

Quality of Life of Cancer Survivors in England : Analysis of Patients' Free Text Comments: Final Report

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Executive Summary

Introduction

There are currently about 2 million people living with or beyond cancer in the UK and this is rising by approximately 3% every year. The life expectancy for individuals diagnosed with cancer has greatly increased over recent decades, which is transforming the experience of cancer to one where today we are beginning to think of cancer as a long-term or chronic condition. Therefore, it is increasingly important that the problems patients face following treatment and how these can be addressed are understood. The National Cancer Survivorship Initiative (NCSI) was launched in 2007 as a key element of the Cancer Reform Strategy and the Improving Outcomes Strategy for Cancer, with the aim of supporting survivors to live as healthy and active lives as possible for as long as possible. However, to date little research has been undertaken to systematically determine quality of life related outcomes for patients following primary treatment for cancer or how the health system can best respond to identified needs.

The National Cancer Survivorship Survey was undertaken to establish that reliable information can be collected on the long-term and unmet needs of those living with and beyond a cancer diagnosis, using a cross-sectional survey of patient reported outcome measures (PROMs) for four common cancers: breast; colorectal; non-Hodgkins Lymphoma; and prostate. The findings from the survey's formal measures have recently been published (DH 2012). The survey also incorporated a final question inviting participants to make comments on anything more they wished to highlight concerning the experience of living with and beyond cancer. This report describes participants' responses and shows how such data can provide rich insights into patients' needs, which can be used to support improvement initiatives.

Method

A cross-sectional population-based postal survey was conducted of a random sample of individuals identified as having been diagnosed with breast, colorectal, non-Hodgkins lymphoma or prostate cancer one, two, three and five years earlier. A total of 4,992 patients were equally distributed between the cancer groups and cohort years, giving an initial sample of 312 in each cohort year and cancer group. Questionnaires were developed for each cancer group, each with a final open-ended free-text question, with the header: *'If you have anything else you would like to tell us about living with and beyond cancer, please do so here:'*.

Comments were analysed using the NVivo software package, using a two stage approach. Firstly, a conventional qualitative content analysis was conducted, involving open coding of all comments and the identification of broad themes within an initial framework. A second level of analysis was then undertaken to identify patterns and relationships within the data and to build a conceptual model of the experiences of cancer survivors. The number of participants writing about a particular theme are not seen as 'representative' of the views of the sample as a whole as they reflect only what individuals chose to write. Nevertheless, simple counts of the number of times a particular issues is raised are used to illustrate the proportion of comments that addressed particular themes, and when an issue was raised frequently, weight was attributed to this as reflecting an important element of experience.

Objectives

The study explored how participants utilised the opportunity to make free text comments as part of the England PROMs survey programme for cancer, and examined how emerging themes complement formal patient reported outcome measures (PROMs) to provide understanding of quality of life issues for cancer survivors.

Findings: Phase 1: Content analysis

Questionnaires were sent to 4992 patients, 126 (2.5%) of whom were found to have moved or died prior to receiving the questionnaire so the final sample size was 4866. Some 3,300 completed questionnaires were received back with an overall response rate of 68%, of whom 1056 (32%) added material to the free text comments box.

Comments were initially coded within three broad themes. The first theme captured participants' experiences of cancer diagnosis and treatment, and almost a fifth (n=209) of participants reported that they had experienced excellent or very good overall care. Positive comments reported by participants included; appreciation of timely diagnosis through screening programmes or by professionals who acted promptly to investigate reported symptoms; being treated with dignity and respect by health care professionals; being provided with information and advice; and that having trust in the system and in health care professionals contributed positively to their recovery.

However, a number of participants (n=81) reported negative experiences of care during the treatment phase in the comments box though these only represented 7% of all comments. The most commonly reported negative experiences involved '*unacceptable*' delays in the diagnostic process and GP referrals to specialist consultations. Other negative comments included many complaints concerning organisational problems: delays in treatment; poor communication with patients caused by unreliable hospital administrative processes; repeated cancellations and delays to clinic appointments; and delays to non-urgent treatment such as reconstructive surgery. There were also a few reported instances of inadequate care, including very poor nursing care, and some complaints concerning poor quality hospital food and car parking charges at hospitals.

A second theme incorporated participants' experiences of living beyond cancer and it was evident that a wide range of on-going physical, psychological and social problems impacted negatively upon their quality of life. Physical problems were reported by 86 participants, primarily the side-effects of cancer treatment (e.g. surgery, chemotherapy, radiotherapy and hormone therapy) and included: problems with bowel and urinary incontinence; constipation; cognitive problems and diminished memory; pain; impotence/ sexual difficulties; fatigue and peripheral neuropathy. On-going psychological problems were reported by 122 participants, which were either a consequence of having had cancer (e.g. fear of recurrence, difficulty planning ahead, fears that the disease will be hereditary and affect their children) or a consequence of the on-going physical problems they experienced (e.g. poor body image, depression). For example, some participants reported poor body image following breast surgery or stoma formation, and many men who had undergone prostate surgery or were being treated with hormone therapy experienced impotence that led to depression.

Some participants (n=36) reported that they believed they had been insufficiently prepared for the potential impact that the cancer diagnosis and the side effects of cancer treatments

might have on their lives. Participants also reported a corresponding lack of information regarding possible coping strategies that might mitigate these effects. Many participants (n=83) also reflected upon their experiences of aftercare, with the majority (n=52) reporting negative experiences. Feelings of being '*cut adrift*' by the health care system once primary treatment was completed were common, which left participants feeling '*lost*' and '*in limbo*'. A perceived lack of aftercare reported by many participants may have contributed to these feelings of isolation and loneliness, and the contrast between good hospital treatment and a lack of aftercare was a source of comment. Several participants who had received treatment as private patients found they were not then picked up by NHS aftercare provision. As part of aftercare many participants commented that there was a need for more practical and psychological support for cancer survivors and their carers. Participants (n=62) also identified several social factors that impacted negatively upon the quality of their lives, including: the stresses of coping with a cancer diagnosis and side effects of treatment when combined with responsibilities for caring for others, particularly children or older parents; a lack of practical support; financial worries and the need to return to work. These social concerns were often linked to on-going physical and psychological factors, which may then compound one another. For example, when respondents mentioned their caring responsibilities they were often accompanied by fears of recurrence and concerns about who would take on these responsibilities should the cancer return. Similarly, financial worries were often caused by respondents not having been able to work for some time, especially amongst self-employed individuals, and these worries often contributed to feelings of depression and anxiety about the future. Difficulties claiming benefits and negotiating with employers regarding a return to work were also widely mentioned. Participants reported a need for advice and support in these regards, and there were suggestions that employers should be provided with information regarding the potential on-going problems that survivors may experience.

Despite the reported lack of preparation many participants received for the side effects of their treatment, a large number of coping strategies were adopted. The most common of these strategies included: focussing upon the '*positive*' aspects of one's life; adjusting work-life balances and adopting healthier lifestyles; gradually increasing activity and social life as a way of getting life back to normal, including a return to work; the use of complementary therapies such as reflexology, aromatherapy, yoga, counselling and talking therapies; and volunteering as a way of maintaining activity and to '*give something back*' in return for the care they had received. Some 56 participants indicated that the support they received from their family and friends and from various charities assisted their recovery and in coping with issues related to survivorship.

Many participants (n=172) commented upon their co-morbidities and old age as on-going problems. Although these varied widely, comorbidities predominantly included hypertension, arthritis, osteoporosis, long-term back pain and general problems relating to old age. However, many also reported that the symptoms caused by comorbidities were as severe as or greater than those caused by their cancer or cancer treatment, and consequently some acknowledged that the negative answers they had given within the PROMs survey reflected their comorbidities rather than their cancer disease or treatment.

A third broad theme captured comments that seemed unrelated to the experience of living with or beyond cancer. Such comments included: criticisms of the questionnaire (n=21), including its structure and terminology; complaints concerning the way the questionnaire was delivered (n=24); dispassionate descriptions by participants of their disease and

treatment pathways (n=116); and miscellaneous comments that were not explicitly related to the experience of living with or after cancer.

Findings: Phase 2: Development of conceptual model

In addition to the content analysis that categorised the ways in which participants chose to respond to the comments box, a second level of analysis was conducted to identify patterns and relationships between the categories of response that emerged from the data in order to build a conceptual model of participants' experiences (see figure 1). Central to this model are the outcomes reported on by participants, including: aspects of their physical and psychological recovery; their level of confidence in the future; and their level of ability to self-manage on-going physical and psychological problems related to the cancer and its treatment.

Six factors emerged from the data that appeared to either positively or negatively impact upon these interrelated outcomes these were:

1. The emotional impact of receiving a cancer diagnosis may create feelings of uncertainty, fears of recurrence and difficulty planning for the future.
2. Quality of life appeared to be influenced by earlier experiences of care during cancer treatment, and where this was perceived to have been efficient and co-ordinated, with effective communication within the treatment team, a positive and confident sense of the future appeared to be engendered.
3. Comorbidities could be an additional burden and had often been exacerbated by cancer treatment, leading to slower recovery and reduced confidence.
4. Cancer treatment very often caused side-effects that negatively impacted upon the physical functioning and quality of life of participants.
5. Social and financial difficulties were common, including caring responsibilities, inability to participate in social activities, debt and financial worries due to pro-longed inability to work, and the need to return to work before they felt ready. Such social problems were sometimes also influenced by poor physical functioning.
6. Inadequate preparation for the potential impact of cancer and its treatment, either by being uninformed about possible physical side effects of treatments, being unaware of the potential psychological impact of a cancer diagnosis and treatment side-effects, not being provided with equipment to manage practical difficulties; and not being advised of potential coping strategies to adopt.

By examining the comments of participants who report good experience and who have learnt to manage on-going problems it was possible to identify the various factors that helped mitigate what might potentially have led to poor life quality. These mitigating factors fell into two groups: professional-led and survivor-led. Survivors describing good experiences often praised the well-coordinated care they had received while undergoing investigations and treatment and had been sufficiently prepared by health professionals for problems associated with cancer and treatment side-effects. Professional-led mitigating factors also included quality aftercare, provided by named health care professionals especially clinical nurse specialists, who supported the development of self-management strategies and with whom survivors could remain in contact and discuss problems as they arose. This level of

continuity often addressed the hiatus that many experienced at the end of their treatment, helped reduce fear of recurrence and increased confidence in the future.

Patient-led mediating factors included self-learning and focussing on the positive. Many participants who coped well with on-going problems had reportedly done so themselves, through a process of trial and error, or through talking to others with similar experiences. Participants had adopted various strategies, such as focussing upon the '*positive*' aspects of life; adjusting work-life balances, adopting healthier lifestyles; gradually increasing activity and social life as a way of getting life back to normal, return to employment or voluntary work; and the use of psycho-social and complementary therapies. The teaching of potential strategies to manage physical problems such as bowel and urinary incontinence, fatigue and sexual difficulties, transcends both patient preparation and aftercare, and several participants argued that affordable access to interventions such as counselling and talking therapies should be available to address issues like altered body image and fear of recurrence.

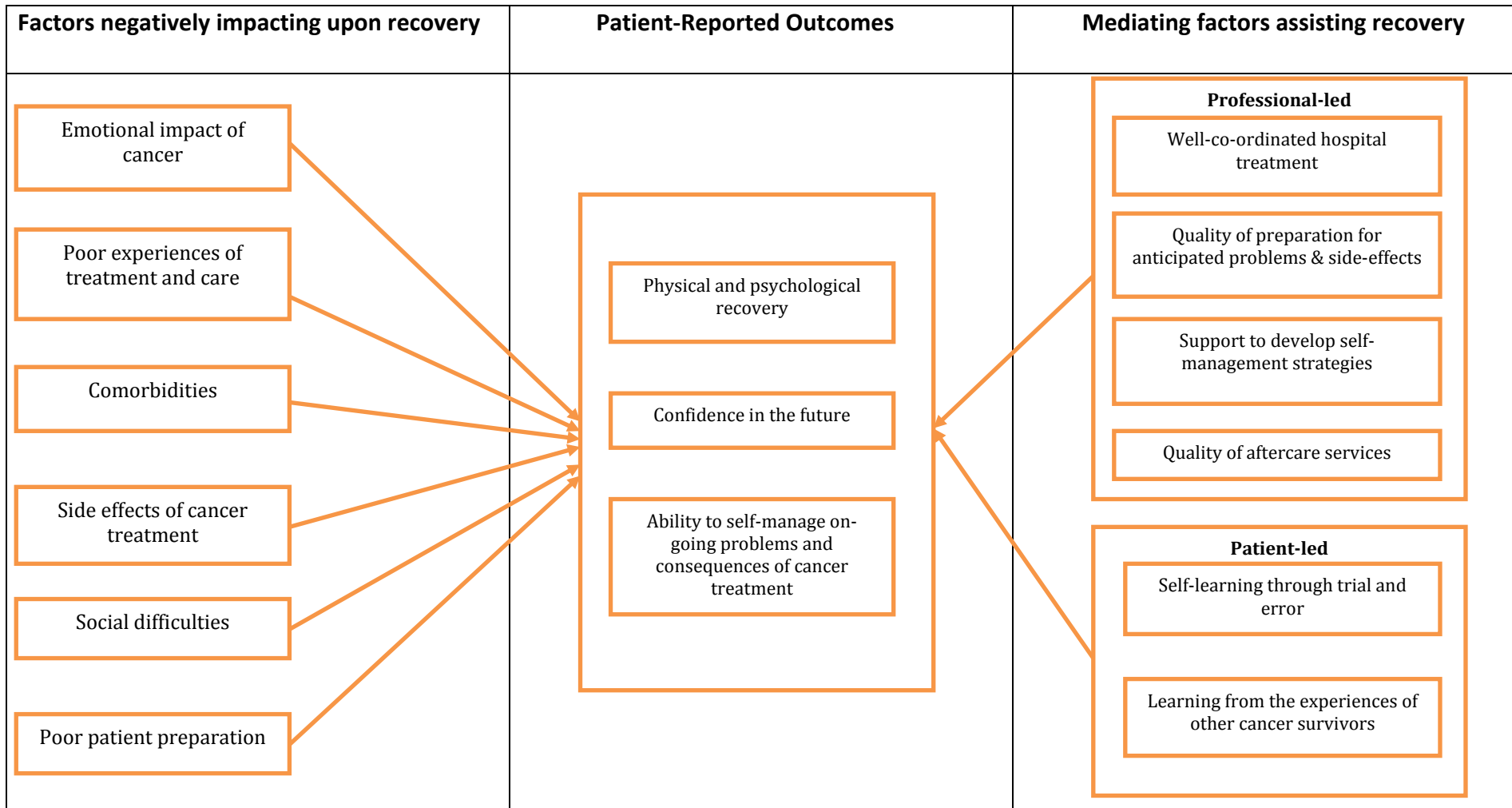
Discussion

This analysis of free-text comments within the pilot PROMs survey complements quantitative analysis of the formal measures by illuminating relationships between factors that impact upon quality of life (QoL) or mitigate against negative effects. These insights can be passed on to NHS providers to help improve quality of patient experience. This approach adopted alongside formal PROMs measures, demonstrates that individuals actively engage with the opportunity to provide comments relating to their experiences, providing data relating to 'why?' health outcomes are reported in formal measures, and illuminating insights from statistical analysis. The free text comments thus support the quantitative findings of the PROMs survey (DH 2012), but also complement them by allowing participants to indicate important issues of priority to them. The study findings can therefore assist policy makers to decide how to target system improvement efforts and to identify risk profiles within the English cancer population. Several recommendations supported by the findings are given below.

Participants described the impact of treatment upon comorbidities, and identified many on-going physical, psychological and social problems that they continued to face many months and years after the completion of treatment. These problems were similar to those reported in previous studies, and were reported across all four tumour groups and time-points from cancer diagnosis, indicating these are widespread and enduring. However, participants often indicated that they had little preparation about what to expect with regards potential physical and psychological impact of the cancer and treatment side-effects. This finding is also supported by previous research showing that cancer survivors do not receive optimal levels of information about life beyond cancer treatment.

Participants reported they lacked information regarding possible strategies for dealing with their on-going problems, while research evidence to date regarding the effectiveness of many such potential self-management approaches remains limited. Recent evidence suggests that patients want more information concerning long term effects of cancer and treatment, and to be given psycho-social support and strategies for self-management. There is a clear need for consideration to be given as to how to improve care for these patients. A fundamental shift is currently underway in the way that cancer survivors are supported after treatment, as part of the Department of Health for England National Cancer Survivorship Initiative and other similar initiatives worldwide. These data indicate that the DH PROMS

Figure 1: Factors impacting upon quality of life outcomes



programme for cancer has the potential for providing data to evaluate the effectiveness of such initiatives in relation to conventional health measurement tools in the form of PROMS and also through feedback framed by patients themselves.

Conclusion

The comments elicited from individuals participating in the Department of Health England, Cancer PROMs Survey reinforce the need for greater emphasis to be given by cancer services to supporting individuals to manage following completion of cancer treatment. Preparation and support for life after cancer treatment is urgently needed. Individuals are often ill prepared for the physical consequences of some treatments for cancer and the psychological aftermath of both receiving a diagnosis of a potentially life threatening illness and the impact of on-going physical side-effects of treatment. The absence of early interventions to investigate and treat serious on-going physical problems that result from certain treatments for cancer is unacceptable. The potential for early intervention and more systematic preparation for individuals to self-manage post treatment problems should therefore be explored.

Implications for practice / Recommendations

The responses of participants to the free text comments box in the Cancer PROMs survey would support the following recommendations:

Quality patient care during the treatment phase:

- During the treatment phase cancer patients need care to be: delivered in a professional and caring way; coordinated with no unnecessary delays to investigations and treatment; accompanied by the opportunity to receive full information about their diagnosis and treatment options;

Preparing patients for survivorship:

- Patients need to be fully informed about the potential physical effects of treatment, and have access to advice about self-management, including how to access post treatment support services;
- Patients need to be informed that psychological issues might take a greater significance in their lives once active treatment is completed and they no longer have regular contact with Health Care Professionals;
- Patients need to be aware of the potential psychological problems they might experience as cancer survivors, and have access to information and advice about possible coping strategies;
- Patients need access to advice to help overcome social and financial problems, including: the availability of social services; their eligibility for state benefits; and their rights concerning returning to work;

Supporting patients during survivorship:

- The current shift towards more personalised aftercare approaches that encourage patients to self-manage their symptoms needs to be accompanied by access to both effective practical and psycho-social support.

1. Introduction

There are currently about 2 million people living with or beyond cancer in the UK and this is rising by approximately 3% every year (Maddams et al 2009). Life expectancy for individuals diagnosed with cancer has doubled over the last 40 years and the majority of individuals with common cancers can expect to live for 10 years or more (CRUK 2007). These developments are transforming the experience of cancer from one where in the past, the disease signalled a potentially life threatening illness, to one where today we are beginning to think of cancer as a long-term or chronic condition (Tritter & Calnan 2002). As a result it is increasingly important that the problems patients face following treatment, and how these can be addressed are understood. There is growing recognition that people living with cancer need support during the survival phase of their illness (Armes et al 2009, Corner 2008, Elliott et al 2011), and may experience significant on-going physical, psychological and social needs (Foster et al 2009, Davis & Batehup 2011, Harrison et al 2011). Other, now seminal, studies show how individuals undergo a process of recovery, adjustment and renegotiation of identity as cancer is assimilated as a life changing and long term illness, and individuals respond to the stigma of cancer, a process that is not addressed by conventional 'medical' management approaches (Mathieson & Stam 1995). More recently a multidimensional model of recovery following cancer treatment has been proposed (Foster & Fenlon 2011).

An increasing recognition that Patient-Reported Outcome Measures (PROMs) can convey important information for assessing the overall cancer burden and the effectiveness of interventions has led to much work to develop psychometrically sound and clinically meaningful PROMs applicable to a range chronic conditions (Lipscombe et al 2007a, 2007b, 2012), although more qualitative work has been called for to examine the processes that contribute to outcomes (Lipscombe et al 2007a). Much of this work has been carried out by the Patient-Reported Outcomes Measurement Information System (PROMIS) cooperative group (Garcia et al 2007, Cella et al 2007, Fries et al 2009, 2005). At the same time, a growing number of surveys across the US and Canada are being undertaken to collect data on cancer survivors, although as a recently published systematic review confirms (Lerro et al 2012), perceived quality of care or on-going needs have received little attention in such surveys. There has also to date been little research to systematically determine quality of life related outcomes on a health system wide basis over the long term or as to how health systems can best respond to needs identified for patients following primary treatment for cancer (Foster et al 2009, Richardson et al 2011, Lerro et al 2012). Within the UK the measurement of outcomes, improving patient experience, and enhancing quality of life for people with a long term condition (LTC) is a Department of Health priority (DH 2011).

The National Cancer Survivorship Initiative (NCSI) was launched in 2007 as a key element of the Cancer Reform Strategy (DH 2007) and the Improving Outcomes Strategy for Cancer (DH 2011). The NCSI is a partnership between the Department of Health, Macmillan Cancer Support and is supported by NHS Improvement, with the aim of supporting survivors to live as healthy and active lives as possible for as long as possible. Part of this aim requires a better understanding of the needs of those living with cancer, but there has to date been little research to systematically determine quality of life related outcomes or how the health system can best respond to needs identified for patients following primary treatment for cancer (Foster et al 2009, Lerro et al 2012, Richardson et al 2011).

The National Cancer Survivorship PROMs Survey was undertaken to establish that reliable information can be collected on the long-term and unmet needs of those living with and beyond a cancer diagnosis, using a cross-sectional survey of patient reported outcome

measures (PROMs) for four common cancers: breast; colorectal; non-Hodgkins Lymphoma; and prostate (DH 2012). The survey also incorporated a final comments box at the end of the questionnaire inviting participants to make comments on anything more they wished to highlight concerning living with and beyond cancer. This report describes participants' responses to the comments box and shows how such data can provide rich insights into patient's needs, which can be used to support improvement initiatives (Robert et al 2011).

Objectives

The study explored how participants utilised the opportunity to make free text comments as part of the England PROMs survey programme for cancer, and examined how emerging themes complement formal patient reported outcome measures (PROMs) to provide understanding of quality of life issues for cancer survivors.

2. Methods

2.1 Study design and process

A cross-sectional population-based postal survey was undertaken of a random sample of individuals identified as having been diagnosed with breast, colorectal, non-Hodgkins lymphoma or prostate cancer one, two, three and five years earlier.

Setting

In England, regional cancer registries maintain population based records of cancer diagnosed in England. The study sample was identified through data held by three cancer registries (Thames Cancer Registry, Eastern Cancer Registry and Information Centre, West Midlands Cancer Intelligence Unit).

Cohort Identification

The cancer registries provided information on all recorded cases of the four included cancer diagnoses registered as being diagnosed between 01/02/2010 - 30/04/2010 (one year ago), 01/02/2009 - 30/04/2009 (two years ago), 01/02/2008 - 30/04/2008 (three years ago), 01/02/2006 - 30/04/2006 (five years ago). Registry recorded cases with the appropriate ICD10 codes were excluded if they were; under the age of 16 years, not alive, non NHS patients, not known to have a UK postal address.

The individual study cohorts for each cancer at time points one, two, three and five years from date of recorded diagnosis were compiled through identification of the 312 cases diagnosed most closely to a specified time-point (First of February for each year), irrespective of the registry source. The overall total of 4,992 patients was split equally between the tumour groups and cohort years, giving an initial sample of 312 in each cohort year for each of the four tumour groups. Patients were randomly selected and are therefore representative of all cases.

Questionnaire design and content

Questionnaires, with generic and specific items, were developed for each of the four cancer groups. Content was identified through review of the literature and consultation with patient groups, cancer charities and tumour-specific expert advisory groups: Department of Health Specialist Advisory Groups (Breast, Colorectal, Haematology and Prostate), National Cancer Intelligence Network (NCIN) Site Specific Clinical Reference Groups and the Department of Health Cancer PROM Group. A number of PROMs measures were included in the survey, including: the EQ5D (Group 1990, Herdman et al 2011); the Social Difficulties Inventory (Wright et al 2005, 2006, 2011); Functional Assessment of Cancer Therapy (FACT) (Webster 2003); items from the Supportive Care Needs Survey (Girgis et al 2011) and the Electronic Patient-Reported Outcomes for Cancer Survivors Study (Ashley et al 2011); experience of care questions (Sheldon & Sizmur 2010); and a free text comments box. Cognitive testing was performed and alterations were made to the questionnaires post cognitive testing.

Survey Process

Identified participants were sent a questionnaire by post by the survey provider, Quality Health. These were sent under cover of a letter from the cancer centre recorded by the cancer registry as having most recently provided treatment. Participants consented to taking

part in the survey by returning questionnaires. Two reminders were sent to non-responders. Quality Health ran a national freephone helpline for participants, and supported completion of the survey through textphone and language translation facilities if requested.

2.2 Ethics and governance

The National Information Governance Board (NIGB) approved an application from the Department of Health for Section 251 authorisation under the 2006 Act for the Cancer Survivorship Survey pilot. The NIGB gave approval to the Department of Health, as the sponsor of the survey. The UK Association of Cancer Registries (UKACR) provided approval for the study. Ethical review was not sought for this survey as it was performed as a service evaluation and the National Research Ethics guidelines state that *'audit and service evaluation do not warrant mandated REC review'* (NRES 2010). Survey participants had access to a telephone support line that could be used to discuss any issues raised by the survey.

2.3 Analysis

The open-ended free-text question was placed at the end of the questionnaire, following the closed questions, with the header: *'If you have anything else you would like to tell us about living with and beyond cancer, please do so here:'*. Comments were analysed using the NVivo software package (Gibbs et al 2002), using a two stage approach. Similar analyses of comments within quantitative surveys have previously been used to research health service issues (Richards et al 2009, Baille et al (2009).

2.3.1 Phase 1 – Content Analysis

Firstly, after careful reading and data immersion (Miles & Huberman 1994), one researcher (RW) conducted a conventional qualitative content analysis (Hsieh & Shannon 2005), open coding all comments and identifying broad themes within an initial framework. Categories were developed inductively, were exhaustive and mutually exclusive (Elo & Kyngas 2008). The preliminary coding schema was then discussed with a second researcher (JC) and revised before all data within each code was re-examined, with some codes combined (Robson 2002).

The number of participants writing about a particular theme are not seen as 'representative' of the views of the sample as a whole as they reflect what individuals chose to write (Jackson & Trochim 2002). Nevertheless, simple counts and percentages are used to illustrate the proportion of comments that addressed particular themes, and when an issue was raised frequently, weight was attributed to this as reflecting an important element of experience. Throughout the process, peer debriefing and negative case analysis was undertaken to ensure credibility and validity of the analysis (Lincoln & Guba 1985).

2.3.2 Phase 2 – Development of conceptual model

A second level of analysis was then undertaken to identify patterns and associations within the data and to build a conceptual model of participants' experiences as cancer survivors (Ritchie et al 2003, Miles & Huberman 1994). The focus of this later stage of analysis was on underlying issues, relationships and causes that may generalise beyond individual cases. The analytical framework and how it was applied to the data were repeatedly discussed between the two analysts (RW and JC) to ensure credibility and trustworthiness of the analysis.

3. Overview of response by participants

Questionnaires were sent to 4992 patients, 126 (2.5%) of whom were found to have moved or died prior to receiving the questionnaire so the final sample size was 4866. Some 3,300 completed questionnaires were received back with an overall response rate of 68%, of whom 1056 (32%) added material to the free text comments box.

3.1 Demographics

Overall there were a relatively equal proportion of participants to the text box question from within the categories of tumour group, time from initial diagnosis, gender and age.

3.1.1 Participants from different tumour groups

The PROMS survey was sent to equal numbers of survivors from the four tumour groups. As the table below shows, the proportion of participants from each tumour group and time from initial diagnosis was relatively similar, with a range of 57 participants who were 1 year from diagnosis of colorectal cancer to 82 participants in the 5 year post-diagnosis breast cohort. The tumour group with the largest proportion of participants was breast cancer.

Table 1: Participants' tumour groups by time from initial diagnosis

Cancer type	1 year ago	2 years ago	3 years ago	5 years ago	Total
Breast	71	70	67	82	290
Colorectal	57	67	70	64	258
Prostate	69	67	50	69	255
Non-Hodgkins Lymphoma	68	67	63	55	253
Total	265	271	250	270	1056

3.1.2 Gender

As the table below indicates there was a relatively equal proportion of male and female participants, with only slightly more that were male.

Table 2: Gender of participants by tumour group

Tumour Group	Male	Female	Total
Breast	1	289	290
Colorectal	143	115	258
Prostate	255	0	255
Non-Hodgkins Lymphoma	138	115	253
Total	537	519	1056

3.1.3 Age groups

The table below shows the age groups of participants, for each tumour group and for gender. There were very few participants in the youngest age group (<34), which reflects the overall numbers for the PROMs survey. The ages of participants were calculated from 'year of birth' rather than 'date of birth', and are therefore approximate. Nevertheless, participants' ages ranged from approx. 25 years (born in 1986) to approx. 101 years (born in 1910), with a mean age of 67.9 years, and the largest age group being those aged between 65 – 74 years.

Table 3: Participants' age groups and gender by tumour group

Age (years)	Breast		Colorectal		Prostate		Non-Hodgkins Lymphoma		Total
	Male	Female	Male	Female	Male	Female	Male	Female	
< 34	0	1	1	0	0	0	2	4	8
35 – 49	0	41	4	6	1	0	15	13	80
50 – 64	0	120	29	30	44	0	43	38	304
65 – 74	1	76	50	33	108	0	34	35	337
75+	0	51	59	46	102	0	44	25	327
Total	1	289	143	115	255	0	138	115	1056

Note: Ages are approximate as they were calculated using 'year of birth' rather than 'date of birth'.

3.2 Overview of findings

Table 4 below categorises the principal ways in which individual participants chose to use the text box. Participants' comments were first categorised between three over-riding themes: experiences of cancer diagnosis and treatment; experiences of living beyond cancer; and issues unrelated to living with or beyond cancer. A number of sub-categories and categories then emerged from the data encapsulating all the various ways in which participants chose to respond, but which fell within one of the three over-riding themes.

The number of participants that provided comments relating to each category are provided in the table along with the percentage of the total number of participants (n=1056). However, only counts are given for each sub-category as the percentage was often very small. Participants often provided comments that were coded into more than one subcategory, thus the number of participants indicated within each category is not the sum of all the subcategories. Caution must also be exercised when using such numbers as they cannot be interpreted as being 'representative' of the sample as a whole, but reflect only what individuals have chosen to write about (Jackson & Trochim 2002).

Table 4: Thematic framework of participants' experiences of living with and beyond cancer

Theme	Category (n)	Sub-category (n)
Experience of cancer diagnosis and treatment	Positive experiences (n=209)	Excellent/ good general care (n=63)
		Timely diagnosis (n=19)
		Coordinated care (n=17)
		Excellent/ good health care professionals (n=115)
		Diagnosis and treatment delays (n=18)
	Negative experiences (n=81)	Poorly coordinated care (n=13)
		Lack of support from staff (n=12)
		Appointment cancellations (n=10)
		Poor explanations / patient communication (n=24)
		Poor in-patient care (n=17)
Experiences of living beyond cancer	Lack of preparation by services (n=36)	Car parking charges (n=5)
		Lack of information on treatment side-effects & diagnosis (n=29)
		Lack of information concerning possible psychological impact of cancer and treatments (n=10)
	Experiences of aftercare services (n=83)	Lack of information on self-management strategies (n=5)
		Positive experiences of aftercare services (n=31)
		Lack of aftercare provision (n=35)
	Experiences of living with co-morbidities (n=185)	Poor patient communication (n=13)
		Lack of GP involvement (n=4)
	On-going Physical problems (n=86)	Impact of co-morbidities on quality of life (n=126)
		Impact of co-morbidities on survey answers (n=37)
Bowels (n=28)		
Cognitive problems/memory loss (n=13)		
Pain (n=22)		
Impotence/ sex difficulties (n=30)		
Fatigue (n=29)		
Peripheral neuropathy (n=10)		
Urinary problems (n=19)		
Hot flushes (n=6)		
On-going emotional /psychological problems (n=122)	Other physical problems (n=20)	
	Anxiety (n=7)	
	Poor body image (n=14)	
	Depression/ feeling isolated (n=34)	
	Fear of recurrence (n=50)	
	Genetic concerns for relatives (n=8)	
On-going social and financial problems (n=62)	Other psychological problems (n=15)	
	Impact of cancer on friends/relatives (n=14)	
	Financial worries/ benefit problems (n=34)	
	Caring responsibilities (n=17)	
Coping/ self-management strategies (n=149)	Lack of social services support(n=14)	
	Keeping active (n=29)	
	Returning to employment (n=20)	
	Use complementary therapies (n=13)	
	Acceptance (n=18)	
	Maintain 'positive' approach (n=41)	
	Adopting healthier lifestyles (n=8)	
	Avoidance (n=3)	
	Adjusting work-life balance (n=2)	
	Pacing oneself (n=3)	
	Religion (n=4)	
	Talking therapy (n=6)	
	Volunteering (n=6)	
Advice to others (n=18)		
Social support (56)	Finding benefit within cancer experience (n=2)	
	Supportive families (n=47)	
No problems experienced (n= 30)	Charities and support groups (n=9)	

Theme	Category (n)	Sub-category (n)
Issues unrelated to the experience of living beyond cancer	Description of disease and treatment pathway (n=116)	
	Issues related to receiving questionnaire (n=9)	Question-raising amongst participants (n=7)
		Psychological impact of survey (n=2)
	Complaints about delivery of questionnaire (n=24)	Sent to wrong address (n=13)
		Query whether appropriate recipients (n=11)
Criticisms of questionnaire (n=21)		
Miscellaneous (n=24)		

Note 1: Categories and subcategories are mutually exclusive, but individual participants often provided free-text comments that were divided between more than one category. Thus, numbers do not add up to 1056.

4. Experiences of cancer diagnosis and treatment

Many participants used the text box to relate their experiences of the diagnostic and active treatment phases of their disease, and a large majority of these were positive. However, not all experiences of treatment were good and there are a large number of comments that indicated where participants felt this fell short.

4.1 Positive treatment experiences

Almost a fifth (n=209) of participants related experiences of excellent or very good care. Very many comments reflected a sense of gratitude to health care professionals and the NHS in general for excellent care provided. Experiences described included: timely diagnosis and treatment; support to 'get through' treatment; good team-working between different health care professionals; and good communication between HCPs and patients. Such experiences engendered great confidence amongst many respondents in the way the system worked.

4.1.1 Excellent/ good general care

Participants (n=63) often conveyed a general sense of gratitude to the health professionals with whom they had come into contact and to the wider NHS for excellent or very good care provided, although these comments were often quite brief.

'I had the best treatment and care during my cancer treatment. The hospital staff were wonderful and caring and I couldn't have wished for a more caring and professional treatment.' (Colorectal, 1 year, Female)

Several participants also commented that the excellent care and support they had received positively contributed to their recovery, and had engendered a level of trust that might even help alleviate some of their fear of recurrence:

'I have had tremendous support and treatment from [location removed] and cannot speak highly enough of all the staff with whom I have come into contact. The support has been invaluable and has made all the difference both physical and mental to my recovery. It is now 2 years since my original surgery and I know that the staff there will deal (and have already dealt) with any concerns.' (Colorectal, 2 year, Female)

'Should there be a recurrent cancer, I have total confidence in the staff and treatment which will be provided at the [hospital name removed].' (NHL, 1 year, Female)

The gratitude that some participants felt for such good care was sometimes expressed in a desire to 'give something back': to help others now facing the same diagnosis and treatments.

'I personally was so pleased from everyone involved with me from the NHS. That after my operation to remove my prostate last year. I wanted to give something back. I have for the last 10 months been a volunteer in the urology dept. at [name removed] hospital. It is something I thoroughly enjoy! I talk to new and old patients, just talk really!' (Prostate, 1 year)

Some participants reported that they had undergone some of their treatment privately, and in almost all instances they reported their experiences of the NHS compared favourably with the private care they had received.

'I feel confident that I received the best possible treatment - [name removed] hospital recommended consultants. I was a private patient, but it has been made clear that NHS clinic

had the best experience, skills, doctors and nurses.' (Female participant with NHL, 5 years after diagnosis)

'I have private health care and found the dipping in and out did not always work. If anything the NHS staff are more knowledgeable.' (Female participant with breast cancer, 2 years after diagnosis)

However, one participant complained that she had had to utilise private healthcare in order for her to access particular treatments that were not available within the NHS.

'I have a rare deviant of mantle cell lymphoma. The drug [drug name removed] is [word unreadable] for all other lymphomas that require it apart from Mantle cell. NICE inform me that the Dept. of Health have never asked for [drug name removed] to be [word unreadable] for mantle cell lymphoma although all clinical consultants consider [word unreadable] essential. This has meant my moving myself to the private sector - something about which I am not happy - as my insurance will finance the drug. This is immoral and totally discriminatory against those who have mantle cell and who do not have private medical insurance.' (Female participant with NHL, 3 years after diagnosis)

4.1.2 Timely diagnosis – screening programmes

Some participants (n=19) expressed gratitude that they had experienced a timely diagnosis that led to fast and appropriate treatment. Several of these participants particularly praised the routine screening programmes that led to their early diagnosis and treatment.

'I will be forever grateful for my routine over 50 mammogram where my cancer was identified in February '08. Fortunately I feel well now. Throughout my diagnosis and treatment I felt well supported by the whole team of doctors and nurses. Treatment and surgery was planned in a very timely manner. I had trust in the people responsible for my care. Thank you to all the professionals involved.' (Female participant with breast, 3 years after diagnosis)

'I believe I was very lucky for the illness to be discovered by the Bowel Screening Programme. Also I had a good consultant/surgeon who did a good job.' (Male participant with colorectal cancer, 2 years after diagnosis)

4.1.3 Coordinated care

Participants (n=17) were reassured by experiences of co-ordinated treatment and care, which involved good communication between different hospital departments and staff, and the provision of adequate information to patients and their carers.

'I was very impressed with the speed with which I received my mammogram appointment (one week after seeing my GP), then having the biopsy the same day and received the diagnosis a week later. The subsequent treatments and surgery followed without any hitches. I am now in a regular cycle of 6 monthly check-ups, which is very reassuring.' (Female participant with breast cancer, 1 year after diagnosis)

'Excellent haematology/oncology team at [name removed] - they communicate well and have provided excellent care. The Macmillan nurses attached to the team were invaluable in providing information and care.' (Female participant with NHL, 3 years after diagnosis)

4.1.4 Excellent/ good health care professionals

There were many comments from participants (n=115) that praised the efforts of specific health care professionals, especially doctors, Clinical Nurse Specialists (CNSs) and Macmillan nurses. Praise was particularly evident where participants described clinicians who had been particularly proactive in their care:

'I found that I could not find a better surgeon. [name removed]. He did not give up and found the cancer (3 attempts) in the early stages.' (Female participant with colorectal, 3 years after diagnosis)

'Specialist nurses were fantastic. Were there at the beginning of the process, right through to the end of treatment. Can always call if I am at all concerned or worried.' (Female participant with breast cancer, 2 years after diagnosis)

'I never think about it - as if it never happened. The credit goes to the original doctor ([name removed]), after being called back from a routine mammogram. The second biopsy came back as negative. But the doctor was convinced this was wrong because the cancer was that small. Another biopsy - on her say so - was positive. Two years down the line, I would have felt a lump!! Well done as well to the surgeon and nursing staff at [location removed].' (Female participant with breast cancer, 2 years after diagnosis)

One participant commented upon the important support she had received from a CNS during the treatment phase, support that was later lacking when the nurse left and was not replaced:

'When I was first diagnosed, and quite a bit into my treatment, there was a specialist cancer nurse to contact which was brilliant. She really helped with all the stuff I didn't want to bother the consultant with (hair loss issues, how to feel yourself when not looking yourself, contact/follow up between the chemo team/surgical team/radiology team, anxiety, etc., etc.). Then she left and was not replaced - suddenly there was nobody to contact, which was a bit unsettling. I do hope for future patients that the cuts will not hit this particular and very important part of breast cancer treatment - she was always there to listen and give advice, but also offered moments of giggling over ridiculous turban tying issues in a way that sad and worried friends and family couldn't. So please save the specialist cancer nurses!' (Female participant with breast cancer, 2 years after diagnosis)

4.2 Negative experiences of care

There were also some negative experiences of the treatment phase related by participants (n=81), who often contrasted aspects of their care that were good with some that were very poor. In particular there were comments contrasting good patient care provided by individual health care professionals and a sometimes inefficient bureaucracy. Participants' negative experiences ranged from *'unacceptable'* delays in the initial diagnosis of cancer that may have impacted upon eventual treatment options and prognosis, to very poor in-patient care, to unreliable administrative processes and repeatedly cancelled/ delayed clinic appointments. Such experiences contributed to the stress related to cancer diagnosis and treatment.

4.2.1 Diagnostic and treatment delays

Comments relating to bad experiences sometimes concerned delays in the diagnostic process. In particular, participants (n=18) from all four tumour sites complained that there had been inappropriate delays to the start of their treatment caused by GPs failing to

recognise symptoms indicative of cancer, not ordering appropriate investigations or referring participants on for specialist consultation. Several participants reported that they were not diagnosed until they became pro-active and insisted something be done or else they were admitted to hospital when their condition worsened. Participants sometimes questioned whether their treatment would not have been more moderate and their prognosis more positive had they been diagnosed earlier.

'There was an unacceptable delay (5 weeks) in my diagnosis - I was diagnosed with mastitis and referred to hospital after the 2nd round of ineffective antibiotics - when I was eventually given an appointment at breast clinic. I was again prescribed another course of antibiotics and appropriate tests (i.e. mammogram, biopsy, scans) were not performed. I then went back to GP and referred back to breast clinic as emergency. At that appointment I was given a mammogram and told I would have to return 2 weeks later for a biopsy - it was only at my insistence that the biopsies were performed that day - if I had not done this the resulting delay could have had catastrophic consequences as the type of cancer I had was extremely aggressive and needed immediate attention. The delay caused further mental trauma which could have been avoided!' (Female participant with breast cancer, 2 years after diagnosis)

'My main concern is not living with cancer but what led up to my treatment. For two years I was being treated for an ulcer, it was not until I was admitted to hospital with sickness and a stomach pain that I was diagnosed with cancer.' (Male participant with colorectal cancer, 1 year after diagnosis)

Once they had received a diagnosis, some participants (n=13) commented on delays they experienced to their treatment due to bureaucratic and administrative problems. Again, in some instances participants believed they needed to be proactive to ensure they received the care they needed.

'The treatment I received from the NHS was appalling. Nine months after I have been diagnosed with prostate cancer they still wouldn't give me a date for an operation. If I hadn't taken matters into my own hands and arranged to have the operation in France I believe I would now be dead!' (Male participant with prostate cancer, 3 years after diagnosis)

'I was referred by my GP with rectal bleeding to [name removed] Hospital on [date removed]. I was told I had cancer on [date removed]. The colonoscopy took 5 months. Chemo started end of July, after recovering from surgery. The policy, apparently, is to have colonoscopy 4-6 weeks from referral. The staff whom you are told by the consultant to make appointments with are unreliable and inefficient.' (Colorectal, 1 year, Female)

A few participants also reported that non-urgent treatments such as reconstructive surgery were delayed for many months. Although non-urgent, these delays may lead to further frustration and depression amongst cancer survivors.

'I would like to say I have been treated very well with all the operations I have had and always made to feel at ease. My only complaint is that I am waiting for some more reconstructive surgery. I was told it would be about October 2010 and it is now October 2011. My problem is that I have one breast much larger therefore am having difficulty with underwear and clothes and certainly am too embarrassed to go swimming. I know this sounds a little trivial but it has made me quite depressed. I know my consultant is busy but they told me it wouldn't be long. I was offered an operation in May this year but with one

day's notice, which I just couldn't do. (Female participant with breast cancer, 3 years after diagnosis)

4.2.2 Lack of support from hospital staff

There were comments from some participants (n=12) regarding a lack of emotional support and advice being provided by health care professionals at the diagnostic and early treatment phase. This was sometimes reportedly due to a lack of key staff, such as a CNS, though this was not always the case.

At the point of diagnosis, I was offered no emotional support by the hospital clinical team. I left the consultation room with nothing but a page from the consultants notepad with the name of the disease written on it. I feel strongly that I was 'short-changed' by the hospital at this stage of my journey. The hospital did not employ a specialist cancer nurse at that time, but has recently secured funding to do so. I trust that this appointment will go some way to remedying the shortfall in emotional support that I experienced. (Male participant with NHL, 1 year after diagnosis)

'Little support from designated clinical nurse specialist. "I only support people after the operation"! That was said when I had 9 months to wait for my operation.' (Female participant with colorectal cancer, 1 year after diagnosis)

4.2.3 Poor in-patient care

Some participants (n=17) reported experiences of very poor levels of care on hospital wards while they were in-patients. Comments related to participants being left sitting in chairs without access to the call bell, no assistance with washing, poor communication between staff and patients, nurses attempting to administer drugs to the wrong patient, poor patient care, dirty wards and toilet facilities. Some respondents made complaints while undergoing treatment while others reported that they felt too vulnerable to do so at the time.

'I would have liked to have filled in a questionnaire about the support I had during my treatment. I was admitted twice into hospital. I had no complaints about care from the doctors but I had some dreadful experiences-with regard to nursing care from both the qualified and auxiliary staff. While having treatment one feels very vulnerable and do not have the confidence to complain at the time.' (Female patient with NHL, 5 years after diagnosis)

'The general nursing staff after my operation left a lot to be desired and the room I was in wasn't cleaned once in a week.' (Female participant with breast cancer, 5 years after diagnosis)

'I spent 2 week long periods at [location removed] hospital, the second of which was extremely stressful due partly to feeling so ill, and partly due to a particularly unpleasant member of the nursing staff who was quite unkind. I should have reported her at the time, but was too scared that if I had to go back to hospital I would be 'cared for' by her again.' (Female participant with NHL, 3 years after diagnosis)

Poor experiences of in-patient care extend to the quality of food that was provided to patients on hospital wards, which several participants complained had been very poor.

'Moroccan Beef and curry is a bit much when you've just had an operation when all one needs is food which is nutritious and slides down easily. One is provided with an excellent diet sheet but this seemed to differ completely from the food offered. I am aware you have to

keep within your daily recommended budget for food and you have to cater for all types but if the food provided is poorly cooked or indigestible then it's a waste of money.' (Male participant with colorectal cancer, 1 year after diagnosis)

'The only thing that will kill you in these two hospitals is the food.' (Male participant with colorectal cancer, 1 year after diagnosis)

4.2.4 Poorly coordinated care

Some participants (n=13) reported what appeared to be a lack of co-ordinated and seamless care between primary and secondary care providers, and a lack of communication between GPs and hospital staff.

'My experience is that once you are in the care of hospital (initially [name removed] and now just [name removed]) the GP seems to have no idea about what's going on. Don't GP's ever read notes before they see you? Every time I go there I have to explain that the drugs they give me are for side effects of a drug only [Consultant] can prescribe. They keep waiting to give me extra blood tests or change the type of statin etc. So many times I have told them I'm on [drug name removed] and they clearly don't know what it is but never admit it, just look a bit blank.' (Female participant with NHL, 5 years after diagnosis)

'Appointments with nurse specialist only on the phone. Informed her of pain in abdomen near implant site (hormone treatment). Told to see GP. He does not have the knowledge keep being fobbed between the two.' (Male participant with prostate cancer, 5 years after diagnosis)

4.2.5 Poor explanations and communication with patients

The provision of information is always important for patients to maintain some control of their circumstances and to participate in decision-making regarding treatment. However, two dozen (n=24) participants reported that such information was inadequate. Patients are sometimes not receptive to the details of their condition at the diagnostic stage, and having more tailored written information would be useful for them to refer to in their own time.

More information is needed to be given to the patient regarding their lymphoma and what it means to them. Doctors need to be aware that even though the type of lymphoma you have may be minor to them, it is not minor to the patient. (Male participant with NHL, 1 year after diagnosis)

I would have liked more information on my diagnosis, my status and the x rays/test results. This is all in [word unreadable] though at the time I just stuck my head down and did what I had to do. I think having a copy of my own hospital notes would have been helpful. (Female participant with NHL, 5 years after diagnosis)

4.2.6 Clinic appointment cancellations and delays

One source of frustration reported by participants (n=10) from all four tumour groups was the frequency with which follow-up appointment dates were postponed, often with no explanation. Some participants reported that it was necessary for them to take a proactive approach with administrative staff to ensure that follow-up appointments with specialist doctors were kept.

'I had a lot of problems during my chemotherapy treatment with the appointments being delayed, sometimes up to 2 hours because the chemo unit couldn't get the drugs from pharmacy in time for my appointments. This made a difficult time more stressful and

sometimes meant I was late for acupuncture appointments which I'd booked to help me cope with the treatments.' (Female participant with breast cancer, 1 year after diagnosis)

'The time it takes to get scans etc. is not very good at all. No one to speak to when diagnosed for weeks and weeks. Constant cancelled appointments with no explanation. Feel as though now chemotherapy has finished no one is really bothered anymore. When a node found on thyroid referred to another consultant, still waiting for a long time worrying about it. Once again appointment cancelled and given a much later date.' (Female participant with NHL, 1 after cancer)

4.2.7 Car parking charges

A very few participants (n=5) found the expense of car parking within hospital grounds when attending treatment clinics very expensive, and this added to the stress of the hospital visit. Two participants argued that hospitals should waiver car parking charges to cancer patients.

'I've also spent quite a few hundred pounds on parking and transport but no one seems to want to help you out with. I think once you're diagnosed with cancer the hospital should give you parking permits for the duration of treatment.' (Male participant with prostate cancer, 1 year after diagnosis)

5. Experiences of living beyond cancer

The largest proportion of participants reported experiences of living as cancer survivors beyond active treatment. The issues raised within the comments box included descriptions of: a lack of preparation for the physical side effects and psychological impact of cancer treatment; a lack of aftercare provision; the impact of comorbidities; the on-going physical, psychological and social problems participants faced relating to their experience of living beyond cancer; the social support participants received from families and charities; and the many coping strategies that participants adopted.

5.1 Lack of patient preparation

A strong theme amongst some participants (n=36) concerned a perception that they had received insufficient preparation from the health system regarding the impact that their cancer diagnosis and treatment would have upon their lives. A lack of preparation involves several dimensions, and includes inadequate information regarding their diagnosis, the physical and psychological side-effects of treatment, provision of equipment to manage practical difficulties and advice about coping strategies to address psychological problems.

5.1.1 Lack of information on treatment side effects

Some participants (n=29) reported that they had received inadequate information from health care professionals that led to unnecessary worries, restricted their capacity for decision-making, and denied them patient choice.

Lack of preparation regarding potential physical side-effects of treatment

A lack of preparation for the side effects of the treatments were reported by 29 participants: that they might suffer with lymphedema after breast surgery or that bowel surgery might lead to altered bowel movements; that chemotherapy could lead to peripheral neuropathy, cognitive problems, and bring on early menopause; and that taking cancer drugs may cause complications with those drugs patients may already take for co-morbidities.

'I have lymphedema in my left arm,...This condition is for the rest of my life. Patients should be told of the fact that they may develop lymphedema after their operation. It was a shock to find out about it later. My lymphedema is the result of having breast cancer.' (Female participant with breast cancer, 5 years after diagnosis)

'I feel not enough interest is shown in the "side effects" of chemotherapy treatment by the oncologist. I am still affected by severe peripheral neuropathy in my hands and feet but no real explanation has been given other than it can affect some more than others and can in some cases never completely clear. No real advice has been given even though my final chemotherapy treatment was not given as my symptoms were so severe.' (Female participant with colorectal cancer, 1 year after diagnosis)

'Patients with multiple illness need to know the side effects of mixing drugs and the physical effect and pros and cons - advantage, disadvantage.' (Female participant with breast cancer, 3 years after diagnosis)

The frustrating side-effects of cancer treatment were often either permanent or took far longer to diminish than participants had envisaged or had been advised.

'Nobody warned me that having 16cm of intestine removed would have such a severe effect on my bowel movements, and little dietary advice has been forthcoming.' (Male participant with colorectal cancer, 1 year after diagnosis)

It may have been worthwhile having discussion with patient and partner prior to surgery to outline the scale of the surgery involved and what the needs of the patient is likely to be. I feel my surgery had been `played down` as it was Laparoscopic, suggested that it is only a few tiny scars, without acknowledge for the internal trauma, and resulting discomforts, to be expected. (Female participant with colorectal cancer, 3 years after diagnosis)

Lack of information denies patient choice

A lack of information regarding their condition restricts the ability of patients in their decision-making. One participant reported her experience of not having her tumour genetically identified prior to surgical treatment decisions being made. She reports that the consequence of this was that she agreed to surgery that may have been unnecessary and which had a negative impact on her quality of life.

'My mother died of breast cancer in 1992 age 39. When I first was diagnosed April 2010, I made reference to this as a concern and was it hereditary? I then had a lumpectomy of both breast to remove the cancer in May 2010. However, I feel this operation was unnecessary now as I was diagnosed with the BRCA1 gene in December `10. If I had been tested earlier when first diagnosed with breast cancer then I wouldn't be left with the scarring I now have from this operation as I later had a bilateral mastectomy with reconstruction in May 2011.' (Female participant with breast cancer, 1 year after diagnosis)

Another participant commented that she had received insufficient advice regarding fertility changes and the options available, and that the information booklet she received was reportedly out of date. This may mean that her ability to make informed decisions was constrained.

'I think more information/thought should have been made available to me on my fertility changes/options - there was one small paragraph - out of date - in the cancer booklet. More info re timings and options such as egg donor etc.' (Female participant with breast cancer, 2 years after diagnosis)

Other participants stated that had they been provided with full information about the treatments they were going to receive they might not have proceeded with them. A lack of information concerning the possible side effects of treatment can effectively deny patient choice.

'I had colorectal surgery, it's side effects affected my life badly. I should have been warned/advised about those side effects to decide. If I knew about them I would not go ahead with the surgery.' (Male participant with colorectal cancer, 3 years after diagnosis)

The on-going lack of patient preparation as an NHS cost

One participant commented that it was odd that there should be an on-going lack of patient preparation given the many hundreds of people annually undergoing the same treatments, suffering the same side-effects and seeking the same advice. He observed that this on-going unmet need may also be creating an unnecessary cost for the NHS.

'I am concerned about the lack of information available in oncology units regarding long term after effects of treatments with chemotherapy and also the [word illegible] antibody therapy. Tens of thousands of patients have been given chemo over many years and a significant proportion including myself must have sought advice on symptoms occurring sometime after treatment has stopped. It would appear that there has been no recorded effort to collate this wealth of information. This must have caused unnecessary stress to patients and cost the NHS a considerable amount through additional patient appointments. There has been critical reports on this subject both on the NHS and Cancer Research websites. Can we not do better than this?' (Male participant with NHL, 5 years after diagnosis)

The issue of preparation for the experience of and help with managing side effects or long term effects of treatment is not just the responsibility of clinical teams, but is also a system wide issue. One participant raised a question relating to reportedly out-of-date information provided by a pharmaceutical company:

'Since the very first dose of [drug name removed] I have been afflicted with bruising and sometimes bleeding on my arms from the slightest bump with door handles and supermarket shelves. I also suffer from tiredness and joint pain of various degrees of severity...the leaflet that accompanies [drug name removed] carries the date November 1997, after nearly fourteen years of the life of a newish drug could not [drug manufacturers name] the manufacturers be prevailed on to bring up to date information that comes in every pack, that cramp is a side effect' (Female participant with breast cancer, 3 years after diagnosis)

Lack of patient preparation leads to unnecessary patient concern

A lack of information about possible side effects may also cause unnecessary concern, even if they are not serious, because patients do not know what to expect.

'The information from the stoma care seems to be 'if you have a problem get in touch with us' but there have been situations that have occurred where if I have been told information prior it would have not have been a concern!' (Male participant with colorectal cancer, 3 years after diagnosis)

5.1.2 Lack of preparation regarding psychological impact of disease and treatment

In addition to the physical side-effects participants (n=10) also reported that they had been unprepared for the psychological side-effects of both cancer and its treatment. Participants experienced psychological impact from both experiencing a cancer diagnosis and as a consequence of treatment side effects, which often did not diminish for far longer than participants envisaged.

I found my hospital treatment was only looking after the medical needs but no information about lifestyle and prevention advice for future. (Female participant with breast cancer, 1 year after diagnosis)

5.1.3 Lack of information on self-management strategies

Another aspect of preparation is for patients to be informed of possible coping strategies to manage both the physical and psychological side effects of the cancer and its treatment. A few participants (n=5) commented that there should be more information for patients regarding this aspect of the post-treatment cancer experience.

I feel I am one of the lucky ones but feel that one should be made much more aware of the magnitude of the side effects of this particular radiotherapy treatment, i.e. how you will feel, the mood swings and how best to deal with them.’ (Male participant with prostate cancer, 1 year after diagnosis)

Lack of information concerning diet

A concern reported by two survivors of colorectal cancer was a perceived lack of information and advice concerning their diet and strategies for practically managing their stoma.

‘After my operation, would have appreciated more information or contact with a diet specialist, as when I eat now I get pains in my side. They experimented with my diet to no effect.’ (Male participant with colorectal cancer, 1 year after diagnosis)

‘I felt could have been given more advice regarding stoma, diet which foods to avoid regards [word unreadable] and bleeding, which has given me some problems since my operation in 2008.’ (Male participant with colorectal cancer, 3 years after diagnosis)

Lack of preparation delays patients taking action to address problems

One participant reported that had more information regarding the side effects of treatment been forthcoming she would have commenced complementary therapies to address the problems earlier.

‘Would have liked to know that the drugs which caused nerve damage could affect my balance and walking and that this could lead to back pain [sciatica]. Then I could have started preventative measure i.e. Pilates which I now do to prevent reoccurrences. (Female participant with breast cancer, 2 years after diagnosis)

5.2 Experience of aftercare services

Participants (n=83) sometimes used the text box to report their experiences of the aftercare services with which they had been provided. In contrast to the comments regarding services received during the treatment phase, a greater number of participants made negative comments regarding aftercare services.

5.2.1 Positive experiences of aftercare

Some participants (n=31) specifically praised the aftercare services they had received, and were grateful for the seamless way it linked with the active treatment phase. Just as with the treatment phase, participants who reported having experienced supportive aftercare indicated it had helped them to more readily overcome the physical and psychological impact of the disease and treatment.

‘I have nothing but praise and gratitude for the nurse led cancer follow up team at [name and location removed]. Their positive attitude and cheerful kindness has helped me to remain positive too.’ (Male participant with colorectal cancer, 2 years after diagnosis)

‘Advice, information, treatment, follow ups and care has been wonderful throughout as both [name removed] and [name removed] hospitals - I cannot suggest any aspect that needed to be improved. Knowing that I could (and still can) directly contact the colorectal nurse specialist has been a major support factor and, at critical moments, a great help.’ (Male participant with colorectal cancer, 5 years after diagnosis)

5.2.2 Lack of aftercare provision

The majority of comments relating to aftercare services were negative (n=52). Participants often made contrasts between good hospital treatment and a lack of aftercare, which left participants feeling ‘*cut adrift*’ by the health care system once primary treatment had been completed. Participants often described feeling quite vulnerable after the treatment phase had come to an end and reported that ‘*there is no aftercare*’ (Breast 2 years) or that they ‘*would have liked more follow up support*’ (Colorectal, 2 year, Female). Participants report that they ‘*need to know [a] precise follow-up regime*’ (Colorectal, 2 Year Female). Consequently, it was often left to family and friends to provide the support that participants required.

‘I felt I had no support following treatment, apart from the occasional check-ups. When treatment ends you feel very vulnerable that the cancer will return, but I had no-one professional to turn to for support, My GP was very kind when I went to him, but at no time did my GP practice contact me to check how I was. It took a year to recover from my treatment and I still feel `haunted` by some of my experiences. I felt very alone, and most of my care and support fell on the shoulders of my daughter.’ (Female participant with NHL, 3 years after diagnosis)

One participant, on receiving the questionnaire, reported that she had not been provided with information regarding her condition.

‘After reading this questionnaire, I was not aware that a care plan is available. Where are they available from? Apart from 4 monthly check-ups at the hospital, I have not been given any information about my condition.’ (Female participant with NHL, 2 years after diagnosis)

Lack of continuity between private treatment and NHS aftercare

There were sometimes problems experienced by participants who had received treatment as private patients and who were then to receive aftercare through the NHS. Again it was often reported that participants needed to be proactive to ensure they received adequate follow-up:

‘I had my operation privately, and I found that I would have been overlooked for follow up treatment (radiotherapy and oncology) if I had not chased up the NHS Breast Care Unit. I did not receive my annual check-up appointment until I chased up for that too. I was assured when I had my operation privately that my other treatment would be dealt with automatically - that I would seamlessly go with the NHS system. This did not happen. Without my having made phone calls at a difficult time for me, I feel that nothing would have happened re. follow-ups.’ (Female participant with breast cancer, 1 year after diagnosis)

Lack of practical support to manage treatment side effects

Several participants commented that they had experienced difficulties accessing particular aftercare services providing post-operative management products such as continence pads and stoma bags. These difficulties often appeared to be due to a lack of coordination between health care and delivery services.

‘Disappointed that continence pads were not provided when the catheter was removed. The continence service were difficult to contact. They eventually sent me a form saying I would have a visit to assess my needs. Some 10 days or so after I had sent the form, they rang to say that as my GP was in a different area, I would need to contact another service. I rang

them but never received a form or any further contact. It is now over 9 months since my op and I am still paying for my own continence pads. Fortunately I only have a slight leak now and most days only use 1 pad, on very active days, 2 or 3. The pads cost £4.50 for a box of 10. I think patients should be given the information to contact to continence service before the op so they have pads.’ (Male participant with prostate cancer, 3 years after diagnosis)

‘Conflicting advice about getting further supplies of stoma care. We did not know where to get more supplied colorectal nurses not very helpful when supply ran out. Did not know when getting supply from [name removed] healthcare of stoma products that 2 weeks advance ordering was in progress. Care after colorectal surgery on [location removed].’ (Male participant with colorectal cancer, 1 year after diagnosis)

Lack of emotional support

Participants often reported that they would have liked more opportunities to discuss the fears they had concerning their diagnosis and the possibility of recurrence with either health care professionals or with other cancer survivors, as part of the emotional support they needed. Several participants expressed a desire to discuss their experiences with other cancer survivors because, having the same experiences, they might be more able to appreciate survivor concerns, which would be facilitated by a support group.

‘I do have a fear of dying and cancer returning (I seen what it did to my mother!) and I would have liked someone to sit down with me for 10 minutes and explain what’s happening and can happen. This has never been done. Maybe the fears of this illness can be reduced by some straight talking. However as I said the people I have been involved with have been very kind and professional.’ (Male participant with NHL, 1 year after diagnosis)

‘I have recently (June 2011) been discharged from the hospital follow-up system. This is a relief and should give me confidence that all is well, foreseeably, but in fact I feel a bit lost. It might be helpful if there was a group to join, to share experiences and worries with fellow sufferers - you feel silly telling non-affected people about the horrors you imagine in the wee small hours!’ (Female participant with breast cancer, 3 years after diagnosis)

The lack of emotional support reported by some participants sometimes could lead to the exacerbation of feelings of isolation and depression.

‘I felt that after the initial re-admission period there is not much psychological support. I felt almost isolated by the fact to be a long/medium term survivor- I should just get on with life and stop worrying. I’ve been searching but I couldn’t find any services that might fit my needs.’ (Male participant with NHL, 5 years after diagnosis)

Lack of support for families

Participants often reported that members of their family also needed some emotional support to help come to terms with the condition of their loved one, and practical advice concerning the support which they could provide them.

‘There should be more help/support for the nearest family members. They very often feel totally helpless, they want to help but they do not know what to do.’ (Female participant with breast cancer, 1 year after diagnosis)

'We received no support other than the district nurse attending to my dressings initially. My partner found this a lonely time as I was the only one trying to comfort and support her.'
(Male participant with colorectal cancer, 3 years after diagnosis)

5.2.3 Poor patient communication

Several participants (n=13) reported problems they had experienced with the level of communication they had with health care professionals and the wider health system despite being monitored during their follow-up. There was a feeling amongst some participants that no longer being actively treated meant they were not accorded the same consideration as previously and generally saw more junior staff. Consultations often felt *'rushed'* and questions unanswered. The problems participants reportedly experienced included a sometimes rather *'dismissive'* attitude from health care professionals during follow up appointments and not being informed of the results of scans and blood results.

'At the first follow up appointment with the surgeon (one year after surgery) I was disappointed to see a registrar who hadn't opened my file before meeting me - had no knowledge of my diagnosis or treatment etc. Found this insulting. Was unable to answer questions about subsequent testing schedule.' (Female participant with breast cancer, 1 year after cancer)

'I finished my treatment a year ago and although I go for check ups because I am always worried about things no one has ever sat me down and spoke to me or my family about this. I have felt very isolated by the professionals, and very silly when I say I am having scans etc. however no one really talks to me.' (Female participant with NHL, 1 year after diagnosis)

5.2.4 Lack of GP involvement

There were a very few (n=4) comments from participants that expressed *'disappointment'* that their GPs had not been more actively involvement in their follow up care. Once active treatment had ceased participants had much less interaction with any health care professionals, and would have appreciated more contact with primary care staff.

'Follow-up at hospital - first 3 months then 4 now 6 monthly has been fine but I never had any input from my GP surgery- not even a phone call to ask how I am.' (Female participant with NHL, 3 years after diagnosis)

'My GP was very kind when I went to him, but at no time did my GP practice contact me to check how I was.' (Female participant with NHL 3 years after diagnosis)

5.3 Experiences of living with co-morbidities

Many (n=185) used the text box to report on their various co-morbidities, including old age. In some instances participants related co-morbidities independently of any reference to their cancer diagnosis and treatment, some indicated that the treatment had exacerbated the symptoms of their on-going illnesses, while others were unsure whether symptoms they experienced were caused by the cancer treatment or comorbidities.

5.3.1 Impact of co-morbidities on quality of life

The comorbidities reported varied widely but hypertension, arthritis, osteoporosis and general complaints about *'old age'* were predominant. Other regularly reported complaints included long term back pain, diabetes and further primary cancers, but were not restricted to the physical, and a few individuals described long-term problems with depression and anxiety. These conditions were often blamed for the pain and mobility problems they experienced, rather than the cancer.

'I have a long term back problem, at least 15 years. This condition causes me a great deal of stress and I am more or less in continuous pain. Last year I had some injections in my facet joints together with a S1 nerve root injection. Unfortunately, the pain returned within 2 days. The back pain specialist said that nothing more could be done for me. Also, to compound my problems in 1997 I was diagnosed to be suffering from Parkinson's.' (Male participant with NHL, 1 year after diagnosis)

Co-morbidities exacerbated by cancer treatment

Participants sometimes reported that the treatment they had received for their cancer had exacerbated symptoms associated with their on-going comorbidities. This was especially the case for arthritis and osteoporosis.

'I do think that the treatment for cancer may have worsened my arthritis over the past 2-3 years.' (Female participant with breast cancer, 3 years after diagnosis)

'I was diagnosed with osteoporosis two years ago, possibly caused by hormone treatment, which ceased two months ago after 5 years.' (Female participant with breast cancer, 5 years after diagnosis)

5.3.2 Impact of comorbidities on survey answers

Some participants (n=37) noted that they had been careful when answering the questions within the main PROMs survey to separate the symptoms that related to these comorbidities. For others, however, symptoms caused by the comorbidities were reportedly as severe, or greater, than those caused by their cancer or cancer treatment, and they had difficulty distinguishing between them. A few participants indicated that any negative answers they gave actually reflected their comorbidities rather than their cancer disease and treatment.

'In January 2010 I fell and broke my right hip. This required a hip replacement operation. In April 2010 I was diagnosed with cancer of the upper bowel. This was operated on at the beginning of June 2010. I now have difficulties with my mobility, general well being etc. which are solely attributable to my hip replacement and which I have ignored in my replies to your survey.' (Male participant with colorectal cancer, 1 year after cancer)

However, other participants acknowledged they had been unable to distinguish the impact on quality of life of symptoms caused by on-going illnesses as opposed to those caused by their cancer treatment.

'I am at present experiencing pain/discomfort following a knee replacement operation which took place [date removed]. Therefore a percentage of these questions that I have responded to relates to how I am feeling at present.' (Female participant with breast cancer, 1 year after diagnosis)

5.4 On-going physical problems associated with cancer and cancer treatment

Participants (n=86) reported a wide range of on-going physical problems that continued to impact negatively upon their quality of life. Participants frequently indicated causal relationships between physical and psychological problems, which sometimes either exacerbated or were exacerbated by the social difficulties they experienced.

It was also apparent that many of these problems were reported by similar numbers who had been diagnosed some years ago as more recently diagnosed survivors, indicating that such problems took years to diminish. Moreover, the reported lack of preparation concerning potential side effects of treatment, and reported lack of aftercare, would also not have helped to address these on-going problems.

5.4.1 Fatigue

Tiredness associated with the disease and treatment was the most commonly reported physical problem and affected 29 participants across tumour groups and time points. Lack of energy impacts upon all areas of life: family, work and leisure, and prevents survivors from getting on with their lives. Fatigue was often associated with other on-going problems such as aches and pains, and could add to participants' fears about returning to work. On-going fatigue could also make planning ahead difficult and sometimes led to anxiety and depression.

'I'm totally frustrated that I don't have anywhere the energy I had before, so I feel like I am just working and don't have the energy for other things and I can't be bothered to go and make an effort to go out with my partner or my kids.' (Female participant with breast cancer, 1 year after diagnosis)

'I have not got the energy for day to day lifestyle, most things in life take a lot longer to complete and you have to work harder i.e. to keep up with challenges at work or even to socialise. Pre-cancer people seem to live life in the fast lane whilst you feel as if you are on the outside looking in.' (Female participant with breast cancer, 5 years after diagnosis)

5.4.2 Bowels

Bowel problems were described as particularly disruptive to life by 28 participants, which left them isolated or unable to participate in activities such as travel or social activities and could impact upon their return to the workplace. Bowel problems were reported mainly by participants who had undergone bowel surgery, but also affected others who underwent chemotherapy. Participants often under-estimated the problems they might face after treatment and were unprepared for the problems they faced. Faecal incontinence often reportedly caused anxiety and was also associated with what were unexpectedly long recovery times.

'Thirteen months after surgery, I had a reversal (stoma). I was not given any advice or information as to what to expect regarding my bowel movements. To this day, I have to have a very limited diet, and choice of food if I do not want to spend all day on the toilet. I was never told that my bowel movements would not return to normal. I do not travel very far from home!' (Male participant with colorectal cancer, 5 years after diagnosis)

'My anxiety has been affected in the sense that I never know when I will have accident with my bowels. This can be a nightmare when driving or on public transport. (Sometimes I have very little warning and I can go 10 to 20 times or more in 2 hours). You never know when going to stop with the diarrhoea. Always have to think what I am eating i.e. about the fibre.' (Male participant with colorectal cancer, 5 years after diagnosis)

5.4.3 Cognitive problems/ memory loss

Loss of memory and the ability to concentrate was reported by 13 participants, and were associated with long recovery periods from the effects of the disease and treatment. On-going problems such as these were frightening and frustrating for people as they often felt

less articulate as a consequence and also because they hindered participants' ability to return to work and to achieve their previous levels of productivity. This in turn could lead to depression and financial worries.

'My mind is very active but I find even now 18 months after chemo finished that my mind is not as sharp, it takes longer to do things and my vocabulary has shrunk and spelling correctly is a thing of the past. It distresses me that my cognitive faculties have diminished.' (Female participant with breast cancer, 2 years after diagnosis)

'Competition is out of the question as your cognitive abilities let you down i.e. no concentration, mind switched off, lose confidence, aggressive and intimidating people and situations muddle, distract and anger you because you feel so defenceless and victimised.' (Female participant with breast cancer, 5 years after diagnosis)

5.4.4 Impotence/ sex difficulties

Comments regarding impotence and sexual dysfunction were reported by 30 participants, affecting predominantly male participants recovering from prostate cancer as a consequence of surgery and/or hormone therapy, but also survivors of colorectal and breast cancer. The effects of this problem often had a deep impact upon intimate relationships with partners, with whom 'lively' sex lives had previously been enjoyed. The loss of sexual function often led to depression, frustration, loneliness and anxiety, a loss of masculinity/ identity and embarrassment at seeking help, and several participants expressed the view that more preparation and advice should have been provided. Nevertheless, as one participant notes, prior to treatment it is often difficult for individuals to fully appreciate the impact that side effects will have on them once treatment is completed.

'My prostate is still there and I expected it to begin to work again after the hormone leached itself from my body. No such luck. I feel like a eunuch with no sign of normal male functionings. ...I feel that I will not survive for too long, and If I knew back in Jan 2009 what I know today (sweating, difficulty peeing, lack of masculinity) I am not sure that I would have taken my chances with no [treatment].' (Male participant with prostate cancer, 2 years after diagnosis)

'Although I was 65 when diagnosed, I was newlywed, the hormone treatment ruined our sex life and we found this extremely upsetting and difficult to live with especially my wife who still gets very upset. A less strong relationship could have split up. We feel that more advice and help should have been forthcoming. [Name removed].' (Male participant with prostate cancer, 3 years after diagnosis)

It was explained to me about the side effects of the operation but the reality of the situation has caused me some concerns. I appreciate that I should seek help (which I'm sure is available) with chiefly my erection problems, but I find this difficult to do. I have taken a small step in this direction - but the pills failed to have any effect, so I feel too embarrassed to seek further advice! (Male participant with prostate cancer, 1 year after diagnosis)

5.4.5 Urinary problems

Problems with passing urine were reported by 19 participants and were predominant among those recovering from prostate cancer. Several participants associated hormone therapy with a reduction of penis size, which led to problems passing urine and with managing incontinence, while surgery was another cause of urinary problems. On-going nocturnal

frequency often impacted upon participants' sleep patterns, which could lead to day-time fatigue. As the quotes indicate, urinary problems were often long-term.

'Hormone treatment: has resulted in diminution of penis size: also increase in appearance of bosoms.' (Male participant with prostate cancer, 1 year after diagnosis)

'The biggest nuisance is having to get up several times at night in order to urinate, leads to very disturbed sleep pattern. Apart from that and the hot flushes everything is hunky dory! [name removed].' (Male participant with prostate cancer, 2 years after diagnosis)

'Generally speaking I have been well after just over 5 years since radical surgery. The main problem has been and is the nuisance of incontinence. Since my operation I have kept the pelvic floor exercises going (although sometimes I forget!) I attended a continence clinic in [location removed] for a short while which was mainly for advice and best method for me in managing the incontinence. I wear pads and the max use is two per day.' (Male participant with prostate cancer, 5 years after diagnosis)

5.4.6 Peripheral neuropathy

Ten participants commented upon on-going peripheral neuropathy caused by chemotherapy. Once again participants reported not having been adequately prepared for the extent to which this condition might affect them and being provided with very little advice as to how to manage it.

'I feel not enough interest is shown in the "side effects" of chemotherapy treatment by the oncologist. I am still affected by severe peripheral neuropathy in my hands and feet but no real explanation has been given other than it can affect some more than others and can in some cases never completely clear. No real advice has been given even though my final chemotherapy treatment was not given as my symptoms were so severe.' (Female participant with colorectal cancer, 1 year after diagnosis)

5.4.7 Pain

Pain was reported by 22 participants, mainly as an on-going consequence of surgery or as a side effect of radiotherapy and chemotherapy. The areas of their bodies in which participants experienced pain, its severity and the extent to which it impacted upon their lives varied widely.

'I would also like to point out I had underarm surgery with 8 lymph nodes taken and this still leaves me with problems, pain and swelling and carrying out everyday duties. Also, pain still in my breast tissue with severe muscle cramps daily.' (Female participant with breast cancer, 5 years after diagnosis)

'Any sexual thought or action brought on horrendous pulling pains inside which eventually drove me to a single bed and caused ill feeling from my wife, or maybe quilt feelings because it was she who triggered the pain at times of intimacy.... Have attended [hospital name removed] input pain clinic course to help me cope with chronic pain. They explained to me how the surgery can cause lesions which has caused the chronic pain I feel all around the prostate area. I'm thankful the surgery allowed me to live. I try to remember that when debilitating pain makes me want to die.' (Male participant with prostate cancer, 5 years after diagnosis)

'Due to the radiotherapy I now suffer from long term damage to nerves in my left hand and arm. My left hand is now useless and I suffer constant pain in my hand and arm. I am

undergoing pain management at local hospital. (Female participant with colorectal cancer, 1 year after diagnosis)

5.4.8 Hot flushes

Hot flushes and sweating was reported by few participants (n=6). These symptoms were associated with hormone treatment and affected both women recovering from breast cancer and men from prostate cancer. The flushes were embarrassing but also led to disturbed sleep patterns and thus fatigue during the day. Amongst men the hormone therapy was also associated with sexual dysfunction.

'After 5 months since my last hormone implant, I expected to see a reduction in `flushes` but this has not happened. If anything they are getting worse. They are embarrassing to say the least because they occur at any time, whilst playing bridge, driving, at the golf club etc. I take [drug name removed] to help me with peeing at night but the `flushes` limit me to a max of 1 1/2 hours sleep and I feel tired all the time.' (Male participant with prostate cancer, 2 years after cancer)

5.4.9 Other physical problems

Smaller numbers of participants reported several other on-going physical problems that had impacted on their lives, including: lymphedema following removal of lymph nodes, loss of mobility following surgery or radiotherapy, loss of the sense of taste and hair loss amongst those undergoing chemotherapy; scarring as a consequence of breast and colorectal surgery; and itchiness around the anus for colorectal survivors. Many of these problems appeared to be permanent or were taking much longer to diminish than participants had expected.

5.5 On-going psychological and emotional factors associated with cancer and cancer treatment

On-going psychological problems were reported by 122 participants, and for many these were caused by the on-going physical conditions they experienced. In many instances psychological problems were also more difficult to overcome than physical difficulties.

'For me, it is the psychological and emotional effects of the cancer that has affected me the most. I was diagnosed when my son was 7 months old and my nights were spent crying in bed that I was going to die and he would never know me and that my husband would be left alone to cope.' (Female participant with breast cancer, 5 years after cancer)

5.5.1 Fear of recurrence

The most commonly reported psychological factor amongst participants was the fear of disease recurrence (n=50), which often had a great impact upon their lives with individuals living in constant anxiety throughout each day. Some participants expressed the view that unless one has personally experienced being diagnosed and treated for cancer one cannot understand the depth of fear that the possibility of recurrence might cause, and it is thus a difficult subject to discuss with their families and friends. Consequently, participants sometimes experienced this fear in isolation, which could lead to depression. Some participants expressed concern that the fear of recurrence would become a permanent feature of their lives after cancer, distracting them from important things in life and from planning for the future. Moreover, the reported lack of emotional support provided through the NHS meant some participants had to seek counselling services privately.

'An important issue is living with the knowledge that the cancer may return, and if it does, it will be worse than before. One lives with an element of distraction. It is hard to plan beyond the near future.' (Male participant with NHL, 5 years after cancer)

'I am terrified my breast cancer will come back. I am afraid of dying. I would hate to go through the trauma of cancer treatment again. I don't want my family to have to face the stress and worry. People say you will be fine but the fear never goes away.' (Female participant with breast cancer, 5 years after diagnosis)

'I think unless someone has experienced cancer they would not [know] what it feels like to worry very much if the cancer will come back. Mine came on out of the blue it was a terrible shock to me. They say I am now in remission. But I will always worry if it will return, it will always be with me.' (Female participant with NHL, 5 years after diagnosis)

One participant, who had survived a previous breast cancer, reported that she had detected a new lump and was maybe facing the prospect of treatment once more.

'Being diagnosed with cancerous cells in my breast, I panicked and was scared as I could see my mother going through the same thing. It spread all over her body and she died with cancer at the age of 69 years. Since having my lumpectomy 18 months ago I have now found another lump, which will be seen in a couple of weeks' time. The black cloud is over me again so I'm worrying again.' (Female participant with breast cancer, 1 year after diagnosis)

Although participants were receiving regular follow-up scans and mammograms this sometimes did little to allay their fears. This was especially the case for participants who had previously had negative scan results prior to their initial cancer diagnosis. Indeed, participants report that the fear of recurrence leads to a fear of follow-up scans.

'I do not feel happy with just having a mammogram, as the mammogram I had three months before I found the lump last year did not show up on this test. I have just received the latest mammogram results, to say that it is clear, as with last year's results, but I still feel a little anxious about them.' (Female participant with breast cancer, 1 year after diagnosis)

'I attend the hospital approximately every 6 months for a scan (it is now yearly). Having a scan scares me more than when I was diagnosed with cancer. That is my own psychological fear. I never, never ask for the results. I got for my scan and forget about it.' (Female participant with colorectal cancer, 2 years after diagnosis)

Fear of recurrence exacerbated by a lack of psychological aftercare

The fear of recurrence can be exacerbated by experiencing it alone and not being able to articulate it to family members and friends. Nevertheless, as the following quotes indicate, having the opportunity to discuss such fears may go some way to alleviating them, and participants commented that this should be provided as part of aftercare.

'The aftercare was really non-existent. I was in such emotional turmoil that I had to see a counsellor privately for treatment because of my fear of cancer and the future.' (Male participant with NHL, 5 years after diagnosis)

'I do have a fear of dying and cancer returning (I seen what it did to my mother!) and I would have liked someone to sit down with me for 10 minutes and explain what's happening and can happen this has never been done. Maybe the fears of this illness can be reduced by some straight talking.' (Male participant with NHL, 1 year after cancer)

Fear that possible recurrence will be inadequately monitored

Part of the fear of recurrence is the concern that it will not be detected sufficiently early to treat. Although, as noted above, participants often had great trust in the NHS to efficiently monitor for any recurrence, others did not, and this lack of confidence exacerbated their anxiety.

'I am concerned that I may not be monitored closely enough when I have finished my treatment. I fear that if I have any concerns about my health that I will not be referred to consultants quickly enough. If I do not have more frequent mammograms, will further breast cancer be missed as this one could not be felt?...It is the future that concerns me and I hope I receive regular aftercare without having to request it.' (Female participant with breast cancer, 1 year after diagnosis)

Fears about future screening

One participant reported his concern that the screening programmes might be unavailable to him in the future due to his age, which he viewed as a form of discrimination.

I worry that as I get older (Now 67) there will be no treatment if it should reoccur. We have read and seen on TV about ageism creeping in e.g. the bowel cancer screening programme stops at 74 years of age. What happens after this? The district nurse stopped coming. My partner had to change the drain bags for me as I was unable to do this myself.' (Male participant with colorectal cancer, 5 years after diagnosis)

5.5.2 Body image

An altered body image was reported by 14 participants and was predominantly a consequence of the impact of surgery for breast (e.g. mastectomy) and colorectal cancer (e.g. formation of colostomy), but also from weight gain secondary to hormone therapy. Some participants indicated that they had been unprepared for the psychological impact an altered body image might have, which could lead to depression. A poor body image following cancer treatment may negatively impact upon relationships with partners, and can also be exacerbated by the negative reaction of some partners. As the quotes below illustrate, a poor body image consequent to surgery may be a permanent psychological condition.

'My husband left me after 22 years so I have had to cope on my own, as he could not cope with my cancer or the way I looked after my operation.' (Female participant with breast cancer, 1 year after diagnosis)

'Cancer has taken my self-esteem. My confidence disappeared as did my sex life. Such a huge sadness for me [I still cry about it in private when I'm low], my husband just couldn't cope with the ugly/smelly/awkward things and wouldn't talk about any of it. He stayed but became distant - I hardly get even a kiss now or a hug. I long to be cuddled.' (Female participant with breast cancer, 3 years after diagnosis)

'Having a permanent stoma following full bowel removal leaves a difficult psychological concern for physical relationship.' (Male participant with colorectal cancer, 5 years after diagnosis)

5.5.3 Genetic concerns for children

Eight participants described concerns that their cancer might be genetic and that their children and grandchildren might be at future risk of the disease.

'I have great concerns about my daughter getting breast cancer (she is 21 years old now), as my mother died as a result of it in her 60s and my sister has had it also (in her 60s) and is now OK after a lumpectomy and radiotherapy - now on [drug name removed]. My daughter may get tested.' (Female participant with breast cancer, 2 years after diagnosis)

5.5.4 Feelings of depression and loneliness

Some 34 participants described feelings of depression and isolation. Many of the on-going problems faced by participants, both physical (sexual dysfunction, incontinence, cognitive problems, slow recovery) and psychological (fear of recurrence, poor body image, loneliness), contributed to feelings of depression, and depression may also be linked to other social problems such as financial worries. Thus, although depression may have many sources, it can be very severe, with two participants admitting to suicidal thoughts. Depression often appeared soon after the end of treatment but, because there is no physical evidence, family, friends and even health care professionals had been unaware that participants were experiencing it. Participants indicated that they had little warning from health professionals about the possibility of depression and that there was little aftercare to address it. The burden of caring for depressed survivors would often therefore fall mainly upon family and friends.

'It's the feeling of depression after care has stopped is awful! Sought help from [name and location removed] as NHS help was very slow and when it came were not nice and not helpful - upset me.' (Female participant with breast cancer, 2 years after diagnosis)

'I am now on anti-depressants, but am doing well. To admit to feeling depressed when you are going to get better is something I feel quite ashamed about - a little bit more support in this area would be welcome.' (Female participant with colorectal cancer, 1 year after diagnosis)

'I had a stem cell/bone marrow transplant a year ago but lately my depression has got so severe I have been to hospital many times on suicide watch. People need to realise that after all your cancer treatment you mind plays tricks on you I have honestly been to hell and back. It is after your treatment that you need care. I feel totally alone and have bought my 16 year old daughter up on my own I have to stay strong so she can have a normal life. I hate it when I'm laid in bed crying and she doesn't know what to do!' (Female participant with NHL, 2 years after diagnosis)

Some participants felt that within the wider community there remained a fear of cancer that led people to want to avoid those who have experienced the disease. Together these issues could lead to feelings of isolation, loneliness and social exclusion. However, loneliness may also be caused by the lack of potential intimate relationships, which was a consequence of treatment.

'I am sad that none of my friends so since my cancer, now do not want to know me. I live alone, and my only family lives in the USA. My cancer experience has been very lonely.' (Female participant with breast cancer, 2 years after diagnosis)

'You are made to feel different. Cancer is still a taboo subject. If you are in your forties when you are diagnosed, others are very unkind through their fear, ignorance and terror of coming into contact with you, just in case they are 'cursed' with the same disease. If you want to have a chance at trying to fit in, don't mention that you have had cancer.' (Female participant with breast cancer, 5 years after diagnosis)

5.5.5 Anxiety

Many participants who described themselves as being anxious stated that the cause was a fear of a recurrence of their disease. However, this was not necessarily the case for all and the anxiety of a few participants (n=7) may have had other causes, which they sometimes speculated on themselves.

'I am feeling very anxious at the moment and this could be due to drugs (hormone therapy) and the fact I need to go back in hospital for further treatment. Infection is something you or any health professional cannot control and this worries me.' (Female participant with breast cancer, 1 year after diagnosis)

'Mentally, my recovery has been a bit of a rollercoaster. I'm a lot more stable now, but still have bouts of anxiety.' (Female participant with NHL, 3 years after diagnosis)

5.5.6 Other psychological difficulties

Smaller numbers of participants described a wide range of psychological issues that related to their cancer and treatment. These issues included; a general feeling of sadness, mood swings, becoming generally more emotional and finding that others are unable to cope with one's emotions, feelings of anger at having the diagnosis and questioning 'Why me?', feeling that one has lost control of one's life and that one has changed in some way and unable to return to normality.

'I did all the right things, ate my 5 (at least) a day, didn't eat junk food, cooked `proper` meals with fresh vegetables, made my own bread... I could go on. The four tests all came back negative but I still got colon cancer, it was shocking, devastating. How could I, a `healthy` fit revered `young` 70 year old who exercised, swam, walked did the garden etc. etc. get cancer? I was angry.' (Female participant with colorectal cancer, 1 year after diagnosis)

'There is so much to take in and from diagnosis to date I have felt very `out of control` in my life. So much is `done` to you that you feel unable to see your life in the same way.' (Female participant with breast cancer, 1 year after diagnosis)

'Living with cancer and beyond cancer is very very difficult. I want to live my life normal but I can't make it. I've got a very beautiful family (my husband and 3 children). At times I want to be normal as before, but I can't. I can feel the difference. I'm 41, I feel I haven't lived my life, I'm still in shock after my diagnosis.' (Female participant with breast cancer, 1 year after diagnosis)

5.6 On-going social and financial problems associated with cancer and cancer treatment

Participants (n=62) sometimes described the various social and financial difficulties they faced, particularly caring responsibilities, worries about declining income and the process of returning to work. These social and financial concerns often compounded on-going physical and psychological problems that already impacted negatively upon quality of life.

5.6.1 Caring responsibilities

Seventeen participants reported having caring responsibilities for children, spouses and older parents, which added to the 'stresses' they experienced at the end of cancer treatment. When such responsibilities were related by participants they often also expressed fears about who would take them on should they experience a recurrence of their cancer. Thus fear of recurrence and the stress of caring responsibilities may compound one another.

'The last five years have been very stressful caring for my mother who is 93 and has dementia. I think many women are in my situation, being a similar age with caring responsibilities.' (Female participant with breast cancer, 5 years after diagnosis)

'I have been a carer to my husband for nine years after he suffered a major stroke. Since then, I have had the sole responsibility in caring for him and my three children. I feel the stresses of this have contributed to my cancer and all the on-going stresses and concerns of our life could cause it to return. This is a big worry as who would my children have to support them?' (Female participant with breast cancer, 5 years after diagnosis)

Fear of becoming a burden

Some participants themselves needed to be cared for and sometimes relied heavily on family and friends for physical and financial support. They sometimes expressed a concern that they might become a burden and corresponding fears concerning their future.

'I rely on friends and family only and would not like to be a burden to them when the cancer gets worse again but have no option. I have a grown son who is 29 and has his own wife and child to support and I don't think close family like to think about losing a parent and I try not to involve him in my diagnosis although I am sure he worries about me. I see so much on the news about care homes and hospices that I am terrified of ending up in them but that would be the only course left open. I have a brother and sister and their children that care for me when I need help and I am sure that they would carry on helping me when the worst happens but it would be difficult for me to ask them. This does worry me, so I keep going so that they won't have to take over.' (Female participant with colorectal cancer, 2 years after diagnosis)

5.6.2 Impact of cancer on family and friends

Fourteen participants described the impact of their cancer experience on their family and friends. The debilitating effects of cancer and its treatment would sometimes change the dynamics of family life, which could have lasting implications for the relationships involved. As noted above, some participants had reported a lack of support for survivors and their families that might have otherwise mitigated some of the impact on family life.

'I found my children although grown up changed towards me. Before I had cancer we were very close. Since then I feel I have lost my family, we don't talk like we used to. It hurts very much. I feel angry what cancer has done to me. Every day I think why me, which I suppose everybody does.' (Female participant with breast cancer, 2 years after diagnosis)

'Living with the after effects of what the cancer has caused, my long term relationship was broken down, by my partner becoming my carer, this changed the whole structure of our relationship. I had 12 chemotherapy sessions and 17 Herceptin. My treatment took 22 months to complete. This takes a great toll on your life.' (Female participant with breast cancer, 2 years after diagnosis)

5.6.3 Financial worries/ Benefits

Some participants (n=34) reported financial worries. These were often related to difficulty claiming financial benefits such as Employment Support Allowance (ESA) and Disability Living Allowance (DLA), or being unaware they could apply for them. In the absence of financial support participants were often using up their savings or falling into debt while they are ill and undergoing treatment, and worried about facing years trying to clear debts. Financial worries were often most acute for those participants who were self-employed but not

confined to them. Financial concerns contributed to feelings of depression and anxiety about the future, and participants often complained that they did not know where to seek advice about claiming financial support, sometimes using the questionnaire to ask for help.

'I know that the cancer I have is incurable. I have now been turned down for DLA and I'm really finding it difficult financially, which is making me very depressed. My GP practice are not up to date with my conditions but my specialist has sent them to my GP who say they haven't got them. I have another 18 months of chemotherapy left and I do worry as last year I had a massive heart attack and was in critical care for 10 days, and I worry it will happen again. I just don't seem to get the support I need. If you or anybody could help supporting me and explaining people who could help me, I would appreciate it.' (Female participant with NHL, 1 year after diagnosis)

'I would have appreciated advice on financial benefits available to me. I am self-employed and was not aware that I could claim Employment Support Allowance. As a result I missed out on the first eight months of my treatment and had to fund this from savings. I was not able to back date my claim.' (Male participant with colorectal cancer, 2 years after diagnosis)

'My quality of life changed when I was diagnosed. My family have missed out on lots of things due to loss of income and we are now in considerable debt simply living day to day. Clearly I am very happy to be in remission but I am very worried about the future and the chance of cancer returning. I don't think I will ever be able to do a job that will pay enough to clear our debts and this scares me.' (Male participant with NHL, 2 years after diagnosis)

One participant encountered difficulties with insurance claims partly as a consequence of not being properly informed about his condition when diagnosed. His financial problems might have been mitigated had he been able to access professional financial advice.

'Can't thank hospital enough for care and treatment. Wonderful caring team at [name removed]. However severe financial problems due to not being told I was considered terminal at diagnosis. Should have been told to complete in 'special rules' form and insurance would have been paid out. Wife still fighting for this 3 years on. DHSS refused us DLA and wife had to go to appeal and then not given on-going payments when I returned to work. Poor advice - treated badly when I had no salary during treatment. It should not happen to others.' (Male participant with NHL, 3 years after diagnosis)

Participants' financial worries were sometimes compounded by their caring responsibilities for others:

'Having worked 25 years with little sick leave, I got very little assistance financially even to the point of refusal from organisations like Macmillan service. I am a single mum having three children. The strain on me has contributed towards career and financial worries. ... After 5 years, I am only now increasing my hours; but I have gone from a very fit person to a disabled one.' (Female participant with breast cancer, 5 years after diagnosis)

A few participants acknowledged that their families had supported them financially during their treatment, and that without their support life would have been much more difficult.

'Over the last approximate 2 years my income has been seriously reduced and keeping things afloat has been very hard. Without the help of family I would not have been able to manage.' (Male participant with colorectal cancer, 2 years after diagnosis)

Returning to work

Participants sometimes reported that they needed to return to work before they had sufficiently recovered from their treatment due to their financial worries, unsympathetic employers or the decisions of agencies delegated by the DWP to assess benefit entitlements. As noted above, several participants have commented that more support should be available for cancer survivors to negotiate a return to work with employers and outside agencies.

'I was forced into returning to work by my employer and, due to the shock illness and weakness, didn't have the stamina to stand up to my employer. I feel looking back there should be a recovery time. I finished my radiotherapy at the beginning of December and, in the following March, returned to work - another six months may have given me time to recover physically and emotionally. I was working for [name removed] council! I still feel unable to work full time. Four and a half years later, my finances are affected by this!' (Female participant with breast cancer, 5 years after diagnosis)

'I have no idea what the future holds and am desperately worried about `being forced` back to work by DHSS as the tiredness makes me feel that I could never work a full week and provide for myself, but I want to play my part in society by doing voluntary work that I could work around my illness. I live in terror of ATOS the health review people who said I was fit for work at the last interview 2 weeks after trying to take my own life by overdose, and only 3 or 4 weeks before I was due to start radiotherapy.' (Male participant with NHL, 1 year after diagnosis)

Lack of assistance in returning to work

Participants returning to work occasionally reported difficulties managing the expectations of their employers. Employers reportedly assumed that if an individual was in remission or had completed primary treatment then *'all was well'* with them, and employers and work colleagues sometimes had little understanding of the on-going physical and psychological problems associated with cancer survivorship, especially fatigue. Participants often described their negotiations with employers as *'stressful'* and *'embarrassing'*, and one form of support frequently suggested was that employers be given access to information regarding potential on-going problems employees may experience.

'There should be more support for those in employment and have understanding for their rights as an employee having cancer. Also, a literature for employers - to understand those employees who are going through this cancer journey. They assume if you look alright on the surface, all is well. Although you explain this is not the case, they assume you are making excuses - being lazy. They don't understand you are still recovering. Rather than trying to find support, it would be nice they contact you - tiring to chase - then you give up!!! Generalising. I hope this helps and makes sense. I'm writing as I speak/in my head.' (Female participant with breast cancer, 1 year after diagnosis)

'I think it would be useful to provide leaflets for employers on how they should manage staff who are receiving treatment. I need to continue working during both chemotherapy and radiotherapy, due to the nature of my employment [financially] therefore, it was very difficult communicating my needs on occasion, especially to male managers. A leaflet to hand them would have been less embarrassing. I do still have issues explaining my need for flexible hours when attending appointments so again, on again care leaflets may help. Many people are very ignorant of long term health effects or requirements so being able to show what you

are referring to, I am sure would help many people in my situation. I find talking to my managers [I have a regular change of manager] and explaining things again and again is also embarrassing, so now use my annual leave entitlement for all appointments. I don't regret working during my treatment as I also felt it gave me a focus other than the illness. But I did find attitudes varied and perceptions ranged from sympathetic to believing you were feigning illness to avoid work.' (Female participant with breast cancer, 3 years after diagnosis)

5.6.5 Difficulty accessing affordable insurance

Several participants (n=9) highlighted the difficulty for cancer survivors to access affordable travel and life insurance. One participant also reported that the need for employers to insure him for work at a higher rate meant they were reluctant to employ him.

'It felt like a kick in the teeth when [named insurance company] turned down my life insurance application after receiving the medical report from my GP. Their letter's style gave me the message "Go away loser"... I'm very angry at [named insurance company].' (Female participant with breast cancer, 2 years after diagnosis)

'I have found that travel insurance quadruples in cost in the last 5 years this I cannot understand as NHL does not make me suddenly ill.' (Female participant with NHL, 5 years after diagnosis)

'As a builder, I have to have a very high insurance to work on site (as I have a stoma bag) but employer's just don't want to employ people with this sort of condition as it is very expensive, so I have hardly worked since my operation in 2008. This is causing very hard, financial hardship for my wife and I. It would have been helpful if we were directed where to go to get advice.' (Male participant with prostate cancer, 3 years after diagnosis)

5.6.6 Lack of social services support

Some participants (n=14) indicated that they relied heavily upon their families and friends for emotional and practical support, and were aware this caused them stress. Consequently, participants reported that more support for families was needed, especially from social services.

'I was given no help by social services when I was discharged from hospital following my hemi colectomy, despite my living alone and needing a home help temporarily.' (Female participant with colorectal cancer, 5 years after diagnosis)

'My children are caring for me and supporting me. I needed real practical help with day to day cleaning, washing, ironing, shopping and no one could help. It was appalling and what will happen when I have to have operations to prevent cancer - nothing - no one wants to come and do the things that need doing.' (Female participant with breast cancer, 2 years after diagnosis)

Although many participants needed to be cared for, many at the same time had their own caring responsibilities, usually for children or older parents, which often entailed corresponding anxieties and physical demands. A few participants indicated that these pressures might be partly alleviated if adequate practical support was provided by social services, but which was often reportedly lacking.

'My children were aged 2 and 4 [diagnosed with ADHD] when I was diagnosed. My mother had to come over from N. Ireland to help me look after them following surgery and again during radiotherapy. Had she been unfit to do so, I would have struggled to cope with them.'

No mention was ever made of possible help available to mothers of young children in this situation and I think help should be offered.' (Female participant with breast cancer, 3 years after diagnosis)

5.7 Coping/ self-management strategies adopted by survivors

As noted above, participants sometimes felt unprepared for the impact of cancer on their lives, the side effects of treatment and the on-going physical, psychological and social challenges they experienced. Nevertheless, many participants (n=149) commented on the coping strategies they had adopted, which they usually found themselves or through others who had been through similar experiences. A few participants commented that more information about coping strategies should be provided.

'I never received any leaflet or information on living with and beyond cancer. I think such information may have been helpful but I coped anyway.' (Male participant with prostate cancer, 5 years after diagnosis)

5.7.1 Avoidance

Three participants appeared to adopt a strategy of avoidance rather than confronting issues related to their illness.

'I try to put all thought of my illness out of my mind until I have check-ups at hospital. That is my way of coping.' (Female participant with breast cancer, 3 years after diagnosis)

5.7.2 Acceptance

Other participants (n=18) accepted the reality of their on-going condition but determined to carry on with life as much as possible and making the most of each day.

'I have I think come to terms with the fact that the cancer will not go away and intend to carry on with my life as always and take each day as it comes.' (Female participant with breast cancer, 2 years after diagnosis)

5.7.3 Adjusting a work-life balance

In the light of their experience of cancer, two participants reported their intention to re-adjust their work-life balance to make more room for the things they felt were most important to them, such as friends and family.

'I am working less hours by choice. Having been diagnosed and having had breast cancer treatment has been a wakeup call for me in terms of work life balance. It is far more important for me to spend time with family and friends than previously - I have always enjoyed socialising and contact with nieces/nephews/god-children, but I find I now pro-actively make arrangements (rather than contact just happening) around their interests - e.g. arts/sports/film etc. I would say that my life has become richer and more focussed (sounds strange, but it's true) following my diagnosis and treatment.' (Female participant with breast cancer, 2 years after diagnosis)

5.7.4 Adopting a healthier lifestyle

Several participants (n=8) reported that they had changed to more healthy lifestyles, which included healthier diets, reducing alcohol consumption and taking regular exercise.

'My lifestyle has changed a great deal since dealing with breast cancer. I am now a vegetarian buying organic food and using products that reflect that. After losing my hair and

gaining quite a lot of weight, I am now feeling fitter than I was before cancer was diagnosed. (Female participant with breast cancer, 2 years after diagnosis)

'I believe diet and exercise are the most important factors and my rules are - eat cereals, eat tomatoes, eat fruit and vegetables, drink cranberry juice, drink juice, drink tea, don't smoke, don't eat too many dairy products, don't drink too much alcohol, don't drink too much coffee, reduce salt and sugar levels, play bowls at least 3 time a week, try to think positively and plan for the future.' (Male participant with prostate cancer, 5 years after diagnosis)

5.7.5 Activity

Maintaining or building up one's activity may be part of adopting a healthier lifestyle, a way of getting life back to normal, or as a way of countering physical and psychological conditions such as fatigue and anxiety. Participants (n=29) adopted a wide range of activities, including walking, swimming, gardening, dancing and cycling.

'As I get better I wish to get to the gym once a week as I did before my diagnosis for prostate cancer. (Cycling, rowing and a few other upper mode exercises. I do some light gardening now. Lawn mowing, digging to control weeds and planting shrubs. Pruning bushes. also, some outdoor paintwork to the house.' (Male participant with prostate cancer, 1 year after diagnosis)

5.7.6 Pacing one-self

Although many participants were keen to be active, three individuals nevertheless recognised that pacing oneself was important to prevent any over-exertion that might be counter-productive.

'Although I am retired, I do a great deal of DIY. This involves sometimes, heavy lifting (logs and hedge cutting machines). If I'm careful and take my time there isn't a problem. Sometimes I unwittingly overdo the work which leads to some pain and exhaustion, but I'm beginning to pace myself better.' (Male participant with prostate cancer, 1 year after diagnosis)

5.7.7 Employment

As noted above, participants sometimes found it necessary to return to work due to financial concerns or unsympathetic employers. Nevertheless, returning to employment was also used by participants (n=20) as a form of activity to cope with the stress of cancer survivorship and getting life back to 'normal'

'I have returned to work full time because I want my life to return to 'normal'. (Female participant with breast cancer, 1 year after diagnosis)

5.7.8 Keep positive

Some participants (n=41) commented that a 'positive' attitude was necessary for them to cope with their cancer and treatment.

'I believe that a positive attitude to the illness has helped me through the difficult periods i.e. from first having the diagnosis and the family distress when learning of this, until the completion of the treatment and subsequently into remission.' (Male participant with NHL, 2 years after diagnosis)

5.7.9 Religion

Four participants described finding that a strong religious faith had helped them cope with the stresses of cancer treatment and survivorship.

'I am a practicing Christian and the prayers of people all over the world have been a tremendous support. To know so many people care about me as an individual has certainly helped me remain positive.' (Female participant with breast cancer, 1 year after diagnosis)

'As a Christian (a convert from Islam), it was a test to my faith (I thank God I have a faith and trust in God, which played a major role during and after my experience with cancer).' (Female participant with breast cancer, 1 year after diagnosis)

5.7.10 Talking therapy

Six participants reported the benefits of simply talking about their experiences and articulating their fears, especially to others who have been similarly affected by cancer. Where this opportunity was not available within the social sphere of cancer survivors, participants commented that talking therapy should be available as part of aftercare.

'I think a course of talking therapy would have been very helpful after treatment due to the psychological effects of the cancer, the treatment and long hospital stays, also getting back into the workplace after a long absence.' (Female participant with NHL, 2 years after diagnosis)

5.7.11 Complementary therapies

Some participants (n=13) reported that they used complementary therapies as part of their coping strategies for the physical side effects of treatment and the psychological impact of their disease. Most individuals were reportedly accessing these services privately or through charities and hospices, but several commented that they would like to see them provided as part of aftercare.

'The hardest thing now is living with the side effects and worry of recurrence. I am lucky I can afford lots of complimentary therapies and spend a fortune on these.' (Female participant with breast cancer, 2 years after diagnosis)

'The support I have received and needed has been provided by the [name removed] Hospice and I received reflexology via the [name removed] hospice. They helped very much with my emotional collapse.' (Female participant with breast cancer, 2 years after diagnosis)

5.7.12 Volunteering

Several participants (n=6) reported their involvement with voluntary organisations, which often involved providing information and advice to others undergoing cancer treatment. Participants sometimes felt they had learned a great deal from their diagnosis and treatment, both factually and about coping strategies, which they wished to pass on to others. There was some concern, however, regarding the necessary bureaucracy associated with voluntary work.

'Since being diagnosed with cancer I have actively become involved with local groups regarding the importance of signs and symptoms of cancer. I have also undergone a one year counselling course on cancer organised by Macmillan. I have become an active member of my local patient's participation group at my surgery. Providing DVD's on health and wellbeing which are shown to patients waiting for appointments. I feel being active and

gaining more knowledge on all health matter has been a tremendous help to me.' (Female participant with breast cancer, 3 years after diagnosis)

'I am concerned about elderly women like me who live alone and do not have my blessings. A friendly person, who could pop in, change a bed or do some shopping occasionally when needed would make a big difference and lessen isolation. I volunteered to do this when I was well; but the police checking and patient confidentiality regulating prevented this. There must be some way of beating this red tape - if the volunteer is known to the hospital and could produce a testimonial, that should be good enough.' (Female participant with breast cancer, 3 years after diagnosis)

5.7.13 Advice for others

A few participants (n=18) used the free text box to provide advice and pass on to others what they had learnt from their own experiences. This advice often took the form of lists, and usually included the comment that survivors should remain 'positive'.

'1. Be positive, don't think it's the end. 2. Buy an expensive wig, wear makeup even if you don't feel like it. 3. Keep a diary of ops and procedures. 4. Spend time with friends and family and if you are tired leave the housework go for a walk- a gentle walk. 5. Tell family and friends how much they are loved and appreciated. 6. Ask questions of doctors and nurses about your treatment and fears. 7. Try to keep a good sense of humour even when you feel unwell and try to be with people who are positive like you and make you laugh.' (Female participant with breast cancer, 1 year after diagnosis)

'Be positive. Always accept advice/help when offered. Don't be an ostrich. Face up to your diagnosis. Mine was a grade 3 carcinoma. I had multiple pulmonary embolisms after chemotherapy. Radiation burns during radiotherapy and days when you wish to die - but you get over it!' (Female participant with breast cancer, 5 years after diagnosis)

'A. Always keep checking for visual signs of bowel cancer. B. Re-join bowel cancer screening schemes. C. Stay positive, mind and body. D. Don't be scared of cancer. "Fight it". E. Don't let cancer interfere with your everyday life. F. Remember your cancer problem frightens your family and friends more than it does you. G. Proper mental and physical attitude to life prevents depression.' (Male participant with colorectal cancer, 5 years after cancer)

5.7.14 Finding benefit from cancer experience

Two participants acknowledged that they had experienced some benefits from their experiences of being diagnosed with cancer and its treatment, especially coming into contact with kind and friendly people.

'As scary as cancer can be I have found it can produce many good side effects such as finding out just how kind people can be and how many new friends it can bring into your life. The balance of good friendly people I met overweighed the few who walked the other way to avoid contact.' (Female participant with breast cancer, 3 years after diagnosis)

'Having cancer is an interesting experience but not without its compensations. All the professionals I have met treated me with kindness, courtesy and encouragement.' (Female participant with colorectal cancer, 3 years after diagnosis)

5.8 Social support

Participants (n=56) sometimes described receiving support from family, friends, charities and support groups, and where they did so their reliance upon the NHS may have been reduced,

and the deficiencies reported by other participants may have had less impact on their quality of life.

5.8.1 Supportive families, friends and neighbours

The predominant source of support outside the NHS for 47 participants was that of their families, friends and neighbours, and where such support from family members was strong there was less need for outside agencies like social services. Social support took the form of practical and financial help, emotional support, gathering information from different sources, and ensuring the right questions were asked of HCPs.

'I do not believe I would have survived if it was not for the support of my children. They asked the medical teams all the relevant questions. Gathered information on my condition through the internet. Fed and cared for me whilst in hospital and when at home.' (Female participant with NHL, 3 years after diagnosis)

'I have been married for nearly 37 years. I would state that the understanding and support of my wife and family made it easier to deal with. I feel those facing this alone or who are afraid to talk about it or even often say the word cancer would need more help and support.' (Male participant with prostate cancer, 2 years after diagnosis)

5.8.2 Support from charities and support groups

Several participants (n=9) found accessing information and support from cancer charities and support groups invaluable to helping their recovery, especially where this did not always seem to be readily available within the NHS.

'I found it very valuable to have information from the charity Breast Cancer Care and used their helpline on many occasions. My husband was diagnosed with cancer on the same day as I was. I obviously found this increased my natural anxiety levels and that the service provided by the specialist nurses did not appear flexible enough to cope with my individual needs. The charity helpline then became a real "helpline" providing a level of access and anonymity for myself and my husband.' (Female participant with breast cancer, 5 years after diagnosis)

'Very good information and support from:- The Prostate Cancer Charity. Their information "tool kit" is very helpful and the forum has lots of patients, doctors etc. who contribute and respond to every question that anyone posts. It is very important that GP's know as much as possible about PCA and are fully able to support [patients].' (Male participant with prostate cancer, 2 years after diagnosis)

'I joined the [location removed] support group for prostate cancer in the grounds of [name removed] hospital. Meet last Tuesday of every month in 2007. They are very active and have the best speakers on this subject. This has been a great help to me and many others.' (Male participant with prostate cancer, 5 years after diagnosis)

5.9 No problems experienced

Some participants (n=30) simply stated in the text box that they had no problems as a result of their experience of cancer and treatment, and all appeared to have recovered well both physically and psychologically. These comments were usually very brief.

'I have had no problems since my operation in June 2010, and I have felt very well throughout the year.' (Female participant with colorectal cancer, 1 year after diagnosis)

'My NHL condition is clearly very mild and is not deteriorating. It is being monitored but not tested. It causes me no problems.' (Male participant with NHL, 1 year after diagnosis)

'I haven't had any serious difficulties either during treatment or after my treatment.' (Male participant with NHL, 5 years after diagnosis)

6. Issues unrelated to the experience of living beyond cancer

There were also comments from participants that did not relate to their experiences of either the active treatment phase of their disease or their experiences of living beyond cancer. Within this general theme were several categories of response: comments that gave a dispassionate description of participants' diseases and treatments; issues that were raised concerning the structure and delivery of the questionnaire; and miscellaneous comments that could not be captured by any other category.

6.1 Description of disease and treatment pathway

Over one tenth (n=116) of participants at least partly used the text box to provide a description of the history of their disease and treatment. These descriptions were often very detailed indicating a good understanding amongst participants of their disease. The descriptions were also related dispassionately, whether their treatment involved a 'watch and wait' policy for NHL or palliative care for extensive metastases.

'March 2008- I was diagnosed with B. cell Non-Hodgkin`s lymphoma, high grade, around the left kidney. [Date removed] Treatment commenced at [name removed] hospital, [location removed]. [Date removed] Cancer invaded bone marrow (stage 4) additional chemo injected direct into the spine, 4 sessions [date removed]. Cancer dissolved, file marked `complete response, now in remission` [date removed]. Lymphoma returned after 3 years in remission. [Dates removed] first chemo given (1 of 6). [Date removed] 2nd chemo given (2 of 6).' (Male participant with NHL, 3 years after diagnosis)

At the moment I am on a `watch and wait` policy with regular check-ups at Haematology dept. at hospital. (Female participant with NHL, 1 year after diagnosis)

'The surgery I received for bowel cancer was successful. Unfortunately the scan I received afterwards showed cancer had now moved to my lungs. After four different cycles of chemotherapy the decision was made this week to discontinue treatment as it was deemed to be ineffective. I am now on palliative care.' (Male participant with colorectal cancer, 2 years after diagnosis)

6.2 Issues related to receiving the questionnaire

Some participants (n=7) indicated that receiving the questionnaire had either caused them to question their diagnosis or had brought back bad memories.

6.2.1 Question-raising amongst participants following receipt of the questionnaire

Several participants expressed surprise at receiving the survey questionnaire and reported that they had not realised, and reportedly not been told, that they had even been diagnosed with 'cancer'. However, some recipients of the questionnaire may have been disease free and yet the terminology of the questionnaire, describing them as 'cancer survivors', may have led to a misunderstanding.

'Until this letter came to me I was not really sure that I had cancer. I was told at the onset that cancer cells were on the bits that were taken from me. I attended [name removed] clinic but was not told I had cancer. I suspected with my 2 monthly injections to keep out of my bones, my head and body scan were clear. I was told. But that was it, I was not told that I had cancer.' (Male participant with prostate cancer, 3 years after diagnosis)

'Until I received this questionnaire I didn't know I had prostate cancer definitely. I had a T.U.R.P operation in 2006 because I couldn't pass water following tests on my kidney during [date removed]. During [date removed] I had a cancerous kidney removed. Following the T.U.R.P my urologist told me that minute traces of cancer cells were present in the removed tissue. I didn't understand that to mean I had prostate cancer. I have recently spoken to my urologist's nurse who confirmed I may, or may not, have prostate cancer. I have had periodic PSA tests but no other treatment since [date removed].' (Male participant with prostate cancer, 5 years after diagnosis)

6.2.2 Psychological impact of receiving the questionnaire

Two participants reported that receiving the questionnaire had *'brought back'* unpleasant memories and associations. They completed the survey as they appreciated its importance, but were reluctant to do so.

'I have filled this questionnaire in on behalf of my husband because he did get quite distressed receiving it (and the other previous copies) as it brought back when he was first diagnosed. He does though realise the importance of the questionnaire for future treatment and help and so he asked me to complete it on his behalf. [Name removed].' (Male participant with NHL, 2 years after diagnosis)

'Documents like this tend to bring back the horror of it all, and although I have filled out this questionnaire this time, I don't want to be [word illegible] in the future with more forms to fill in, so I hope this will be the only one. I suffer from white coat syndrome and get extremely nervous if I have to go to hospital, so please take this into consideration. Thank you.' (Female participant with breast cancer, 2 years after diagnosis)

6.3 Complaints about questionnaire delivery

Some participants (n=27) used the text box to make complaints about the structure and delivery of the questionnaire.

6.3.1 Sent to wrong address

More than a dozen participants reported that the questionnaire had been sent to the wrong address, and although not all were concerned about this occurrence, some respondents worried that this represented *'a breach of confidentiality'*.

'This is the 2nd survey questionnaire you have sent to me - apparently. I received an earlier letter informing me that you had inadvertently posted a previous questionnaire to me at an incorrect address near to my actual address. This presumably went to someone who may well know me (I have lived here for 30+ years) but it was not passed on to me. Given the climate of distrust currently surrounding so many bureaucratic institutions playing fast and loose with large quantities of private individuals' details, what guarantee is there that my herein disclosed details will be kept securely or used effectively?' (Male participant with colorectal cancer, 3 years after diagnosis)

'Please get my address correct. This was delivered to a neighbour and [word illegible] in error because the name could not be read, whereas the house number could be. He then realised it was for me. This was a breach of your duty of confidentiality.' (Male participant with colorectal cancer, 2 years after diagnosis)

'Concerned that my first questionnaire was sent to wrong address and now somebody else knows about my illness when only friends and family were told!! I really hope this doesn't happen to anyone else.' (Female participant with breast cancer, 2 years after diagnosis)

6.3.2 Query whether appropriate recipients

A few respondents commented that they were not sure they were appropriate recipients of the questionnaire, either because their cancer experience had been very brief or treatment had not been necessary or extensive.

'I have been diagnosed with non-Hodgkin's lymphoma but my treatment has been 'wait and see'. I have found some questions in this form difficult to answer as there has been no option for someone in the 'wait and see' phase, only for those who have already started/finished a treatment plan.' (Male participant with NHL, 1 year after diagnosis)

'A lot of the questionnaire does not really apply to me because the small cancer in my [word unreadable] was removed at the initial operation, at the time my surgeon was unable to tell if all the cancer cells had been removed and so we went ahead for more surgery to remove part of the rectum. The result being no further treatment was necessary, but I am having a yearly check-up.' (Female participant with colorectal cancer, 2 years after diagnosis)

'I do not consider that I have or have had cancer because pre-cancerous cells were detected in one breast at a routine mammogram and I underwent a mastectomy. My diagnosis was DCIS. I sometimes wonder whether I would have developed breast cancer at all! However, I was put under no pressure to have a mastectomy, at the time, I felt prevention was better than cure. I do not feel that I should be a breast cancer statistic at all and my inclusion somewhat skews the data. I wonder how many other like me are included in the statistics!' (Female participant with breast cancer, 5 years after diagnosis)

6.4 Criticisms of the questionnaire

Just over a dozen participants used the comments box to criticise aspects of the survey. A very few participants were entirely negative, but others offered positive criticism, mainly regarding the pertinence (e.g. 'sexual attractiveness'), and ambiguous phrasing, of certain questions. As noted above, some participants who had experienced only minor disease and little treatment questioned the relevance of their information to the purpose of the survey.

'This seemed like a pile of random garbage. Did you think what it was for before you commissioned it?' (Male participant with NHL, 3 years after diagnosis)

'Indeed, at the age of nearly 91, some of the questions e.g. 'sexual attractiveness' seem somewhat irrelevant!' (Female participant with breast cancer, 1 year after diagnosis)

'I have completed the form to the questions which I consider to be relevant though I consider some to be personal and rather pertinent. Questions which I have decided [not] to answer I consider to be of a very personal nature.' (Male participant with prostate cancer, 5 years after diagnosis)

'What a ridiculous survey to send out! A complete waste of time. I had DCIS - 98% of these questions are not relevant to me. I ignored it the first time but you sent a reminder and told me if you didn't hear from me within 2 weeks, you would re-send! I'm happy to help the NHS with any relevant information but I don't think for a minute you'll be able to draw any conclusions from my answers here - other than it's obvious this is a waste of paper, postage etc.' (Female participant with breast cancer, 5 years after diagnosis)

With regards the impact on patients' quality of life and their ability to carry out usual activities, a couple of participants commented that no distinction had been made within the

questions between impact of the disease rather than the effects of treatment, or for the impact of on-going comorbidities they might have.

'There are no questions about side effects of chemotherapy of which I have at this time, after finishing chemotherapy six weeks ago, hence my answers to questions 27, 42, 44.' (Male participant with colorectal cancer, 1 year after diagnosis)

One participant commented that there were no questions relating to the spiritual dimension of the experience of a cancer diagnosis and treatment, and the changes it may stimulate amongst participants concerning their priorities in life:

'There is, however, a spiritual dimension to this condition, which your survey has failed to recognise. The diagnosis has definitely impacted my priorities, my life-work balance and my relationship with God.' (Male participant with prostate cancer, 1 year after diagnosis)

There were a few criticisms concerning the restriction of possible answers, such as the treatment participants had received or the likert scale for the EQ5D on quality of life:

'Thoughts on your survey: Radiation and Brachytherapy are very different treatments, by lumping them together, survey results will be misleading i.e. side effects are much more severe with conventional radiation treatment. By blending the two forms of treatment will produce an average that is meaningless. I therefore question your methodology.' (Male participant with prostate cancer, 1 year after diagnosis)

Two participants made general criticisms regarding the phrasing of questions which they found ambiguous and difficult to answer.

'Some of the questions/responses to could be better worded. They are quite obscure. It needs a comprehension of English that may be beyond some respondents.' (Male participant with prostate cancer, 5 years after diagnosis)

However, there was also praise for the questionnaire, with some participants reporting that they found the opportunity to write down their feelings in the text box helpful.

'Thank you for this opportunity to write on paper how I feel.' (Female participant with breast cancer, 1 year after diagnosis)

6.5 Miscellaneous

A proportion of participants (n=24) completed the text box by describing issues that were not obviously or explicitly related to their experience of cancer or treatment or issues of survivorship. These miscellaneous comments were very varied. Several participants described their good health prior to cancer, their past careers, while other comments were very personal in nature, describing intimate relationships, divorce and forced marriage, but these descriptions were never explicitly linked to their experience of cancer, treatment or survivorship. Other participants used the text box to indicate they would be happy to be contacted again while others emphasised that they did not wish to be.

I think I have completed this to the best of my ability but please feel free to contact me if you feel I have not completed all areas. (Male participant with prostate cancer, 2 years after diagnosis)

If answering this questionnaire means there will be any seminars or any meetings of any kind, I do not wish to take part in any discussions whatsoever. (Male participant with prostate cancer, 2 years after diagnosis)

Two participants reflected upon the experiences of family members, and this may suggest underlying anxieties concerning their own cancer, even though it might be a different type. However, these meanings would be latent rather than explicit.

An aunt had breast cancer and was clear for 10 years with the aid of Tamoxifen. Now she has bone cancer and also lung cancer. (Female participant with colorectal cancer, 5 years after diagnosis)

Similarly, some participants reflected upon the possible causes of their cancer, and these may be associated with those individuals seeking to make sense of their diagnosis.

I do not understand why I often read in the press or hear on TV that people with breast cancer are overweight, smoke and drink more than the average alcohol. I know 8 women who have had breast cancer - none smoked, none were overweight when they were diagnosed and none drank much alcohol. My own suspicions are stress, contraceptive pill and HRT. (Female participant with breast cancer, 1 year after diagnosis)

As a matter of interest. Cause of NHL. I was in the Korean War (52/53). Surveys from America, Canada, Australia have compared people involved in war had a 30-35% more illnesses compared to the same age group living at the same time (not involved in conflict) and symptoms diseases name NHL generally other cancers heart disease and chest problems never recognised by British Government. (Male participant with NHL, 3 years after diagnosis)

7. Summary of findings

There was a relatively high response rate to the comments text box within the survey, and just under a third (32%) of those survivors that completed the questionnaire also completed the text box. There were also relatively equal proportions of participants from the four different tumour groups, and from participants' time from cancer diagnosis, gender and age. These findings indicate that the comments box represents a useful tool to gather further information from survivors regarding their experiences that complements the quantitative findings of the survivorship survey (DH 2012). The researchers undertook two phases of analysis with the data.

7.1 Content analysis

The first phase involved a conventional qualitative content analysis, which developed categories and themes within which to code data, and included simple counts to indicate the number and proportion of participants who had written on particular themes. Comments were coded within three overarching themes: experience of cancer diagnosis and treatment; experiences of living beyond cancer; and issues unrelated to the experience of living with and beyond cancer. Within these themes several categories and sub-categories were developed inductively from the data, which captured the many and various ways that participants had chosen to complete the free-text comments box.

The first theme captured experiences of cancer diagnosis and treatment. Almost a fifth of participants praised the excellent or very good care they had received during their treatment phase, and a smaller proportion praised the post-treatment aftercare provided. However, there were also some complaints about the quality of care participants received during treatment, involving diagnostic and treatment delays, appointment cancellations, and a lack of support, communication and co-ordination of care. Such communication and coordination issues are essential to quality care (Schrag 2005), and previous research has indicated that negative experiences of cancer care early on can lead patients to expect their future care to be subject to similar problems (Schaepe 2011). There were also a very few complaints of poor nursing care, dirty hospital wards and poor food quality, but these experiences clearly had a lasting impression upon participants who were describing them months and years later.

The second theme incorporated participant's experiences of living beyond cancer and it was evident from the responses that unmet physical, psychological and social needs existed amongst participants. Most of the on-going problems mentioned replicated those found in other studies examining problems facing cancer survivors (Rechis et al 2011, Foster & Fenlon 2011, Hewitt et al 2006, Armes et al 2009, Jefford et al 2008), although there is little current evidence concerning the prevalence and nature of many such problems (Richardson et al 2011, Foster & Fenlon 2011, Lerro et al 2012). On-going physical problems included: problems with bowel and urinary incontinence, constipation, cognitive problems and diminished memory, pain, impotence and sexual difficulties, fatigue, hot flushes and peripheral neuropathy. These had a considerable impact restricting activities such as employment, travel and social activities, and were reported across all four tumour groups and time-points from cancer diagnosis. This indicates such problems were widespread and took longer than might be expected to diminish (Armes et al 2009).

Psychological problems reported by participants were a consequence of either the cancer diagnosis (fear of recurrence, difficulty planning ahead, fears that the disease might be hereditary and affect children or grandchildren) or of the side effects of cancer treatment

(e.g. poor body image following breast surgery or stoma formation; depression caused by sexual difficulties following bowel or prostate surgery or hormone therapy). Two participants referred to attempted suicide or suicidal feelings. The social and financial issues reported by participants included caring responsibilities for children or older relatives, debt and financial worries and the need to return to work. Again, these are similar concerns as found in previous research (Hewitt et al 2003, Rechis et al 2011), and were often exacerbated by the on-going physical and psychological problems experienced by participants (e.g. problems of fatigue and depression impacting upon the ability of participants to function as carers of children or returning to work; fears of recurrence being exacerbated by concerns about who would look after dependents should the cancer return). Linked to these on-going difficulties were complaints amongst some participants that there was a lack of social services support, and there were also suggestions that the employers of cancer survivors should be provided with information regarding potentially enduring side-effects of the diagnosis and treatment.

Many participants indicated they had little preparation about what to expect with regards potential physical and psychological impact of the cancer and treatment side-effects, and the time it might take for them to diminish. These findings also replicate previous study findings that have shown cancer survivors do not receive optimal levels of information about life beyond cancer (Ayanian et al 2010, Harrison et al 2012). Amongst participants there were also complaints that they lacked information regarding possible strategies for dealing with their on-going problems, although current research evidence regarding the effectiveness of many such potential self-management approaches remains limited (Richardson et al 2011, Foster & Fenlon 2011, Lerro et al 2012). However, the issue of preparation is not just the responsibility of clinical teams but is system wide and includes, for example, pharmaceutical companies who should ensure they provide up-to-date information concerning side effects of drugs.

Participants often described illnesses they had in addition to their primary cancer and the impact they had upon quality of life. Previous studies have indicated a greater incidence of poor health amongst cancer survivors who also have another comorbid condition in addition to their cancer (Elliott & Corner 2011, Hewitt et al 2003, Elliott et al 2011), and this was also reflected in the quantitative analysis of the survivorship survey. A few participants also commented that they believed their cancer treatment had worsened their comorbidities, especially arthritis.

Experiences of aftercare services were often related by participants, and, as has been found in previous studies, many were dissatisfied with those services (Armes et al 2009, Penny & Mallet 2000). Participants often felt '*cut adrift*' by the health system after the '*intense*' period of treatment and were left feeling vulnerable (Cox & Wilson 2003, Ward et al 1992). Some participants commented that they were ill-prepared both for the emotional impact once active treatment was completed and for the on-going physical and psychological problems they experienced, and were unsure where to find help. Recent evidence suggests that patients want more information concerning long term effects of cancer and treatment, psycho-social support and self-management strategies (Rutten et al 2005), and health providers need to consider how to improve care for these patients (Rowland et al 2006). This may be partly addressed by the fundamental shift currently underway, as part of the Cancer Reform Strategy (CRS), in the way that cancer survivors are supported after treatment. The aim is to replace traditional routine follow-up systems with services that empower individuals to self-manage their condition and the effects of treatment (DH 2010, Macmillan Cancer Support 2008, Davies & Batehup 2011).

Participants who found ways of managing their various on-going problems often described them in the comments box. Strategies offered by participants included: acceptance; focussing upon the '*positive*' aspects of life; adjusting work-life balances; adopting healthier lifestyles; gradually increasing activity and social life as a way of getting life back to normal; returning to employment or voluntary work; and the use of complementary therapies such as reflexology, aromatherapy, yoga, counselling and talking therapies. Participants often appeared to have discovered these coping themselves or through talking to others who had been through similar experiences, while another key element to coping was found to be the social support provided by family, friends, charities and support groups.

A third general theme capturing participant's responses comprised issues that appeared to be unrelated to the experience of living beyond cancer. The category with most responses in this theme comprised participants dispassionately describing their disease and treatment pathway, often in great detail. Participants may have thought providing such information would assist researchers to assess the relevance of their answers to the survey. Other participants criticised the questionnaire, complained about deficiencies in the delivery of the survey to participants' homes, a few conveyed the psychological impact of receiving the questionnaire, while others responded in ways that were categorised as miscellaneous.

7.2 Development of a conceptual model

A second level of analysis was conducted to identify patterns and relationships between the categories of response that emerged from the data in order to build a conceptual model of participants' experiences (see figure 1), which is similar to that developed by Foster & Fenlon (2011). Central to this model are the outcomes reported on by participants, which included: aspects of their physical and psychological recovery; their confidence in the future; and their ability to self-manage on-going physical and psychological problems related to the cancer and its treatment.

Six factors emerged from the data that appeared to either positively or negatively impact upon these interrelated outcomes these were:

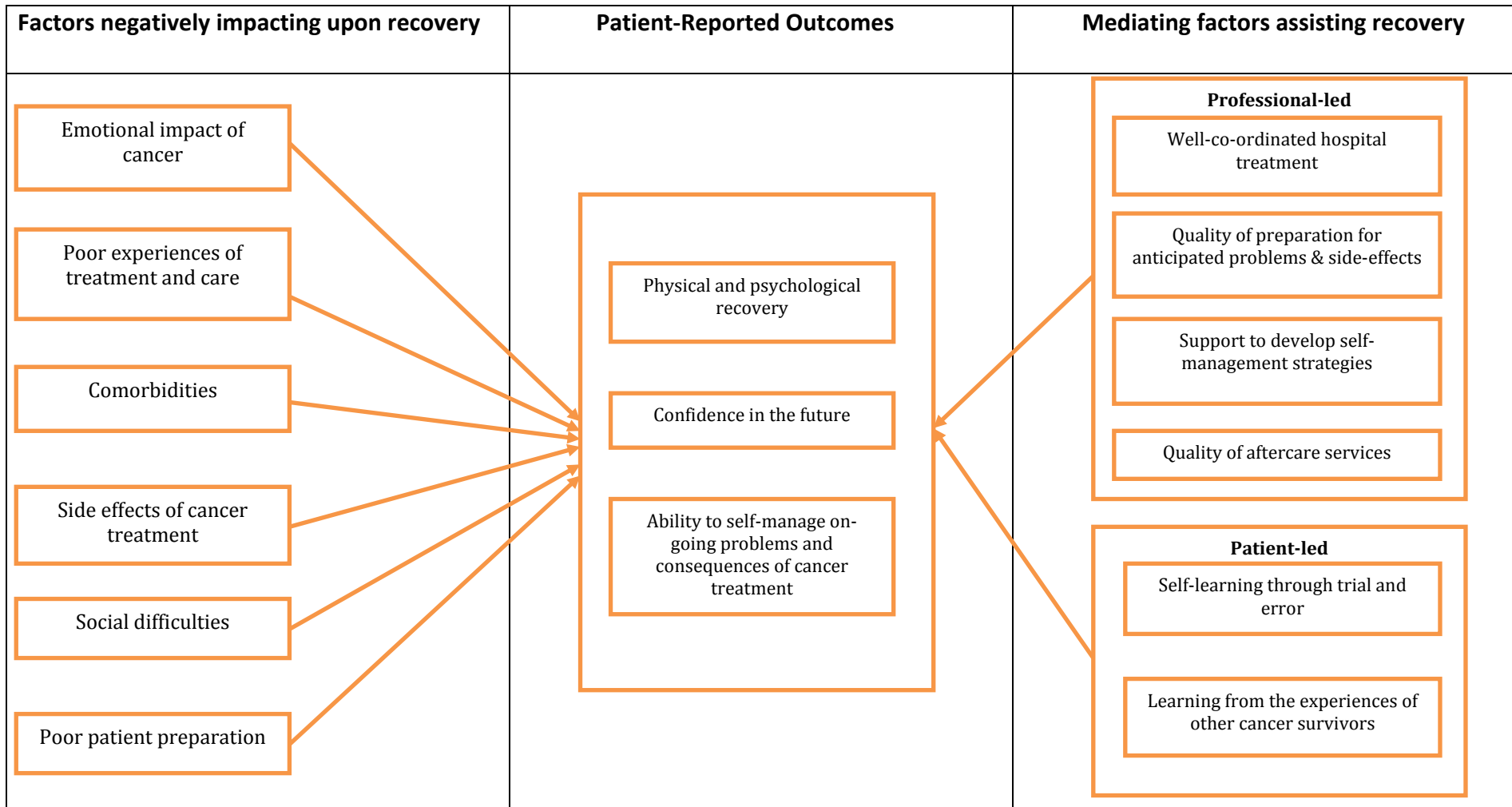
1. The emotional impact of receiving a cancer diagnosis may create feelings of uncertainty, fears of recurrence and difficulty planning for the future.
2. Quality of life appeared to be influenced by earlier experiences of care during cancer treatment, and where this was perceived to have been efficient and co-ordinated, with effective communication within the treatment team, a positive and confident sense of the future appeared to be engendered.
3. Comorbidities could be an additional burden and had often been exacerbated by cancer treatment, leading to slower recovery and reduced confidence.
4. Cancer treatment very often caused side-effects that negatively impacted upon the physical functioning and quality of life of participants.
5. Social and financial difficulties were common, including caring responsibilities, inability to participate in social activities, debt and financial worries due to pro-longed inability to work, and the need to return to work before they felt ready. Such social problems were sometimes also influenced by poor physical functioning.
6. Inadequate preparation for the potential impact of cancer and its treatment, either by being uninformed about possible physical side effects of treatments, being

unaware of the potential psychological impact of a cancer diagnosis and treatment side-effects, not being provided with equipment to manage practical difficulties; and not being advised of potential coping strategies to adopt.

By examining the comments of participants who report good experience and who have learnt to manage on-going problems it was possible to identify the various factors that helped mitigate what might potentially have led to poor life quality. These mitigating factors fell into two groups: professional-led and survivor-led. Survivors describing good experiences often praised the well-coordinated care they had received while undergoing investigations and treatment and had been sufficiently prepared by health professionals for problems associated with cancer and treatment side-effects. Professional-led mitigating factors also included quality aftercare, provided by named health care professionals especially clinical nurse specialists, who supported the development of self-management strategies and with whom survivors could remain in contact and discuss problems as they arose. This level of continuity often addressed the hiatus that many experienced at the end of their treatment, helped reduce fear of recurrence and increased confidence in the future.

With regards patient-led mediating factors, many participants who coped well with on-going problems had reportedly done so themselves, through a process of trial and error, or through talking to others with similar experiences. Participants had adopted various strategies, such as focussing upon the '*positive*' aspects of life; adjusting work-life balances, adopting healthier lifestyles; gradually increasing activity and social life as a way of getting life back to normal, return to employment or voluntary work; and the use of psycho-social and complementary therapies. The teaching of potential strategies to manage physical problems such as bowel and urinary incontinence, fatigue and sexual difficulties, transcends both patient preparation and aftercare, and several participants argued that affordable access to interventions such as counselling and talking therapies should be available to address issues like altered body image and fear of recurrence.

Figure 1: Factors impacting upon quality of life outcomes



8. Discussion

This analysis of free-text comments within the pilot PROMs survey complements quantitative analysis of the formal measures by illuminating relationships between factors that impact upon quality of life (QoL) or mitigate against negative effects. These insights can then be passed on to NHS providers to help improve quality of patient experience (DH 2010). This approach adopted alongside formal PROMs measures shows that individuals actively engage with the opportunity to provide comments relating to their experiences, thus providing data relating to 'why?' health outcomes are reported in formal measures, and illuminating the insights gained from statistical analysis. For example, analysis of the survey's closed questions indicate that the cancer population in this study demonstrate poor quality of life relative to the general population, and that a substantial proportion of individuals report on-going health needs (DH 2012). However, statistical data do not shed light on the experiences of treatment care, aftercare following cancer treatment, or on what might improve health outcomes or patient experience. The free text comments thus complement the quantitative results by allowing participants to indicate important issues of priority to them, which can assist policy makers to identify risk profiles within the English cancer population and to decide how to best target efforts at system improvement. While these comments cannot be viewed as necessarily 'representative' of patient experiences' more generally, they nevertheless provide rich insights into these, and are data not available in other large scale surveys of cancer survivors (Lerro et al 2012).

Both the survey's formal PROMS measures (DH 2012) and the free text comments indicated the impact of treatment upon comorbidities, and a greater incidence of poor health has previously been shown to exist amongst cancer survivors with comorbid conditions (Hewitt et al 2003, Elliott et al 2011). Participants also identified many on-going physical, psychological and social problems that they continued to face many months and years after the completion of treatment. These problems were similar to those reported in previous studies (Foster et al 2010, Hewitt et al 2003, 2006, Rechis et al 2011, Foster & Fenlon 2011, Armes et al 2009), although there is little current evidence concerning the prevalence and nature of many such issues (Foster & Fenlon 2011, Lerro et al 2012, Richardson et al 2011). Similar problems were reported across all four tumour groups and time-points from cancer diagnosis, indicating these are widespread and enduring (Armes et al 2009). However, participants often indicated that they had little preparation about what to expect with regards potential physical and psychological impact of the cancer and treatment side-effects, and lacked information regarding possible strategies for dealing with their on-going problems. While recent evidence suggests that patients want more information concerning long term effects of cancer and treatment, and to be given psycho-social support and strategies for self-management of problems (Rutten et al 2005), cancer survivors nevertheless continue to receive sub-optimal levels of information about life beyond cancer treatment (Ayanian et al 2010, Harrison et al 2012), and research regarding the effectiveness of many potential self-management approaches remains limited (Richardson et al 2011, Lerro et al 2012).

There is a clear need for consideration to be given as to how to improve care for cancer survivors (Rowland et al 2006). A fundamental shift is currently underway in the way that cancer survivors are supported after treatment, as part of the Department of Health for England National Cancer Survivorship Initiative (DH 2010, Davis & Batehup 2011), with the aim of empowering survivors to self-manage their condition and treatment effects. The

findings from this study indicate that the DH PROMS programme for cancer has the potential for providing data to evaluate the effectiveness of such initiatives, both in relation to conventional health measurement tools in the form of PROMS and also through feedback framed by patients themselves. Several recommendations supported by the findings are given below.

9. Limitations of the study

Data were volunteered by individuals and were not systematically recorded according to a structured list of topics of areas and, therefore, are not necessarily representative. The broad phrasing of the question elicited a varied range of responses from participants, which may reduce validity and interpretation, and recall and response bias may be present. However, qualitative analytical approaches are based on a long tradition of valuing individual experiences as providing insights that have high authenticity and validity. The fact that the free text comments mirror scores from the PROMS measures suggests that these are a valid representation of the views of participants. Strong themes emerged from the data, with clearly inter-related associations, that enabled the development of a framework encompassing all responses, and which illuminates the findings of the quantitative survey.

10. Conclusion

The comments provided by individuals participating in the Department of Health, England, Cancer PROMS Survey reinforce the need for greater emphasis to be given by cancer services to supporting individuals to manage following completion of cancer treatment. This is in keeping with the priorities of the National Cancer Survivorship Initiative (DH 2010) and cancer charities. Preparation and support for life after cancer treatment is urgently needed. Individuals are ill prepared for the physical consequences of some treatments for cancer and the psychological aftermath of receiving a diagnosis of a potentially life threatening illness. The absence of early intervention to investigate and treat serious on-going physical problems that result from certain treatments for cancer is unacceptable. The potential for early intervention and more systematic preparation for individuals to self-manage post treatment problems should be explored.

11. Implications for practice / Recommendations

The responses of participants to the free text comments box in the Cancer PROMs survey support the following recommendations:

Quality patient care during the treatment phase

- During the treatment phase cancer patients need care to be: delivered in a professional and caring way; coordinated with no unnecessary delays to investigations and treatment; accompanied by the opportunity to receive full information about their diagnosis and treatment options;

Preparing patients for survivorship

- Patients need to be fully informed about the potential physical effects of treatment, and have access to advice about self-management, including how to access post-treatment support services;

- Patients need to be informed that once active treatment is completed, and they no longer have regular contact with health professionals, that psychological issues might take a greater significance in their lives;
- Patients need to be aware of the potential psychological problems they might experience as cancer survivors, and have access to information and advice about possible coping strategies;
- Patients need access to advice to help overcome social and financial problems, including: the availability of social services; their eligibility to state benefits; and their rights concerning returning to work;

Supporting patients during survivorship

- The current shift towards more personalised aftercare approaches that encourage patients to self-manage their symptoms needs to be accompanied by access to both effective practical and psycho-social support.

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Appendix 1

The following tables indicate the number of participants within each age range at each time point from initial diagnosis for each of the tumour groups.

Table 1: Age range of respondents by time from initial diagnosis: Prostate

Age	1 year		2 years		3 years		5 years		Total
	Male	Female	Male	Female	Male	Female	Male	Female	
<49	1	0	0	0	0	0	0	0	1
50 – 64	14	0	13	0	8	0	9	0	44
65 – 74	29	0	30	0	25	0	24	0	108
75 +	25	0	24	0	17	0	36	0	102
Total	69	0	67	0	50	0	69	0	255

Note: The mean age of participants amongst the prostate tumour group was 68 years, and ranged from between approx. 91 years (born 1920) and approx. 49 years (born 1962).

Table 2: Age range of participants by time from initial diagnosis: NHL

Age	1 year		2 years		3 years		5 years		Total
	Male	Female	Male	Female	Male	Female	Male	Female	
35 – 49	6	6	4	5	5	1	2	5	34
50 – 64	8	17	13	7	11	7	11	7	81
65 – 74	8	8	15	7	4	13	7	7	69
75 +	9	6	12	4	11	11	12	4	69
Total	31	37	44	23	31	32	32	23	253

Note: The mean age of participants amongst the NHL tumour group was 68.6 years and ranged from between approx. 94 years (Born 1917) and approx. 27 years (born 1984).

Table 3: Age range of participants by time from initial diagnosis: Colorectal

Age	1 year		2 years		3 years		5 years		Total
	Male	Female	Male	Female	Male	Female	Male	Female	
< 49	1	0	1	2	0	4	3	0	11
50 – 64	6	10	8	8	12	5	4	7	59
65 – 74	11	8	18	12	13	8	9	5	83
75 +	13	8	8	12	16	12	22	14	105
Total	31	26	35	34	41	29	38	26	258

Note: The mean age of participants amongst the colorectal tumour group was 71.5 years and ranged from between approx. 97 years (Born 1914) and approx. 25 years (born 1986)

Table 4: Age range of participants by time from initial diagnosis: Breast

Age	1 year		2 years		3 years		5 years		Total
	Male	Female	Male	Female	Male	Female	Male	Female	
<49	0	10	0	17	0	6	0	9	42
50 – 64	0	35	0	25	0	27	0	33	120
65 – 74	0	15	0	13	0	23	1	25	77
75 +	0	11	0	15	0	11	0	14	51
Total	0	71	0	70	0	67	1	81	290

Note: The mean age of participants amongst the breast tumour group was 62.5 years and ranged from approx. 34 years (born 1977) to approx. 101 years (born 1910)