with changes to their body image and associated physical attractiveness than to possible fertility impairment. For example, one talked about the impact of hair loss, acquiring scars in sensitive places and feeling unattractive.

**TF:** ..... it does take your confidence. I think in everything. Because at one point I got that stressed I started having anxiety attacks. .... it does take it out on you and people don't understand that. They only see you. They like see you 'oh, she's ill. She's got no hair' but they don't see the real side of what people feel like. They don't understand it..... I lost all confidence and the fact that my scar is like 'down there'. It is a very big problem [in relationships].

**Teenage female 17:20**

Two of the females praised their doctors for being careful in surgery to reduce the impact of scars and assumed they had done so because of their youth and, by inference, their 'need' to retain sexual attractiveness. Most of those whose reproductive organs had been directly at threat from surgery praised the efforts of surgeons to retain as much of them as possible. Hence, the influence of retaining 'healthy' fertility and sexuality was present for this group in a different way to those using fertility preservation services and was seen by them too as an important buffer against the impact of fertility concerns and a source of hope no matter how slim:

**TF:** Had they taken everything out I think I'd have been a bit devastated now when I was thinking about it. Cos at least I know now there is a possibility and as long as there's a little bit of hope there then it's always got to be better than everything being gone and you not knowing. It'd be horrible. So I'm very grateful that they battled to save my fertility .....

**Teenage female 18:20**

Nevertheless, the concerns were present for a number and one of the teenage males described how the *undercurrent* of fertility concerns combined with concerns about sexual attractiveness had the potential to rise to the surface from time to time during treatment itself and affect his sense of self:

**TM:** When I looked at myself [after starting on steroids] I had put loads of weight and everything like that, no hair and that. So you don't think about your sexuality and everything cos you lose all that, you think no-one will want to do it with me, or whatever like that. Make you feel like that. So it [sex and fertility] doesn't really cross your mind or anything at the time. And then it's

just certain days, you know, when it does come back and hit you and everything like that.

**Teenage male 18:19**

A number talked of the strangeness of the time after treatment ended. The immediacy of the treatment regime was replaced by something of a void until other activities could take its place. For some, this transition was fairly short but others were still struggling to feel that they had secured meaningful activities some considerable time later. In a few cases, sustainability of moving forward was a particular challenge and threatened their sense of emotional and social wellbeing, especially those with residual health problems. This time of transition was also, for some, a time when unprocessed thoughts and feelings about their experiences came to the fore including fertility matters. One teenage male described how his return to his 'normal' context following treatment heightened his awareness of how his potential fertility impairment more than his cancer experience made him feel different to his peers:

**TM:** It's [fertility] hit me more since I've been out of hospital, you know when you're feeling back to normal and you're back in every day life, that's when it starts to, you know, you think to the future, you think what do you want to do in the future....

**Teenage male 17:18**

While some talked of feeling more or less back to their old selves at the time of the interview, others felt held back in this by the prospect or fear of facing a relapse or more treatments as they knew how hard it would be to cope with them another time. Yet others felt that they were still a way off feeling stable again and some were anxious that they might never attain 'full' recovery. Some identified fertility concerns as playing their part in holding back the recovery process and, for a number, these had risen to particular prominence.

Across gender and age, there were some who referred to what might be called 'role models' - cancer survivors (with whom they could identify) who had gone on to achieve parenthood. Such information came through different routes including through professionals, the media and social networks. For example, one of the males who had been carrying distress about being told when younger that he was at 98% risk of being infertile had more recently been told by a consultant that he has known people who have had his treatment and gone on to have children. He found that comforting. Several, as reported in Part Two, had read media reports of, among others, the man who had gone on to successfully use his sperm 21 years after he had stored it. A few had seen ex-patients coming onto to the ward with their children. None cited role models of cancer survivors who had coped successfully with remaining childless. However two talked of family members who had either undergone unsuccessful fertility treatment or who were otherwise living without children and now appeared to be enjoying life and reported that as being a source of hope. And another had an aunt who had an ovary removed (as she herself had) and went on to have children and this had provided comfort directly as well as being an example to aspire to.

**Recovering global self esteem**

It was helpful to look more closely at the ways in which people appeared to manage the recovery process to try and understand the differential impact of fertility matters.

***Those 'actively in recovery from cancer' through striving for normality***

In the early stages after treatment, many were focussed primarily on getting back into the trajectory that they might have been following except for the 'interruption' of the cancer experience. For those who felt '*actively in recovery from cancer*', or remembered going through this stage, progress was typically measured by the extent to which they had achieved a return to 'normal for them'. In other words, the return to 'normality' was being used as a milestone to be achieved and a way of coping with the impact of cancer and/or infertility: Some did this mainly by trying to 'forget' about the past and put it behind them:

**AM:** So you started picking up the threads of your life again. I just wanted to get back to where I wa' before. I just wanted forget it ever happened in a way and get back as what's classed as normal.

**Adult male 16:22**

Others did revisit the past regularly (both pre treatment and treatment times) partly to keep processing what had gone on but also to see how far they had come since.

A number talked of the importance to their recovery of others treating them as 'normal' and of meeting people who did not know that they had cancer and therefore did not relate to them in that identity. The attitudes of others were an important factor for some in building, or rebuilding, resilience:

**TF:** I'm back to the person that they knew before, kind of, I'm still a little bit messed up in my head but I don't think you ever get over that really. Erm but I'm kind of back to normal, and new people that I meet and stuff they don't know about it. So they don't treat me any differently anyway.

**Teenage male 15:18**

This included peers. One of the adult males remembered having been in what might be called 'active recovery' (before fertility concerns slowed this) and spoke of the importance to this of being treated as 'normal' by friends:

**AM:** And, you know, it was difficult at first but then I've got good friends and they all treated me like normal, you know there was a danger that I would be treated as slightly special, erm, different and they didn't do that and because of that I soon got into, you know, 16, I was going down the pub and getting drunk and doing all the things that sixteen year old boys do. And then, you know, and it just sort of enabled me to put behind me many aspects of what happened .....

**Adult male 13:28**

Normality meant different things to different people given its contextual nature. Acting 'normally' was thus influenced, among other things, by age, gender and culture. For example, one female aged 21 explained her lack of preoccupation with her fertility as being because she was still a 'child' herself whereas another aged 20 gave this as the reason that she had started to become more preoccupied with it as she saw this as the age to start *contemplating* parenthood (even though she did not expect to try for a child for another few years).

For at least one of the males, being one of the crowd and acting in 'peer group' character (in his case by not using condoms) was more important than fertility concerns as he grew up – i.e. age plus gender plus culture played their part:

**AM:** ... was young wan't I? Every lad's the same.

**Adult male 13:25**

However he, along with several others, had challenges of another kind to contend with. Several had been very keen on sports before diagnosis and indeed some thought that it might have been sporting injuries that led to them getting cancer. For most if not all of them, their sense of self was very much caught up with their sporting identity and their recovery involved them having to develop an identity in which sport was less prominent. For example, two of the adult males had had promising rugby careers and rugby was an important part of their identity and lifestyle. One of them described the changes that cancer brought about for him:

**AM:** .... I'd gone from being like first team rugby player to being, barely could walk or was really fat and could barely walk. And so I was just very angry at everything.... and then that [fertility] came along and it was something else to be angry at I think, something else to go and cry in my room about when I was younger.....It [cancer] never really hit me until afterwards, right. .... And all my rugby playing friends just made me think of that [what he'd lost in terms of time and friends] more I guess, so I just kind of lost touch with them all .... I was 'cancer boy' do you know what I mean? I was just the guy who turned up with no hair every so often and didn't have to wear a uniform and things, and I just didn't want to go back to that school.

**Adult male 13:21**

Like others with a sporting history, this young man had to work out a way of adapting and feeling good about himself within a changed self identity *and* identity as seen by others and this presented him with an additional challenge. In the end, he opted to change schools, develop new friendships and pursue academic studies. Normality for such as him had been rather different before cancer and although this group too were engaged in *active recovery of normality*, some took a while to redefine what it meant to them now.

Fertility concerns rose to the fore quite dramatically for the young man above during this period when he was confronted by a girlfriend with whom he'd been having regular sex. As reported in Part Two she had, unbeknown to him, not been using contraception and wanted to know why she had not got pregnant (even though they were both only in their mid teens at the time and still in education). Although he found this distressing and reported other instances too when he had been very upset about the likelihood that he was infertile, his primary concern appeared to be to take action around minimising the differences between himself and peers as he re-entered 'normal life' and moved ahead within it. Hence, he located the negative influences on his sense of self as being primarily to do with the differences arising from his cancer experience, of which fertility impairment was only one part:

**AM:** .....I think the reproduction thing..... it was more something I was upset about while I was upset rather than something that sparked the whole

thing off.. **Interviewer:** So it wasn't that that sparked the floodgates for everything else, yeah AM8: I don't think so.

**Adult male 13:21**

By the time of the interview, he reported that he felt largely recovered from the cancer experience but was starting to engage differently with his probable infertility by seeking fertility analysis. This was prompted by a 'desire to know' even though he was not actively contemplating fatherhood in the near future, if at all, and did not identify his probable infertility as having a major impact on his current wellbeing.

Physical appearance, making relationships and gaining sexual experience (or at least giving the appearance of doing) were also cited as key aspects of being seen as 'normal' by both genders. This was made more difficult for those who had to drop a year at school, as reported in Part Three but the drive to achieve normality was nevertheless insistent.

The moves towards recovery of self esteem often included taking the plunge into romantic relationships, albeit with some trepidation. One teenage female identified her feminine identity as having taken a battering during treatment (she was mistaken for a boy on several occasions). She and others from both age groups saw access to romantic relationships as part of the process of recovering self esteem and as an important source of affirmation of their attractiveness. This too appeared to encourage a down-play in attention to fertility by some because of its potential to adversely affect that process (see later in this section and in Part Three).

For a small number, being older at diagnosis was cited as the reason that they were able to cope better with cancer related fertility matters. One of the females who was 19 at diagnosis (and 21 at interview) had been well travelled prior to diagnosis and felt that she had fitted a lot into her life. She considered that this had contributed to her ability to feel more relaxed about coping with possible infertility (and she considered it highly likely that she was) although she also talked at times of her strong desire to become a parent one day. While another who was also 21 but diagnosed at 15 reported on her actual experience of having been through some very difficult stages of reactions to her probable fertility and reported it as better at the time of interview (though still distressing):

**AF:** But now I'm mature, I'm twenty-one, I'm an adult now, now it's just like, I'm much stronger to be able to deal with it, I mean if I'd spoke to you two years ago I wouldn't have been able to talk without crying.....

**Adult female 15:21**

However this contrasted with those reported earlier who felt that it would have been worse for them if they had been older at diagnosis and given the news. They anticipated that it would become *more* of a problem for them as they got older.

Even though some of those who appeared to be in 'active recovery' knew that they were at high risk of fertility impairment *and* held a strong desire to become a parent one day, the desire to return to 'normality' appeared to take precedence. This also appeared to be the case for some of those living with uncertainty about whether or not they had been affected as well as those who were confident that they had not been. While the impact of fertility concerns was not missing completely, it appeared

to have been constrained. While this approach may not have been uniformly effective over time and in different contexts in keeping thoughts and feelings about fertility at bay, it appeared to work for much of the time and thus had the potential to act as a buffer to any fertility-related anxiety or distress.

There was an additional buffer for some of the males. Those who had banked their sperm (i.e. mainly the teenage males) reported limited preoccupation with the desire to be a parent on the whole even if it was conscious and strong pre-diagnosis:

**TM:** Well I've always wanted a family from when I was young. So it [sperm banking] was a natural thing cos I love me family and being with my family all the time. And having brothers and sisters I thought was the greatest thing. So I've always wanted a family so that is what I want for the future. So hopefully I will be able to do it naturally but if not then, I'll have to use the frozen sperm ..... before I knew [I could bank sperm] it [concern about fertility impairment] was like really, really high. ... I was really worried about that. .... but once they said I could bank sperm then it was really low and it was at the back of my mind and I was really calm about it after that. ...

**Teenage male 18:19**

This 'active recovery' group had not, in the main, experienced any significant shift in the relative significance of cancer and fertility. Perhaps the majority did not appear to see fertility as (yet) holding back their progress towards recovery from cancer – although a number thought that it might come to do so. Respondents in this group were more likely to see fertility as primarily about reproducing children rather than holding any major significance for their present self esteem and identity. In keeping with the approach of many to 'live life now', they were not overly concerned most of the time with whether or not they might achieve a pregnancy when they chose to try, even though they recognised that they *might* regret it later:

**AF:** Yeah, you cannot read that far ahead. You might not need to go into them things as well, so. I mean I don't, it seems like I've thought about lots of different things when I'm talking about [it in the research interview], but in actual reality I don't really think about these things that often. It's not something that really bothers us much. **Interviewer:** It's not something that troubles you? **AF:** No, it doesn't keep us awake at night at all. I don't think it would. It's maybe later on in life as I say, it would keep us awake thinking I really want a child .....

**Adult female 19:21**

There was also a strong sense that *they had no control over fertility* whereas their 'active recovery' from cancer was underpinned by the belief that it was increasingly possible to exercise agency over other aspects of their life. Perhaps this too encouraged concentration on such active coping.

This group were drawn either from the teenage group or from those who had most recently finished treatment or from those for whom parenthood was not (yet) an important (and certainly not an immediate) goal. Their priority was to cope with the 'here and now', continuing for some the approach that had got them through the early stages after diagnosis as seen in Part One.

**TF:** But if the worst comes to the worst [and you're infertile], as long as you're alive and healthy, what's more important. There's always other ways of trying..... Cos it [fertility] is important but there are more important things than that [at the moment].

**Teenage female 17:20**

They were more likely to see themselves as 'in recovery' than through it but with the expectation that recovery of self esteem would come in time. However the test might also come of the effectiveness of such an approach for those who reached a stage when they could not achieve 'normality' in exercising reproductive choice or when any strain of acting 'normally' on the outside while not feeling congruent with that in their inner thoughts and feelings proved too great.

***Those where fertility concerns were adversely affecting recovery from cancer***

There was a small number for whom the potential impact on fertility was a source of concern from the early days onwards and others where its significance relative to cancer had shifted. Some who appeared to be in *active recovery through striving for normality* were starting to struggle because of the impact of possible or actual fertility impairment. These were drawn from both age groups and genders (although were more likely to be adults) and common features were that they:

- considered themselves at high risk of being affected – and this sometimes changed as new information about their fertility was acquired or as changes in their reproductive systems occurred – and had a strong desire to be a parent from childhood
- found the uncertainty surrounding fertility impairment difficult to handle
- were either not yet in a permanent relationship or were in a permanent relationship but not yet with the children that they desired.

Some of those who held strong and conscious desires to parent at diagnosis reported that concerns about the threat to this desire came to the fore at regular intervals from that point onwards with comments such as 'I can't see myself not as a grandma when I'm old, not as a mother...'. The strength of their sadness at possible barriers to parenting came through strongly:

**TM:** Cos like family and things, it's like the key stage of life in't it? So it's like, one of things, definitely, it's one of most important things in life to me.

**Teenage male 14:16**

**AF:** I don't see myself without them. I don't want to be just me. .... No I just think there would be nothing better than holding your own wee baby. I just, you know, just born and.... Nothing could be better than that.

**Adult female 20:23**

And for one of the teenage males who had failed to bank and who had a strong desire to have children one day, there were early indications of it being troubling for him as he talked of looking at small children around him and wondering whether he would ever have one of his own.

One of the adult males who had banked sperm but knew that it was of poor quality and who had a strong and longstanding desire to be a father reported that fertility

carried much higher significance for him over time than did the cancer and delayed full social and emotional recovery from early on. This was despite having the 'all clear' on his cancer and not having any fears about relapse. If anything, this was getting worse for him over time and increasingly impacting on his self esteem.

**AM:** I think more than anything it [fertility] was probably the most important thing that was said to us during the treatment. That's the one that's stuck in my mind and that's the one that.. you know. Cos I mean physically I'm perfectly well... Touch wood...Perfectly healthy now. But that's the one thing that you know, the lasting effect, that will have probably the biggest impact in my life ..... it knocks your confidence completely and it takes a while to get back.....I accept the fact that I've had cancer cos that doesn't. I don't resent it in any way. That is just something that has happened, you know. But this [fertility] is the one thing that really, you know, you think why? Why, Why me? .... And there's no answer to it.....this [fertility] is the thing that is constantly, you know, there and thereabouts.

**Adult male 18:21**

For he and others in this group, attempts to regain a sense of normality and/or agency in their lives were *adversely* affected by the undertow that came with feeling that fertility was beyond their control and could not be handled as actively as some other aspects of their cancer. Unlike the earlier group, they had strong reactions to their perceived lack of control. The significance of the fertility threat relative to cancer had now shifted for them (for some quickly, for some more slowly) and was experienced as a threat to self as well as to life style and life opportunities. The tentacles of cancer were therefore coming from the unexpected source of cancer-related infertility. Although fears of mortality were by no means universal across the cohort (see Part One), none had anticipated beforehand that the threat to their 'cure' would come from infertility rather than relapse. For several adults and a small number of teenagers, it was fertility impairment and the realisation that this was not necessarily going to 'go away' rather than cancer that was now having perhaps the major impact on self esteem. One adult female eleven years on from diagnosis talked of it as '.. the only stumbling block that I have yet to overcome... not a day goes by without me thinking how much I long for a child'. Another said:

**AF:** I never thought I'd die or anything like that. I always thought, I always knew I'd get better. But the thing is like at the time you think right once this is all past me that's it, it's behind me. But it's dragged on, other things have dragged on all this time and for the rest of my life really. And like changed my life in all these ways, you know. And that's not only cos of my brain tumour it's cos of the treatment I had to fix it you know what I mean, so.  
**Interviewer:** You can't fully leave it behind. **AF:** Well yeah, it's just like well that's it. You think it's all, that's the thing you think it's all behind me now, its all behind me but it's not, it just haunts you, you know.....

**Adult female 16:24**

One of the females talked of the daily reminder that came for her with taking hormone replacement therapy in the daunting knowledge that this would be necessary for years. Another talked of having repressed her emerging realisation that she might be gay because she was so keen to have children and thought the only route to that was through a heterosexual relationship. It was only by her mid 20s that

she was at last starting to explore that possible sexual identity and realising that fertility treatment may be available to her as a lesbian woman.

Some of these saw themselves as at high risk of being infertile, indeed two had been told that they *were* infertile (and this had come as a shock to both). All reported having had a longstanding desire to be parents that predated diagnosis – hence it was an important part of their present and anticipated future sense of self. Most were not in permanent relationships (and some thought that fertility matters had contributed to that) and several were a way off the age at which they would have anticipated wanting to become parents. Several felt positive about other aspects of their lives – that is to say that they were achieving to their own satisfaction in other aspects of their identity.

There were also others in the study who were in, or moving towards, this state. This included ones who had not held strong or conscious views at diagnosis about wanting to become parents as well as ones that did. Across the whole cohort, there were many who said that they had assumed that they would become parents one day but had not given it much, if any, thought prior to diagnosis (see Part One). Thus they might be seen as passively pro-natalist at that time. Although the males had been faced with making a decision about whether to secure a future reproductive choice through sperm banking, this had nevertheless been made relatively passively by most as part of the relentless and rapid move towards treatment. Many of the females reported seeing references to the impact on fertility at diagnosis as important to hear about but largely irrelevant to them at that time because of their age. There were others who reported being distressed at the prospect of losing their fertility at diagnosis but who put those fears to one side and who still appeared to be firmly in ‘active recovery through striving for normality’ while others appeared to be increasingly troubled by the prospect. It was interesting to look more about the experiences of those whose active recovery appeared to be *in danger* of being jeopardised.

Some, including this teenage female, located their increased preoccupation with fertility as to do with growing up and being faced with decisions about career and life plan that might be affected by whether or not one is intending to become a parent:

**TF:** You keep thinking about it in another course. And this time it changes. It's not can I or can I not. This time it's if I did have a child, will this career benefit that and you don't think about will I make enough money for me to go out drinking. My thought pattern and process was will I have enough money to support a child if I had one in the future. Which is quite a grown-up way of thinking about it. **Interviewer:** So at different stages as you've been moving through it there's been different thoughts that you've been having to process. **TF:** Yeh. It's like the same question you just think of it in a different way.

**Teenage female 15:20**

Others approached this change in preoccupation with fertility in terms of the way that they thought about romantic relationships as they got older (or anticipated that they would). In other words, they were more likely to think about relationships as a route to parenthood and therefore had to contemplate what the possibility of fertility impairment meant for that process.

Some of these, together with others who were less focussed on the impact on growing up but nevertheless were experiencing a shift in concerns, identified the uncertainty surrounding their fertility status as proving difficult to handle. Not knowing what they were dealing with and hence not being able to develop appropriate coping strategies was mentioned by several in both age groups and genders:

**TM:** I'd just like to know like how will it come back? Will it come back in a year or will it come back in another 20 odd years? I'd like to know like certain like date or something like that. It's like a guessing game really knowing when it will come back and everything, but.....

**Teenage male 15:17**

For a few, the lack of certainty about their fertility added to their uncertainty about whether their future would be free from cancer to leave them feeling insecure about looking ahead.

There were gender differences in this, reflecting those indicated elsewhere. The males were, on the whole, coping with uncertainty about whether function would return or whether any fertility impairment was permanent (if it had indeed been affected) whereas the females faced uncertainty about if and when their fertility might disappear permanently. Not surprisingly, the uncertainty appeared more likely to impact on females as they had neither the back up of stored gametes nor the arguably more optimistic outlook of temporary impairment but with outward appearance of 'normal' function (i.e. ejaculation). Rather they were dealing with temporary impairment through disruption to menstrual cycle followed by possible permanent impairment with a premature menopause.

Additionally, some of the females were coping with a possible premature menopause *together with* the likelihood of pregnancy related difficulties if they were to conceive. This latter combination appeared to place an additional strain on self esteem even though all those in this small group were in permanent or long lasting relationships and reported that the presence of those relationships helped (though few discussed their thoughts and feelings in any depth with their partner). They recounted deep seated fears and anxieties that they had not been able to shift. One illustrated the impact of uncertainty on her ability to 'move on':

**AF:** I would maybe consider doing things like that [fertility treatments] if I knew there was no hope whatsoever. But I would definitely rather have kids, a child of my own, erm.. *pause*. ....I don't really know if I can [get pregnant] or I can't at the moment. If I knew a definite answer I could maybe. .... I would be able to make a lot more decisions ..... I feel as if there's no end to it. .... you're thinking I'll just try, see if my periods'll regulate and in the glimmer of hope that I will fall so, but I could be waiting years still.

**Adult female 18:23**

Another female had been advised to delay pregnancy because of the risk of triggering a relapse of her cancer and yet was also facing a possible premature menopause and found the resulting pressure difficult to handle. She could at least share the dilemma with her permanent partner (with whom she did discuss her feelings) but another of those facing premature menopause felt pressured as she had

been advised to have children early but had not yet established a long term relationship. Indeed she appeared to have been in 'active recovery' in the early years after treatment ended and had enjoyed a full social and romantic life. That had changed more recently, her 'active recovery' had faltered and the likelihood of fertility impairment appeared stronger.

A small number were resentful of having had cancer either at the time or as an ongoing feeling while a similarly small number felt that their personality had changed for the 'worse'. Their concerns about fertility impairment were part of their general disquiet and they could therefore be seen as struggling with coping on both fronts. For example, one teenage male was still very much in the early stages of adapting to life back at school and picking up his life again and reflected how difficult it had been and continued to be, especially given his worries about his fertility and his sexual performance being affected:

**TM:** You feel like you're under a barrier and it's just awful. Sometimes you just really lose it. .... I never used to show.. like how upset I wa', I used to keep it inside and like in hospital I was trying to be calm and things but it just wan't, it were just awful. .... it's made me short tempered and I can't think properly some times, and I don't feel, I feel right weird now. I don't feel right and things. I think it's sort of messed my life up a bit, and the way I think about things. It's just, it's not really, but I try, I'm trying.. .... I think it's still quite a long time to go before I actually feel better.

**Teenage male 14:16**

As in the 'active recovery' group, there were also some indicators of the importance of retaining hope of achieving biological parenthood. The emotional need to keep a window open that all may yet turn out well was clear for a number even if they believed intellectually that they were infertile. This was often aided by significant others – parents, partners - voicing that hope as well:

**TF:** So my Mum I think lives in hope that one day I'm going to ring her up and say Oh by the way Mum I'm pregnant. And I suppose when she told me that, I clung on to that and always at the back of my mind is well it might not be true, you know, they were wrong about the fact my fertility wouldn't be affected, they could just as easily be wrong about the fact that it has been affected, but then, you know, I say to myself don't be stupid, so..

**Teenage female 13:19**

Indeed one of the adult males who had been told when younger that he was definitely infertile (even though he had not undergone testing) and found the impact devastating felt strongly that he would have found it easier to cope with if he had been told that it was highly likely but not 100% certain.

**AM:** Factually, there's a possibility, it's not definite but there's a possibility that I will be infertile.....it's a high percentage, but then that's, you know, there's still a small percentage that I would be able to, so I'll sort of cling on that as long as I can until it becomes necessary. ....That's how I would probably have preferred to have heard it.....that someone said it's not definite, it's a possibility that you will have them but it's a strong probability that you won't.... which is very, very different..

**Adult male 13:28**

Finally, even in this group, there were variations in the intensity of preoccupation about fertility matters over time and context reflecting the dynamic nature of the threat. For example, one of the adult males who had not (yet) become a father and harboured a strong desire to do so talked of having been through peaks and troughs of coping with this and having therefore had to draw on a range of strategies. Although more relaxed about it at the time of the interview, he did not under-estimate the significance to him of fatherhood or the possibility that it would get worse again, especially as more and more of his peers were starting to have children. He put his current state down in part to emotional and social maturity but also to having had two serious relationships in which he shared the fact of his probable infertility and that was not the reason in either case for the relationship ending – i.e. he gained the knowledge that relationships (and he) might be able to cope with such openness:

**AM:** I think that every stage of your life is different. I think now I'm in a stage where my career path is pretty much set, whereas I think I went away to school then I went away to University, and then I worked in a job, had a change of career, did a different degree and then down this path. And I think that each, you know at school the most important thing is you know making the team or whatever it is, or the school heartthrob, you've got different priorities. And then at University you've got your mates, you're out on the beer and having fun and then but now and so at each stage you do have different concerns and different things are important and I think now I've got my house, I've got my job, it's a long term job, well it's a career path to head down, so I'm sort of set up in much of my life. The only thing that's really missing is a family, or not having a family now, but having the root of the family seat. And I think that's..*pause*.. something that will become more and more of an issue.

**Adult male 13:28**

There were parallels with the experience of another of the other adult males who reported the threat to fertility as not important immediately prior to diagnosis, rising dramatically in importance once the danger was pointed out, reducing once his sperm was banked and then lingering until the unexpected arrival of a child in his early 20s eliminated the threat almost completely (but who nevertheless retained his fertility as his partner went for sterilisation instead of him once they decided that their family was complete).

### ***The particular impact on recovery of living with physical impairments***

Several respondents were left dealing with residual physical difficulties and/or ongoing close monitoring or active investigations. For some, this appeared to affect their self esteem, their return to mainstream activities and/or their approach to life planning, including parenthood. They also talked about the way in which this influenced the impact of fertility, where it did.

Physical and cognitive impairments and ongoing challenges were plentiful. More females were affected than males (10 females and five males<sup>6</sup>) but the distribution by age group was even (7 teenagers and 8 adults).

- 2 had concentration difficulties, short term memory loss and some loss of cognitive function

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<sup>6</sup> One male appeared in two categories

- 6 had either artificial joints or limb amputations leading to some mobility impairments
- 4 continued to be monitored very closely and had a number of complications that had already required further interventions and were likely to require more yet
- 2 were left with significant hair loss
- 2 talked of having significantly low stamina several years on

Four had had to cope with relapses or second cancers.

Many of the physical difficulties were tangible, visible and required active self management whereas very few knew with such clarity whether or not their (invisible) fertility had actually been affected and, in any case, there was nothing to be done actively to secure it once banking (for males) was done.

For many, the threat posed by their physical condition and its impact was experienced as greater than the impact of possible infertility at the time of the interview whereas for others, the two were intertwined. For example, one was coping with significant headaches and hair loss many years on. She reported that the visible effect of her hair loss added to the invisible fact that she is probably infertile to reinforce her sense of impaired attractiveness both physically and as a possible permanent romantic partner.

For some of the females, physical after effects impacted more on their thoughts about becoming pregnant and/or becoming a parent than on concerns about fertility impairment. One teenager who definitely wanted children one day was nevertheless anxious about getting pregnant as her ongoing health problems were associated with her menstrual cycle, her digestion and her bowels. Not only was she fearful of a physically difficult pregnancy but she also anticipated that she may become depressed:

**TF:** I just worry now that if I was to have a child it frightens me to get pregnant in case I take it the wrong way. Then rather than somebody who went through a nice pregnancy, I'd probably go through depression and all that. I can imagine it would take its toll, so. That's what frightens me.....

**Teenage female 17:20**

And two of the adult females had similar anxieties. For example, one had continuous pain, ongoing treatment, limited mobility and dexterity and was facing further medical interventions. She considered herself too disabled by this for the foreseeable future to contemplate becoming a parent. She was not able to live independently and needed a lot of practical and emotional support:

**AF:** .....maybe if my situation were different, maybe it [fertility] would be more important, but at this moment in time all I want to do is try to get myself right. And be able to eat and drink again. ...

**Adult female 18:25**

Another adult female had a part-amputated limb. She was not concerned about managing a pregnancy but was nevertheless revising her earlier desire to have children as she felt that she could no longer be the sort of physically active parent

that she previously expected to be and that she admires. She too was aware that she may need further medical interventions:

**AF:** I think it may be unfair to bring up a child when I cannot run around with them and things like that. I mean I have thought that, I wouldn't want to stop a child from having a normal happy relationship with parents; I mean I know there are plenty of people who manage as good parents with disabilities. But when I was younger I saw myself as someone who would run around for the rest of their life doing all sorts of stuff ..... I don't know if it would be fair considering the raising that I've had and the running around, playing football with me brothers and everything, everything like that. .... there's potentially a lot of operations ahead in me life, if not a lot then there's going to be the loss of a leg at some point I would imagine. So it's, when I'm getting into a serious relationship, whoever this person in question, the bloke, that I find, they're gonna have to deal with a lot.....

**Adult female 19:21**

None of the males in this group expressed concerns about the impact of their physical condition on either coping with a partner's pregnancy or with becoming a parent.

Some respondents also described the reality of struggling with the disabling effect of other people's reaction to their acquired physical impairments, especially visible ones, and the impact that this by itself was having on their sense of self and attractiveness:

**AF:** I do get paranoid, well like wi' this, wi' people, people looking and looking away I don't mind like just out of curiosity. But it's them that carry on staring I can't do with..... Wi' that one I do get really offended by it....

**Adult female 18:25**

However, other respondents could see that they were making progress in coping with the impact of their residual physical impairments and therefore felt more in control of them than they did with fertility impairment. One spoke of it even more positively as she felt that her popularity and hence her confidence grew as a result of becoming 'of interest' when she started going out again socially without her false leg.

### ***Those who felt their recovery from cancer to have been largely achieved***

It became clear that there were some who felt that they had, by and large, achieved a satisfactory recovery from their cancer experience including two adult males who reported that it had little ongoing impact in their lives. That is not to say that they never thought about their experience or that they considered it to have had no lasting impact, but rather that they did not need to expend emotional energy on dealing with it. They had both considered themselves to be infertile (though one has since gone on to be a father) and one had had a negative fertility test. Both described their reactions to both cancer and fertility impairment as being located in their laid back approach to life and tendency to not worry about anything (which both felt predated their cancer experience and was, if anything reinforced by it).

One of the adult females who had had a second cancer also felt that the cancer (and fertility) experience was now no longer holding her back. She had been through times when the impact of possible infertility had felt overwhelming and saw the surrounding uncertainty to have been a key influence at that time:

**AF:** No, but it was the uncertainty, it was the not knowing that if I was or if I wasn't [fertile]. Were me periods going to start again, was I infertile and.. it was the one thing that I possibly might not be able to do and it was the first thing that I might not be able to do since with everything I'd gone through and I didn't like it.....

**Adult female 19:25**

Despite the fact that she had a long standing wish to be a parent from pre diagnosis and that she believed herself likely to be infertile at the time of interview, she had come to accommodate that. She felt that her survival (twice) had shifted her outlook so that she was determined to 'live for the day' as a childfree woman ('I want to be me for a bit') in the belief that, if she were not able to have biological children eventually then she would feel comfortable and confident at adopting children. In other words, she had not changed her desire to be a parent but had delayed the time in her life when she wanted to fulfil that desire and had opened up other acceptable scenarios when she realised that parenthood per se was more important to her than biological parenthood.

There were others who felt that recovery had been largely achieved and expressed positive experiences that had emanated as a result of their cancer experience (including a raising of their self esteem) but who continued to find fertility aspects difficult and draining. Indeed many respondents were positive about the cancer experience and these were drawn from all four groups in the study, including some of those from the above categories. Effects were variously described as having made them more resilient, outgoing, confident, compassionate or better people and/or that it had made them 'grow up'. Several spoke of being glad that they had had cancer:

**TM:** And I think I've got a lot more confidence since I've had cancer. It's a bit strange but every cloud has a silver lining.

**Teenage male 18:19**

Others talked about the personal strength that came out of the experience for them – including seeing themselves as resilient, as someone who had coped with the major adversity of *cancer* and survived and could therefore face the future with confidence:

**AM:** I think that was the determination and the desire to achieve things that had come out of having cancer. The determination to, to make it happen.....And so in some ways, yes I'm glad I had cancer. You know it sounds bizarre, a bizarre thing to say you know, it prepared me with a lot more worldly experiences than I probably would have got..erm, certainly a different view on life. And, er, it forced me to grow up.

**Adult male 15:26**

A move towards being more reflective as well as resilient was described by some including one of the adult females who had come to realise that life was not necessarily fair but that she now knew that she could handle whatever was to come:

**AF:** It's probably made me grow up as well, but not too much either, just grown up in a way that like you have to accept that you can't really get everything you want, but then that kind of makes you think well you can get through things and whatever you do want you have to work at it, I dunno, it's

kind of made me grow up in a way, but like it's made me strong as well, so like if I have to cope with other things in my life, well I can get through that as well....

**Adult female 15:21**

No similarly positive comments were made about dealing with potential or actual fertility impairment. In contrast, a number referred to the stigma that attaches to fertility impairment and felt this made a difference to how they saw themselves or perceived that others might see them. For some, this added to their sense of anger or upset at the way that cancer itself was often portrayed. However the way that they perceived stigma to operate in relation to cancer and to infertility was different. A number talked of the 'false' portrayal of cancer treatment that made its harshness more invisible than they thought it should be:

**AF:** I had a problem with the hair loss, not for myself but the advert, the Cancer Research advert, when they had that little girl on and she's got hair. It really gets to us because there's not - when I've been on this ward there's not been one child that hasn't lost their hair. And I hate how they had that advert ... I think they should have it changed to the way it is because it's sugar coating it for people, and it shouldn't be.

**Adult female 19:21**

Others were angered at media coverage of childhood cancer patients as 'poor angels', as being 'brave' or 'fighters' or as inevitably facing death. In each portrayal, the message is that cancer patients are worthy of sympathy through their portrayal as victims and this was challenged by several respondents. Similar political awareness around media portrayal of infertility was missing. Indeed the only references to media portrayals in this context were, interestingly, (as referred to earlier) of those who were 'fighting' cancer as adults and who had spoken openly about the need to use fertility preservation services (the pop star Kylie Minogue) or of those who had 'overcome' their infertility through successful fertility treatment (the man who had successfully fathered a child using his sperm banked 21 years previously). In both cases, these were cited as positive images.

Even among those who reported positively on the impact of their cancer experience on themselves, none expressed similarly positive comments about the experience of coping with potential or actual fertility impairment. This was illustrated well by one of the adult females who reported that her self esteem had improved as a result of her cancer experience and she felt 'normal' yet was highly distressed by her probable fertility impairment. Others reported seeing themselves as 'damaged goods' when they started to talk about their feelings about possibly being infertile even when they too felt good about themselves as cancer survivors:

**AF:** I suppose it makes you feel a bit like you're [i.e. a possible boyfriend] not really getting a full package I suppose. I don't know what way to kind of describe it really. You feel a little bit like faulty goods I suppose; you're not quite how it should be, erm, you can't offer everything that maybe somebody else can.

**Adult female 14:25**

References to stigmatised portrayal of infertility lead into consideration of the way that identities can be constructed or influenced within the social world that we inhabit. Social constructions have an effect on the way that individuals see themselves, depending on the level of exposure that they have to such influences and their and their carers' ability to accept or reject such influences and so on. The next section therefore looks further at social influences on self esteem and identity in order to try and add further pieces to the developing jigsaw.

## **Social identity**

### ***Ethnic and cultural norms***

Some respondents were aware of how their views about whether to be a parent had been influenced by the wider social milieu and the internalising of messages acquired through such routes:

**TF:** Basically I can't see us without kids and stuff like that, so. It's just the way we've been brought up, just the way you are, it's just the way you feel inside.....

**Teenage female 15:20**

Others spoke of 'rules' or 'norms' about the age and/or circumstances at which they were expected to have children and the influence of this on managing cancer-related fertility matters:

**AF:** But it seems that that would be the normal thing to do- get married, have house, have kids, have car, have a job, the normal nuclear family or whatever it is. But I just kind of assumed I would have children, but I never really thought that much of it. I thought I'll take it as it comes.

**Adult female 19:21**

Even for those who were not anticipating trying for a baby yet this sort of 'social rule' was, for some, the cause of a niggling worry that such 'rules' might push them to leave it 'too late' if they had a premature menopause:

**TF:** His mam and dad only had him and his mum and dad brought him up in the best way that he loves to have children but he is not daft in the way that he wants children now, he wants them when he is 25. But that worries me. Would that be too late for me? That's the only thing that ever goes through me mind with what happened. Would I go through the changes a lot quicker than somebody normal or? That's the only thing that worries me. What would be the appropriate age, you know, to do it, before worrying about whether it's gonna be took away, you know, completely so.

**Teenage female 17:20**

For others, the expectations came from their cultural and/or religious beliefs. Four respondents came from families which were wholly or partly comprised members of a different culture to White British. It is of note that it was only these participants that made reference to their ethnicity/culture as an influential factor whilst none of the white participants did. One of the adult males had an Anglo-mainland European heritage which incorporated a strong family culture and clear beliefs about patterns of child rearing and the importance of having children. However his parents were able to tolerate the possible non-realisation of those beliefs (after preliminary difficulties

when he refused to bank sperm) to the extent that they appeared able to adapt their approach to enable their son to move through to adulthood without feeling adversely affected by his probable infertility. As he has since had children (to his parents' great delight) and at an earlier age than most of his peers, he can only speculate about whether or not the underlying cultural beliefs would have become more of an adverse influence on his well being if he had continued childless for much longer.

While the other adult with an Anglo-mainland European heritage did not feel that this carried any particular significance for fertility issues (though it did for other family related matters), the experience of the two adults of Asian heritage was different.

The two adults from an Asian background had both similarities and differences in their views. While both acknowledged the strong expectation in their communities that adults should marry and have children, both also felt that their probable inability to have children could be accommodated by themselves, their immediate families and some members of their communities. The female thought that the expectation was especially strong for women in her community to marry and have children. Both were prepared to consider having arranged marriages although the female thought that her possible fertility impairment was likely to prove a barrier to this. The male anticipated that his wife would come from within his extended family and that his cancer history would therefore not prove to be a barrier. He had not thought about the likely impact of his fertility impairment. The female was more concerned about the impact of her possible fertility impairment on any relationship as she felt that Asian males would, on the whole, find it difficult to cope with either a childless marriage or with using egg donation as a route to parenthood:

**AF:** And a lot of Asian boys and young men and stuff, they're really old fashioned in the way they like, if you can't give me any kids I don't really want anything to do with you, it is kind of like that, a lot of Asian men are like, I only want my kids, my blood, so they wouldn't really accept other things and obviously you've got to take other things into consideration....

**Adult female 15:21**

Both drew on their religious beliefs to inform their approach to managing the impact on themselves. They both referred to their belief that children were a 'gift from God' and that they should be prepared to accept their fate as this was determined for them by a higher order:

**AF:** ... like we believe in fate, like our religion we believe in fate so, the gods write something for you already, so everything's already written out for you and obviously whatever you do does change that in a way, like every decision we make kind of alters the course, but really everything in the future is written out for you because it's going to happen so basically I can't change my fate, so if I wasn't meant to have kids I wasn't meant to have kids, it's just the way it happens isn't it.

**Adult female 15:21**

The female had nevertheless found this difficult to accept when younger but was finding it increasingly comforting as she got older (though was still not at the stage of entering a permanent relationship or coping with the onset of peers having children). The male also had significant physical after effects to cope with which reduced the importance to him of having children. While the male had experience of other adults

within his family and community being childless (though he did not know the reasons why) and appearing to be happy, the female did not. The presence of 'role models' appeared helpful for the male.

### **Sexual orientation**

Only two of the females identified themselves as lesbian and none of the males said they were gay. One of the females had a partner and they had already discussed the fact that her partner may be the (only) one to carry the children.

Both respondents' sexual orientation had become clearer following their treatment so they had been negotiating that alongside everything else. As reported elsewhere, one had assumed that she would not be able to access fertility treatment as a lesbian so had remained in heterosexual relationships in the hope of getting pregnant until it became clear that this was not going to prove successful. It was only at this stage that she felt free to explore her sexuality.

### **Gender**

There were fairly high numbers of respondents in all four categories that referred to gender as a possible influence on their experience of the impact of and coping with potential cancer-related infertility, though more females than males. This adds to gender aspects that are recounted elsewhere.

One of the adult males explored the impact on his sense of male self since becoming aware that he was probably infertile in his mid teens and growing through to full adulthood. He did so by reflecting on the preferred status of males as fertile and virile (with the two often being entwined) and on the socially respected state of fatherhood. As a teenager, when he considered his male identity to be less secure than as he got older, he thought that this was manifest through his fear that he would be 'found out' in his 'sub-masculine' state and labelled as lacking virility and sexual prowess whereas this started to shift as he got older and incorporated the (male) parenting dimension as provider and protector. As well as affecting his self esteem, this also affected the patterns of his verbal communications (see Part Three).

He and others went on to consider how far the differences in reactions to cancer and to (in)fertility were gender based:

**AM:** .... it goes back to the virility thing I think, and the essence of manliness. I think if you start talking about fertility, that's a much more personal, because it's a much more personal topic, in some respects. Having cancer doesn't mean anything particularly to people. It's a disease, don't know much about it, don't know what part of your body it affected and if you start going into detail about body parts people are probably slightly less interested, not less interested but people aren't as concerned. It's a category whereas if you start talking about fertility, we're into the embarrassing subject erm of.. well, it's a very personal thing. I mean it is a very personal thing, and as soon as you start on about reproduction, fertility, manliness again, it's all awkward for everyone. And because a lot of guys do have hang ups about it, I think it makes them feel uncomfortable.

**Adult male 13:28**

One of the other adult males had already talked of fertility analysis enabling him to find out if he was a 'real man' and several of the females talked of fertility impairment as threatening their sense of femaleness or womanliness. While one saw herself as 'damaged goods' in terms of romantic relationships (as referred to earlier), others spoke of women's *need* to be mothers and the threat to a woman's sense of self if that need was put in jeopardy.

**AF:** .....like obviously women are, you know, they're made to have kids and...*sighs*. yeah, you, it's, I don't know, it's just odd, it's just odd. .... you almost feel like less of a woman or something,. *pause*. ..... I can't really describe it...*pause*... ..... You just don't feel like you're all there or something, do you know what I mean? Because you know, I don't know. Like obviously I get periods and stuff but they're not real, they're fake do you know what I mean? And it's like I don't know, it's just odd I suppose.

**Adult female 16:24**

One of the adult females was surprised to learn that males were included in the study and that some of them had expressed distress as a result of potential infertility as she had only considered that females would be affected emotionally. She found it comforting to hear of this and said that it shifted her expectations of future relationships somewhat. One of the teenagers unpacked this a little further when she explored the impact on sex and relationships and speculated that males and females may both be affected but differently (though she still drew on gender stereotypes):

**TF:** But I do think that women would feel totally unattractive that they couldn't have sex, or they'd lose confidence. And that it'd totally break their relationship and it would be worse the fact that they would probably end up fighting. And it would make the girl feel worse because she would think that it was all her fault why he was being the way he was. I think it would be a big problem. But I think it's the same for men as well. Because what would it be like for a man to say that he couldn't give you a child, you know what I mean. They'd see it worse because they'd think women always need children, you know.

**Teenage female 17:20**

Several females considered that males were less well able to cope with fertility difficulties than females but saw this as primarily located in their perceived lower emotional literacy.

### **Fertile identity**

Some respondents were referred to above as reporting that they *felt or believed* themselves to be fertile or not while others were unsure one way or the other and yet others were sure that they had not been affected – what we have called here a 'fertile identity'. In order to try and understand better how such views were formed or informed, this section explores it in more detail as part of seeking to understand the 'impact on self' of possible cancer-related fertility impairment.

There were no indications that any respondents had seen themselves as being infertile or unsure prior to having cancer with only one female saying that she had worried about being childless at times when younger as a favourite auntie had not been able to have children.

Relevant responses were categorised in order to see if this influenced impact. These were statements that they made about what '**fertile identity**' i.e. how respondents appeared to identify themselves in relation to their fertility:

- *Impaired* – this included all who thought of themselves as highly likely to be infertile
- *Uncertain* - this included all who thought of themselves as unsure whether or not their fertility had been affected
- *Fertile* - this included all who thought of themselves as highly unlikely to have been affected

Adult males were fairly evenly distributed across the categories (though 2 of the 3 who had a 'fertile' identity were parents).

Only two of the twelve adult females appeared to hold a 'fertile' identity (both of whom were parents); the rest were evenly distributed between the other two groups.

Only two teenage females held an 'impaired' fertile identity with the bulk of the remainder appearing to feel 'uncertain'.

Only one teenage male appeared to see himself as having an 'impaired' fertile identity, two saw themselves as 'fertile' with the remainder 'uncertain'.

Adoption of 'fertile identity' did not appear to correlate with factual knowledge that respondents had though, for some, it did seem to affect or be affected by the level of impact that was experienced.

As indicated in Parts One and Two, factual information about the effect of treatment on reproductive systems was provided almost wholly by paediatric oncology consultants and, to a lesser extent, by reproductive health professionals. Some respondents had been told that the threat to their fertility was low and yet reported believing themselves to be affected while for others the opposite was true.

Many male and female respondents lived with factual uncertainty about the impact of the cancer and treatment on their fertility from the beginning and were continuing to do so. Part Two indicates the ways in which such uncertainty had the potential to affect understanding and use of contraception, HRT and parenthood planning. Part Three explored the fact that uncertainty appeared to be experienced differently by different respondents in its impact on self esteem and recovery. By looking at fertile identity, this offered further insights into the differences in management of uncertainty. Eight females (3 teenagers and 5 adults) remembered having been given further information after diagnosis to suggest that they ran the risk of a premature menopause; in some, but not all, cases this augmented information that they had been given at around the time of diagnosis. All in this group appeared to have incorporated this into their fertile identity but some identified themselves as 'impaired' and others as 'uncertain'. The uncertainty about if and when a premature menopause might happen was proving difficult to cope with for most but especially those who held a strong and longstanding desire to be a parent one day, who did not have a permanent romantic partner and/or those who saw themselves as having an 'impaired' fertile identity rather than an 'uncertain' one.

Another group of females and males had acquired new information to indicate a change to the apparent risk of their fertility being affected. This worked both ways. Some who had previously thought that they were likely to have been affected were surprised to learn that this was not necessarily the case (including those who had become parents). Some shifted their thinking and awareness in the opposite direction.

The change from an 'impaired' or an 'uncertain' fertile identity to a 'fertile' one appeared to be more difficult to make (for some) than the other way round. One adult female illustrated this when describing that she was still far from convinced that she was fertile, even though medical advice and her body's functioning suggested that she was:

**AF:** ... obviously my periods stopped when I was having me chemo, er, and for a long time they stopped afterwards, and it was a major concern and I spoke to [consultant paediatric oncologist] about it on a few occasions, cos I'd, I'd convinced myself I was infertile..... And it was two year before I had my first period. By this point I'd totally convinced myself that I was infertile ..... I still had it in my head that I was infertile. ....I was really happy when it [periods] started again. .... That doubt's still in me head that although yes my periods are going, you know that still doesn't mean, I might have always been infertile, so that I've still got that doubt in me head that I could still be infertile.

**Adult female 19:25**

And the female referred to in Part Two who had learnt at a conference she attended that the risk to her fertility may not be as high as she assumed still remained sure that she was infertile:

**AF:** .... you automatically assume that with cancer you cannot have kids straight away. You just assume, you don't think that you can have them anymore. You think it's not right and, I mean it's proven wrong at the thing [meaning the conference]. I mean he did say that, but ...., to this day I still think I'll be one of the ones that cannot have it because of the way me body's reacted afterwards. It's took a long time for it to get back to normal and functioning normal, or what is as normal as it can do without the limp and everything.....I've just always assumed that I won't be able to have them.

**Adult female 19:21**

The presence of an 'impaired' or 'uncertain' fertile identity did not, however, appear to trigger universal reactions. Many, but not all, of those holding an 'impaired' fertile identity indicated that this was a source of distress or preoccupation for them. Many reported using strategies to distance themselves from that identity at times in order to reduce stress. However a few reported experiencing little adverse reaction arising from it – some because they could contemplate using alternative routes to forming a family so did not assume that parenthood was denied to them, some because they had as yet a low desire to parent and yet others because they considered other things more important. This has been illustrated in the sections describing the recovery process.

Similarly some holding an 'uncertain' fertile identity reported distress or preoccupation arising from this while others did not. Some who had adverse reactions felt that greater certainty one way or the other would ease matters. Others were fearful of this if it meant that they would find out that they were definitely affected so preferred to live with an 'uncertain' fertile identity. Those who reported less associated distress were far more likely to see fertility as of little immediate relevance and/or something that they could do little about actively, especially not until such time as the level of impairment became clearer – such as this adult male:

**AM:** I hardly think about it now.... I don't want to find out now if I am fertile because if I am not fertile it will plague me for the rest of my life..... I don't want to have the uncalled-for worry; it doesn't help me at all. If I am infertile and I find out now, it would mean years of upset looking at children whereas now I can enjoy life ...

**Adult male 16:21**

Those appearing to hold a 'fertile' fertile identity appeared to be the least likely to be distressed or preoccupied.

Thus, there appeared to be differences in the way that respondents arrived at their fertile identity and dealt with any perceived threat to their fertility and associated threat to their emotional or social well being. This could not be explained by the presence of factual information alone. While it appeared to be the case that the desire to parent did not fluctuate for most, *fertile identity* may be informed by more than a simple relationship to procreation. It may be that the combination of uncertainty about fertility status, an 'impaired' fertile identity and a strong desire to parent may pose the strongest threat to sense of self. This may also go some way to explaining the fact that some respondents experienced negative or disturbing thoughts and feelings in relation to fertility ahead of either romantic activity or a stage of active contemplation of parenthood.

## **PULLING IT ALL TOGETHER ON IMPACT ON SELF**

On a scale of 0 to 10, about half of all respondents rated the threat to their fertility as greater at the time of interview than they did at the time of diagnosis; a number rated it highly throughout and only a very small number saw its threat reduce. The only group where the majority did not increase their rating were teenage males who were more likely to rate it highly throughout.

Numbers of adults were evenly divided between those who had a strong and conscious desire to parent from before diagnosis and those who had given it little or no thought. More teenage males and less teenage females reported a strong desire. Those who had given it little thought had nevertheless assumed they would become parents one day. Although there was an undercurrent of concerns relating to fertility for a small number (and where this was present, it affected self esteem), most were preoccupied with coping with treatment matters during the treatment stages and this only started to shift over time and only for some.

The priority following treatment for most was re-entry into the social and educational trajectory that they were on prior to diagnosis. For many this entailed achieving a 'return to normality for them'. For those focussed on such an approach to 'active

recovery', fertility concerns were either consciously put to one side or 'forgotten'. This was reinforced by the potential for fertility matters to make them 'different'. Normality meant different things in different contexts and over time and was variously affected by gender, ethnicity, culture, sexual orientation and so on. Some recognised such norms but were not as governed by them as were others.

The impact of fertility concerns was likely to increase over time and in different contexts, especially if new information became available or if uncertainty of fertile status was present – i.e. it was dynamic not static. However, the presence of ongoing cancer-related physical impairments affected the experience of coping with fertility concerns for some, especially where this was an added source of stigma and/or where it affected outlook for parenthood.

The likelihood of a premature menopause brought particular challenges and illustrated the gender differences of coping with uncertainty. While some of both genders were coping with possible temporary impairment, some females were facing a possible shortening of the reproductive lifespan whereas males were awaiting its permanent return. The presence of stored sperm appeared to provide an important source of reassurance that was not available to those without.

'Fertile identity' (using categories of 'impaired' 'uncertain' and 'fertile' fertile identities) as well strength of desire to parent and the presence of a permanent relationship appeared to influence the extent of any impact on sense of self. The retention of hope of reproductive function or successful fertility treatments by the individual concerned or professional or informal carers even where there appeared to be a strong likelihood of damage was an important boost to coping.

A number who felt that they had recovered from cancer on the whole – and indeed felt that it had a positive impact on their sense of self – did not feel similarly about fertility impairment. They reported neither correspondingly positive role models of (in) fertility survivors to those of cancer survivors to assist with this nor positive images.

## **IMPACT ON FAMILY AND FAMILY RELATIONSHIPS**

While Part One focussed exclusively on the time around diagnosis and included reference to the family context and Part Three looked at the verbal communication patterns within families, this section considers non-verbal impacts on the family over time. The earlier sections concentrated on fertility aspects; this section offers the broader overview of what was happening in the background family context within which fertility matters were managed.

At the time of diagnosis, over three quarters (79%) of respondents were living in a two parent family (including two who were away at university and then returned home for treatment) with most of the remainder in lone parent families (all but one of which were female-headed) and one living with mother and step father. Almost two thirds (61%) were still in that situation at the time of interview. Three were only children but most had two or three siblings (a small number had more). Just under half (45%) were the oldest child.

There were practical impacts for the family to manage, especially during treatment. One was living away from home at university at the time and her parents had to manage releasing her mum to come to live with her during the major early stages of treatment until she could be transferred home for treatment (she had several younger siblings). Others too returned home to live for a while or delayed planned departures. Practical repercussions were also present where the teenager was still living in the family home including around alternative care arrangements for siblings; transport; parental employment patterns and financial costs. Wider family members and friends were also drawn in to provide support.

Apart from the individual affected, the brunt of the emotional and practical work of coping with cancer and cancer-related fertility impairment may be borne by parents, especially mothers. Some respondents reported strengthening of relationships with parents and improvements of what had been there before cancer whereas for a small number it, if anything, deteriorated. Of those that deteriorated, two had pre-existing tensions that worsened and one relationship had been very good prior to diagnosis but deteriorated during treatment and this trend continued afterwards.

Many respondents talked of the importance to them of the help and support that their parent(s) gave them in general:

**AM:** OK I was twenty, old enough to make decisions for myself but, you're at a very vulnerable stage, and you do like to have reassurance from people who know you and love you. And my parents were the absolute rock, in my experience you know. .... I think it's quite important for people to have their parents or loved ones near to them. I think it does make a huge difference.

**Adult male 20:22**

**AF:** I don't know what I would have done without my Mom being there she was. I mean I'm sure every parent's obviously there, but she was really there for me, every second of the way you know..... She was wonderful..... I couldn't have done it without her you know.

**Adult female 16:24**

The heightened presence of parents in their lives and/or their style of coping were not experienced universally as a positive, even among those who acknowledged that they nevertheless made a significant contribution. Parents' needs occasionally, and unhelpfully, overshadowed their own and sometimes their 'reading' of their child's needs appeared to have been inaccurate. Some had not wanted their parents around all the time during treatment and felt that this, among other things, inhibited them from being able to make relationships with others on the ward and, for one, being able to use professional sources of help (see Part Three). A few found the presence of parents to be intrusive and running counter to their emerging sense of independence:

**AM:** ..... you're classing yourself as independent at that time, you're trying to get away from your parents as much as possible, to be out with your friends, and suddenly you can't go out with your friends, cos you're being wrapped up in cotton wool.....It's such a strange feeling the way you suddenly get treated, have to deal with things, have to look at the world.

**Adult male 15:30**

Where there were difficulties, it was not always easy to manage. Sometimes this was because of not wanting to upset parents and family:

**AM:** For some reason I remember, not resenting my parents because they didn't do anything wrong, they never, but just not wanting them there a lot of the time. I didn't want anybody there, but especially them, I don't know why. It upset me quite a lot after I'd finished my treatment because I was so horrible.

**Adult male 13:21**

The level of parental involvement was affected to a certain extent by the approach of the services and this is also covered in the earlier sections. As reported there, although many felt that the level of involvement of parents by professionals appeared about right, there was a minority for whom it was not. This, of course, changed for some over time with most reporting that any changes were improvements as they were allowed to take more of a front seat. The key point is that those who were regularly offered a meaningful choice about the ongoing involvement of their parents welcomed this as it contributed towards enabling them to involve their parents at a level that felt right for them.

Some differences also emerged between parents in their ongoing reactions, some of which reflect fairly typical gendered family roles with mothers being very actively involved practically and emotionally with fathers taking more of a backseat. Other differences reflected different coping styles with one parent being more likely to be pessimistic than the other and vice versa; one being more likely to show their feelings and the other not and so on.

Some respondents made specific reference to changes in their relationships with fathers. Two placed some of those changes within a cultural context as well as a cancer one. For example, one adult female had drawn closer to her father in what had previously been a fairly distant, culturally common father-daughter relationship:

**AF:** Asian Dads are a bit more out of the circle so you don't really talk to them, that's not a bad thing, it doesn't mean he's a bad Dad, you just don't talk to them you know, but now it's like I'm so much closer to him, like I can talk to him about anything, it's like my relationship's grown stronger, it's really nice now, it's like he's my best friend now, so it's really good...

**Adult female 15:21**

For another adult female, the cancer treatment heightened the cultural differences between her and her father (he came from a very different European culture) and contributed to driving them further apart. Another felt more distant from her father as his role in caring for siblings during her treatment led to her feeling somewhat abandoned by him. One of the adult males felt that his father's approach to life of 'grin and bear it' led to him being less sympathetic than his mother during treatment and this too reinforced a pre-existing relationship distance.

Two of the females found themselves having more contact with estranged fathers during treatment. Only their fathers drove a car so they provided help with transport – in both cases for lengthy journeys. In one case, this resulted in an easing of a previously distant relationship but, for the other, it proved particularly difficult to

manage in relation to appointments to do with cancer-related fertility matters (see Part Three).

Others talked of the particular impact on their siblings. Many reported their concerns about the impact of cancer on their siblings. Two of the adult males said that their sisters (both younger) had longstanding difficulties that appeared to be related at least in part to the cancer experience and possibly also fertility matters. Both had unexpectedly gone on to become parents (unexpectedly for the family as well as the individuals concerned) but neither sister had yet done so. This led the males to wonder how far this had fuelled existing feelings of jealousy and generated resentment towards parents who showed delight at being grandparents.

A number reported feeling closer to at least one of their siblings through the cancer experience but also in relation to fertility as reported elsewhere (see Parts One, Three and Five). A teenage male had talked through the decision about sperm banking with an older brother. One adult female had considered her younger sisters as surrogates or egg donors if necessary; another had been offered eggs by her sister; another talked about the strength that she gained from being close to one of her older sisters and talking at length with her over time about her feelings about her probable infertility, alternative routes to parenthood and a strategy for telling her boyfriend about her probable infertility.

Another of the adult females 'shared' her sister's baby during treatment and re-diagnosis and felt that helped her to cope with her potential fertility impairment. One of the teenage females also talked of the pleasure that came from having a close relationship with her new baby brother. Another of the teenage females drew strength and comfort from her shared experiences with siblings of being adopted.

In contrast, one adult female had a younger [childless] brother and their close relationship (strengthened through various shared adversities arising from family troubles) was lessening as he got older. This was a source of particular regret for her, particularly as she was finding life increasingly difficult as it was becoming clearer that her physical difficulties may be permanent, her fertility was almost certainly impaired and she has not yet been able to establish a permanent romantic relationship.

Others had never been that close to any of their siblings. For example, one adult female's sister had had mental health problems following her cancer which are still not fully resolved. The sister has gone on to have children and appeared insensitive to the fact that she herself remains involuntarily childless. And one of the teenage females spoke of both of her older sisters [both with children] being supportive – including offering their help with alternative routes to parenthood – but that she considered both to have considerable personal difficulties and therefore relatively little to offer.

There were, not surprisingly, differences between the impact of the cancer on the individual concerned and on family members. For example, a number of respondents talked of feeling less affected by the cancer experience than the rest of the family. Some became aware of parents turning to medication, for example, to help them through. Some thought it was worse for those having to look on helplessly whereas they themselves had to concentrate on managing, especially during active treatment:

**AF** ..... I think they see the pain more, whereas I'm going through it, yes it's hard for me, but I know how I'm getting through it and all they see is me just lying there you know and it's not very nice seeing me attached to all the machines and having chemotherapy, losing my hair and all that.....

**Adult female 15:21**

This led to a number saying that one of the most difficult parts of the cancer experience was seeing the effect that it had on family members, including when they themselves took it out on others verbally or through their behaviour.

Some talked of one family member holding the role of 'worrier' in the family leaving them to feel more worry free. Although this was usually held by the mother, it very occasionally fell to the father, grandmother and for one adult male, it passed from his parents to his wife.

As time went by, some respondents moved into fertility related discussions with professional advisers without their parents present. Some kept their parents up to speed with what was happening while others appeared to have chosen actively to exclude them from ongoing discussions. For some this was about the need for privacy within a basically sound relationship whereas for others it reflected a poor prior relationship or the need to protect themselves from parents who found the subject difficult to deal with.

**AF:** They don't even know that I'm going, that we're going to the fertility clinic. It's just, I don't have a relationship with my Mum and Dad that I feel is that great, and I've never been able to talk to them about personal things really, erm, partly because they're not very good, they are not very good about talking about personal things. I don't think they really know how to. But I think there's also a bit of a trusting issue, that I don't trust them not to tell other people, erm, so. And I also don't trust them to know me well enough, to know when not to talk to me about it, and when to stop asking questions. So I've just found it easier them not knowing.

**Adult female 14:25**

For some, it reflected the changes that came as romantic partners got involved.

There was evidence of positive family (and professionals') adaptation to the cancer experience itself and of 'coming through and moving on' as the journey unfolded:

**AF:** .....I think everyone's fine about it now you know, we still talk about it, when we were at the children's hospital and all that but it's more kind of like, we've got over it, it's more just like, 'ah yeah it was a bad part of life but we're over it now, so..... with my family it hasn't changed one bit, if anything it's made it stronger, because like we've gone through it, and like I feel I can tell anyone you know, talk to them about anything.....

**Adult female 15:21**

There was limited reference to the effect of fertility concerns on such recovery, perhaps reflecting the findings in Part Three that this subject was discussed infrequently within many families. However, it was an ongoing cause for distress for

some. The adult male who was not told until several years after diagnosis about his probable infertility spoke about the particular impact of this on his family:

**AM:** But my family, if you talk about it now, my family get quite emotional about it, more so than I do, I think, cos Mum's desperate to have grandkids. Erm and I think my Dad gets upset cos I think he sees or thinks that it must be upsetting for me which it is, but I think he doesn't like to see me upset. And my sister's just very emotional and gets generally upset anyway .....

**Adult male 13:28**

Although there was little about longer term impact of fertility per se on the wider family, some illustrated the potential for the wider kinship system to play a part in helping the coping with this particular aspect. Some reported that the presence of small children within the wider family network helped them cope with their feelings about the possibility of fertility impairment. Others found it helpful when family members shared the fertility experience, even though non-cancer related.

**AF:** I found it easier to talk to my cousin cos she's, she hasn't had cancer but she's having fertility problems, so I think I found it easier to talk to her cos she's sort of going through the same thing as I have.....

**Adult female 18:23**

However, this contact also meant that some were aware that fertility treatments can be unsuccessful and that was a source of anxiety.

### **Parents becoming grand-parents – loss of a dream?**

Several respondents talked explicitly about the fact that cancer-related infertility might lead to them not being able to 'provide' grandchildren for their parents whereas for a number of others, this was implicit. Some were comforted by knowing that their siblings had already produced children or were likely to do so. Others did not feel that they were letting their parents down and appeared to feel supported by them in any shared disappointment rather than distanced.

As shown in Part One, the impact of the potential loss of being a grandparent affected one family at diagnosis when the strongly pro-natalist father could not cope with his son refusing to bank sperm. A very fraught situation was eventually resolved by his grandmother intervening and persuading his dad to back off. He had never spoken with his parents about it after diagnosis – an approach which he himself preferred (see earlier) but it became clear how difficult this had been for them when he told them of his pending parenthood:

**AM:** We told my mum and dad before we told anyone else. Me mum was working and she just screamed down the phone. Me dad thought I was lying. Well my mum thought, shut up, and then she screamed and then she were crying. Mum had to sit down and cry. **Partner:** And when they came to visit us in the hospital after we'd had [oldest child] they were in tears weren't they? 'Oh thank you thank you, we didn't think this day would ever come'..... **AM:**... when they found she were pregnant I thought that was enough but when she was actually there [born]. Really grateful. You don't realise how much.. looking back..I don't realise how, at

the time, didn't realise how much me dad did for me. Cos sometimes he may be a bit too forceful.

**Adult male 13:25**

The parents of the other adult male who had become a father got a shock of a different kind and had less positive reactions when they were told as this was an unplanned pregnancy and the couple were not living together. There followed some major tensions and adjustments before it all settled down with the partner reminding them that they should be pleased that their son was still alive rather than worrying about whether the circumstances were good for him becoming a father:

**AM: Partner:** I said look you should be happy that (a). your son's here, because he could quite not easily be and you should be thanking your lucky stars that you're getting a grandchild, you know naturally, not through IVF,..... we're not having to adopt. I think they'd set their mind to the fact that you would have to adopt, and I mean she got all upset and tearful and whatever, but it brought her round. And I said you know you should be thankful that he's here walking around, never mind sort of everything else.

**AM:** Yeah. I think that was the start of it. Then their attitude changed completely

**Adult male 15:30**

## **PULLING IT ALL TOGETHER ON THE IMPACT ON FAMILY AND FAMILY RELATIONSHIPS**

While many parent-child and intra family relationships strengthened through the cancer experience, a small number deteriorated. Where changes with individual family members were cited, these were typically in relation to fathers and siblings. Changes were mixed and many were unexpected. Where the respondent felt in control of the level at which their parents and family members were involved in their lives both in the past and in the present, this was experienced positively. While a number of respondents were saddened by the strain that their cancer experience had imposed on the whole family, some also referred to their worry that they may add to this by not being able to provide grandchildren if their fertility has been damaged.

## **IMPACT ON FRIENDS AND FRIENDSHIPS**

Friendships are key sites for discussing matters to do with sex and relationships as well as sites for experimenting with getting ready for entering such relationships. Reference is made in PartThree to the 'telling and talking' that went on within friendships. In this section, I have therefore explored what *impact* the fact of having cancer and potential cancer-related fertility impairment had on these relationships and tried to see how far the 'telling and talking' informed that and/or was a reaction to it. Responses are drawn from those made about the wider context of the impact of cancer as well as specific references to the impact of cancer-related (in)fertility.

There were perhaps three main aspects to the impact of cancer and/or fertility on friendships:

- (i) a range of reactions amongst friends were reported – some withdrew while others remained steadfast.

- (ii) the reactions of the individual with cancer towards friends differed over time and context – some always wanted their friends to be around; others pushed them away at times.
- (iii) friendship patterns changed and/or had to be managed as circumstances relating to cancer and cancer-related fertility changed – for example, re-entry to education or employment; change of circumstances necessitating the making of new friendships.

The reactions of friends were both immediate and longer lasting. Some respondents had generally good levels of support throughout their cancer journey and found that very helpful. This is illustrated by one of the teenage females who was very open about her *cancer* at the beginning and had very good levels of support in general from then on (although her pattern of telling later friends has changed and she has always told far fewer about fertility matters). It worked best for her when this was on her terms as, like a number of others, she wanted them there sometimes and not others, especially during treatment.

For a small number, there were times early on where the presence of friends normalised, albeit briefly, a very abnormal time and this too helped with managing the impact of cancer and treatment.

A small number found that their friendship circle grew, not least as they became a source of interest or curiosity in the early days. However others found that friends quickly dropped by the wayside once treatment was underway often because they could not sustain the contact for various reasons (not being able to cope with illness; geographical distance from hospital and so on) but sometimes because the teenager themselves did not want the contact, at least temporarily, or because infection control concerns interrupted contact. The latter was particularly true during treatment when the individual could not cope with contact with friends because they felt too ill or out of sorts or, for some, because they did not want to be seen in this changed state and/or changed relationship to them. When it was to do with infection control, many found the resulting isolation difficult to handle especially where contact with friends to play games or watch television was an important source of distraction, confidence building and normality.

Even though most friends dropped by the wayside, some respondents said that a core of close friends remained solid throughout and, where this was the case, it was more likely to prove a site for aiding their coping with both cancer and cancer-related fertility matters.

Some could understand why friends dropped away, did not take it personally and were able to re-establish those relationships at a later stage, if they so wished:

**TF:** ..... they [friends] just found it really difficult and they didn't like it when I talked to them about it [cancer], they didn't like it when I said 'I feel absolutely shit today, I feel really, really down, I just don't want to see anybody, I just don't want to do this'. They didn't like it when I talked like that. They said to my other friends, 'I don't want to talk about it with her cos I just don't want to' and they feel uncomfortable. ....but afterwards, now, they're OK about it cos it's not like the centre of everything anymore.....

**Teenage female 15:20**

Another with this approach found that she had re-established contact with some but this was also compensated by the establishment of new, important relationships with others with cancer.

Others who experienced a fall off in support and nevertheless coped well with re-entry to peer groups were those whose primary motivation at that stage appeared to be returning to 'normality' – what we have called 'active recovery' in Part Three. For this group, perhaps the return to 'normality' was more important than holding grudges against those who 'deserted' them. However, the 'price' for this may have been a downplay in attention to fertility matters.

We have reported in Part Three that those who returned to a lower educational year found it particularly difficult to establish new friendships there. Some felt quite different to those around them as a result of their cancer experience and, perhaps, age. For one in particular this brought the added complication of having two friendship groups – one in school and one of older friends outside of school and this brought its own tensions.

**AM:** So when my hair grew back and I was back out nightclubbing and clubbing, the friends that I had at school were good friends for the canoeing, for football, for sports, and for schoolwork. And then on an evening I met other friends that I knew from work, part-time work, that I knew from sixth form .....

**Adult male 13:28**

Some of those who felt sure that their fertility had been affected were aware that this erected something of a barrier with friends and looked forward to a time when they might have friends who also faced fertility difficulties. They anticipated that this would only happen as more of their friends embarked on trying to become parents and encountered difficulties in conceiving. They also anticipated that the common ground of shared fertility difficulties would lower the barrier of not sharing the cancer and cancer-related fertility experience.

Others were less sympathetic to their existing friends' reactions and some continued to feel angry, upset or resentful about it, even some years on.

Finally, one of the adults talked of times when he feared that others may not want to have contact with him because he had had cancer and might therefore be seen as 'different' in a negative way – and there were hints of this from a few others:

**AM:** To have close contact with me, yes it worried me, because they wouldn't want to be associated with someone who has cancer or who's had cancer or that sort of thing..... All of a sudden you're something different and you're something that needs to be protected or put to one side or... and in some ways I aided that by trying to be different myself but I didn't want to be, erm, and so you.. .. Yes I did think that people avoided me because I had cancer

**Adult male 15:30**

## IMPACT ON CURRENT AND FUTURE ROMANTIC RELATIONSHIPS

As with previous sections, this section explores what *impact* the respondents thought that the fact of having cancer and potential cancer-related fertility impairment had on current and future romantic relationships. In doing so it offers further indicators about how far the 'telling and talking' in romantic relationships (see Part Three) informed the impact and/or was a reaction to it.

### Patterns of relationships

In a study of this kind, we were not looking for frequency patterns but for the range of experiences and views. With that in mind, it is important to know something of the range of romantic relationships that were present in the cohort overall and within each of the four groups and the impact of possible cancer-related fertility on them.

As reported in Part Three, eleven (29%) of the cohort were in a permanent relationship at the time of the interview of whom five (3 females and 2 males) were living together with their partner. Two were teenage females, five were adult females and four were adult males. Five (two males and three females) were parents of whom one was also a step parent (two of whom were living in the parental home and not with their partner) and another was a step parent but not yet a biological parent. Both the step parents were female and in neither case did the children live with them and the father.

At least nine (24%) were in a non-permanent relationship at the time of interview of whom two were teenage females, one was an adult female, four were teenage males and two were adult males. As far as we could tell, the majority of the remainder had had relationships since having cancer though were not in one currently. Some were very inexperienced prior to diagnosis so were coming to new relationships with little experience to draw on. Others had some prior experience but augmented that with a lot of subsequent experience. The remainder were middling. A small number had either not had a relationship at all so far or not had once since having cancer but this was for various reasons, i.e. not simply because of age or cancer and/or fertility related factors.

Put another way, five (42%) of the twelve adult females interviewed were in permanent relationships, one was in a non-permanent relationship and six (50%) were not in a relationship at the time of the interview. Four (40%) of the ten adult males interviewed were in a permanent relationship, two (20%) were in a non-permanent relationship and four (40%) were not in a relationship. Two (22%) of the nine teenage females interviewed were in permanent relationships, three (33%) were in a non-permanent relationship and four (44%) were not in a relationship. None of the seven teenage males interviewed were in permanent relationship, four (57%) were in a non-permanent relationship and three were not in a relationship (43%).

Quite a number had experience of relationships prior to cancer but none were permanent at that stage. Several were in relationships at diagnosis though most of those ended before treatment was complete. The only surviving relationship weathered it well, deepened and they now have a child.

## **Impact on actual and anticipated subsequent relationships**

Many said that they did not feel that the possibility of them having cancer-related fertility difficulties had affected their potential or actual approach to relationships – except in the major aspect of deciding whether and when to disclose information about fertility impairment as covered in Part Three - though the reality appeared to be less clear cut.

Of those where a pre-existing relationship had ended, this was reported as primarily because the relationship could not withstand the strain of cancer and its treatment and/or that they grew apart (that is to say that it may have ended anyway). For some, this included the impact of fertility threat but that was not a dominant factor.

**TF:** He couldn't deal with this kind of thing. It was hard because I was taking it out on him and when I was down... he couldn't relate to how I felt and because he was young he didn't understand, you know, 'oh she's not as bad as she makes out'. It was that kind of immaturity that just said it all, so. You know, boys are a lot younger than girls. So we'd split up in that time it was me illness I was on me own, which I couldn't have been with anybody cos I couldn't deal with it. I didn't want nobody to look at me. You know, it was a big thing. I couldn't let anybody see me without a hat and that was a deal for me.

**Teenage female 17:20**

Four of the females (three teenagers and one adult) said that fertility matters had had an impact on a non-permanent relationship formed after treatment. In two cases, the partner said that they could not contemplate the relationship moving forward because of the potential fertility impairment, though it was not clear in either case whether this was the major reason for the relationship to end. A third reported that her probable infertility had had a major impact on her relationships. She had had a large number of relationships as she was trying to use them to 'test' her fertility and therefore ended them quickly when she did not become pregnant (she did not tell these partners of her motives or of her probable infertility). She now felt that she would never achieve a long term relationship as she could not contemplate making someone childless as a result of having her for a partner. Finally, one of the teenage females whose self esteem had been deeply affected from the cancer experience and who thought that she was infertile explained her caution in entering a romantic relationship and her need to try to ensure that her boyfriend was fully aware of her situation and therefore hopefully less likely to walk away later:

**TF:** You don't want to be hurt again, it's a different kind of hurt but you're still not going to put yourself out for it, if you know what I mean, and erm, I'm lucky I've got a lovely boyfriend and I've been seeing him for like a year and a bit now, over a year. But I did sit down and talk to him and just said I'm not going to be made a fool of, I've just got my self confidence back in myself, I've just got my self esteem back, I don't need it to be knocked down I said.

**Teenage female 15:20**

For the relatively small numbers that talked about their approach to sex specifically, most said that the possibility of fertility impairment made little or no difference to this (quite a number appeared to still be virgins though this information was not formally requested). This included ones who had had relationships post diagnosis and those

who are yet to have one. However, sexual activity was affected for a small number by the after effect of treatment through matters such as:

- having to learn how to cope with a prosthesis during sex
- having difficulty with erections
- coping with exposing scars that were 'embarrassing'
- having to abstain during recovery after surgery
- having to take more care with contraception than they thought they would need to otherwise
- feeling too tired to have sex sometimes because of low stamina.

Some of the younger ones (and some of the older ones looking back) were more concerned with the impact of temporary and permanent body changes on their physical/sexual attractiveness - hair loss, changed body shape, scars and other physical impairments – and it was difficult to disentangle where, if at all, these incorporated fertility factors. At least one of the males had worried early on that girls only went out with him because they felt sorry for him and another thought that girls were attracted to him either because of their curiosity or because they saw him as a 'super hero' whereas others worried that they would not be able to attract a partner if their possible fertility impairment were known about. Even the combination of a casual relationship and being a teenager did not always remove the impact of the undercurrents of the fertility issues. One teenage male who very much wanted to become a father one day had not had a girlfriend for a while after treatment. At interview, he had been going out with someone for two months or so but was already thinking about whether and when to tell her about the fertility aspects (she knew about his cancer). In other words, he was having an additional factor to accommodate from these early stages and could not let the relationship unfold in the same way that it might if fertility issues were not present:

**TM:** It's [fertility] always something in the back of me mind thinking everything. So it's hard and everything like that...

**Teenage male 15:17**

Of those who had relatively little experience in relationships, a few felt that they were not yet ready for relationships and were concentrating on other aspects of their lives. The two Asian respondents (one male and one female, both adults) said they would not enter non-permanent relationships for religious and cultural reasons. However one of the teenage females reported that she felt that her probable infertility got in the way of responding to encounters that might lead to a relationship forming in the first place:

**TF:** I think it does [have an effect], I always, you know if I'm out and a guy chats me up, for some reason alarm bells always go off. I don't know why that is and you know, Mum and Dad are divorced and he had an affair and left when I was about eight. So I think is it because of that, that I just don't trust blokes maybe, or is it because I don't want to get into a serious relationship, then have to explain that I can't have children - obviously not that I'm intending to get married yet, I'm only nineteen - and then for them to say 'sorry not interested, I want to marry an incubator'. You know, I just, I don't know what it is but I do think it does affect, especially now, I'm getting older...

**Teenage female 13:19**

A few of the adults reported that their pattern of relationships had changed over time in that they had enjoyed a lot of relationships in the aftermath of leaving treatment but romantic involvement had then slowed. Their main thoughts at interview were focussed on their ability to form and sustain longer lasting relationships and wondered how far their possible fertility impairment had only really come into play in affecting relationships as they got older.

Some across all four groups had concerns about the effect of possible cancer-related fertility difficulties on their ability to establish a permanent relationship though only one of those currently in a permanent relationship expressed concern at retaining it once established. The depth to which this was troubling varied considerably – for some it had been a passing thought, for others it was preoccupying at times. However most of the females facing premature menopause reported this as having an impact on the way that they thought about relationships as they were aware of their biological clock ticking *and* of the need to tell a partner. The same appeared to be true of most of those males and females who understood themselves to be probably infertile already. For some, concerns about their ability to establish a permanent relationship (as reported earlier for some thinking about casual relationships) were located in their attractiveness as a ‘mate’ if they might not be able to have a child with a partner. For a few others – all female - it was perhaps more complex: could they themselves imagine falling in love with a person who could love someone with whom they could not have children?; did they have the potential to hurt partners who might *think* that they could cope without children and then find that they couldn’t once they had ‘fallen in love’?:

**AF:** But you know how it is, I suppose if you meet someone and they love you for what you are they'll accept that I think, they should accept that. And really if I was in a relationship and if I felt it was going somewhere from the start I'd be honest with him and say this is the situation, look I can't help it, but would you be willing to stay with me and do you want to give it a go and if they don't that's fair enough. And I wouldn't ever blame them either cos if they accept it, I'd be able to last cos I'd never want to ruin their dreams you know, cos if they've always been set on having kids and I've told them and they're like 'Oh sorry', then that's fine, that's totally fine cos I'd rather be straight up and leave it so, it's better you know.

**Adult female 15:21**

As has been seen, some were already anticipating what they might need to be prepared for on entering a permanent relationship and therefore were starting to develop strategies around this. Two of the females had used their contact with male friends to ‘rehearse’ strategies (see Part Three); three adult males and one teenage male had identified the need to prepare themselves by gathering relevant information, perhaps undergoing fertility analysis and talking with others in order to be ready to help a future romantic partner cope:

**AM:** I keep thinking well maybe I should go and do it [analysis] and get it out of the way. Because, you know, it's not something, like down the line, like I say, if you meet a girl and that and it might be best to deal with it myself now rather than two or three years down the line and then with it being more emotional at that time.

**Adult male 18:23**

Several males and females identified the need to know about fertility treatment options for similar reasons.

The aspect that was mentioned most frequently across all four groups in relation to permanent and non-permanent relationships alike was disclosure – whether and when to tell and how. This is reported on extensively in Part Three and takes various aspects including:

- should one always tell a romantic partner that there is a possibility that fertility may be impaired?
- should one only tell a romantic partner that there is a possibility that fertility may be impaired in certain circumstances – for example where the risk is high; when the relationship becomes permanent?

In other words, there are very real dilemmas to be faced about the perceived rights, wrongs and risks around disclosure and these are tangled with thoughts about how to go about disclosure and the ongoing involvement of a partner. For some, this posed few dilemmas - especially those who took an open stance without appearing to experience prior anxiety whereas the picture was very different for others.

The varied picture around disclosure also appears to reflect the occasional discrepancy between the verbal and non-verbal messages in the interviews about the impact on relationships – perhaps particularly by those who saw themselves as more likely to have been affected. For example one adult female who said that it had not affected her relationships so far (or which she had had a number but not currently) was deeply troubled by her probable infertility, appeared to have low self esteem and had not told any boyfriends to date about this. Another adult female in a permanent relationship had told her partner but they rarely discuss it. She took the decision to tell him early in the relationship at which time he reassured her that she was enough for him with or without children (he also had children from a previous relationship). Now that she is increasingly concerned at the possibility of not being able to conceive, she does not verbalise this with him (or anyone else) even though she identified him as her key source of support and comfort in general:

**AF:** ..... I don't even really talk about it that much to my husband [...], not because I don't feel at ease talking to him, it's just not one of those things I like to talk about. I mean I don't keep him in the dark about anything but if the situation doesn't need to be brought up I won't bring it up.

**Adult female 18:23**

One of the adult males described different approaches to relationships at different times of his life following cancer. This included differences in whether or not he told girlfriends about his probable infertility as well as in his approach to contraception (see Part Two). However it was not wholly clear at interview that he was as comfortable with his probable infertility as he said he was as, like the adult female above, he said that he and his permanent partner rarely discussed it *and* referred to his partner talking about what names they would give their children:

**AM:** I mean sometimes like, she'll mention kids, like just joking, like 'oh, we'll call our first kid whatever', not being serious, in the same way you'd joke

about marriage or whatever, erm, but I always think, I don't know, yeh, it's definitely, it's definitely something we bypass quite well.

**Adult male 13:21**

And the same was true for another adult male who talked very openly at times of the way that his probable infertility had affected romantic relationships over the years but at other times downplayed that. At 16, the fear was that a girlfriend would find out and ridicule him (and he did not disclose); in his late teens it was that a girlfriend said she would not want to be with someone long term who was infertile (and he did not disclose); in his mid 20s he did disclose and it was that girlfriends were then able to cope and explore options with him but did not turn into permanent relationships (probably for other reasons); in his late 20s he had still not found a permanent partner, was fearful of pending loneliness if he did not do so and friends settled down into family life but also that he was not sure that he could be satisfied with non-biological fatherhood even if he did find a permanent partner.

However others spoke openly of the ongoing anxieties posed for their permanent relationships by fertility matters. One of the teenage females who was engaged to be married had entered a relationship with someone who did not at that time know about her cancer history (which she preferred). As it became more serious, she started to tell him about it and, eventually, about her probable infertility. This also affected their approach to sex and her use of HRT continues to affect that side of their relationship (see Part Two). At interview, she talked of feeling more secure in relation to fertility though there were hints of some residual insecurity.

And one of the adult females also referred to the comfort of knowing that she and her partner were coping together with her probable infertility at the same time as having what she called occasional 'wobbly' patches when her fears of rejection resurrected themselves:

**AF:** I have kind of wobbly, wobbly periods where I start telling him 'You know, I understand if you want to go'. Erm, I think it's probably always there. It's something that I am quite aware of.....I don't know how I'd cope if I wasn't in a long term relationship to be quite honest erm, I mean it crossed my mind that if anything happened to [husband] or he did decide to go, I suppose, that that probably would be my chance of having my own family lost as well

**Adult female 19:21**

## **PULLING IT ALL TOGETHER ON THE IMPACT ON ROMANTIC RELATIONSHIPS**

Respondents talked at some length about the impact of fertility matters on romantic relationships and this section has pulled out particular aspects to augment those found elsewhere in the report. There was a range of experiences in the cohort with some being in permanent relationships at interview, some in non permanent relationships, some who had had relationships in the past and many who were yet to have one. Although many said that the fact that their fertility may have been affected did not influence their approach to anticipated and actual relationships, including sex, there were many examples of how it had done.

For most of those closer to treatment, the impact of body changes was of more concern than was the possibility of fertility impairment.

There were a number of concerns about establishing relationships. Some were anxious about finding someone willing to enter a relationship within which it may not be possible to have biological children; others were concerned about the potential to find a permanent partner and cause them later distress through not being able to have children together. A few were concerned that they themselves might not feel attracted to a partner willing to contemplate a childless relationship.

Anxiety about disclosure matters – when and how to tell - were dominant in interview based discussions about romantic relationships. For those in relationships, such thoughts were present from very early on; for those not in relationships it was also present as an anticipated concern. The possibility of not being able to have a child together had contributed to the ending of a small number of relationships but was never the sole cause.

Several across the age and gender range identified the need to be well prepared themselves for coping with the possibility of undergoing fertility treatments or adoption and/or remaining childless through gathering relevant information and developing coping strategies so that they would then be able to help a prospective partner to cope. Some of the older ones had wondered whether to undergo fertility analysis as part of this.

Some of the older group had enjoyed a number of post treatment relationships (mainly casual) but this had changed more recently and they reported a drop off in this aspect of their lives. Some older ones had only ever had casual relationships.

There were varying reports of the comfort and reassurance that came from being in a permanent relationship; while there were accounts of feeling that fertility impairment was now a shared 'problem' there was also evidence of ongoing loneliness surrounding it.

Reactions were not static but changed over time and across different situations and within different romantic relationships.

## MANAGING THE EXPERIENCE OF THINKING ABOUT, OR ACHIEVING PARENTHOOD

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There have been references in previous sections to different aspects of respondents' views about fertility matters in so far as they relate to parenthood. This has included variously: strength of desire to become biological parents at different stages before and during the cancer journey; verbal communications with others about future parenting; the relationship of one's fertile state to the desire to parent; and the relative significance of fertility to cancer.

This section takes the story further by focusing on the ways in which respondents had considered alternative routes to parenthood together with the experiences of becoming and being parents.

### **ALTERNATIVE ROUTES TO PARENTHOOD**

Many had thought about becoming parents at some stage in the future, a number of whom had considered the possibility of using alternative routes to becoming parents.

#### **Range of options considered**

There were gender differences in the extent to which alternative routes to parenthood had been considered in the light of possible fertility impairment.

All the adult females and about half the teenage females had thought about adoption as an alternative, albeit fairly fleetingly for some. Some also talked about infertility treatments but were more likely to refer to adoption when they first mentioned alternatives. All but one of those teenage females who did not mention adoption talked instead about infertility treatments, including the use of egg donation and surrogacy. Only one said that she had not (yet) considered alternatives.

**AF:** But it's like now right I can't have kids, but you can adopt, you can do loads of other things, like just because one option's closed, the others are all open, so it's like it's easy to dwell on that and say 'oh I can't have kids, I can't do this, can't do that' but just because of that you can do other things, and another way it could be good is if you're adopting you're giving other kids a chance, you know, and that can be just rewarding in itself.

**Adult female 15:21**

A number of the females spoke of the importance to their well-being of knowing that there might be alternative routes available should they be infertile.

A few talked of the importance of having children within their family or friendship groups of whom they could 'share' the parenting.

In contrast, only half of the adult males and two of the seven teenage males said they had considered alternatives and, even then, were less likely to be specific about what they had considered. Three of the adult males made non-specific reference to 'options' but did not take this any further in the discussion, one talked briefly about

adoption as an option but did not expand and one talked about donor insemination. Both teenage males also talked about donor insemination.

Only two females (one adult, one teenage) and two males (both adults) said specifically that they would consider remaining childless and not try alternative routes to parenthood. As discussed in Part Four, some of those females coping with ongoing health difficulties and/or physical impairments had deferred any decision about parenthood for the foreseeable future.

One of the couples who were pursuing fertility treatments at the time of the interview voiced the fact that they might have to remain childless if the treatments proved unsuccessful.

### **How they had come to consider the alternatives**

Here again there were differences between the genders. Among the females who had thought about alternatives, this was more likely to be as a result of their own prompts or through conversations with family, partners or friends than as a result of professionals raising it. Some adult females referred to television as a source of information about adoption, surrogacy or fertility treatments but none of the males did. Most males who had thought about alternatives did not talk about the context of this. However one teenager had had it raised by a professional and one of the adult males recalled having a female friend share her views on adoption with him, not knowing that he was probably infertile (she thought people should adopt rather than become biological parents in order to provide much needed family homes) and that had greatly influenced his thinking:

**AM:** She told me she would never have children cos there are so many children that need adopting, so many children that need looking after, and like that put me a whole new perspective on it, and I always thought since then that if I'm desperate to have a child then I can have a child, there's no stopping me having a child, it's just, you know. **Interviewer:** So that gave you a different perspective on how you get to be a parent, it gave you an alternative. **AM:** Definitely.

**Adult male 13:21**

A number of females had had offers from relatives or friends to donate eggs or to act as surrogate and this was true across both age groups. Three (2 adults, 1 teenager) said that relatives (sisters and a cousin) had offered to either be surrogates or donate their eggs, one teenager thought that her sisters might be willing to act in this capacity and one adult had asked her sister if she would in principle be her surrogate (she refused but the respondent herself had had second thoughts about it by then). None of the males had received offers to donate sperm.

### **The importance of biological parenthood**

Many females and males were driven by their belief that having one's own biological children was preferable to adoption or gamete donation. Some thought that it was highly unlikely that they would ever go down the alternative route and this brought added stress to their ability to cope with potential fertility impairment:

**AM:** I don't really like any of the other options is the other problem, I want my own child in the sense that I want it to be part of me that I've created.

**Adult male 13:28**

Others could at least contemplate alternatives but, on the whole, very much as a second best option:

**AF:** And people say, oh you can adopt you can adopt, I don't think it will ever be the same as having one of your own.

**Adult female 20:23**

Interestingly, adoption was seen as preferable to using donated gametes for a number even though donated gametes would mean that the child was the biological child of their partner. Only one, a female, *said* that gamete donation was preferable to adoption – though that is not the same as saying that none held this view.

A few were less concerned in general with the primacy of the biological connection and saw parenthood as a desirable state in and of itself. Some females, for example, viewed adoption in this light and cited the need for existing children to be found loving parents:

**AF:** I'd always had it in me head that if I was infertile that there are other ways to go. That just because I couldn't give birth to a child doesn't mean that I can't have children, and that's always been the way that I've been. That's just the kind of person I am. That you get crap thrown at you from one direction and you just bat it off and keep on going. Find a way out and there's always another option. Generally there's always another option.

**Adult female 19:25**

However there were hints of the potential for movement of views for those who did prioritise the biological connection. Some used the interviews as an opportunity to 'think aloud'. One of the teenage males said earlier in the interview that he would only want a child if it were of his 'own flesh and blood'. As we talked further, there were hints of his willingness to consider the lack of a blood tie in some situations, provided that the children were young enough for them to become attached to him. In doing so, he drew on his own positive experience of having a step father.

There were similarities with one of the other teenage males who could contemplate adoption provided that it was of a baby that could be 'moulded' to his way of being.

One of the adult males who held a strong desire to be a parent one day and considered himself highly likely to be infertile had not spent time considering alternatives - but also used the interview to start that reflection. He was clear that, in his view, biology was *not* the most important ingredient for fatherhood and that enabled him to realise that alternative routes to parenthood might be worth contemplating:

**AM:** I think you can be a biological father and not be someone's dad, you know. I lass... personally I think the two things are completely different. Umm, I mean, you know, I haven't really considered like adoption or, you know, whatever at the moment. But, umm, it will be something that has to be brought, the subject'll have to be brought up eventually but. Not really, I

mean, you know, obviously I'd like to have kids but, you know, I might have to explore other.....

**Adult male 18:23**

There was more evidence of prior moves to accommodate the possibility of non-biological parenting among the females than the males. For example, one of the teenage females, like the two teenage males above, saw egg donation as a possibility because it would enable parenting to begin much sooner than would adoption. She also said that the adoption process would take too long.

### **Influence of actual or prospective partner (or other)**

A few of the females and one of the males talked about whether their decision would be influenced by their partner's views. Most concluded that it would and that they would therefore need to be open to this. However, one female said that it would be *her* decision once she was with a partner given the potentially greater implications that it would have for her.

Some of the respondents drew on their *actual* experience of taking partners' views into account. Three females (one teenage, two adults) who had discussed alternatives found that their partners were willing to consider adoption and one had agreed to consider egg donation if need be (the other two did not refer to egg donation). One of the adult males was comforted by the fact that he had had serious adult relationships in which the partner was willing to consider alternatives whilst another speculated that he and his partner had held different views about the desirability of children and this might have proved difficult if their accidental pregnancy had not solved the problem.

### **Influence of sexual orientation**

Two females in the sample identified themselves as lesbian. As referred to previously, one had previously assumed that her sexual orientation would cut off her access to fertility treatments so had not considered alternative routes until shortly before the interview when she became aware that she may be able to access them as a lesbian woman. The other had discussed with her partner (who attended the interview) the possibility that she would be the carrying mother if treatment were sought.

### **Views about advantages and disadvantages of alternative routes to parenthood**

As already indicated, there were differing feelings expressed about the importance of a biological connection in parenting.

Those who could contemplate adoption saw it as having the potential to provide a family for existing children and/or to have the spin off of making the adopter feel good about themselves.

The only male respondent who talked in any depth about adoption also did so from a predominantly altruistic viewpoint, tinged with the sense that it offered him a fallback

position if he decided in the fullness of time that he did want to become a parent (he was not sure at the time of interview).

Others who did not appear in principle to be against the idea of adoption or fostering were nevertheless apprehensive because of the time that was involved in the process or because, in the case of fostering, they might get too attached.

Only one female said that it was preferable to use egg donation rather than adoption as at least that way the child would feel more 'theirs' and/or may relieve her feelings of guilt at not being able to 'give' her husband a child (she was part of a couple about to embark on fertility treatment so it was very much a pertinent issue):

**AF:** That yeh, we needed a bit of help to get going but then it would still be ours, I suppose, whereas fostering and adopting bring up a lot more other, a lot different issues that it's not your child it's somebody else's child and actually how we'd feel about that.....I think maybe from my point of view that, one thing that has always concerned me was that I might not be able to give [husband] his children, erm, and egg donation would still be [husband's] children, erm, so I think maybe I'd feel a little bit less guilty about that in a way..'

**Adult female 14:25**

Some females had considered surrogacy and egg donation though only in the abstract. Among the issues identified were the financial costs, its invasive nature and the exposure of the surrogate or egg donor to hormonal regimes; the fact that it might not work and/or that, in the case of surrogacy, the surrogate might not be willing to give the baby up; the reluctance to parent a child with the surrogate's genes (this was by someone whose sister had offered);

One female referred to what is often called the 'yuk' factor in the non cancer-related infertility literature. With egg donation, she speculated that it might feel as if her partner husband had 'slept' with the egg donor and that it would be 'their' child. However, as with some of the males referred to earlier, she also recognised the possibility that she might change her mind on this if a future partner desperately wanted his own biological child.

Both the adult male and the two teenage males who talked about donor insemination (DI) were also very against the idea, each citing their resistance as being because it would involve the impregnation of their partner with another man's sperm and that their 'ownership' of the child might be in doubt:

**TM:** I wouldn't really like that [DI], because it's like it's not your kid is it, it's like, it's still your wife's, but it's like another man's sperm in't it, it's a bit funny and like one day what if the kid wanted to see their real Dad. Then you'd feel like proper heartbroken. So I wouldn't like that. **Interviewer:** Yeah, yeah. ....But it doesn't feel like that with adoption? **TM:** No because like, it's not both of youse, it's not the woman and the man's, it's somebody else's all together. It would feel a lot better, for some reason. **Interviewer:** Yeah, yeah, that's understandable that, it's like both being in the same boat, instead of one of you.... **TM:** Yeah. And if you ever like split up, like she could say that she's the real Mum and you're not, and then you wouldn't be able to see that kid and things like that. If owt like that happened.

**Interviewer:** Mmm, that's interesting. So you'd feel you might have less claim over.....**TM:** The child yeah.

**Teenage male 14:16**

## **PULLING IT ALL TOGETHER ABOUT ALTERNATIVE ROUTES TO PARENTHOOD**

Females were more articulate about alternatives and appeared to have thought about it more frequently and in greater depth than had males, though this varied. They also appeared to have had this subject raised with them more than did males and they were more likely to have watched relevant television programmes – i.e. they were more likely to be exposed to different social and verbal discourses. Some females across both age groups had received offers of surrogacy or donated eggs from family members but no males had been offered sperm. Although reservations were expressed across genders and age groups about alternative routes to parenthood, there appeared to be more concerns about gamete donation than adoption. Males were likely to express their opposition to this primarily in terms of the insertion of another man's sperm into their partner whereas the introduction of another woman's egg into their body was not cited by any of the females. The response of romantic partners was seen as important though few had yet had actual experience of this.

So, against this backdrop of the strength of any long term desire to become a parent and the range of options towards parenthood that had been considered post diagnosis, the experiences of the particular sub section of respondents who were actively pursuing parenthood or who were already parents is now explored.

## **BECOMING AND BEING A PARENT**

Five of the respondents in the study had become biological parents since having cancer though none had been biological parents beforehand. Of these, three were females (of whom one was a teenager) and two were adult males.

Two in the study were step parents (both adult females), one of whom was also a biological parent and the other was trying to conceive. One other adult female was also trying actively to get pregnant at the time of interview.

### **Those trying to become parents**

One couple were actively trying to become parents and had thought long and hard from early in their relationship about what to do and when. They were due for a further appointment at the assisted conception unit soon after the research interview. This couple had known since early in their relationship that the female was at risk of premature menopause and this was covered in some detail in Part Three and elsewhere. This had affected their life planning as a couple and brought forward the age at which they would start a family – though they had still thought about this carefully.

**AF:** We kind of.... we decided that it's something that we would, we did want a family and that it's something that we would embark on quite early, probably earlier than we would have done otherwise. We got married in [...] and at our appointment previous to that we kind of said well once we are

married we'll start trying to have a family, and we discussed that with [consultant oncologist] and he kind of said 'Yeh, that's a good idea'. And then we got married and kind of straight away started. I came off the pill and we started trying to have a family and we're still trying.. *Laughs*. A few months ago, we had our first appointment at the assisted conception unit, for the first sort of round of tests, and we've got our next appointment in [.....] to go and see what the results of those tests were to see where to go next really I suppose. That's it at the moment. We're just waiting and trying.

**Adult female 14:25**

The woman had chosen to be interviewed with her husband present and some differences emerged in their views of the impact of encounters with professionals on their handling of 'their' potential infertility. While the husband felt that the paediatric oncology staff tended towards negativity over his wife's fertility status and preferred the more upbeat approach at the ACU, she preferred the former approach as she felt that it was more honest and carried less possibility of 'false hope' being generated. This may relate to a number of factors – gender, the fact that the partner has not been through the cancer experience, preferred coping style and so on. It nevertheless illustrates the challenges that can accompany integrating new and significant actors into these encounters.

**AF's Partner:**...from what I've heard of the consultants [paediatric oncologists], he only tells you the bad things; in a way, what more can they say really, they just leave you with a negative feeling. Like when I went, and you just start thinking that we're not going to have children. All the assisted conception stuff has been really positive hasn't it? [to AF] There's never been anything to say ... she's never been told that she's not going to have children, but you're probably thinking in your own mind that you're not. And there's no reason to think that is there? You've never been told that you're not going to be able to have kids? **AF:** No I've never been told that definitely won't be able to, it's just.. ..always been it's more likely that I can't than I can. ... But they've never given us false hope. **AF's Partner:** but there's never any evidence to that, sort of thing.. **AF:** No, and it was one of those things that you just don't know until you start trying, really.

**Adult female 14:24**

Another couple were also in the process of undergoing investigations and seeking help though this was currently on hold. There were indications of more ambivalence for this couple as the female was also coping with unresolved treatment related complications. Reference has been made earlier to the ways in which she has coped by limiting severely the people that she talks to about this matter (including her husband and mother, both of whom she otherwise considers herself to have a very close relationship to) and saying in public that she does not want children.

### **Those who had become parents**

Among those who were already parents were one adult male with one child; one adult male with two children; one adult female with one child and pregnant with another; one adult female with one child; and one teenage female with one child. Only two of the five who were parents (one male, one female) had planned their pregnancies; the remaining three were the result of accidental conceptions. None

had children prior to diagnosis and all the conceptions took place following the ending of treatment.

### ***Unplanned pregnancies***

All those with unplanned pregnancies were using contraception at the time of conception. Another couple (who were not living together at the time) had not been using contraception as they were sure that the male cancer survivor was infertile and it was only after testing (and being found to be fertile) that they started using contraception and then got pregnant accidentally within a few months. They had previously not resolved the fact that the male wanted children (though believed himself to be infertile) while his partner did not. Indeed, it was the announcement of the pregnancy that finally made him believe that he was not infertile and they subsequently set up home together:

**AM:** And I was like 'Oh, so I'm not shooting blanks then, right, OK'. And that was just.... cos in some ways I still hadn't believed what they'd said, because.. I'd heard nothing for five, six years, I'd been for one little test, they'd suddenly said 'yes you're fertile, now start using contraception'. It was a... from having one view I suddenly had to take on another view and until that moment....

**Adult male 15:30**

One of the females who became pregnant had not sought medical advice for some time after developing symptoms as she had been convinced that they heralded a return of her cancer rather than a pregnancy and had been fearful of going to the GP. In the end she went alone having told her boyfriend but not her mother, her intention being to protect her a little from the anticipated bad news. She then had to pluck up courage of a different sort to tell her boyfriend and her mother about the unexpected news that she was well into a pregnancy.

Although the other female had talked with her partner about their joint desire to have children, the pregnancy had not been planned and had come at a difficult stage in their relationship. The couple were still together at the time of the interview and were hoping to move into shared accommodation before too long (she was still in the family home). However, she had experienced bouts of depression both following the cancer treatment and again after the birth of her baby and was still receiving treatment for this.

### ***Planned pregnancies***

One of the couples who had a planned pregnancy had started out with little hope of success as the male was sure that he was infertile. The female partner had not previously wanted children and the male had little or no interest in parenthood at that stage but their views appeared to have shifted and the decision to try was made jointly. They thought that their low expectation of success, their philosophy of 'if it happens, it happens' and their decision not to tell either set of parents may have helped them to cope with a fairly lengthy period of trying for the first pregnancy (a year). They now have two children with the second pregnancy happening within a few months of trying. They said that they were among the first couple in their friendship group to have become parents. The couple were taken aback at the strength of feeling that flowed from the male's parents on being told of the first pregnancy which suggested that they had retained strong desires to be grandparents

throughout the time during which they too had believed him to be infertile (see Part Four – *parents becoming grandparents*).

For the female whose pregnancy had been planned, the circumstances were a little different. She had entered a permanent relationship when still relatively young with someone who already had a child from a previous relationship. She and her partner worked together and she assumed (but was not wholly sure) that he was aware of her possible infertility through conversations in the workplace. They did not discuss their views on parenting prior to moving in together; she said that it had simply never come up as a topic. She was not aware of consciously avoiding telling him. It was some time later that her partner suggested spontaneously that they try for a baby, she agreed with little further thought or discussion and, despite thinking that it might take time for her to become pregnant, it happened almost straightaway:

**AF:** .....I think we were just sat one day, and.. I think it was my partner who said, er, I think we should start trying for a child and I just laughed, and he said no I'm being serious so I said if you want, type of thing. So I came off my pill a couple of days later and then within just over two months I fell pregnant.. *laughs*. **Interviewer:** So that was a fairly straightforward decision to make was it in the end? **AF:** Yeh. I think I always said I didn't want them but I felt comfortable in the relationship to actually have one when the time came. **Interviewer:** Yeh. So it was something about being in this relationship. **AF:** Yeh.....I never thought it would be as quick as it would be, with having all the treatment and then being on the pill, I didn't think, I thought it would be a couple of year before I fell pregnant.

**Adult female 15:24**

### ***Reactions of prospective grandparents***

In all these cases, the prospective grandparents had to take on board that their child, whose fertility had previously been uncertain, was now going to become a parent. These were not referred to extensively in the interviews and are covered in the section on '*parents becoming grandparents*' in Part Four -.

### ***Managing the pregnancy***

Several referred to the level of monitoring during pregnancy. One of the females had been greatly reassured by scans that indicated that there were no obvious health problems and welcomed the generally close monitoring throughout her pregnancy even though it involved her in additional visits from a geographical distance. She had vivid memories of fears that the pregnancy may trigger a relapse and face her with difficult decisions about whether or not to continue with the pregnancy. The attention to monitoring continued into her labour and again was a source of reassurance.

The other female was also closely monitored by the consultant and welcomed that but she did not voice fears about her own cancer being triggered. However, she had been off treatment longer and had already had the 'all clear'.

### ***Fear of hereditary transmission***

All the parents mentioned fear of transmission, including the two female partners who were present in the interviews. One of the adult females reported that it was not until after the baby was born and she had discussed this with her paediatric oncologist at her routine check up that she felt more reassured. It was not clear why this appointment had not happened sooner:

**AF:** I was scared to start with in case what I had, would be, [baby] would get type of thing with her, if she got like a tumour for her thingies but they said that it was a so many percentage, a one off type of thing, because there was only me and another little, at the time there was me and another child that had only ever heard of this cancer that we'd got.

**Adult female 15:24**

The female who was trying to conceive did not appear to be too concerned about any risk of the cancer returning with a pregnancy but was worried about possible transmission to the child and, again, welcomed the reassurance from having the opportunity to discuss this with her consultant – in this case before the conception. She also speculated in more positive vein about her greater ability to handle such a situation if it were to happen than her own parents had, given her direct knowledge of cancer. This was echoed by a few others in the study, both parents and not yet parents.

One of the adult males had found that the fear of his child getting cancer grew, if anything, with the passing of time:

**AM:** Yes I'm worried about it, and yes I'm constantly worried about it. I don't know why. I don't know what I'd do if I've passed it on to [son]. It's an upsetting thought. Erm..*pause*..In the back of my mind, you hear all sorts of different stories, I remember seeing one on the news or something that they'd just released that said that cancer was hereditary, and I immediately emailed it to [consultant] and said 'have you read this rubbish? They've just announced that cancer's hereditary on the BBC news. .... Yeah, it's a constant thought in the back of my mind. It's not one that I like having .....

**Adult male 15:30**

With another of the couples, it was the non-cancer survivor who worried more about transmission (though this was in keeping with the man's laid back approach to life). She explained that they too had sought medical advice from her partner's paediatric oncologist and a genetics expert prior to conceiving and that helped – though her concerns nevertheless remained throughout the pregnancy, not least because the medical information available was limited.

## **PULLING IT ALL TOGETHER ABOUT BECOMING AND BEING A PARENT**

The numbers who were trying to become parents or were already were small. For those trying to get pregnant, the strain of this was clear. Both were undergoing infertility investigations with a strong possibility of needing fertility treatment. There were indications of the challenges of integrating the partner into the medical arena where the respondent had prior longstanding experience of such contact to draw on (albeit in a different sector). The extent to which the emotional impact was shared by each partner appeared to vary.

Among the parents, some had had planned pregnancies and others not. None had used fertility treatments. Several (males and females) had believed themselves highly likely to be infertile beforehand so the early parts of the pregnancy were taken up with adjusting to their unexpected state. Increased levels of monitoring of the

pregnancies of the affected females were greatly welcomed for the reassurance this brought as some were fearful in case the pregnancy triggered a recurrence of cancer. Others, including non-affected females, were concerned about the risk of transmission of cancer to the unborn child. For some, the opportunity to get information about this did not happen until after the birth although would have been welcomed earlier.

One parent reported that the fear of his child getting cancer had been lower in the early years but had grown over time. Several commented that they thought that they would be better able to cope with their child getting cancer than their parents had as they would draw on their experience and on the strengths that had come with that experience.

On the whole, all appeared to have adjusted well to being parents.

## CONCLUSIONS

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### **Background**

This interview study set out to address the following research questions:

- Does a diagnosis of cancer in the teenage years which is accompanied by the information that the cancer or the treatment might impair fertility have an impact on the process of growing up? And if so, what are the ways in which those involved are affected?
- Are there any aspects that appear to be related to gender?
- How far does the way in which services are currently provided help or hinder these experiences?

In doing so, in depth interviews were conducted with thirty eight individuals, all of whom had been diagnosed between ages 13 and 20 and were aware that there was a risk, no matter how small, that their fertility may have been affected. Of the thirty eight, twenty one were females (nine teenagers and twelve adults) and seventeen were males (seven teenagers and ten adults). The cohort was drawn from a range of backgrounds with regard to educational achievement, employment and family situation and ethnicity. While none had a prior major impairment, several were left with impairments following treatment.

Respondents were recruited through three regional paediatric oncology centres in the North of England. Take up rates were the same for adult males and females (40%) though lower for teenage males (24%) than teenage females (36%). Overall, slightly more females (38%) than males (31%) agreed to take part and rather more adults (40%) than teenagers (29%). Recruitment to studies involving face to face contact with teenagers (including those affected by cancer) and/or on sensitive subject areas is known to be difficult and these take-up rates were therefore encouraging. There is no data on the reasons why some of those approached did not accept and how far their experiences may have replicated or challenged the findings here. However given the intention to try and map a range of experiences, it is of note that these findings achieved this and there was evidence that fewer new factors were emerging in later interviews suggesting that the sample size proved sufficient for the purposes intended. That said, there were only low numbers from minority ethnic groups, those with prior impairment and those who identified themselves as gay and lesbian and this makes any analysis of their experience particularly difficult.

The literature review could not identify any studies that focussed on the particular impact of potential fertility impairment on growing up following cancer diagnosed during the teenage years. However there was some literature from studies where reference was made to fertility matters within other cohorts, especially childhood cancer survivors. As so few studies have taken fertility as their primary focus, findings that reported on fertility matters as part of a wider study were also reviewed.

### **At the time of diagnosis and using fertility preservation services**

The strong support in this study among both genders for the potential impact of treatment on fertility to be stated at around the time of diagnosis and fertility

preservation services to be offered (specially for males) reinforces and extends findings reporting similar support among male teenage and adult cancer survivors (Crawshaw et al 2003; Schover et al 1999; Schover et al 2002a) and others (CancerBACUP 2005; Shaw et al 2005). The adverse impact on those males who did not accept the offer to bank their sperm or were not offered it also reflects similar findings obtained through practice accounts (Broome and Allegretti 2001; Marik 2004; Pacey 2003) or studies (Crawshaw 2006; Saito et al 2005). The fact that those who tried and failed – including some who were very ill at the time - were nevertheless positive about being afforded the opportunity adds to the limited evidence of this from an earlier study (Crawshaw 2006). The positive impact on females of being told at diagnosis and (for some) of being offered fertility preservation has not been reported elsewhere.

The study found good levels of understanding and recall of information about fertility matters received at around diagnosis, as with our earlier study (Crawshaw et al 2003; Crawshaw 2006). A range of reactions were apparent at this stage from lack of concern to significant distress for both the individuals affected and their parents. This contrasts to studies that have reported limited recall of fertility related information (Green 2003; Schover et al 1999; Schover et al 2003; Zebrack et al 2004) and suggests that limited recall may be more a feature of not having been told in the first place than having been told and then forgotten.

Some females would have liked greater clarity about the fact that any interruption to their menstrual cycle through treatment might mean that their reproductive system was being affected. Some would have liked an explanation at this stage about why egg freezing was not on offer. There was also some evidence of a range of interpretations about the level of likely risk to fertility arising from what was said (and not said) by professionals. It was not possible from this to determine how far any incomplete or ambiguous information was because of professional attitudes as reported elsewhere (Schover et al 2002b; Koepfel 1995). However it was the case that many individuals reported the positive impact of professionals appearing to take a genuine interest in fertility matters both at this stage and later.

Decision making about, and preparation for, fertility preservation was largely straightforward and aided by clarity of information sharing, the manner and context within which it was shared, being spoken to directly and having parents involved (provided that the young person wanted their parents present) and this reinforced earlier findings (Crawshaw 2006). This took place predominantly within the paediatric oncology setting (and was done well) with the consent and semen collection process taking place within the sperm bank. Some would have preferred consent to be taken in the paediatric oncology setting. Age and stress of coping with diagnosis did not appear to be significant to the ability to decide and act on that decision, on the whole. That contrasts with findings from a recent questionnaire study (Edge et al 2006); respondents in this study *said* that their age and life stage made a difference but this appeared in reality to affect what they *thought* about undertaking this task rather than their *ability* to do it.

Paediatric oncology professionals were rated consistently highly by respondents; the picture was more variable amongst those encountered in the sperm banks. Where there were difficulties, these centred on the professionals being too formal, using too

complex language, not smiling enough and not employing appropriate humour, again reflecting concerns expressed elsewhere and adding new information (Crawshaw 2006; Wilford and Hunt 2003).

The banking process was eased when the young person could exercise choice about being accompanied. Many chose to have family members present and this helped; others were accompanied by professionals or went alone. This contrasts with other studies that have suggested that the presence of family members had an adverse effect (Edge et al 2006; Bahadur et al 2002). However those studies did not involve face to face interviews so the advantages and disadvantages of being accompanied, the degree of control that the individual felt and its meaning to them would not have been explored. Being given the choice may therefore be more important than imposing a standard formula. However the finding from elsewhere (Edge et al 2006) of the negative impact of having to manage a journey to a different centre (whether on site or off site and whether accompanied or not) and a preference for semen collection to take place away from the sperm bank was confirmed.

There was considerable confusion about the consent conditions, including about 'consent to disclosure' and whether or not other couples would be able to use the stored sperm. There was also very limited awareness that these can be revisited. As in a previous study (Crawshaw 2006), some were distressed by questions about posthumous arrangements for semen disposal.

The need for improvements to the semen collection room was identified. These included making it more homely, more private, ensuring that pornographic magazines were clean and unambiguously available, providing written instructions and a clear procedure for handing in the sample. The reference to pornographic magazines for all ages reinforces the support for their provision in an earlier study (Shaw et al 2005) but the need for improvements overall was supported by our previous study (Crawshaw et al 2003; Crawshaw 2006) but not by the only other study on sperm banking (Edge et al 2006). Although many took a 'matter of fact' approach to semen collection and saw it as a required part of the process towards treatment, a few found it made them feel 'smutty'. All found it embarrassing. Similar findings were identified by Edge et al (2006).

There were variations in getting the results; getting them quickly seemed to be particularly well received. There were good levels of knowledge about storage matters.

### **Following diagnosis through to present day**

A more varied picture of information sharing emerged following diagnosis with only about half of the respondents feeling that it was sufficient. There was strong support for professionals to raise the subject sooner, more frequently, in a low key way and without ambiguity – in other words oblique references to the subject were inadequate. This, they felt, would enable them to pick up on it for information gathering or for allowing discussion about concerns as and when they felt ready to. This reflected findings from our earlier study (Crawshaw 2006). Although most preferred their consultant to take the initiative on this, there was also support for other professionals to do so – or for consultants to refer on to other professional services as appropriate.

Some would have liked named staff on the wards to deal with sex and fertility matters or a wholly independent service delivered from elsewhere. The lack of relevant psycho-social services, the need for them (if available) to be offered proactively and, sometimes, to be home based (regionally based services being costly in time and money to access) and to draw in part on outreach nursing services and social work reinforced and extended earlier work (Cooke et al 2003; Davies et al 2001) including some which recommended their provision through psychological therapies (Eiser 1998). This was the case for respondents at different stages and was not necessarily related to any imminent desire to become a parent.

Preferred professional attributes were similar to those cited at diagnosis – including being honest, clear and unambiguous in dialogues, friendly, approachable, compassionate, competent, not embarrassed with the subject. Respondents wanted to be treated as partners and hence prioritised over their parents and this reflects the wider literature on this subject (for a useful review see Young et al 2003). They valued professionals who were interested in fertility matters and who engendered hope.

Although there were gender differences in understanding, *recall* seemed broadly similar across genders. Males understood that their reproductive system may be temporarily or permanently affected but, if it were to return, then it would return indefinitely. None expressed knowledge or interest in the sperm production process. While females also understood that their system may be temporarily or permanently affected, they reported poor understanding of how this related to their menstrual cycle despite spending time talking to professionals and parents about it, and being asked frequently about their periods. This was a source of confusion and/or distress. Understanding of hormone replacement therapy appeared to be particularly problematic. These patterns did not appear to differ by age group or educational level.

Many were coping increasingly with feelings surrounding their uncertain fertility status as the uncertainty around cancer diminished. Several females were facing a possible shortening of their reproductive lifespan through the possibility of a premature menopause (which was also uncertain in itself) and this was a source of distress on many levels. This, together with the lack of stored gametes, brought its own imperative to life planning for some. Conversely, the presence of stored sperm was an important source of reassurance to males, providing that they were confident in its quality. Similar findings have recently been reported among adult male cancer survivors (Saito 2005) but have not yet been reported on for the younger age group. The retention of hope of reproductive function by the individual concerned or by professional or informal carers - even where there appeared to be a strong likelihood of damage - was an important boost to coping. It was noticeable that those who had been told that their fertility was permanently and irreversibly damaged were particularly badly affected.

Information about contraception was limited across genders and age groups. When combined with attitudes towards its use, sometimes driven by possible fertility impairment, a worrying picture emerged. This was also present in an earlier study involving mixed gender childhood cancer survivors (Zebrack et al 2004) and extends understanding of this area.

Some had sought information on fertility related matters from sources other than their professional supporters or family members. Several wanted more age-appropriate written and/or internet based information to be made readily and discreetly available (see also Crawshaw 2006; CancerBACUP 2005).

Gender differences emerged with regard to fertility analysis. Some females became aware of fertility damage as a result of gynaecological investigations (and had not expected this); none were expecting to be called routinely for fertility testing. All but one of the males who had banked sperm (but none of those who had not) anticipated being recalled routinely. Those awaiting recall did not express any particular anxiety about this but others of both genders talked of the complexity of such decision making especially the older ones. Some of both genders reported little impact after testing (including some who were found to be affected) though others did. Several remarked that they would have welcomed access to psycho-social services but none was offered. Both ambivalence and a range of reactions towards fertility testing were also found in a study of childhood cancer survivors (Green et al 2003) but these results provide more information about the impact on survivors prior to fertility analysis being raised directly by professionals.

Few had knowledge about fertility treatment options but wanted to know more. A number saw them as a source of hope for the future. Females were far more likely than males to be aware of others in their family or social networks that had been through fertility treatments. None had yet accessed fertility treatments though two were starting down that path. Some in all four groups cited media coverage as a prompt for them to think about their own situation.

### **Involvement of family**

Some pre-existing patterns within families were maintained or strengthened but others changed. Families were much less likely to talk about cancer-related fertility matters than cancer matters at any stage. Where families were more open, this usually reflected either pre-cancer patterns or a particular (new) need for information or reassurance by the respondent (for example sex, contraception and fear of transmission to unborn child). Some respondents talked to siblings and extended family members more than to parents. Sometimes the lack of discussion was because the respondent had not felt troubled; sometimes it was because the respondent feared upsetting others, or being upset themselves, by such a discussion. A small number would have preferred either to feel able to broach it themselves or for others to take the initiative in doing so. Where the respondent felt in control of the level at which their parents and family members were involved in their lives both in the past and in the present (including in relation to professional services), this was experienced positively. While a number of respondents were saddened by the strain that their cancer experience had already imposed on the whole family, some also worried that they may add to this by not being able to provide grandchildren. These are all areas with little or no prior research.

## **Involvement of friends**

Respondents across all four groups were more likely to discuss cancer-related fertility matters with friends than with family members but nevertheless reported different reactions towards, and from, friends around this area than to cancer matters. Discussions were often restricted to a small number of close friends and proved helpful. A small number did *not* talk with friends; that worked well when it was because the subject was of little concern but distressing when it was of concern. Some found this aspect of their cancer experience particularly difficult to manage in their re-entry into the education-based context.

The stigma attached to (in)fertility and the desire to appear 'normal' appeared to influence the decision of some not to disclose this aspect of their cancer to friends either in the early stages or over time. This appeared more difficult to sustain over time.

There were also gender differences in the impact of fertility matters on friendships. Females were particularly likely to find themselves managing conversations about parenthood plans (and actual pregnancies). Some of both genders used humour to diffuse the awkward nature of some conversations but males reported particular difficulty in coping with 'laddish' jokes about virility and sexual prowess. This was made more stressful where friends were not aware of their possible fertility impairment. A small number discussed it with opposite gender friends though the majority restricted it to same gender friendships. A few females had used discussions with male friends as a 'rehearsal' for anticipated discussions with boyfriends

Some reported changes over time with friends either becoming less interested in cancer-related fertility matters or becoming more involved and supportive. Some females had been involved by friends in bringing up their children.

There was mixed evidence of respondents talking about fertility within friendships made through cancer – sometimes it had not come up at all whereas for a small number, it was an important site of shared experience. None had yet got friends facing fertility difficulties for non cancer related reasons.

Although there is some research on the experience of friendships in relation to the wider cancer experience, none was identified that looked at this particular aspect. These may therefore add useful evidence to extend understanding of those wider patterns.

## **Involvement of actual and prospective romantic partners**

Some in the study were now in permanent relationships but many were not; some had no experience in this area at all. Most of those closer to treatment were more concerned with the impact of body changes than of the impact of possible fertility impairment. Although many said that the possibility of fertility impairment did not influence their approach to relationships, including sex, there were many examples of how it had done in reality.

Previous studies have indicated that childhood cancer survivors may fear or experience difficulties in attracting and retaining adult relationships (Langeveld et al 2003; Rauck et al 1999; Thaler-Mers 2001; Zebrack et al 2004) and concerns in this study centred on the impact of fertility matters on this. The findings here reveal a complex picture as some were anxious about finding someone willing to enter a potentially childless relationship while others were concerned about the potential to find such a permanent partner who might then come to experience later distress. A few were concerned that they themselves might not feel attracted to a partner willing to contemplate a childless relationship. The possibility of not being able to have a child together had contributed to the ending of a small number of relationships but was never the sole cause.

Anticipated and actual concerns about disclosure – when and how to tell - were dominant in the study and often present from very early on in relationships as well as anticipated for future relationships. Fears of rejection and avoidance of disclosure in casual relationships were as found in an earlier study (Zebrack et al 2004) but there was more evidence of disclosure within permanent relationships in this study (all had told). However, our findings add to the picture in that respondents across all four groups were far more likely to talk to partners about their cancer experience than about cancer-related fertility matters, mirroring communication patterns with family and friends. This applied regardless of the level of distress associated with the subject. Those who held a generally open stance to relationships where complete honesty was a strongly preferred feature were more likely to disclose early on in permanent and non permanent relationships and feel less anxious about the process. Some had not disclosed in order to withhold the fact of their probable infertility; some because they felt that this should be restricted to ‘serious’ relationships and/or that it might give the wrong message if done too early; and one had not done so in the hope of being able to become pregnant. Many feared rejection and this was again fuelled in part by the stigma that was perceived to attach to fertility impairment and hence to feeling that they were ‘damaged goods’. This was reinforced for some by the fact that the subject had rarely been raised in other contexts and this contributed to them feeling that it was therefore something to be cautious of raising. This was especially pertinent as the initiative in this context rested very firmly with them to disclose.

Those who had told a romantic partner typically found the outcome to be more positive than anticipated and led to them feeling relieved and reassured. In other words, the anticipation of disclosure appeared worse than the reality. However there was variance in the extent to which fertility matters had been discussed following disclosure. Some did not discuss it very often even though (or perhaps because) they found it deeply distressing and this may add some understand to Zebrack et al’s (2004) finding of tension of some relationships following disclosure .

There were aspects to managing relationships that have not been reported on elsewhere. Uncertainty about fertility status also affected relationships. Some felt that they needed more information or better coping strategies either about the likelihood of being affected or about treatment or non-medical options (such as adoption or remaining childless) in order to help a partner when the time came to disclose. Some of the older ones had wondered whether to undergo fertility analysis as part of this preparation and strategy building process.

Some of the older group had enjoyed a number of post treatment relationships (mainly casual) but this had changed more recently and they reported a drop off in this aspect of their lives. Some older ones had only ever had casual relationships.

There were varying reports of the comfort and reassurance that came from being in a permanent relationship; while there were accounts of feeling that fertility impairment was now a shared 'problem' there was also evidence of ongoing loneliness surrounding it.

Reactions were not static but changed over time and across different situations and within different romantic relationships.

### **Becoming and being a parent**

Females were more articulate about alternative routes to parenthood and had thought about them more frequently and in greater depth than had males, though this varied. They had this subject raised with them more often than did males and only females had received offers of surrogacy or donated gametes from family members. Both genders and age groups held reservations about non biological parenthood with more concerns about gamete donation than adoption as had been mooted by an earlier review (Schover 1999) The response of romantic partners to alternative routes was seen as important though few had actual experience of this.

Only a few in the study were trying to become parents or had already done so. For those trying to get pregnant, the strain of this was clear. The extent to which the emotional impact was shared by partners appeared to vary as did responses to the styles of medical intervention.

Among the parents, some had had planned pregnancies and others not. None had used fertility treatments. Several had believed themselves to be infertile beforehand so had to adjust to their unexpected state. Increased levels of monitoring of the pregnancies of the affected females were welcomed; most were fearful of the pregnancy triggering a recurrence of cancer. Others, including non-affected females, were concerned about the risk of transmission of cancer to the unborn child and this confirmed findings from elsewhere (Zebrack and Chesler 2001; Zebrack et al 2004). This was made worse where information about such risks was not provided until after the birth. Although some had sought advice pre-conceptually, this did not appear to be widespread and professionals did not appear to be proactively raising it, as had been found in an earlier US study (Schover et al 2002a). One parent reported that the fear of his child getting cancer had grown over time. Several commented that they would be better able to cope with their child getting cancer than their parents had because of their own experience and resulting strengths. On the whole, all appeared to have adjusted well to being parents.

### **Summary**

Coping with the impact of cancer-related fertility concerns has been shown in this study to be a dynamic process with different aspects arising at different times, in different contexts and at different stages throughout the transition to adulthood and

beyond. Although certain themes emerged from this study, it is of course true to say that there are dangers in making assumptions based on these about any affected individual. It is rather the case that they offer the backdrop against which to review current service provision, professional practice and individual experience.

One key aspect that ran through the accounts was the relative invisibility of fertility matters compared to cancer matters in dialogues between the individual affected and those around them – be they professionals, family members, friends or romantic partners. Survivors were coping alone with their thoughts and feelings for much of the time. Where individuals felt little or no associated concern, this was fine but for others it was stressful and this may go some way to explaining previous evidence that fertility concerns rose over time (Blacklay, Eiser and Ellis, 1998; Gray et al 1992 cited in Weigers et al 1998; Lozowoski, 1992; Reid, 2000; Roberts, Turney and Knowles, 1998; Schover et al 1999; Schover et al 2002a; Self, 1999, 2006; Zebrack et al 2002). Lack of professionals' and others' attention also limited opportunities to correct misinformation, provide new or repeated information or help build strategies for longer term coping. Their invisibility also appeared to reflect and reinforce the perceived stigma that attached to (in)fertility and thus the potential for hopelessness that comes with holding a 'spoiled identity' (Goffman 1968).

Although immediate concerns aroused about fertility impairment at diagnosis were overtaken quickly by coping with treatment (especially once males had completed the sperm banking process), they reappeared from time to time during treatment for a small number. Once treatment had ended, the picture changed with larger numbers (though still not the majority) gradually reporting associated concerns especially if new information was received that confirmed likely damage. Indeed some reported that the threat to wellbeing from fertility concerns had overtaken cancer-related concerns. This did not appear to relate to gender, thus reinforcing some studies of childhood cancer survivors (Schover et al 1999; Langeveld et al 2003) although age and life stage did appear to be an influence and there was evidence of some aspects being differently experienced according to gender.

Findings emerged to suggest how threats to wellbeing from fertility concerns may be formed and maintained. For some, these were influenced by a strong and conscious desire to become a biological parent one day. Those who had given it little thought had nevertheless assumed they would become parents one day so also experienced some degree of threat. This has not been reported elsewhere. The threat was also affected by the way that individuals (and sometimes their parents) interpreted information received from their doctors about the likely risk of damage. Similar levels of factual information were 'heard' differently and influenced behaviours and reactions, as was also found by Zebrack et al (2004). Finally, the threat was incorporated into what we have called the individual's fertile identity and this did not always relate either to factual information or to desire to parent. This too has not been reported elsewhere. Prior to diagnosis, all appeared to have held a 'fertile' fertile identity though some had shifted to an 'impaired' or 'uncertain' fertile identity through treatment. It seemed to be particularly difficult to shift back to a 'fertile' identity. The combination of these factors appeared to contribute to impact on wellbeing. Given the lack of ongoing discussions with professionals or others, these potentially important aspects appeared to have remained a hidden part of the experience.

Next we looked at the recovery process following treatment. The priority following treatment was re-entry into the social and educational trajectory being navigated prior to diagnosis. We have called this 'active recovery through striving for normality'. For those focussed on this, fertility concerns were either consciously put to one side or 'forgotten', reinforced by their potential to make survivors appear or feel 'different'. Normality is contextual and is variously located in gender, ethnicity, culture, sexual orientation and so on. There was evidence of this influencing some attitudes to contraception and social friendships. Those less focussed on 'normality' in their recovery appeared less likely to strive for conformity to fertility related expectations and could therefore accommodate the possibility of remaining childless for the foreseeable future. Similarly some of those who remained fearful of relapse or who were coping with significant physical impairments or health difficulties (some with associated stigma) were preoccupied with those and less affected by potential fertility impairment and this is similar to findings about the impact of those with CNS tumours for example (Langeveld et al 2003). However there were some who felt near to, or beyond, the active recovery phase and others for whom this approach was working less well who reported that fertility concerns were not resolving.

Where recovery was starting to be affected by fertility concerns, many nevertheless spoke positively of being a cancer survivor. They felt good about themselves and their achievements and pointed to positive role models and images among cancer survivors, including some who had become parents. However there were many reports of more negative associations with (in)fertility and none identified positive role models or images. This was adversely affected by the ongoing impact of uncertainty as referred to above.

The opportunity to exercise reproductive choice about whether or not to enter the social state of parenthood is one that most young people expect to acquire as they move towards adulthood. For those being diagnosed with cancer in their teens, that opportunity is threatened and is often an unexpected consequence of cancer treatment. When placed alongside the threat to life, it may appear as of secondary concern and become invisible. However, if life is for living, then it is of little surprise that many in this study reported that it did not stay invisible to them. Perhaps it is time that those around them to also make it more visible.

## DEVELOPMENT OF INFORMATION MATERIALS

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One of the aims of the study was to produce information materials for teenagers and young adults about fertility aspects of cancer, a need that had been identified in the earlier study conducted by the researchers (Crawshaw et al 2003). The original intention had been to run workshops for participants in the present study (and their parents if they wished) at which the format and content of such materials could be determined. However, when Cancerbackup<sup>7</sup>, the national charity that provides patient information on cancer, heard about this MC was approached to produce a booklet as part of their national series though with Candlelighters' involvement being acknowledged prominently. This had the merit of the information being produced with the assistance of highly skilled and experienced staff at Cancerbackup and then being available free of charge and throughout the country to all cancer patients. However it involved a change of approach to the compilation of the information and a bigger time commitment from both the research staff and from those members of the Advisory Group who agreed to contribute text.

The Advisory Group were drawn on in two different ways in putting together the booklet:

- Some members agreed to provide written information
- All agreed to comment on the proposed range of areas to be included as well as on the content itself.

It was important that the principle of service users informing the content and style of the booklet be maintained. This was assured in part through the involvement of the two service user members of the Advisory Group. It was also agreed that research participants should be given the opportunity to comment on the booklet. Thus, this opportunity was offered to all who took part during the production stages and a number agreed to do so. Finally, Cancerbackup themselves sent the final draft for comment to a number of teenagers and young adults with whom they are in contact.

After a lengthy and detailed process, the booklet 'Relationships, sex and fertility – for young people affected by cancer' was published in late summer of 2005 and has been very well received. It is already into its second print run, has been distributed to all members of CLIC Sargeant staff who work with young people and was distributed at the subsequent Teenage Cancer Trust 'Find your sense of tumour' conference for teenagers and young adults with cancer. In addition, MC took it to the International Society of Paediatric Oncology (SIOP) conference in Vancouver in September 2005 where it was very well received, with interest in it from various parts of the world.

The idea to produce a DVD for young people at around the point of diagnosis that deals with fertility issues was also mooted as a result of the earlier study undertaken by the researchers (Crawshaw et al 2003; Crawshaw 2006) and reinforced through this study. This initiative was eventually taken up by the Teenage Cancer Trust. A DVD on sperm banking called 'Whack to the Future' was produced in July 2006 with the assistance of some of the research team and Advisory Group together with other advisers. One for females is now in the pipeline.

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<sup>7</sup> Previously known as CancerBACUP

## FOCUS GROUPS WITH PROFESSIONALS

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### Background

It is increasingly acknowledged that the dissemination of research findings by publication alone is not sufficient to lead to changes in individual professional practice or service delivery. It was anticipated that involvement of link Consultant Paediatric Oncologists in each site in the recruitment process and as members of the Advisory Group would assist with implementation of the findings, especially as:

- (i) they are key players in the direct service delivery process, in that they are typically the staff member to explain at around diagnosis (or later) that fertility may be affected through treatment and, if it is raised at all in later medical consultations, it will be most likely to be raised by them
- (ii) they carry sufficient status to have the potential to influence service delivery within their own NHS Trust and interagency setting and within the national paediatric oncology multi-disciplinary community

It was also decided to include in the study design an opportunity for invited members of the multi-disciplinary and inter-agency network in two of the three geographical areas to come together in focus groups to receive the findings, discuss them and consider possible implementation strategies as part of the data collection. The aims were to:

- (i) increase the potential for implementation of findings on the assumption that those multi-disciplinary professionals most closely involved might be more likely to engage in implementation than those who would only hear about it through the written word or conference presentations, and
- (ii) increase our understanding of the potential for this sort of exercise to improve implementation *if it is included as part of research study design*.

There were to be two focus groups run in each site (i.e. 4 in total) with a 6-8 week interval between them.

### Recruitment

As the study unfolded, it became clear that the original timing for running the focus groups was too early in the process, especially as recruitment to the interviews had been slower than anticipated and this had had a knock on effect on the analysis stages. The focus groups were therefore rescheduled with a view to running the first group in the spring or early summer of 2006. It was anticipated that there would need to be a long lead in time as the recruitment drew from four different services:

- paediatric oncology health professionals
- assisted conception health professionals
- social workers
- psychologists (one centre only)

MREC approval allowed for all the recruitment sites to be approached. However, the link Consultant at one of the centres decided that they were not in a position to participate in this part of the study because of staffing difficulties. Focus groups in the other two centres went ahead.

Together with the lead Consultants, up to 10 staff were identified to be approached in each of these centres. The criteria were:

- that they were actively involved currently in managing fertility aspects to some degree
- that they were drawn from all the relevant services
- that, where there were different professionals involved from any one service, each discipline was included as far as possible
- that staff involved outside of the acute treatment services were included where possible.

Letters of invitation were sent to all those identified which explained the purpose of the focus groups, the information sheet and consent forms as approved by MREC and suggested possible dates for Focus Group One.

The set of groups in one centre ran in April and June 2006; those in the other centre ran in May and July 2006.

## **Format**

Offering a single intervention focus group with an opportunity to discuss the findings has the potential to yield more actions than not running one at all. However, it is known that energy created by exposure to thought-provoking information can quickly dissipate without reinforcement of some kind (Effective Health Care, 1999; Sloper et al,1999). Drawing on MC's experience in running a research dissemination and implementation project for social care and health service providers, the researchers had decided to run two groups with a 6 to 8 week gap in between (Crawshaw and Wates 2005). This was to allow participants to go away and reflect on the first group in their work setting and come back with an opportunity to reflect further in the (second) focus group setting. Written notes from each group were to be provided by the researchers as soon as possible after each meeting. It was intended that the composition of the groups would remain the same for each session.

It was determined that each group would follow a similar format:

- introduction and explanation of purpose
- presentation of findings
- time for clarification questions only
- set questions for discussion
- reflections sheet to complete (Focus Group 1 only<sup>8</sup>)
- action planning exercise and sheet to complete (Focus Group 2 only<sup>9</sup>).

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<sup>8</sup> See Appendix A

<sup>9</sup> see Appendix B

The set questions for discussion were as follows:

### **Focus Group 1:**

#### ***For joint working***

How far do the present *inter-departmental communication systems* between the two services help or hinder the process of sperm banking and/or fertility analysis for teenage and young adult cancer patients?

#### ***For the Assisted Conception Unit (ACU) part of the service***

What are the ways in which staff could increase their effectiveness at working with this patient group in terms of (i) their age and (ii) their disease specific issues?

#### ***For the Paediatric Oncology Centre (POC) part of the service***

Where, when, how and by whom can discussion about sexuality and fertility issues be introduced more frequently? i.e. during treatment, early and longer term follow up

- Which roles are discipline-specific and which are not?
- Which services are discipline-specific and which are not?

### **Focus Group 2**

1. How far does the present *inter-departmental communication* between the two services help or hinder any of the areas that have been identified in today's findings?
2. How far do any practices, policies and professional styles in *either* the ACU *or* the POC (within and outside the hospital) help or hinder?

#### **Action planning**

- In what areas is it possible to introduce implementation of improvements? (refer back to notes from Focus Group 1 as well as today's discussion)
- Who will do what; by when; how; who else needs to be involved and what resources need to be identified/found?

Different sets of findings were presented at each of the Focus Groups though MC took care to remind participants of findings from the earlier set of data at the second meeting.

Group discussions were transcribed and key points were distributed to members shortly after each meeting. Key points were a mixture of affirmation of existing good or good-enough practice (as identified by participants) and pointers for possible actions.

Participants agreed to be contacted later in the year to see whether any actions had resulted from their participation *either at an individual, service or inter-service level*. It would also be interesting to see what participants recalled from the findings and the accuracy of that recall. (**Note:** This will take place after the completion of the study so will not be reported here.)

## Findings

**In one of the centres,** 8 staff attended the first focus group:

- Consultant Paediatric Oncologist
- Consultant Paediatric Haematologist
- MacMillan Nurse (Outreach)
- Sister, Late Effects Service
- Charge Nurse with responsibility for sperm banking
- Consultant Reproductive Physician
- Fertility Nurse, ACU
- Social Worker for Late Effects service

The psychologist was unable to attend as was the ACU Senior Embryologist

At the second focus group in this centre, seven staff attended and this included all the above staff members except for the Sister, Late Effects Service who was on sick leave.

**In the other centre,** 10 staff attended the first focus group:

- Consultant Paediatric Oncologist
- Consultant Paediatric Oncologist
- Ward nursing staff from RVI (2)
- Ward nursing staff from Newcastle General (1)
- BMT Nurse Specialist
- Consultant Reproductive Physician
- Fertility Nurse, ACU
- Embryologist, ACU
- Social Worker

At the second focus group, eight attended but two were new to the group (both research sisters). One of the Consultant Paediatric Oncologists, two of the non-specialist nursing staff, and the Embryologist all had to withdraw their availability for a variety of reasons.

## Key points from Focus Groups' discussions

There were many similarities in the key points that were made and the potential actions identified across both centres. These are broadly grouped as follows, noting where there was anything particular to only one site:

- **Referral systems between the two services** – there was high satisfaction with the existing referral systems. They were seen on the whole to be

straightforward and efficient and the responses of the ACUs were identified as prompt, appropriate and flexible. One centre noted that they needed to increase referrals from one of their sites.

- **Consent process for sperm banking** - there was discussion about the potential for flexibility around how consents for sperm banking might be taken. Consents in both centres were usually taken by the ACU staff and this was considered appropriate given their complexity and the Human Fertilisation & Embryology Authority licensing requirements. For some patients, this was seen to be of benefit in that they became familiarised with the unit before having to go into the room to produce the sample. For others, especially if they were very poorly or particularly traumatised, this could prove difficult. Both centres discussed the potential need for flexibility around this on a case by case basis. This might include the ACU staff coming to the ward to take consent on occasion or the POC staff member who had prepared the patient for sperm banking being present at the ACU when consent was taken.
- **Location and attributes of sperm collection facilities** – there may need to be greater flexibility about where samples are produced to accommodate those who find it particularly difficult to attend the ACU. Both centres also agreed that there may be room for improvement with the sperm collection room attributes in the ACUs. The need for a budget to ensure a regular supply of new porn magazines was identified; the fact that young men were allowed to bring in their own magazines, videos and music (e.g. iPods) needed to be made clear to the young men and the POC staff *in advance* of their appointment at the ACU; rooms should be made more comfortable and 'homely' where possible. The need for the provision of clear written laminated instructions about the process that included how to hand over the sample was confirmed.
- **Costs of storage and associated tasks** – the lack of funding for this service was identified, especially as demand continues to grow.
- **Written information** – there were full discussions about the potential role of written information on a range of reproductive health issues including:
  - sperm banking (at diagnosis) – for patients and parents/partners
  - undergoing semen analysis
  - contraception during and after treatment
  - the use of HRT
  - short information leaflet on the 10 key messages from the Cancerbackup booklet 'Relationships, sex and fertility' for new patients

There was also discussion about how to make appropriate use of existing written and electronic information including:

- the timing of when and how to make the 'Relationships, sex and fertility' booklet available
- making the 'click 4 tic' plastic cards and posters about the Cancerbackup teenage cancer website readily available in both the POC and ACU

- making sure that any posters include tear-off portions and that all leaflets and cards are prominent enough to be seen but discreetly placed enough to enable people to pick them up without drawing attention to their actions
  - considering when and how to make written information available to parents
- **Contraception** - the question of when, how and by whom contraceptive advice should be raised for both males and females was covered (during treatment and afterwards) and its medical complexity was acknowledged. The role of primary care services in relation to this and related matters and the need for greater liaison and potential training were discussed. One centre was considering whether or not to include contraception as part of their pre-discharge planning discussions.
  - **Sexual activity** – this is another area that is challenging for professionals. It was acknowledged that professionals can run the danger of making inaccurate assumptions about sexual activity. Patients can be sexually active at all ages and all stages of treatment. The need for routine pregnancy testing prior to treatment and for consideration of the impact of sexual activity during as well as after treatment was discussed. The need to be willing to address sexual activity as well as contraception was acknowledged.
  - **Ongoing attention to fertility matters** – the complexity for all professionals of deciding how, when and whether to raise fertility issues after diagnosis and on an ongoing basis was addressed (including at what age and how quickly after diagnosis). In particular the relative merits of it being raised routinely, from time to time or reactively were covered. Decisions about this may differ over time and context but it was agreed that this needed to be a regular part of the professionals' thinking. The particular issue of how any related needs may be met for those who are no longer in frequent contact with health and social work professionals was identified.
  - **Involvement of parents** – this was acknowledged as a particularly sensitive aspect in relation to sex and fertility matters and generated much discussion. On balance, it was felt that patients should be asked when they were on their own whether or not they wanted their parents involved - but this needs to be handled carefully.
  - **Fertility analysis services** – there was discussion about the fact that those males who banked sperm were covered by a system that ensured that they were routinely contacted and invited to consider semen analysis. No such system exists for those males who did not bank or for females. One centre was also particularly concerned about the low take up of appointments for semen analysis from men who have said that they wish to attend, make an appointment and then fail to show. It was unclear whether the referral process has any detrimental effect on take up or whether it is predominantly down to ambivalence amongst the males. Alternative approaches were discussed.

- **Cultural awareness** - there was general agreement that there is room for improvement in religious and cultural awareness in relation to the impact of potential cancer-related fertility impairment at all stages of contact.
- **Gender awareness** - both centres discussed the potential impact of the gender of the professional providing a service and the need for awareness of gendered issues for patients. One of the centres discussed whether the choice of professional gender should be made more widely available as it is currently only offered to Muslim women.
- **The value of regular inter-departmental contact** – staff were positive about the spin offs where they had regular contact with each other through their operational contact. Where there was less regular contact around fertility matters – including in some acute treatment services but especially with services for patients outside of the acute treatment context – this might need to be attended to more pro-actively and various options for this were explored.
- **Training needs** – there was general agreement from all disciplines and sectors that this is a challenging area of work in which staff do not always feel comfortable or competent. ACU staff had relatively little experience with either this age group, those newly diagnosed with cancer or those accompanied by parents. POC staff often did not feel confident in their knowledge base around reproductive health and fertility treatments. Given the complexity of the issues and the information gaps among health professionals, one centre identified a need for a seminar that focuses on adolescent sexual and reproductive health. Training needs in terms of skill and information were identified by all disciplines to help them provide an appropriate service in different contexts and at different times. The issues and needs unfold over time and are medical, emotional and social.
- **Gaps in current services** – both centres identified the need for additional services to address the emotional and social needs of this patient group in relation to sex and fertility matters. Options considered included:
  - the provision of an independent professional service available on the ward and outside of the treatment context
  - existing staff who could receive additional training and be freed up to provide dedicated space for this work
  - groups run by psycho-social professionals
  - open sessions for patients run by health professionals from the ACU

Finally there were some areas that were pertinent to, or discussed by, only one centre. These included:

- Affirmation of the value of the **joint clinic** that is run by medical and nursing staff from paediatric oncology and reproductive medicine in one of the centres. Apart from the value of the clinic in and of itself, there was a sense that this had led to closer working practices between the two staff groups, improved levels of knowledge and confidence, and spin offs for the way in which reproductive medicine services for adult oncology services were provided.

However, it was also acknowledged that running the clinic did require additional investment of time and other resources.

- The need for a system of **feedback** from patients to the ACU staff providing the sperm banking service either directly or through paediatric oncology staff in order to learn from what works well and what might need attention.
- It was suggested at one centre that the term '**reproductive health**' would be a better one to use in general than sexuality or fertility in order to avoid any confusion between (i) sexuality and sexual orientation and (ii) fertility, infertility and subfertility.

## Summary

The mix of presenting findings and facilitating discussion on those findings around provided questions seemed to work well. Focus groups members appeared to engage readily and constructively with the exercise. The size and composition of the groups assisted with this although it was disappointing that there was a significant drop off in attendance (for various reasons) at one of the sites. The opportunity to identify areas of good practice by staff from different disciplines and sectors that rarely come together to discuss their linked services appeared to be important affirmative action. It is possible that this enabled energy to then be paid to areas where developments might be made. It is certainly the case that a number of clear and achievable actions were identified that linked clearly to the research findings. However, within the time available, there was not the opportunity to allocate responsibility for taking forward those actions and it will be interesting to see how far any progress is made.



APPENDIX B



**ACTION PLANNING**

<i>What are the possible improvements that can be taken forward?</i>

**Decision Making Process**

<i>What are the key decision making forums or staff roles where agreement has to be sought?</i>	<i>What steps need to be taken?</i>	<i>By whom?</i>	<i>By when?</i>

**Tracking Process**

<i>How will progress be tracked?</i>	<i>Where?</i>	<i>By whom?</i>	<i>How often?</i>

### Resources Assessment

<i>What resources will be required? (including staff, finance, changes in policy/procedures)</i>	<i>Who can access or authorise them?</i>	<i>When?</i>	<i>Are any relevant resources due to come on line?</i>

### Immediate Action Plan

<i>What are the immediate steps necessary to begin to implement a plan for change or development?</i>

### TOPIC GUIDE FOR INTERVIEWS

#### **Experience of being told about impact of treatment on fertility at the time of diagnosis and starting treatment**

- Experience of being told about impact of treatment on fertility at the time of diagnosis and starting treatment
- Memories of the process leading up to diagnosis, diagnosis itself and immediately afterwards
- Emotional experience; cognitive understanding of being told that treatment might affect fertility
- Prior experience if any of talking about fertility *or* sexual matters – (i) with professionals, (ii) with family members (iii) with peers
- Sort of help, information, people to talk to, available, if any (about fertility & related matters)?
- What made it worse; what made it easier?
- Who/what *could* have been helpful if available?
- On a scale of 0-10, where would they place the importance to them of potential fertility impairment at this stage (for males, this means before banking, if applicable)?
- Mapping of who was *actually* involved in relation to fertility and related aspects – what was helpful; what not (professional and family/friends)
- Use of written materials or video, if any – actual or potential use at different stages
- *For those who used fertility preservation services* – level of help, information, people to talk to, in making the decision and acting on it; getting ready to go to the ACU – professional and family/friends etc. Level of involvement of parents/carers/partners by professionals
- Who/what *could* have been helpful if available?

#### **During the fertility preservation process**

*Note: This section only applies where services were accessed –banking or egg collection according to whether male/female (very few females are offered egg freezing)*

- Memories of the process of *getting* to the ACU
- Emotional experience; cognitive understanding
- Memories of the process of *being at* the ACU
- Emotional experience; cognitive understanding

- Sort of help, information, people to talk to, available, if any? Professional, family, girlfriend/boyfriend, friends etc
- What made it worse; what made it easier?
- Who/what *could* have been helpful if available?
- Level of involvement of parents/carers/partners by professionals
- Mapping of who was *actually* involved in relation to fertility and related aspects – what was helpful; what not (professional and family/partner/friends)
- Use of written materials or video, if any, to explain the process etc – actual or potential use at different stages
- Consent form - who completed it with them? Recall of the experience and reaction to it; level of understanding of it; understanding of whose decision it was, reference to Deceased Fathers Act (if appropriate) etc. And now. Memory of getting a copy and, if so, where it is now?
- 'Consent to disclosure' – memory and understanding of who else (among health professionals) would know what happened; memory of signing 'consent to disclosure'
- How well prepared for what happened at the ACU?
- Recall of HIV or other screening at this stage. If so, what impact if any, did this have?
- Knowledge of *where and how* the sperm is stored and does it matter whether they know or not?
- Payment for storage costs or fertility treatments - knowledge, expectations and so on about this

#### **Afterwards – bringing it up to present day**

- Memories of the impact of potential or actual fertility impairment up to present day (broken down into different periods of time, if applicable)
- Emotional experience; cognitive understanding
- Experience of forming and maintaining friendships post diagnosis; role of peers in discussing sexual and romantic relationship matters
- Experience of forming and maintaining sexual and 'romantic' sexual and 'romantic' relationships
- How far are any difficulties attributable to fertility impairment and how much to cancer
- Some professionals have expressed concerns that undertaking sperm banking at the time of diagnosis might lead to sexual and relationship problems in this area in the future. Any views on that?

- On a scale of 0-10, where do they place the importance of potential fertility impairment at this stage in their lives?
- For teenagers, where do they hope to be in terms of adult relationships, parenting etc by their mid to late 20's? And is this any different to what they *think* they would have wanted if they had not had cancer?
- Understanding of the practical and financial implications and processes of fertility testing, treatment etc
- Sort of help, information, people to talk to that was, is and might be available, if any (professional and family/partner/friends)
- Mapping of who has *actually* been involved in relation to fertility and related aspects
- Have they had their fertility checked? And if so, what motivated/triggered them to do so?
- Who/what *could* have been helpful if available, and when would they have preferred it? And what sort of involvement?
- Experience of decision making (if any) about having children, seeking assisted conception treatment etc; and experience of acting on the decision
- Use of written materials or video, if any – actual or potential use at different stages
- Raising of the subject by professionals and/or by parents/family members/friends/partners/others
- Specific offer of services related to the effect/s experienced
- *For those who used fertility preservation services only* - Annual Review of Storage letter

**Looking back** (prompting review/summary of what they've said)

- Frequency of thinking about the fertility aspects of cancer treatment outcome – what triggers thoughts; what sort of thoughts?
- Anything about the *manner* of the professionals that helped or got in the way at the different stages of the process of coping?
- Did it matter whether they were:
  - Male or female
  - Near in age or not
  - Same ethnicity or not
  - Anything else
  - Did this differ over time or context?
- Did any of these matter more or less depending on what their job/role was?
- Looking back, did they feel that they knew and understood as much as they wanted to at each stage, including now?

- Looking back, how do they feel about the fact that they were given/not given the opportunity to use fertility preservation services?
- Looking back, do they think that any aspect of it has had an effect on them (i) at the time (ii) immediately afterwards (iii) in the intervening time (iv) now?
- How did they feel about the level of involvement that their parents, carers, partner had in the whole process, at each stage?
- Looking back, what, if anything, could have been done better, by whom and when?
- Looking back, what was done well, by whom and when?
- One or two things/people/events that made this whole process more difficult than it might have been otherwise? (*vulnerabilities*)
- One or two things/people/events that made this whole process more manageable than it might have been otherwise? (*buffers, protectors*)
- Any surprises for them?
- *For those who were offered fertility preservation services only* - how do they feel about the decision they made (whatever it was)?
- Looking back now, did anything particularly affect that decision?

### **Messages**

- What messages would they send to the professionals involved?
- What messages would they send to parents, partners involved?
- What messages would they send to the others about to go through all this?

## APPENDIX D

### ADVISORY GROUP MEMBERS

Bernadette Brennan	<i>Consultant Paediatric Oncologist, Royal Manchester Children's Hospital</i>
Richard Clapham	<i>Service user</i>
Ian Cooke	<i>Emeritus Professor of Obstetrics &amp; Gynaecology</i>
Marilyn Crawshaw (researcher)	<i>Research Fellow, University of York</i>
Simon Davies	<i>Chief Executive, Teenage Cancer Trust</i>
Adam Glaser	<i>Consultant Paediatric and Adolescent Oncologist, Leeds Teaching Hospitals NHS Trust</i>
David Green	<i>Clinical Psychologist, University of Leeds and St James's University Hospital, Leeds</i>
Juliet Hale	<i>Consultant Paediatric Oncologist, Newcastle upon Tyne Hospitals NHS Trust</i>
Sue Morgan	<i>MacMillan Clinical Nurse Specialist, Leeds Teaching Hospitals NHS Trust</i>
Allan Pacey	<i>Senior Lecturer in Andrology, University of Sheffield and Head of Andrology, Sheffield Teaching Hospitals NHS Foundation Trust</i>
Sheila Pike	<i>Counsellor, Centre for Reproductive Medicine and Fertility, Sheffield Teaching Hospitals NHS Foundation Trust</i>
Clayre Sanderson	<i>Service user</i>
Stephanie Croker <sup>10</sup>	<i>Policy Manager, Human Fertilisation &amp; Embryology Authority</i>
Tricia Sloper (researcher)	<i>Professor of Children's Healthcare, University of York</i>
Jane Stewart	<i>Consultant in Reproductive Medicine, Newcastle Fertility Centre at LIFE</i>
Hamish Wallace	<i>Consultant Paediatric Oncologist, Sick Children's Hospital, Edinburgh</i>
Ann Wilson	<i>CLIC Sargeant Social Worker, Newcastle</i>

<sup>10</sup> Previously Jenny Dimond then Cathleen Schulte

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