HEALTH BEHAVIOURS IN CANCER SURVIVORS

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Declaration

I, Chloe Marie Grimmett, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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ABSTRACT

As cancer outcomes improve there is growing interest in the role of health behaviours in enhancing health and wellbeing in cancer survivors. However, there have been few studies of health behaviours in cancer survivors in the UK.

Study 1 used data from the English Longitudinal Study of Ageing to conduct the first investigation of health behaviours in an English sample of cancer survivors compared with the general population of older adults. Rates of current smoking and alcohol consumption were comparable, however cancer survivors were more likely to be ex-smokers and less likely to be physically active than adults without cancer. Study 2 examined health behaviours in a large sample of colorectal cancer (CRC) survivors. The results broadly confirmed suboptimal health behaviours in this population. Study 3 also demonstrated that better health behaviours were associated with better quality of life. In this same sample, believing that lifestyle factors may have contributed to cancer occurrence was associated with improvement in health behaviours following diagnosis (study 4). Receiving advice on secondary prevention from a clinician was also associated with an increased chance of health behaviour change (study 5). In addition the perceived barriers of age and mobility were associated with participating in less physical activity (study 6).

Evidence that healthful behaviours improve quality of life, coupled with their preventive effect on second primary cancers and other diseases for which cancer survivors are at an increased risk, suggest cancer survivors are an important population for health promotion. However, evidence for effective lifestyle interventions among CRC survivors is scarce. Study 7 therefore examined the feasibility and acceptability of a lifestyle change intervention in a small pilot sample of CRC survivors (n = 11). The intervention was feasible and acceptable and associated with positive health behaviour change. This research has contributed to the understanding of health behaviours among cancer survivors in the UK, and provides insight into how to encourage health behaviour change in this vulnerable population.

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Chapter 1

Introduction to cancer survivorship

Cancer survivors; the growing population

Advances in cancer detection and treatment have meant that survival rates for many types of cancer have increased steadily over the past 40 years in both men and women. In 2010, Cancer Research UK commissioned analysis of survival trends in England and Wales from 1971-2 to 2007. They revealed an increase in 10 year survival rates for all cancers from 24% to 45%. These include increases of 40-77% for breast cancer and 23-50% for colorectal cancer (CRC). The trends towards an ageing population (and therefore more cancer diagnoses) coupled with continuing advances in early detection and treatment, means the estimated 2 million 'cancer survivors' in the UK today is expected to increase by 3% year on year (Maddams et al., 2008).

Defining a 'cancer survivor'

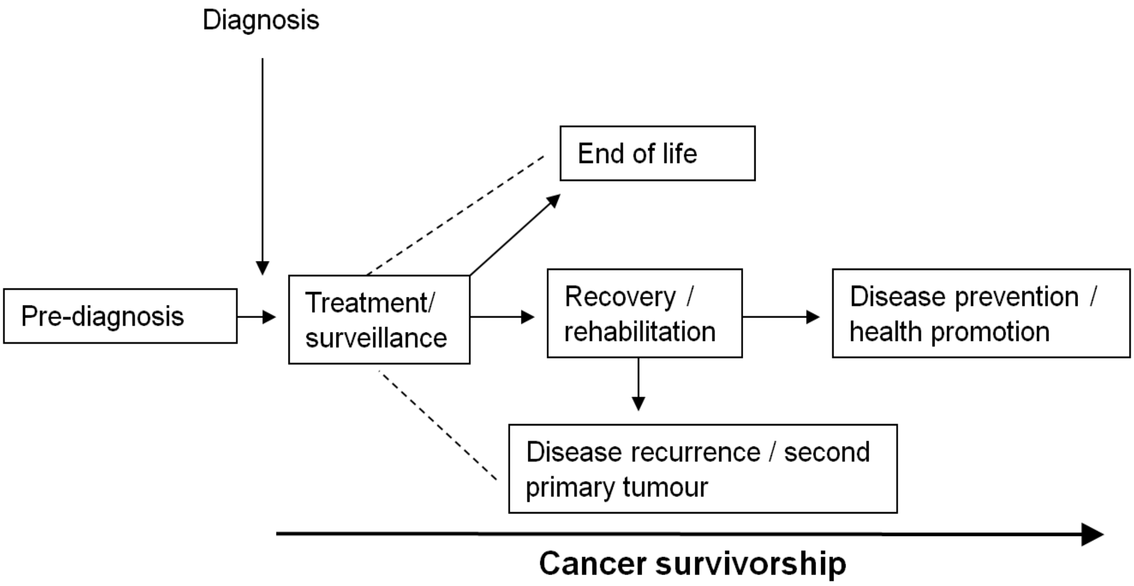
It is important at this stage to define what is meant by a 'cancer survivor'. There is no agreed definition of a cancer survivor, but the concept of survivorship is not a new one. In 1985, the paper "Seasons of survival: reflections of a physician with cancer" was published in the New England Journal of Medicine (Mullan, 1985). In this paper Mullan summarised the current perceptions that an individual was either a cancer patient or was 'cured'. He argued that such a simply dichotomy did not accurately reflect the experiences of people diagnosed and treated for cancer, and instead suggested use of the term 'survival'. He went on to highlight many of the challenges faced by people living with a cancer diagnosis and outlined the importance of a specific focus of research on survivorship. Since then, and particularly over the last decade, there has been a surge in research which aims to improve the health and wellbeing of those living beyond a cancer diagnosis, underscored by the launch in 2007 of the Journal of Cancer Survivorship; Research and Practice. Over this period, a number of definitions have been proposed but the most commonly used in the survivorship literature, and the one adopted for this thesis, is the definition proposed by the National Cancer Institute and

Institute of Medicine; ‘a person is defined as a cancer survivor from the time of diagnosis and for the balance of life’.

Stages of the cancer experience

While the definition of a cancer survivor encompasses everyone from the point of diagnosis and for then on, the cancer experience can be broken down into stages. Two frameworks to guide cancer survivorship research have been suggested. Figure 1.1 presents an adaptation of Courneya and Friendrich’s (2007) P*hysical Activity and Cancer Control* (PACC) framework, and Saxton and Daley’s (2009) S*tages of the cancer continuum*.

Figure 1.1 Stages of the cancer experience (adapted from Saxton & Daley, 2009 and Courneya & Friendrich, 2007).



Although not included in the definition of cancer survivor, both frameworks propose the first phase of the cancer experience to be pre-diagnosis. The second phase is diagnosis which tends to be followed by a treatment phase. After treatment a large proportion of survivors will enter the recovery/rehabilitation phase with the aim of re-establishing health and wellbeing, and they should then progress into the disease prevention/health promotion phase. Some however experience disease recurrence or develop second primary tumours. These survivors will either enter the treatment phase again or the palliative end of life phase. The work included in this thesis focuses on the recovery/rehabilitation and disease prevention/health promotion phases, exploring the role of health behaviours in enhancing health and wellbeing in this vulnerable population.

Physical and psychosocial consequences of cancer survivorship

Improvements in survival are immensely encouraging for those facing a cancer diagnosis, but survival can be accompanied by physical and psychosocial difficulties. Although treatments received vary, the majority of cancer survivors will experience some adverse effects. Long-term effects include side effects that occur during or soon after treatment and can persist for weeks, months or years afterwards. Late-effects refer to effects that manifest themselves months or years after treatment.

There has been a good deal of investigation into the late and long-term effects of survivorship for childhood cancers, and they indicate a raised risk for developing many chronic health conditions, particularly CVD, second primary cancers, musculoskeletal problems and renal dysfunction (Oeffinger et al., 2006; Skinner et al., 2006). The late and long-term effects in survivors of adult-onset cancer are likely to differ from childhood survivors because of different types of malignancy and age-related changes (Fossa et al., 2008).

While research in this area is still in relative infancy, accumulating evidence suggests that survivors of adult-onset cancer are also at greater risk of developing cardiovascular disease (CVD) (Wingo et al., 1998). Additionally a study in the US compared 1.2 million cancer patient records from SEER (Surveillance, Epidemiology, and End Results) with an age-matched population from the National Centre for Health Statistics (Brown et al., 1993) and found higher rates of non-cancer deaths among cancer survivors than in the general population, 50% of these being attributed to CVD. The exact cause of this high prevalence of CVD is unclear, but it is thought to be multi-factorial. Cancer treatments can result in cardiovascular damage and induce hormonal and metabolic changes associated with cardiovascular risk. The older age of cancer survivors is also thought to play a role, as are suboptimal health behaviours. Poor health behaviours such as low physical activity may be the result of musculoskeletal and cardiorespiratory restrictions caused by treatments, but may also reflect a predisposition for health-risk behaviours; factors that have a shared aetiology with cancer and CVD.

Cardiovascular risk factors tend to cluster and have been termed ‘metabolic syndrome’. Metabolic syndrome is classified by the presence of dyslipidamiea, hypertension, central obesity and insulin resistance (de Haas et al., 2010). A number of studies that have found higher rates of metabolic syndrome in survivors of testicular, prostate and malignant haematological disease compared to controls. Weight gain often associated with cancer treatments, particularly breast cancer and is of concern due to its association with CVD and the fact that it has been identified as a risk factor for recurrence and mortality in several cancer sites (Calle et al., 2003).

Cancer survivors are also at an increased risk for the development of second primary cancers. Travis et al (2006) note that second primary cancers are one of the most serious consequences of successful cancer treatment, with breast cancer being the leading cause of death in long-term survivors of Hodgkins lymphoma. As with CVD, this increased risk is thought to be due to a number of factors. Iatrogenic effects of treatment contribute to the high incidence of breast cancer after Hodgkins disease, and lung cancers after breast cancer treatment. Genetic predisposition has also been suggested, for example, cancers related to the HNPCC gene include colorectal, bladder, ovarian and pancreatic so individuals who survive one could get the other (Aziz, 2007). Lifestyle and environmental risk factors are also thought be play a role (Travis et al., 2006).

As well as susceptibility to chronic disease, cancer survivors commonly experience other cancer-related effects. Functional decline is often associated with the ageing process, but cancer survivors commonly report greater decline than those without a history of the disease. A comparison between 22,747 cancer survivors and an equal number of age-matched controls found that cancer survivors had significantly poorer scores on all subscales of the SF-36 (including physical function and role limitations due to physical reasons) (Baker et al., 2003). It is unclear whether this association is due to the effects of cancer *per se* or confounded by the presence of comorbidities. Schroevers et al (2004) found accelerated functional decline in the year after cancer diagnosis, whereas Garman et al (2003) reported functional decline to be significantly associated with comorbidities. In a very large study comparing 4,878 cancer survivors and 90,737 matched controls, cancer survivors were twice as likely to report at least one functional limitation, but when another comorbidity was present the odds ratio increased to 5.06 (95% CI 4.47-5.72). It is therefore clear that functional decline is a significant problem in this population (Hewitt et al., 2003).

A number of studies also suggest that a substantial proportion of cancer survivors experience depression and anxiety disorders, although the reported prevalence varies. A review published in 2004 reported a range of 0-38% for major depression and 0-58% for depression spectrum syndrome (Massie, 2004). Literature published since this review remains inconsistent. For example, Fossa et al (2003) reported no difference in depression levels between testicular cancer or Hodgkins disease survivors and the general population. In contrast, 48% of breast cancer survivors experienced “clinically significant” depression or anxiety in the first year after diagnosis (Burgess et al., 2005), although a year after diagnosis, levels of depression were no different from the general population. The inconsistencies in the literature may be partly explained by variance in time since diagnosis, with the possibility that depression may be short-lived. Studies also vary in terms of the definition of depression that they use and the cancer sites that are considered. Higher prevalence of depression does seem more common in patients diagnosed with more advanced stage disease (Lynch, 1995). However a recent review concluded that although diagnosis and treatment of cancer are associated with depression, levels have generally been over-estimated (Simon et al., 2007). As such, drawing general conclusions in this area is problematic and research in more homogenous samples required.

Fatigue is a commonly reported and distressing symptom among cancer survivors. It is most prominent during treatment but often persists for several years after treatment is complete (Fossa et al., 2003). Cancer related fatigue is reported by as many as 76-99% of cancer survivors. Cancer-related fatigue is distinct from other fatigue as it is not relieved by a period of rest and is more persistent. It can have a significant and negative impact on quality of life (QoL), ability to perform daily tasks and emotional wellbeing (Ng et al., 2007).

The presence of fatigue, depression, anxiety, physical function limitations, impaired cardiovascular and pulmonary function (as discussed above), as well as numerous treatment side effects such as nausea, pain, weight gain and insomnia combined can impact on the physical, functional, psychological and social aspects of QoL (Courneya & Friedenreich, 1999a).

These effects on QoL are most acute between diagnosis and shortly after treatment completion and levels appear to recover over time (Lemieux et al., 2007). Indeed a number of studies report few differences in QoL between long-term breast cancer survivors and general population controls (Dorval et al., 1998; Tomich & Helgeson, 2002). However, a review of QoL in long-term survivors that considered the various facets of QoL concluded that although there was significant heterogeneity in results (likely to due variations in instruments used and sample characteristics), many survivors experience negative effects of cancer and its treatments for many years after diagnosis (Gotay & Muraoka, 1998). Indeed a more recent review confirmed that long-term breast, non-hodgkins lymphoma and prostate cancer survivors have continuing concerns that impact on physical and psychological QoL (Bloom et al., 2010). Furthermore, breast cancer patients have been reported to have fatigue that impacts on QoL up to 5 years after diagnosis (Meeske et al., 2007).

The growing population of cancer survivors and the associated long term and late effects of cancer treatment and chronic disease burden has now been recognised as a public health priority in the UK. The Cancer Reform Strategy (Department of Health, 2007) identified survivorship ("living with and beyond cancer") as one of ten key areas to be addressed (Department of Health, 2007). As part of this programme for action, the Department of Health (DH) formed the National Cancer Survivorship Initiative (NCSI), a partnership between DH and Macmillian Cancer Support. Officially launched in September 2008, the NSCI aims to improve the care and support for those living with and beyond cancer, highlighting the importance of cancer survivorship as an area for future research (Department of Health & Macmillan Cancer Care, 2008) .

Health behaviours and outcomes in cancer survivors

Health behaviours may present an opportunity to improve the health and wellbeing of cancer survivors. For example exercise may play a role in ameliorating some of the adverse squealae of cancer and its treatments previously discussed and may even impact on prognosis.

Physical activity and outcomes in cancer survivors

The greatest body of work in this area relates to acute outcomes, such as impact on treatment side-effects, QoL and physical function. The literature has accumulated rapidly in recent years with numerous qualitative systematic reviews (Brown et al., 2003; Courneya, 2003; Galvao & Newton, 2005; Knols et al., 2005; Kuhn et al., 2005).

These reviews have varied by search terms, inclusion criteria, and key outcomes. Some conduct separate analyses by treatment status (i.e. during or after treatment completion) or, in the case of Knols et al (2005), by cancer site (breast vs. other solid tumours). In spite of such variation, the literature consistently shows physical activity to be associated with improvements in QoL, fatigue, anxiety and depression as well as fitness, muscle strength and flexibility. There are also suggestions of improvements in health-related biomarkers (e.g. blood pressure and circulating hormone levels), and immune variables (e.g. natural killer cell cytokine activity), although fewer studies have assessed these outcomes.

Systematic reviews are a useful way to synthesise findings, but when a positive effect is found the magnitude of this effect is unknown. To this end, meta-analysis is used to determine effect sizes and thus infer clinical relevance. Four meta-analysis have been conducted to assess physical activity in cancer survivors and results are summarised in table 1.1 (Conn et al., 2006; Holtzman et al., 2004; Schmitz et al., 2005b; Speck et al., 2010).

As with the qualitative systematic reviews, the meta-analyses have varied by study inclusion/exclusion criteria. For example Conn et al (2006) included both unpublished and published studies. They also include single group, pre-post studies. The rationale for this decision was that at the time of publishing the area of research was in its infancy and unpublished and uncontrolled studies provided important data. In table 1.1 only results from the meta-analysis of controlled studies are presented. In contrast Schmitz et al (2005) excluded any studies that did not have a control group. The most recent review published this year, is an update of Schmitz and colleagues review and includes only RCTs (Speck et al., 2010). This is the most methodologically rigorous and up-to-date review of existing studies. There were also more interventions in the post-treatment period published in contrast to the previous meta-analysis.

Using criteria proposed by Cohen (effect sizes of 0.2 – 0.5 are described as small to moderate, 0.51 – 0.8 as moderate to large, and >0.8 as large) Speck et al (2010) report large effects for post-treatment interventions on lower and upper body strength, small to moderate effects for aerobic fitness, QoL, fatigue and symptoms and side effects, and small to moderate effects for body strength, body weight and anxiety for interventions conducted during treatment. Some larger effects can be seen from previous meta-analysis for cardiovascular fitness and vigour, although estimates may have been exaggerated by inclusion of poorer quality trials.

Table 1.1: Mean effect sizes for meta-analysis of outcomes in cancer survivors

Outcome	Holtzman et al (2004)		Schmitz et al (2005)		Conn et al (2006)$		Speck et al (2010)	
	During tx	Post tx	During tx	Post tx	During tx	Post tx	During tx	Post tx
Cardiovascular fitness	0.64		0.51*	0.65*			0.33*	0.32*
Symptom side effects	0.40		0.39*	NC	0.29		-0.07	-0.30*
Physical function					0.45*			
Quality of life	0.42		0.07	0.30	0.14		0.28*	0.29*
Pain			-0.08	NC			-0.33	-0.12
Vigour	0.85		0.43	0.82*			0.22	0.17
Fatigue	0.22		0.13	0.16	0.11		-0.01	-0.54*
Depression/mood	0.42		0.09	0.44	0.12		NC	-0.39*
Anxiety	0.33		0.22	0.20			-0.21*	-0.43
Upper body strength							0.39*	0.99*
Lower body strength							0.24*	0.90*
Body fat/composition	0.19				0.27*		-0.25*	-0.18*
Immune variables			0.54*	0.24			-0.18	-0.73

*significant to at least <0.05
NC = non calculable
$ Results presented are for two-group comparison studies

Reviews also suggest that larger effects may be experienced after treatment as opposed to during treatment. It is probable that this is due to the acute and over-riding effects associated with receiving treatment, such as nausea, vomiting and fatigue. This is supported by Mutrie et al (2007) who conducted a 12 week supervised exercise programme in women being treated for breast cancer and found improvements in physical function (as measured by a 12 minute walk test) post-intervention, however no improvements were seen in general QoL until 6 months after the intervention. This improvement was above and beyond that experienced by the usual care control group, therefore suggesting it is not merely a time effect.

The current literature is also biased towards breast cancer samples, and some evidence suggests a greater effect of physical activity in breast cancer survivors compared to survivors of other sites (Conn et al., 2005). There are a number of possible explanations for this. It may be that women react more favourably to exercise interventions; but there are too few mixed-sex studies to test the moderator effect. Differences in treatment may be another possible explanation, but again, large-scale studies that compare outcomes by treatment are not available. In Conn et al’s (2005) meta-analysis, they reported that studies in breast cancer survivors tended to include younger participants and that this may contribute to the favourable outcomes.

Although not a meta-analysis, a recent synthesis of the evidence on the safety and efficacy of physical activity conducted by a panel of experts on behalf of the American College of Sports Medicine (ACSM) is an important contribution to this field (Schmitz et al., 2010). By and large, the results support those presented by Speck et al (2010). Evidence is categorised as either A: overwhelming data from RCTs, B: fewer RCTs or they are small and results inconsistent, C: results stem from uncontrolled/observational studies, and D: evidence is insufficient for categories A-C. There were numerous A’s assigned to outcomes in breast cancer survivors both during and after cancer treatment, including aerobic fitness, strength and physical function. Scores were predominantly B’s for QoL, fatigue, depression and body size. Evidence was more limited for other cancer sites but results were suggestive of some positive outcomes. For example, in prostate cancer survivors evidence for improvements in aerobic fitness, muscular strength and fatigue was robust, and evidence for improvements in physical function and QoL were rated B’s. Only four studies were identified that included CRC survivors, but the evidence suggested improvements in aerobic fitness, oxidative stress, physical function and inflammation.

An important consideration in this area of research is the potential for physical activity to result in adverse events. Unfortunately the majority of studies failed to report such data. A review by Schwartz (2008) found that only 14 (of 35) trials documented adverse events although only two studies found any. One was a single case (nausea was reported by a patient who engaged in an exercise intervention while nearing completion of radiotherapy). The other found borderline lymphedema in the physical activity group in a breast cancer trial. The ACSM review also reported overwhelming evidence from RCTs that exercise is safe in breast and prostate cancer survivors. It is therefore reasonable to conclude that exercise interventions in cancer survivors are generally safe. However caution should always be exercised when prescribing physical activity. The ACSM review highlighted cancer site specific considerations such as CRC survivors with an ostomy seeking physician approval before taking part in contact sports, and breast cancer survivors commencing resistance training at a low intensity and slow progression to avoid risk of lymphodema.

Conclusions

In general, studies in this field reported favourable effects across numerous outcomes. The meta-analyses reported small to moderate effect sizes, which look reasonable compared with effects in general population samples. However, there are a number of methodological limitations common to almost all studies. These included low recruitment rates which limit the generalisability to the overall population of cancer survivors, variation in methods and instruments used to measure outcomes (limiting comparability), small sample sizes, short-term follow-ups, heterogenous samples (regarding cancer type, time since diagnosis, treatment received, stage of disease etc) and variation in type, intensity and duration of exercise delivered. Including studies conducted during and after treatment in the same analysis is also not advisable due to differences in effects discussed previously; therefore more separate analysis is warranted.

The majority of the literature examined outcomes in breast cancer survivors and few studies have been conducted among other cancer sites. Lee Jones' group at Duke University are embarking on research in lung cancer patients and have recently published a study protocol for an RCT comparing aerobic and resistance exercise training in postsurgical lung cancer patients. The primary end point is V02 peak (a measure of cardiovascular fitness) and secondary outcomes include quality of life, fatigue and depression (Jones et al., 2010). Similar research in other understudied groups is required.

Current evidence is also insufficient to deduce the most effective mode, intensity, frequency and duration of exercise to achieve maximum benefit. Large-scale, RCTs with homogenous samples, long study durations and high methodological rigor are required. This of course is a great challenge, requiring large resources and multicenter collaboration. Promisingly, one such study is currently in the field with Kerry Courneya and colleagues having recently published the design of the Colon Health and Life-Long Exercise Change (Challenge) trial (Courneya et al., 2008a). This is a multinational, multicentre phase III randomised controlled trial run by the Canadian Clinical Trials group (part of the National Cancer Institute). The aim of the trial is to determine the effects of a structured physical activity intervention on outcomes in colon cancer survivors with stage II or III disease. The primary endpoint of this trial is disease free survival, with secondary outcomes including Qol, fatigue, sleep quality, anxiety, depression, cardiovascular fitness and physical functioning.

In conclusion, questions remain as to the optimal modality of physical activity to induce the most favourable outcomes in cancer survivors, or the magnitude of effects that can be expected. However current evidence supports the efficacy of physical activity in this population and given the potential for such favourable outcomes in health and wellbeing, research will undoubtedly continue to develop in this area. At the present time it can be concluded that moderate physical activity is safe and likely to result in favourable (and certainly not damaging) outcomes.

Physical activity and cancer survival

Despite the plethora of evidence relating lifestyle factors to the aetiology of several cancers (Kruk & boul-Enein, 2006), comparatively little is known about the association between health behaviours and either cancer-related or all-cause mortality in cancer survivors. However interest in this area is growing, particularly for breast cancer survivors.

A landmark paper published in 2005 was the first large-scale, prospective trial to report a significant protective association between physical activity after breast cancer diagnosis and recurrence, cancer-related mortality and overall mortality (Holmes et al., 2005). The cohort examined was from the Nurses' Health Study (NHS). Established in 1976, the NHS recruited 121,700 female nurses in the US who completed mailed questionnaires assessing risk factors for cancer and CVD. Follow-up questionnaires were sent every 2 years until 2004. After adjustment for numerous confounders including BMI, stage of disease, energy intake, age and treatment, breast cancer survivors who participated in 9-14.9 Met-h/wk[1] of physical activity had a 41% risk reduction of total mortality, 50% risk reduction for breast cancer death and a 43% risk reduction of breast cancer recurrence. These associations were strongest in postmenopausal women and those with oestrogen-positive tumours.

Since this publication a number of other studies have examined the association between pre and post-diagnosis physical activity and breast cancer death and all-cause mortality, and a recent meta-analysis summarised the results (Ibrahim & Al-Homaidh, 2010). This review included six studies, four examined the association between post-diagnosis physical activity and survival, and two examined pre-diagnosis physical activity. Physical activity was categorised as low (<3 met.-h/wk), intermediate (2.8 to <8.9 met.hr-wk) intermediate to high (≥ 8 met.hr-wk) and high (≥ 15 met.hr-wk). Pre-diagnosis physical activity had no effect on breast cancer survival but did reduce all-cause mortality by 18%. However, when examining results by weight status the effect was only seen in women of a healthy weight (≥25kg/m^2). Any level of post-diagnosis physical activity was associated with reduced breast cancer (34%) and all cause-

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[1] Abbreviation Met-h/wk, Metabolic equivalent hours per week.
9 Met-h/wk is equivalent to 3 hours of walking per week at average pace.

mortality (41%), relative to low physical activity. However only intermediate to higher levels of physical activity were associated with a reduction in cancer recurrence. When considering tumour estrogen receptor (ER) status, reductions in all-cause and breast cancer deaths were only seen in ER positive tumours. It is interesting to note that there was no evidence of a dose-response relationship, with similar reductions seen in mortality at all levels of physical activity above 3 met.hr-wk. It is possible that this was due to measurement error. For example in one study the proportion of women reporting vigorous physical activity was well above the national average, suggesting over-reporting (Sternfeld et al., 2009). This may be a result of a social desirability bias, or misperception as to what constitutes vigorous intensity physical activity.

It is important to note that two studies were excluded from this meta-analysis and both reported null results. A Canadian study measured physical activity by the frequency (from ‘a few times a year’ to ‘more than once a week’) with which participants engaged in various activities, such as jogging, walking and swimming. A variable of total number of activities per week was calculated and then dichotomised into ≥ 3 times per week vs. < 3 times per week. No association was found between any activity variables and cancer mortality (Borugian et al., 2004). This study was excluded from the meta-analysis as it did not provide data for total physical activity. The other excluded paper was drawn from data from the Women’s Healthy Eating and Living (WHEL) study (Pierce et al., 2007). Here there was no independent association between physical activity and mortality, rather only a combination of consuming ≥ 5 portions of F&V a day *and* being physically activity was associated with reduced all-cause and cancer mortality. Despite this study providing data on total physical activity it was excluded due to potential confounding from the WHEL intervention, designed to promote a plant-based diet in breast cancer survivors. However the data presented in this study are from the control group of this intervention. Presumably the authors of the meta-analysis felt that participants may still be influenced by participation in a lifestyle study. Nonetheless, current evidence in the main supports the hypothesis of a beneficial effect of physical activity in survival after breast cancer, particularly among overweight and ER positive cancer survivors.

Although the literature is dominated by studies of breast cancer patients, two large prospective studies have also been conducted in CRC survivors. Meyerhardt et al (2006a) used data from the Nurses Health Study (NHS) and reported a reduction in all-cause mortality with >9 Met-hr/wk of moderate physical activity (adjusted hazard ratio 0.50 95% CI 0.28-0.90). However the threshold for a protective effect for cancer-specific mortality was >18 Met-h/wk (HR 0.39 95% CI 0.10-0.82). This is higher than the >9 Met-hr/w reported for breast cancer survivors in a previous study using the same dataset (Holmes et al., 2005). Meyerhardt and colleagues replicated these findings in a mixed-sex, clinical sample in the same year (Meyerhardt et al., 2006b). This had the advantage of being a more homogenous group with regard to stage of disease, surgery and chemotherapy treatment. Findings were similar, with survivors who engaged in >18 Met-hr/w having a disease-free survival hazard ratio of 0.51 (95% CI 0.26-0.97) and 0.71 (95% CI 0.32-1.59) for overall mortality. This study also found that those who increased physical activity levels after diagnosis had lower risk for CRC mortality and all-cause mortality than those who did not change.

It could be argued that those who are more physically active after cancer diagnosis were also more active prior to diagnosis and develop less aggressive disease hence favourable survival. Therefore Meyerhardt et al (2006a) included pre-diagnosis physical activity in their analysis and the results remained unchanged, leading them to conclude that the effect of post-diagnosis physical activity is independent of pre-diagnosis levels. It is also possible that lower levels of physical activity may be a sign of poorer health and therefore prognosis, but in both studies Meyerhardt and colleagues found no significant associations between physical activity and other factors known to be associated with cancer survival. The association also remained after excluding participants who developed cancer recurrence or died within 6 months of the assessment. These analyses therefore support the independent protective association of physical activity in CRC survivors.

It remains unclear why there was a higher threshold of physical activity for protective effects in CRC survivors than breast cancer survivors. It could be differences in sample size or study design, (though the NHS samples was used in both cases), or that different physical activity has a genuinely different impact on the adverse outcomes linked with each cancer site.

While encouraging, generalisability of this data is limited as studies have only considered two cancer sites (breast and colorectal). Only a handful of population-based studies have been published that assess a range of cancer sites (Hamer et al., 2008; Hu et al., 2005; Leitzmann et al., 2007; Orsini et al., 2008). Orsini et al (2008) examined the association between physical activity and cancer incidence, mortality and survival in a population-based sample of men. Over an average follow-up of 7 years 3714 of the 48,654 men enrolled in the study were diagnosed with cancer, 1153 of whom died. The authors reported a strong inverse linear association between total daily physical activity and cancer death. For every increase of 4 Met-h/day of physical activity, cancer mortality decreased by 12% (95% CI 6-18%). In addition, those who exercised for 30 minutes a day or more had a 33% improvement in 5-year survival compared to those who hardly ever exercised. Numerous confounders were controlled for in these analysis including smoking status, alcohol consumption, education, parental history of cancer, diabetes, age and BMI.

Similar trends were reported in a US cohort of men and women from the National Institute of Health – American Association of Retired Persons (Leitzmann 2007). There was a linear trend for hours of moderate physical activity and mortality from cancer ($p = 0.02$); relative risk 0.86 (95% CI 0.78-0.96) for 1-3 hrs/wk, 0.88 (95% CI 0.79-0.98) for 4-7 hrs/wk and 0.83 (95% CI 0.74-0.93) >7 hrs/wk. They also reported relative risk separately for those adhering to moderate intensity physical activity recommendations (at least 5 a week), vigorous activity recommendations (20 minutes at least 3 times), and meeting both. Those meeting both recommendations had the greatest reduction in mortality; RR 0.74 (95% CI 0.65-0.85), although cancer mortality was also reduced in the other two groups (0.83 95% CI 0.72-0.95 and 0.79 95% CI 0.68-0.91 respectively). Comparable data have also been reported in a Finnish sample (Hu et al., 2005) with a 27% reduced risk of cancer death for those in the ‘moderate’ physical activity group (subjects reported moderate or high levels of either occupational or leisure time physical activity) compared to the lowest group, and a 44% reduced risk for those in the ‘high’ group (subjects reported moderate or high level of both occupational and leisure time physical activity) compared to the lowest group.

At present there has been only one study in a UK population-based sample (Hamer et al., 2008) and this used data from the Scottish Health Survey, with a sample size of cancer survivors significantly smaller than studies summarised previously (n = 293). There were 78 deaths during follow-up (average 5.9 years) with a lower risk of all-cause mortality for those who took part in sports activity verses those who did not (HR 0.47; 95% CI 0.23-0.96). However light and moderate activities such as domestic chores or regular walking did not confer any protective effect. The authors concluded that most of the protective effect of physical activity was explained by participation in vigorous physical activity, and consequently current recommendations of physical activity may be insufficient to achieve reductions in all-cause mortality in cancer survivors; although given the modest size of the study, it may have been underpowered to detect smaller effects. Nonetheless, evidence supports the notion for a protective effect of physical activity on mortality.

Inevitably, the existing literature has a number of limitations. All studies relied on self-reported physical activity, well documented to result in recall bias. Studies also vary in cut-offs used to classify activity levels. In addition, adjustment for confounding factors varied across studies. Also, despite evidence for an association with breast cancer aetiology, only one breast cancer study considered alcohol intake and two considered any dietary components. In addition, none of the breast cancer studies considered functional limitations or comorbidities (such as arthritis), factors that may affect physical activity participation. The relatively small number of cases of recurrence and deaths across studies may be suggestive of selection bias. However most performed separate analysis excluding those who died within the first year of follow-up and results did not change. This suggested the associations with survival and recurrence were not attributable to reverse causation (i.e. more unwell participants not being able to participate in physical activity). In addition, a number of these studies reported on data from existing studies designed to examine risk factors for cancer. Therefore the time at which behaviour data was collected in relation to diagnosis will vary.

In the population studies there is considerable heterogeneity in sample characteristics, study design, and confounders considered. For example, participants' ages have ranged from 45-79 (Orsini et al 2008) to 24-64 years (Hu et al., 2005). Length of follow-up also varied with a mean follow-up of 5.9 years in the study by Hamer et al (2008) vs. 17.7 years in Hu et al's (2005) study. As with the breast and CRC literature, covariates considered in the models varied considerably. Leitzman et al (2007) controlled for a wide range of behavioural variables (including smoking, fruit and vegetable consumption, meat consumption and BMI), while Hu et al (2005) adjusted only for smoking. There was also variation with regard to measures of physical activity used and how participants were classified. For example Orsini et al (2008) used a continuous physical activity score whereas the other studies categorised participants either into active vs. non-active, or into quartiles. A general criticism of this literature is that the time period between physical activity assessment and cancer occurrence was not discussed. Given that the pattern of physical activity appears to vary with time since diagnosis (see later section), this may be an important consideration. And inevitably the studies all relied on self-reported physical activity.

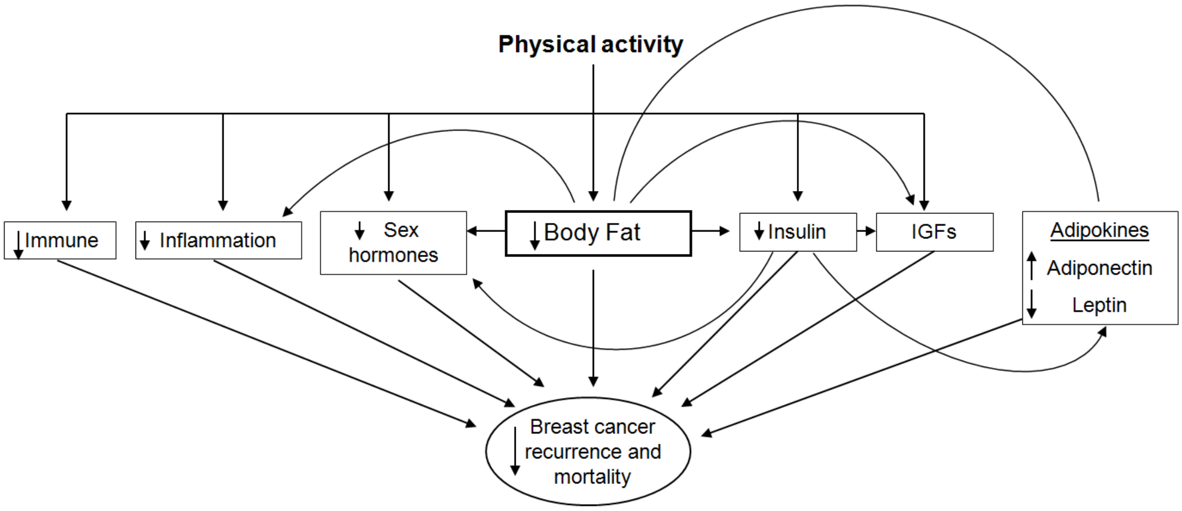
Addressing the limitations of self-reported physical activity are two studies that examined the association between cardiorespiratory fitness and cancer mortality. Jones et al (2010) measured VO_{2peak} (the gold standard assessment of cardiorespiratory fitness) in a sample of non-small call lung cancer survivors. They reported a negative linear trend for all-cause mortality with increasing cardiorespiratory fitness, and a 21-24% reduction in risk of mortality for the highest vs. the lowest fitness level. Cancer-specific mortality was not assessed. In a Finnish, population-based, cohort study those in the highest tertile of $V0_{2max}$ had a 37% reduced cancer mortality compared to those in the lowest tertile (Laukkanen et al., 2010).

In conclusion the current literature suggests a protective effect of physical activity on both all-cause mortality and cancer-related mortality, particularly among breast cancer survivors and possibly among CRC cancer survivors, although it is not yet possible to draw conclusions either about optimal intensity, duration or mode of activity to incur greatest benefit, or the minimum to achieve worthwhile benefit.

Physical activity and survival – Biological mechanisms

Despite the mounting evidence for improved survival through physical activity, the mechanisms underlying this effect are poorly understood. Irwin (2010) summarises the proposed mediating mechanisms in breast cancer survivors (see Figure 1.2).

Figure 1.2: Hypothesised mechanisms mediating an effect of physical activity on breast cancer outcomes (adapted from Irwin, 2010).



Obesity and weight gain are risk factors for the aetiology of numerous cancers and there is also evidence that weight gain after diagnosis is associated with less favourable outcomes. A very large (n = 900,000) national prospective study with a follow-up of 16 years found BMI was significantly associated with higher rates of mortality in cancers of the esophagus, colon and rectum, liver, gall bladder, pancreas, kidney, non-hodgkins lymphoma, multiple melanoma, breast, prostate, cervix, ovary, and stomach (in men only). The authors concluded that overweight and obesity accounted for 14% of deaths from cancer in men and 20% in women. Physical activity may therefore exert effect indirectly through an association with body fat.

One suggested pathway relates to sex hormones such as estrogen which have been linked to breast and endometrial cancer occurrence possibly due to their mitogenic effects, thus stimulating tumour growth. Adipose tissue secretes sex hormones and BMI has been found to be positively associated with sex steroid hormone concentrations in breast cancer survivors in the HEAL study (McTiernan, 2004). If physical activity offers protection by reducing fat mass this could work through sex steroid concentrations. A direct relationship has also been proposed as physical activity levels have been found to be related to lower oestrogen levels and higher sex hormone binding globulin (SHBG) in women (van Gils et al., 2009). Only one RCT however has examined the effect of exercise on hormone concentrations. This study was carried out among a healthy sample of post-menopausal women. Physical activity was associated with reductions in serum estrogen and SHBG, with a greater effect in women who lost fat.

High insulin and IGF-1 levels have also been associated with increased risk of all-cause mortality in cancer survivors. For example, in a study in breast cancer survivors there was a 3 fold increased risk of all-cause mortality among women in the highest quartile of fasting insulin levels vs. the lowest (Goodwin et al., 2002). It has been suggested that hyperinsulinemia/insulin resistance, commonly seen among obese individuals, reduces levels of insulin like growth factor binding protein 1 (IGFBP-3), therefore increasing free levels of IGF-1. Insulin and IGF-1 are known to have mitogenic properties and may therefore stimulate tumour cell proliferation. In addition, hyperinsulinemia is associated with lower levels of sex hormone binding globulin, thus interacting with the mechanism discussed previously. Studies examining the effect of physical activity on insulin and IGF-1 levels in breast cancer survivors have produced equivocal results (Ligibel et al., 2008; Schmitz et al., 2005a). However those that found a reduction in insulin and IGF-1 report this result to be independent of changes in body weight, suggesting a direct mechanism of physical activity on these hormones. Data from a prospective study also adds support to this hypothesis. Haydon et al (2006) classified participants as active or inactive on entry to the prospective study. After a median follow-up on 5.6 years 526 developed cancer. Those in the active group were found to have higher IGFBP-3 levels which related to a 48% reduction in cancer death. In summary, evidence is accumulating to suggest an important role of insulin, IGF-1 and IGFBP-3 in cancer prognosis and that this is influenced by body weight and/or physical activity. However more research is needed to clarify the exact nature of the mechanisms involved.

Adipokins such as leptin and adiponectin have mitogenic effects and increase cell proliferation. High levels have been linked to breast cancer prognosis (Jarde et al., 2008; Vona-Davis & Rose, 2007). Higher levels of leptin are associated with higher body mass. Therefore physical activity may improve survival by reducing adipokin circulation as a result of reduction in fat mass (Irwin, 2010). Also, inflammation has been identified as a risk factor for cancer (Balkwill & Coussens, 2004) and has also been linked to poorer survival in breast patients (Ardizzoia et al., 1992). Therefore physical activity may improve survival by reducing inflammation, either directly or my reducing fat mass.

Another proposed mechanism not associated with body weight is improvements in immune system function. One popular theory is the “Inverted J” hypothesis (Woods et al., 1999) whereby immune system function and reduced susceptibility to cancer is enhanced with regular moderate physical activity, but compromised by repeated bouts of exhaustive exercise. A review of this literature (Fairey et al., 2005) revealed predominantly favourable findings. Improvements were seen in natural killer cell cytolytic activities, monocyte function and circulating granulocytes. Although promising, studies are limited by small sample sizes, variations in exercise interventions and study design.

Mechanisms have also been proposed specifically for the protective effect in CRC survivors. Reduced gastrointestinal transit time may be protective by reducing exposure of the colon to carcinogens (Harriss et al., 2009). Changes to prostaglandin levels/ratios have also been implicated (Stevinson et al., 2007a) as mechanisms for physical activity protection in CRC survivors however more research is required. In addition, similar mechanisms described above for breast cancer prognosis may also influence CRC outcomes. For example insulin and hyperinsulinemia are thought to be linked to CRC and a hazard ratio of 2.99 (95% CI 1.27 – 7.02) for CRC mortality have been reported among participants with insulin resistance in a large prospective study (Trevisan et al., 2001).

Thus far the discussion has focused on mechanisms that may affect cancer prognosis. However, as was seen earlier cancer survivors are at increased risk of CVD, a disease which accounts for a significant proportion of deaths among survivors. Physical activity therefore may influence all-cause mortality by reducing cardiovascular risk factors, a number of which were discussed above, i.e. insulin resistance and weight management.

In conclusion, there is no definitive evidence for the mechanisms through which physical activity exerts its effects on cancer death and all-cause mortality, but it seems likely that they do not occur in isolation. Interest in this areas of research is increasing in the hope that this relationship can be better understood, and in turn contribute to the growing body of evidence that ultimately attempts to enhance disease free survival.

Nutrition and outcomes in cancer survivors

For decades, research into the effect of diet in cancer has focused almost exclusively on its association with cancer aetiology. To this end, there is a plethora of evidence that implicates poor dietary habits in the development of numerous cancers (WCRF/AICR, 2007). The potential role of nutrition in cancer prognosis and survival has attracted less attention. However, over recent years interest in this area has increased, particularly in relation to nutrition and breast cancer survivorship. The following section will discuss the existing studies assessing post-diagnosis nutrition on outcomes in cancer survivors, and the evidence emerging from RCTs that address the effect of dietary manipulation on disease-free survival and mortality.

The earliest work in this area used existing cohort studies designed to investigate the role of diet on cancer development and manipulated them to assess cancer recurrence and survival. A review in 2002 examined the evidence from these early studies in breast cancer survivors (Rock & Demark-Wahnefried, 2002). Twelve studies included in the review assessed total dietary fat intake and survival, five of which reported an inverse association. Ten studies also assessed various types of fat, but the evidence for their role in disease progression was inconsistent. There was evidence of a protective effect of vegetable intake but the strength of the association was modest with large heterogeneity in effect sizes. All studies failed to find a link between dietary fibre and survival.

The use of existing studies has obvious advantages in terms of eliminating the need to invest new funding and resources, but it also results in limitations (some of which were mentioned in relation to the physical activity literature). Kushi et al (2007) highlighted three major problems associated with this method of data collection; 1) the time point at which baseline dietary assessment is carried out in relation to cancer diagnosis will be inconsistent throughout the sample because the study is designed to collect dietary information periodically as opposed to when cancer is diagnosed; 2) many studies will only have pre-diagnosis data and extrapolating this to be representative of post-diagnosis is of unknown validity; 3) if data collection does occurs after diagnosis, survival bias may exist.

The Nurses' Health Study is one prospective study that overcomes some of these limitations. Dietary questionnaires were completed every 2-4 years resulting in a maximum of 4 years between diagnosis and dietary assessment, although the length of time between cancer occurrence and assessment will vary across the sample. Results from this study found women who gained more than 2.0kg/m^2 after diagnosis had a 1.64 (95% CI 1.07-2.51) relative risk of breast cancer death compared to those whose weight remained stable (Kroenke et al., 2005a). Analysis of dietary intakes close to and before diagnosis found no association with survival, but there was a positive (non significant) association with consumption of a Western diet (characterised by high intakes of refined grains, processed and red meats, high-fat dairy and deserts) and all-cause mortality. Considering diet post-diagnosis, those with the highest intake of a western diet also had a 1.53 (95% CI 1.03-2.29) relative risk of all-cause mortality, mostly explained by deaths from causes other than breast cancer. High intake of a prudent diet (characterised by high intake of fruit, vegetables, whole grains and low-fat dairy products) was not related to breast cancer mortality, but did result in a significant lower risk of death from other causes (RR 0.54 95% CI 0.31-0.95) (Kroenke et al., 2005b). These results suggest a healthful diet post-diagnosis may protect against mortality among breast cancer survivors, but not against breast cancer death *per se*.

Further analysis of the NHS found animal fat intake to be associated with increased cancer death, and cereal fibre intake associated with reduced cancer death, although when analysis also adjusted for physical activity, these associations were no longer evident. This suggests that the association between diet and breast cancer survival may be confounded by the effect of physical activity (Holmes et al., 2009).

A more recent review including observational studies up to 2009 found study results were more consistent but still inconclusive (Patterson et al., 2010). For example studies examining macronutrients or F&V consumption revealed a protective trend, but studies were still few and examined a wide range of dietary exposures which precluded definitive conclusions. Studies examining dietary fat showed a trend towards an increased risk for all-cause mortality but few reached statistical significance. Three studies on dietary fibre also showed a protective trend. Studies considering dietary patterns (i.e. western vs. prudent diet) were sparse but there was evidence that a prudent diet was protective and a western diet associated with a non-significant increase in all-cause mortality.

This early data prompted the development of two RCTs designed to assess the impact of dietary intervention and cancer prognosis. The Women’s Healthy Eating and Living (WHEL) Study was a multi-centre phase III RCT that recruited 3088 women with stage I-III breast cancer. Participants were enrolled within 4 years of diagnosis, had completed treatment, and were disease-free at recruitment. The intervention involved telephone-counselling sessions, cooking classes and newsletters with the aim of encouraging increased fruit, vegetables and fibre consumption and reducing fat intake (Newman et al., 2005). The intervention was effective in changing women’s diet as reflected by 24-hour dietary recall data (Thomson et al., 2003) and increases in plasma carotenoid concentrations (Pierce et al., 2004). However, there was no effect on breast events or all-cause mortality over the 7.3 year follow-up (Pierce et al., 2007). These findings remain true even after adjustment for age, energy intake, BMI, tumour characteristics and years from diagnosis to trial entry.

The Women’s Intervention Nutrition Study (WINS) was another multi-centre RCT that examined the effect of low-fat diet on prognosis in women with early stage breast cancer. The intervention sought to reduce percentage of calories from fat to ≤15%. A between-group difference in dietary fat of 9% was reported at 1 year follow-up and this was maintained at 5 years (Chlebowski et al., 2006). However data for 3 and 5 years fat intake were calculated from low response rates of 70% and 40% respectively, with the assumption that non-responders would have comparable dietary intakes as responders; a tenuous assumption at best (Pierce, 2009). Results in these respondents suggested that women in the intervention group had a 24% lower risk of relapse compared with those in the intervention group (HR 0.76; 95% CI 0.60 – 0.98), although this was only borderline significant and was largely seen in women with hormone receptor negative tumours. There were no differences between the intervention and control groups for all-cause mortality.

The design of the WINS and WHEL study are very similar and therefore possible reasons for the variation in results have been debated. One proposed possibility is that improvement in relapse-free survival in WINS was partially explained by a weight reduction in the intervention group (mean of 6 pounds). A recent review concluded that adiposity was associated with a 30% increased risk of cancer-related mortality (Patternson et al., 2010). A similar weight loss was not seen in the WHEL study. In addition participants were enrolled into the WHEL study up to 4 years after diagnosis, whereas most participants in WINS were recruited within 1 year. There was also variation in length of follow-up; median of 8.7 years in the WHEL study vs. 5 years in WINS. WINS also reported a greater reduction in fat consumption with 21.6% of total calorie intake from fat compared to 28.5% in the WHEL study. Furthermore the WINS study included postmenopausal women only whereas the WHEL study recruited both pre and postmenopausal participants (Pierce, 2009). These conflicting results reflect the inconsistent findings reported in the prospective studies for the effect of fat on outcomes in breast cancer survivors. Experts in the field, including the authors of these trials, have been keen to emphasis that despite null findings this does not imply diet is of no importance among breast cancer survivors. In a news article in the Journal of the National Cancer Institute John Pierce (principal investigator of the WHEL study) stated that the results show that “a healthy diet in moderation probably matters, but there’s no evidence that going above a certain threshold is beneficial” (Nelson, 2008). This comment was based on the fact that baseline F&V consumption in the control group was already high at an average consumption of 7.3 servings a day. In the same article Cheryl Rock (another investigator in the WHEL study) highlighted the point that benefits may be seen in specific groups of women, such as those not adhering to dietary recommendations.

More recently, several prospective cohort studies specifically designed to address the effects of post-diagnosis diet on breast cancer outcomes have been developed in an attempt to build on the limited existing evidence. These studies overcame the limitations of using existing studies, with measurement of behaviour at consistent time points. The studies include the Health, Eating, Activity and Lifestyle (HEAL) study, which has enrolled 1182 women with early stage breast cancer from three centres in the United States (US), with baseline data collected 4-12 months post-diagnosis, the Shanghai Breast Cancer Survival Study which began recruitment in 2002; baseline data was collected 6 months post-diagnosis with follow-ups at 18 and 36 months, and *Pathways*; a study of breast cancer survivorship is another US-based study that is recruiting women as soon after diagnosis as possible (usually within 2 months) with follow-ups at 6 and 18 months. Recruitment began in 2006 and is ongoing. One study is also being conducted in the UK at University College London within the Department of Academic Surgery. Diet CompLyf aims to examine the role of diet, complementary treatments and lifestyle in breast cancer survivors. Participants are being recruited from over 40 sites in the UK with baseline data collected 9-15 months post diagnosis. So far, 2500 women have been recruited with a final target of 3000 by the end of 2010 (Velentiz L, personal communication). No data on the association between dietary factors and survival have yet been published.

Although evidence of the effect of diet on outcomes in cancer survivors has almost exclusively focused on breast cancer, one large cohort study of 1009 colon cancer patients taking part in a chemotherapy trial has been reported (Meyerhardt et al., 2007). Two dietary patterns were identified; a prudent diet (characterised by high intakes of fruit, vegetables, poultry and fish), and a western diet (characterised by high intakes of red meat, fat, refined grains and desserts). Median follow up was 5.3 years during which time 324 participants had a recurrence, 223 died as a result of cancer recurrence and 28 died of other causes. A western dietary pattern was found to be associated with worse disease-free survival, adjusted hazard ratio of 3.25 (95% CI 2.04-5.19) for those in the highest quartile of western diet vs. those in the lowest quartile of the western diet (trend p <0.001). A similar trend was seen for overall survival (HR 2.32; 95% CI 1.36 – 3.69). Results were unchanged when controlling for age, sex, disease stage, BMI and physical activity. No associations were found between the prudent diet and cancer recurrence or mortality. These preliminary results show promise for the potential impact of diet on survival in colon cancer patients.

In contrast to the breast cancer studies, this trial collected dietary information in the middle of treatment and 6 months after treatment was completed, and calculated an average in order to determine dietary patterns. However, it is likely that diet during treatment will be affected by treatment side effects (such as change in taste, nausea and vomiting) and thus comparability with diet at any other time point is questionable. It would have been useful for the authors to present results based on separate analysis of these two time points. Further analysis which attempts to determine the specific components of the western diet that have the strongest association with survival would also be a useful addition to this area of research.

I also identified a small (n = 146) Spanish study examining the role of fruit and vegetables (F&V) intake in survival of oral cancer. High intake of F&V following diagnosis was associated with reduced risk of recurrence, oral cancer mortality and all-cause mortality (Sandoval et al., 2009). However results from this study should be interpreted with caution as only those participants capable of oral intake after treatment (N=75) were included in the follow-up analysis.

A small number of studies have also examined the association between diet and QoL. A study of older long-term survivors found those reporting a higher score for diet quality had higher physical QoL (Mosher et al., 2009). A similar relationship was found among breast cancer survivors with reports of a direct association between diet quality and mental and physical function (Wayne et al., 2006). Also, a large, population-based US study found F&V intake to be related to higher QoL (Blanchard et al., 2008).

Nutrition and survival – biological mechanisms

The mechanisms through which diet may impact on cancer occurrence are not well understood. However several pathways have been suggested and similar mechanisms may be important in cancer prognosis. An indirect effect of diet -induced reductions in fat mass is one possible pathway. The mechanisms associated with fat mass and cancer survival were discussed previously. Fat intake may also have a direct impact on endogenous estrogen concentrations (Berrino et al., 2001). The proposed mechanisms through which F&V consumption may impact cancer occurrence are complex and a detailed discussion is beyond the scope of this thesis. In brief F&V may contain anticarcinogenic substances, such as vitamin C and E and beta-carotene. F&V has also been found to affect immune function (Kubena & McMurray, 1996). Phytochemicals found in F&V may also influence the regulation of gene expression in cell proliferation and apoptosis (Chu et al., 2002). However no specific anticarcinogenic compounds have been identified. In addition, high intake of dietary fibre has been associated with low serum levels of estradiol among post-menopausal breast cancer survivors (Wayne et al., 2008). It is thought that sex hormones bind with dietary fibre therefore increasing its excretion (Adlercreutz et al., 1986). In addition, a recent study reported diet quality to be inversely associated with a biomaker of inflammation (George et al., 2010).

Suggested mechanisms explaining the association between red and processed meat and risk of CRC have also been offered. Heme iron found in red meat may catalyse the formation of endogenous N-nitros compounds (NCO’s), high levels of which have been associated with an increased risk of colon cancer (Santarelli et al., 2008). In addition nitrates and nitrites are often added to processed meats and are thought to contribute to the formation of NCO’s (Cross et al., 2010). It has also been suggested that the method of cooking red meat could increase the risk of CRC rather than red meat intake *per se*. Cooking red meat at high temperatures increases the amount of heterocyclic amines which have been linked with risk of cancer (Butler et al., 2003). Finally the protective effect of dietary fibre on CRC may be due to the increased stool bulk diluting potentially carcinogens and decreasing transit time. Fibre also decreases faecal pH, this reduces the solubility of free bile acids which have been associated with tumour growth (American Gastroenterological Association, 2000).

Alcohol consumption and outcomes in cancer survivors

A review published in 2002 (Rock & Demark-Wahnefried et al., 2002) identified eight studies examining alcohol consumption and prognosis in cancer survivors. No significant associations were seen between alcohol intake and breast cancer recurrence, breast cancer mortality, or all-cause mortality. However, the timing of alcohol intake assessment varied considerably. Some studies examined intake before diagnosis, some soon after and some >12 months after diagnosis. There was also heterogeneity in covariates controlled for in analyses.

Since this review, several other studies have been published; however few studies have explicitly examined alcohol consumption after diagnosis. Data from a large sample of breast cancer survivors drawn from the Epidemiology and Risk Factors in Cancer Heredity study revealed a beneficial effect of alcohol consumption on survival (Barnett et al., 2008). The authors reported a 2% reduction in risk of death per unit of alcohol consumed per week. However, when controlling for age, stage, grade of disease, and estrogen receptor status this association was no longer significant. In addition, no information was presented about the measure used to assess alcohol intake, nor did the authors adjust for other covariates which have been related to cancer mortality such as BMI and physical activity. In addition, only total mortality was examined, with no data available for breast-cancer death or recurrence.

Alcohol intake was also assessed as part of the WHEL study. In this cohort of 3,088 breast cancer survivors alcohol intake was assessed using a food frequency questionnaire on entry to the study (average 2 years post-diagnosis). Follow-up was a median of 7.3 years during which time there were 518 breast cancer events and 315 deaths, 83% of these were breast cancer-related. The analysis controlled for disease stage, grade, education, physical activity, BMI and smoking status. Compared to non/minimal drinkers (<10 g/mo), moderate/heavy drinkers (>300g/mo) had a reduced risk for all-cause mortality; HR 0.69 (95% CI 0.49-0.97) and breast cancer mortality; HR 0.70 (95% CI 0.48 – 1.02). No effect was seen for breast cancer recurrence (Flatt et al., 2010). Examining the cohort by weight status, alcohol intake was associated with a reduced mortality in non-obese, but not obese breast cancer survivors. In general those classified as moderate/heavy drinkers were consuming relatively low amounts, an average of one alcoholic drink per day. The authors did however recognise that non/minimal drinkers were significantly more likely to have more serious disease, a factor which may contribute to the differences in mortality between groups.

In contrast, data from the LACE study presented as a conference proceeding showed alcohol consumption of >6g per day (compared to <0.5g/day) was associated with an increased risk of recurrence (HR; 1.34; 95% CI 1.00 -1.82) and breast cancer death (HR; 1.51 95% CI 1.00-2.28). No association was found for all-cause mortality. There was also a trend for a greater effect among postmenopausal and overweight/obese women (Kwan et al., 2009). Unfortunately a peer-reviewed publication is not available for this study so it is not possible to compare aspects of the study design or participant characteristics that might help explain these differences.

It is also important to note that levels of alcohol consumption in all the aforementioned studies have been very low. Therefore it is not possible to say what effect higher intake of alcohol consumption may have on outcomes among breast cancer survivors.

A small number of studies have also examined the relationship between alcohol consumption and prognosis in head and neck cancer survivors, and the results suggested a negative effect. Early stage head and neck cancer survivors who continue to drink have a raised risk of second primary tumours (RR; 1.3; 95% CI 1.0-1.7) compared to those who abstain (Do et al., 2003). An earlier study of oral and pharyngeal cancers found a non-significant increased risk of second primary cancers among drinkers vs. non/light drinkers. However, when examining by type of alcoholic drink the greatest increase in risk was seen for beer with an OR of 3.8 (95% CI 1.2-12) for those consuming >15 drinks per week of beer vs. <1 (Day et al., 1994).

The relationship between alcohol consumption and QoL in cancer survivors has also been explored in a small number of studies. Again, results are inconsistent. Some have found no association between alcohol consumption and QoL in head and neck cancer patients (Duffy et al., 2002; Duffy et al., 2007), where as others have reported favourable QoL among drinkers compared to non-drinkers (Allison, 2002). More research in this area and among survivors of other cancer sites is warranted.

Alcohol and survival – biological mechanisms

Despite the inconsistent data on the association between alcohol consumption and increased risk of breast cancer recurrence a mechanism has been proposed through which alcohol may be damaging. Alcohol intake has been found to be associated with circulating levels of sex hormones (Singletary & Gapstur, 2001), described previously as being associated with increase breast cancer risk.

Smoking and outcomes in cancer survivors

The impact of smoking on outcomes in cancer survivors has received considerable research attention. Numerous studies have reported beneficial outcomes among survivors who quit before or at the time of diagnosis compared to those who continue to smoke. A review of the evidence of the effect of smoking cessation on bladder cancer survivors concluded that most studies reported poorer prognosis in smokers compared to non-smokers (Aveyard et al., 2002). Breast cancer survivors who smoke have also been found to have an increased risk of death from any cause compared to never smokers (Holmes et al., 2007). Lung cancer survivors who were smokers at the time of radiotherapy treatment have been found to have shorter survival (Fox et al., 2004). Stopping smoking has also been associated with reduced risk of recurrence of bladder (Carpenter, 1989; Thompson et al., 1987), and head and neck cancers (Khuri et al., 2001). Smoking cessation is also associated with a reduced risk of second primary cancers (Kawahara et al., 1998; Murin & Inciardi, 2001; Richardson et al., 1993) and continued smoking and alcohol consumption have been associated with an increased risk of second primary tumours in head and neck cancer survivors (Do et al., 2003). Furthermore survivors of non-hodgkins lymphoma, who are at an increased risk of lung cancer, have an even higher risk if they continue to smoke after treatment (Vanleeuwen et al., 1995). However a recent study examining the impact of smoking on patients with colon cancer found only a trend for poorer disease-free survival and recurrence among smokers which did not reach significance (McCleary et al., 2010).

In addition to the impact on recurrence, disease progression, and survival, smoking during treatment can also increase the risk of complications and reduce effectiveness of treatment. Survivors who smoked during radiotherapy for head and neck had a lower rate of response to treatment (Browman et al., 1993). In addition, smoking during treatment for head and neck cancer is a risk factor for pulmonary complications (McCulloch et al., 1997). Continued smoking among cervical cancer survivors has also been found to be associated with bowel complications (Eifel et al., 2002).

A number of studies have examined the association between smoking and QoL in cancer survivors. Data consistently show a negative association with smoking associated with poorer QoL in samples of smoking-related cancers survivors (Gritz et al., 1999) and population-based mixed cancer samples (Blanchard et al., 2008).

Although this research consistently supports the argument for encouraging smoking cessation in cancer survivors, it is important to note the methodological limitations inherent in this literature. Standard definitions of smoking status have not been used and former and never smokers are often combined in analysis. Furthermore some studies have classified recent quitters as current smokers (Aveyard et al., 2002). Large scale prospective studies with accurate and well defined definitions of smoking behaviour are necessary to confirm current findings.

Smoking and survival – Biological mechanisms

Nicotine, found in tobacco is known to contain carcinogens which increase the risk of primary cancers. However data on the influence of these carcinogens in cancer survivors is sparse. Some in vitro studies have examined the effects of nicotine on lung cancer cells. Results suggested effects on numerous proteins ultimately inhibiting apoptosis (Heusch & Maneckjee, 1998). Studies have examined the impact of smoking on chemotherapy. Nicotine has been found to impair immune response (Geng et al., 1996) and increase the incidence of infection (Arcavi & Benowitz, 2004).

Conclusions

In conclusion, evidence is equivocal as to the role of diet on survival in breast cancer survivors and only one study has looked at colon cancer survivors. Large scale studies have been restricted to these two cancer sites and research needs to be extended to other groups of cancer survivors. Not surprisingly, the studies are subject to limitation inherent in all observational studies in that causality can not be inferred. They also rely on self-reported diet and were restricted to mostly white, high socioeconomic status samples. In addition, subjects who agree to participate in such studies are likely to be atypical, with high levels of motivation and interest in the role of lifestyle factors in their future health.

The limited data available suggest a negative impact of alcohol consumption on survivors of head and neck cancers, but evidence on the association for breast cancer survivors is equivocal. Interpretation of this literature is limited by many of the short-comings outlined in the diet data. There is a reliance on self-report measures of alcohol consumption and data is limited to cross-sectional observation studies. There is also heterogeneity in length of follow-up and the point of alcohol assessment.

In relation to smoking, results consistently support negative effects of continued smoking following cancer diagnosis. Numerous methodological limitations need to be addressed but smoking cessation should be encouraged among cancer survivors.

Agreement has been reached as to the protective role of a healthful diet and not smoking in chronic diseases such as CVD and diabetes and development of cancer, comorbidities for which cancer survivors are at increased risk. There has also been support for the finding that obesity is related to increased breast cancer recurrence (Kroenke et al., 2005a), and evidence is growing for impaired prognosis in other cancer sites (Calle et al., 2003). Therefore consuming a healthful diet can play a role in the achievement of a healthy body weight and thus improved survival.

Health behaviour recommendations for cancer survivors

Given the importance of health promotion in cancer survivors, efforts have been made to develop guidelines for health behaviour practices in cancer survivors. The WCRF concluded that evidence was too limited to inform specific guidelines for cancer survivors but suggested survivors are likely to benefit from adhering to population based guidelines (see box 1.1).

Box 1.1: WCRF health behaviour recommendations

1. Be as lean as possible without being underweight
2. Limit consumption of energy dense foods and avoid sugary drinks
3. Eat mostly foods of plant origin
4. Limit in take of red meat and avoid processed meat
5. Limit alcoholic drinks
6. Limit consumption of salt
7. Aim to meet nutritional needs through diet alone (i.e. avoid supplements)
8. Be physically active as part of everyday life

Similar recommendations are proposed in the American Cancer Society (ACS) guidance on nutrition and physical activity during and after cancer treatment (Doyle et al., 2006). However, recommendations for alcohol are complicated by the conflicting evidence of a protective effect of moderate consumption on CVD, the robust association between alcohol consumption and risk of primary cancers of many sites, and the equivocal evidence for alcohol consumption and cancer prognosis. In the ACS guidelines, reference is made to the fact that alcohol may also be an irritant to survivors of oral cancers. Data described above also suggested a negative effect of alcohol consumption and survival of head and neck cancers. This is in contrast to limited evidence that moderate alcohol consumption may be protective following breast cancer. The authors conclude that a health care provider should tailor advice on consumption based on cancer type, risk of recurrence and other comorbid disease. However if survivors choose to drink, they should do so within population guidelines (Doyle et al., 2006).

Recently the ACSM convened an expert panel to establish guidance on physical activity recommendations in cancer survivors (Schmitz et al., 2010). With reference to guidelines previously established for the general population including the ACS, the American Heart Association, and the US Department of Health and Human Services (DHHS); physical activity guidelines for Americans (150 mins wk of moderate intensity exercise or 75mins of vigorous exercise or an equivalent combination of the two), they concluded that these are appropriate for cancer survivors. The US DHHS recommendations for people with chronic conditions, suggests that those who's condition prohibits exercise participation to this level should do as much as their condition allows, and should avoid inactivity. However they recognise that exercise programs may need to be adapted for individual cancer survivors based on their health status and treatment received. They present advice on general and cancer-specific contraindications for starting an exercise program in cancer survivors, and note the reasons for stopping exercise.

Prevalence of health behaviours in cancer survivors

It is clear that a healthy lifestyle – including a healthy diet, regular physical activity, not smoking and no more than moderate alcohol consumption, is likely to be beneficial for cancer survivors. Determining the prevalence of health behaviours is therefore an important first step in order to establish the need for the promotion of health behaviours in this population. In (2005a) Demark-Wahnefried et al reviewed studies that examined health behaviours in cancer survivors of various sites. They concluded that cancer survivors had favourable rates of health behaviours (engaging in regular physical activity, a healthful diet, not smoking and limited consumption of alcohol) compared to general population estimates. However this conclusion was limited by the fact that most of the studies were small and with heterogeneous, convenience samples, there was also a possibility of a "healthy respondent" bias (i.e. those who take part being more likely to engage in healthful behaviours).

Since this review several larger population-based studies assessing longer-term cancer survivors have been published; with conflicting results. The LACE study examined fat and F&V consumption and physical activity in a cohort of 2321 breast cancer survivors (Caan et al., 2005). Participants were on average two years post-diagnosis. In this sample behaviours were similar to levels in the general population. However this is limited to survivors of just one cancer and used national survey data to compare behaviours. Such data could have different response rates and biases and the measures of behaviour were not identical, although the conclusions were consistent when comparing prevalence rates across several large scale studies.

In a US study using data from the 2000 National Health Interview Survey (NHIS) (Coups & Ostroff, 2005), cancer survivors were identified with the question “have you ever been told by a doctor or other health professional that you have cancer or any kind of malignancy”. Those who said they had (n=1646) were asked to specify the kind(s) of cancer with which they were diagnosed. Smoking, physical inactivity, diet and alcohol were compared between cancer survivors and 32,346 non-cancer controls. With the exception of smoking, the prevalence of behaviours did not differ between cancer survivors and non-cancer controls. Younger cancer survivors (18-39 years) however did report higher rates of current smoking than non-cancer controls (37.7% vs. 26.2% respectively). There were also few differences in prevalence of health behaviours between cancer sites other than a higher rate of current smoking in cervical and uterine cancer survivors and relatively high prevalence of consuming five or more F&V servings a day in prostate and melanoma survivors. However, caution should be exercised when interpreting these findings as samples sizes were not sufficient to power analysis between cancer sites.

A study by Bellizzi et al (2005) extended the previous study using four years of data from the NHIS (1998, 1999, 2000 and 2001). This resulted in a sample of 7384 cancer survivors and 121,347 noncancer controls. The larger sample provided sufficient statistical power to assess differences in behaviours between cancer sites. Findings comparing all cancer survivors with noncancer controls were largely consistent with the previous study except that they did not find any difference in smoking status between cancer survivors and controls at any age. Fewer cancer survivors (30%) met CDC/ACSM recommendations for physical activity than non-cancer controls (37%) in unadjusted analysis, but after adjusting for demographics, health characteristics and functional limitations more cancer survivors met recommendations (OR 1.09; 95% CI 1.03 -1.16). Coups & Ostroff (2005) had not adjusted for functional limitations which may explain this inconsistency. Comparisons across cancer sites revealed a number of differences. Rates of smoking in breast, prostate and CRC survivors were lower than non-cancer controls, and rates in gynaecological, lung, larynx and pharynx higher. Also, more breast, prostate and gynaecological cancer survivors were meeting physical activity recommendations compared to other sites. There were also higher levels of heavy drinking among survivors of prostate, lung, larynx, and pharynx cancer.

Analyses of a smaller US sample using the National Cancer Institute's Health Information National Trends Survey (HINTS) data also reported no difference in self-reported smoking, F&V consumption and physical activity between 619 (self-reported) cancer survivors and 2141 controls (Mayer et al., 2007). A similar study from Australia (Eakin et al., 2007) used self-reported data from the National Health Survey to identify 968 cancer survivors and 5808 age and sex-matched controls. Again, there were no differences in physical inactivity or F&V consumption, but cancer survivors were more likely to be current smokers (OR 1.35; 95% CI 1.12-1.62), with younger cancer survivors showing the highest rates, being 69% more likely to be smokers compared to controls.

All of the aforementioned studies are subject to limitations inherent to national surveys; the data are cross-sectional so causation cannot be determined, they are limited to native speakers, exclude individuals in institutions, have self-report measure of behaviours, and in some cases limited sample sizes resulting in insufficient power to analyse differences across cancer sites. One other limitation is the use of self-reported cancer diagnosis, known to underestimate prevalence (Paganinihill & Chao, 1993) and therefore may minimise apparent differences between groups. There is also a lack of information on disease stage.

A more recent study overcame a number of these limitations by identifying cancer survivors through the American Cancer Society's Study of Cancer Survivors-II (ACS SCS-II) (Blanchard et al., 2008). Data on cancer diagnosis, date of diagnosis and stage of disease and were therefore not self-reported. This also resulted in a very large sample of cancers survivors (n= 9105) allowing comparisons of health behaviours across cancer sites. Health behaviours of cancer survivors were compared with national prevalence data from the Behavioral Risk Factor Surveillance System Survey (BRFSSS) conducted by the Centre for Disease Control and Prevention. Result showed comparable levels of F&V consumption between cancer sites. However the proportion meeting population guidelines for physical activity varied between 30% in uterine cancer survivors and 49% in skin melanoma cancer survivors. Most groups however had lower rates than the 49% reported in the BRFSSS sample. Current smoking was lower in the cancer survivors groups with 88%-92% of cancer survivors not smoking compared with 80% in healthy adults. Lifestyle behaviour clusters were also identified. Up to 12.5% of cancer survivors were not meeting any of the three lifestyle recommendations measured, and fewer than 10% were meeting two or more.

Despite the study's strengths regarding registry-identified cancer survivors and disease stage information, it is also subject to a number of limitations. Firstly, the response rate of 33% is low compared to previous studies, for example response rates ranged from 67% to 74% between 1998 and 2001 in the NIHS samples. The respondents were also more likely to be young (18 to 54 years), female, white, and with local or regional disease, thus limiting its generalisability to all cancer survivors. In addition, Blanchard et al (2008) compared their results to general population prevalence, gleaned from the BRFSSS which used different measures of health behaviours to the ACS SCS-II. For example, Blanchard and colleagues used the Godin Leisure-Time Exercise Questionnaire to measure physical activity and then created a dummy variable for those who did and did not meet the ACS physical activity recommendations, whereas the BRFSSS asked participants to report time engaged in particular activities. The measure of F&V consumption also differed, with the ACS SCS-II asking respondents to report "how many days per week did you eat at least five servings of fruits and vegetables a day" compared to the BRFSSS which asked about fruits and vegetables separately.

Overall, it appears that, contrary to early studies, long-term cancer survivors' health behaviours are little different from the general population. However the early studies generally collected data closer to the time of diagnosis. There is evidence that 30%-60% of cancer survivors make healthful dietary changes after diagnosis (Demark-Wahnefried et al., 2005). However longitudinal data suggests that despite this initial motivation to make lifestyle changes there can be relapse to pre-diagnostic behaviours in the years following treatment completion. For example, Wayne et al (2004) tracked 260 breast cancer survivors over a two year period and reported that despite initial reductions in fat and increase in F&V consumption post-diagnosis, there was a relapse by two years.

It is also plausible that changes in health behaviours vary depending on the behaviour in question. For example cancer survivors often make dietary improvements at the time of diagnosis, but levels of physical activity may be adversely affected. A recent study (Emery et al., 2009) followed 227 breast cancer survivors for five years with data collected every four months for the first year and every 6 months for four subsequent years. They reported a curvilinear pattern of change in physical activity with 20% meeting physical activity recommendations of 150min/wk of moderate intensity exercise at baseline (soon after breast cancer surgery but before commencing adjuvant treatment), 37% meeting recommendations at year one and 18% at year five. Participants were also asked to retrospectively report physical activity three months before baseline; these levels were very similar to those reported at year one, suggesting that physical activity participation at year one reflects a return to before diagnosis levels.

Of concern is a finding that participants were performing less physical activity at five years post-diagnosis than before diagnosis; though this could also be an ageing effect. A recent longitudinal study of recreational physical activity in breast cancer survivors found a 50% reduction in activity in the year following diagnosis relative to before diagnosis. Activity levels recovered somewhat by 30 months post-diagnosis but were still on average 3 met-hours a week lower than pre-diagnostic levels (Littman et al., 2010). This confirms earlier work by Courneya & Friedenreich (1997b) in which breast cancer survivors retrospectively reported activity levels before diagnosis, during treatment and after completion of treatment. A sharp decline in activity during treatment was reported, with an increase on completion of treatment but levels were still lower than those reported before diagnosis, even several years after treatment completion. Similar results have also been reported in other cancer groups including lung cancer survivors (Coups et al., 2009). In the largest study to date of CRC survivors (n=1996), 21% fewer were meeting physical activity recommendations after a diagnosis of cancer than before (Lynch et al., 2007a), although in this study the data were collected just six months after diagnosis when treatment effects are likely to inhibit physical activity participation; indeed presence of a stoma and fatigue were associated with reduced participation in this group. A further follow-up at 12 months found only 15% fewer were meeting physical activity recommendations compared with before diagnosis (Hawkes et al., 2008), suggesting that activity levels were beginning to recover.

Retention rate of the sample at the 12 month follow-up was relatively good at 84% suggesting that this was not a result of healthy response bias.

Conclusions

It can be concluded that despite evidence that some cancer survivors make healthful lifestyle changes soon after diagnosis, there appears to be relapse to pre-diagnosis, or even below pre-diagnosis levels within a few years of treatment. This observation is supported by data from the large population-based comparison studies which suggest a similar level of health behaviours (and perhaps lower levels of physical activity) as seen in the general population; a population characterised by low levels of activity and poor diet. However not all data are consistent, for example Satia et al (2004) found that physical activity participation and vegetable intake increased significantly ($p < 0.01$) in a sample of CRC patients assessed one year before and two years after diagnosis. It is clear that more research in this area is warranted. There are no population-based data on the prevalence of health behaviours among cancer survivors in the UK. There is also a need to investigate cancer groups currently under-studied, i.e. non breast cancer samples.

Overall it appears that cancer survivors have no better health behaviours than adults without a cancer diagnosis. They are therefore likely to reap at least as much benefit, from health behaviour changes as the general population, perhaps more. Cancer survivors therefore present a particularly important target population for health promotion.

Thesis aims

It is clear that cancer survivors, where possible, should be engaging in healthful behaviours. However there is no evidence on the prevalence of health behaviours among cancer survivors in the UK. Study 1 (chapter 2) therefore examined physical activity, smoking and alcohol consumption among older cancer survivors from the English Longitudinal Study of Ageing (ELSA). From chapter 3 the focus of this thesis narrows to CRC survivors, the justification of which will be outlined in chapter 3. Study 2 (chapter 3) examines the prevalence of health behaviours and reported change in behaviour among a large sample ($n = 479$) of CRC survivors. Studies 3 to 6 use data from this prevalence survey to examine; the association between health behaviours and QoL, the effect of health professional recommendations for secondary prevention and attribution of cause of disease and possible recurrence on behaviour and behaviour change and perceived barriers and benefits to regular physical activity. Attention is then turned to behaviour change interventions with chapter 8 presenting a discussion of the existing literature on multiple health behaviour interventions in cancer survivors. Study 7 then describes the development and evaluation of a pilot study of a personally tailored, distance-based lifestyle intervention in CRC survivors. Finally general conclusions and implications for future research and clinical practice are discussed in chapter 8.

Chapter 2

Study 1: Health behaviours in older adults in the English Longitudinal Study of Ageing [2]

Introduction

There is currently no evidence regarding the health behaviours of cancer survivors in England. This chapter therefore sought to assess the prevalence of smoking, alcohol consumption and physical activity in older adults with a history of cancer compared with those with no cancer history using data from a population-based sample, ELSA. Results will be compared with previous data from the US and Australia. I also assessed whether the association between smoking and inactivity and quality of life (QoL) and depressed mood was similar among cancer survivors and people with no history of cancer.

Methods

Participants:

Data for these analyses were from wave 1 ELSA carried out in 2002. This nationally-representative, population-based sample was drawn from people aged 50 or over who had taken part in the Health Survey for England in 1998, 1999 or 2001. Data from 11,515 adults aged 50-99 are used for these analyses. Details of the ELSA methodology have been published (Marmot et al., 2003) but briefly involve a nurse assessment, an interview during a home visit, and a self-completion questionnaire to return by post which includes simple items on smoking, alcohol and physical activity, as well as established measures of depression and QoL.

Measures:

Demographic: Participants reported their gender, age, race/ethnicity (coded as white vs. non-white for these analyses) and marital status (coded as married or cohabiting vs. single, divorced, separated or widowed). Education was used as an indicator of

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[2] A version of this chapter has been published in the European Journal of Cancer. See appendix 1.

socioeconomic status (SES). Participants were divided into three groups; higher education, intermediate qualifications and no educational qualifications.

Health behaviours: Smoking was assessed by asking participants if they smoked currently, were former smokers, or had never smoked. Alcohol consumption was assessed by asking if they had consumed any alcohol in the last 12 months. Among those who reported having alcohol, respondents were divided into those who had two or more vs. less than two drinks a day. Physical activity status was categorised as taking part in vigorous or moderate activity more than once a week vs. once or less a week.

Cancer history and arthritis: Participants were asked if they had ever been told by a doctor or other health professional that they had 'cancer or any other kind of malignancy'. All those who answered yes were categorised as cancer survivors. This is in accordance with the National Cancer Institute's definition of a cancer survivor which states that from the time of diagnosis and for the balance of life, a person diagnosed with cancer is a survivor (National Cancer Institute, 2009). Those reporting a history of cancer were asked to specify the kind(s) of cancer with which they were diagnosed and if they had received treatment for their disease in the last 2 years. Arthritis was assessed as a confounder of opportunities for physical activity, and participants reported if they had ever been told by a doctor or other health professional if they had arthritis (including osteoarthritis and rheumatism).

Quality of Life and Depression: Quality of life was assessed using the CASP-19. This is a 19-item Likert-scaled index containing four sub-domains from which the acronym is derived; control, autonomy, self-realisation and pleasure. The CASP-19 was developed specifically to assess QoL in early old age, and is based on a needs satisfaction perspective. Scores range from 0-57 with a higher score indicating higher QoL. The four sub-domains have shown good internal reliability (Cronbach's alphas between 0.6-0.8) in a non-institutionalised population of older adults. The scale correlates well with the Life-Satisfaction Index ($r = 0.63$, $p = 0.01$) demonstrating good concurrent validity (Hyde et al., 2003).

Depressive symptoms were assessed using the Centre for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). A shortened 8-item version with binary response options that was developed for the Health and Retirement Study (HRS) was used, as in several previous publications from ELSA and HRS (Amirkhanyan & Wolf, 2006; Choi KL, 2007; Gallo et al., 2000; Siegel et al., 2004). The Cronbach α is 0.82, and the scale shows good sensitivity and specificity in comparison with the Short Form Composite International Diagnostic Interview clinical screener for depression (Gallo et al., 2000). Scores could range from 0-8, with higher scores indicating a greater number of depressive symptoms.

Statistical Analysis

Demographic characteristics of cancer survivors and those with no cancer history were compared using t-tests for continuous variables and nonparametric methods for categorical variables. Results are also presented adjusting for age and sex. Multiple logistic regression was used to assess whether health behaviours differed between cancer survivors and those with no cancer history. The three behaviours (smoking, alcohol consumption and physical activity) were modelled separately. For each behaviour, I first calculated the odds of engaging in the behaviour in cancer survivors vs. those with no cancer history adjusting for age and sex, and then adjusted for additional variables that might affect health behaviour. For smoking and alcohol consumption, these models included age, sex, and education. Since the number of ethnic minority cancer survivors was very small, ethnicity was not included as a covariate. Because physical activity may be impaired in people with mobility restrictions such as rheumatic conditions, the presence of arthritis was included as a covariate in the analyses of physical activity, along with age, sex and education. Adjusted odds ratios with 95% confidence intervals are presented.

Relationships between physical activity or smoking and QoL and depression were analysed using linear regression with the health behaviour as the independent variable, and including age, sex, education, and arthritis (for the analyses of physical activity). Checks were made to ensure no multicollinearity was present. R^2 for the regression analysis are presented, along with standardised regression coefficients (β) and standard error.

Results

Sample characteristics:

There were 716 cancer survivors in the sample (6.2%) and 10,799 men and women who did not report a diagnosis of cancer. The most commonly reported cancer was breast (31.3%); 12.6% reported a diagnosis of colorectal cancer (CRC), 10.1% had skin cancer or melanoma, 3.6% had leukaemia/lymphoma, 2.2% had lung cancer, and 40.2% had 'other' cancers. These results are comparable to prevalence rates reported in the cancer registry dataset for England (Maddams et al., 2008). Forty three percent of cancer survivors had received treatment for cancer within 2 years of survey completion.

Cancer survivors were older ($p < .001$) and more of them were female ($p < .001$) than those without a history of cancer (Table 2.1). They did not differ from the rest of the sample with respect to marital status, ethnicity, education, or the occurrence of arthritis, but they did have lower QoL ($p < .05$) after controlling for age and sex. Cancer survivors also had significantly more depressive symptoms ($p < .001$); however, both these differences were small.

Health behaviours in cancer survivors:

Table 2.2 presents the prevalence of each health behaviour in cancer survivors and those with no history of cancer. Adjusted odds ratios for the association between cancer survivor status and health behaviours are also presented.

Overall, 15% of cancer survivors were current smokers compared with 18% of those with no history of cancer. This difference was not significant. However, cancer survivors were more likely to be former smokers (52% versus 46%), and this was significant after adjusting for age, sex, and education (OR 1.26 CI 1.08-1.17 $p < .05$). There was no difference in alcohol consumption; 31% of cancer survivors and 33% of those with no history of cancer reported drinking no alcohol. Of those who drank, 8% of cancer survivors and 6% of those without a history of cancer reported ≥2 drinks per day. This difference was not significant after adjustment for covariates.

Table 2.1. Characteristics of sample. Percentage (n), mean (SD).

Characteristics	Cancer Survivors	No cancer	P	P (adjusted for age and sex)
N	6.2% (716)	93.8% (10799)		
Breast cancer	31.3% (224)			
Colorectal cancer	12.6% (90)			
Lung cancer	2.2% (16)			
Lymphoma/leukaemia	3.6% (26)			
Skin cancer/melanoma	10.1% (72)			
Other cancer	40.2% (288)			
Age (years)	68.27 (10.55)	64.92 (10.44)	<.0001	
Male	38.1% (273)	45.9% (4956)		
Female	61.9% (443)	54.1% (5843)	<.001	
Ethnicity (% minority)	1.4% (10)	2.9% (316)	.018	.059
Educational qualifications				
Higher education	24.3% (174)	22.0% (2372)		
Intermediate	32.1% (230)	35.5% (3823)	.140	
No qualifications	43.6% (312)	42.5% (4573)		
Married (%)	62.0% (444)	66.9% (7220)	.008	.914
Arthritis (%)	32.5% (233)	28.5% (3079)	.021	.507
CES-D depression score (0-8)	1.87 (2.13)	1.57 (1.98)	.000	.009
CASP-19 quality of life score (0-57)	41.36 (8.95)	42.57 (8.67)	.001	.011

Table 2.2. Prevalence and adjusted odds ratios (OR) for health behaviours by cancer survivors/no history of cancer. Percentage (n) and OR with 95% confidence intervals.

	Former smoker (vs. rest) N = 11345	**OR (95% CI)[a]**	**OR (95% CI)[b]**
No cancer	46.1% (4902)	1.00	1.00
Cancer Survivor	52.5% (368)	1.26 (1.08 - 1.47)**	1.24 (1.06 - 1.45)**
	Current smoker (vs. rest) N = 11345		
No cancer	18.0% (1919)	1.00	1.00
Cancer Survivor	15.3% (107)	0.93 (0.75 - 1.15)	0.97 (0.78 - 1.20)
	Complete sample: No Alcohol N = 11342		
No cancer	31.2% (3320)	1.00	1.00
Cancer survivor	43.0% (238)	0.94 (0.80 - 1.12)	0.94 (0.84 - 1.18)
	Drinkers only: ≥ 2 drinks per day N = 7784		
No cancer	6.2% (457)	1.00	1.00
Cancer survivor	8.0% (37)	1.22 (0.86 - 1.73)	1.21 (0.85 - 1.75)
	Physical activity N = 11523		
No cancer	58.8% (6355)	1.00	1.00
Cancer survivor	51.4% (368)	0.81 (0.73 - 0.99)*	0.81 (0.69 - 0.95)[c] *

a – Adjusted for age and sex, b – Adjusted for age, sex, and education, c – Adjusted for age, sex, education and arthritis
** p <0.001 * p<0.05

Fewer cancer survivors reported being moderately or vigorously active on more than one day per week compared to those with no history of cancer (51% vs. 59%). The difference was significant after adjusting for age and sex (p<.05), and remained after additional adjustment for education and arthritis status (OR 0.81, CI 0.69-0.95, *p* <.05).

Secondary exploratory analysis compared health behaviours among those who had received treatment within the last 2 years and those who had not verses those without a history of cancer. There were no differences for alcohol consumption or smoking rates.

Ancillary analysis however showed that physical activity was only lower when comparing non-cancer controls to cancer survivors who had recently received treatments; OR 0.71, CI 0.56 -0.89, p <0.01, with 49% of recently treated cancer patients reporting moderate or vigorous activity verses 54% for other cancer survivors.

Health behaviours, quality of life and depression:
The associations between health behaviours and QoL and depressive symptoms are summarised in Table 2.3. Physical activity was associated with better QoL in both cancer survivors and those with no history of cancer (*p* < .001). There was no interaction with cancer status. Physical activity was also negatively associated with depressive symptoms in both groups (both *p's* <.001). Mean scores on the CASP-19 and CES-D by activity status (adjusted for covariates) are presented in Table 2.4.

Table 2.4. Mean scores (adjusted for covariates) for QoL and depression by activity status

	CASP-19 (mean; 95% CI)[a]	**CES-D (mean; 95% CI)**[a]
Cancer	N = 568	N = 678
Active	43.11 (42.15 - 44.07)	1.36 (1.13 - 1.58)
Inactive	37.99 (36.89 - 39.08)	2.37 (2.14 - 2.61)
No cancer	N = 8831	N = 10380
Active	43.49 (43.25 - 43.73)	1.37 (1.32 - 1.43)
Inactive	39.55 (39.25 - 39.24)	2.05 (1.99 – 2.16)

a – Adjusted for age, sex, education and arthritis

Among cancer survivors, QoL was better in women and those with more education, and worse in those with arthritis; the reverse associations for education and arthritis were observed for depressive symptoms. The same relationships were found for those with no cancer history with the addition of a negative association of age with QoL and greater depressive symptoms in women.

Table 2.3 Association between physical activity and smoking and quality of life and depression.

	Quality of life (CASP-19)				**Depression (CES-D)**			
Physical activity	**Cancer Survivors** N = 568		**No Cancer** N = 8831		**Cancer Survivors** N = 678		**No cancer** N = 10379	
	Regression coefficient β (SE)	**p**	**Regression coefficient β (SE)**	**p**	**Regression coefficient β (SE)**	**p**	**Regression coefficient β (SE)**	**p**
Physical activity	.283 (0.04)	<.001	.220 (0.01)	<.001	-.236 (0.04)	<.001	-.169 (0.01)	<.001
Age	.026 (0.04)	.522	-.023 (0.01)	.031	-.049 (0.04)	.317	.007 (0.01)	.714
Sex	.079 (0.03)	.048	.081 (0.01)	<.001	.053 (0.04)	.147	.072 (0.01)	<.001
Education	.198 (0.04)	.001	.134 (0.01)	<.001	-.160 (0.04)	<.001	-.124 (0.01)	<.001
Arthritis	-.167 (0.03)	<.001	-.166 (0.01)	<.001	.091 (0.04)	.015	.156 (0.01)	<.001
	Adjusted r^2 = .183		Adjusted r^2 = .121		Adjusted r^2 = .108		Adjusted r^2 = .097	
Smoking	N = 557		N = 8717		N = 676		N = 10374	
Current smoker	-.113 (0.04)	.006	-.110 (0.01)	<.001	.091 (0.04)	.018	.098 (0.01)	<.001
Age	-.067 (0.04)	.112	-.092 (0.01)	<.001	.030 (0.04)	51	.057 (0.01)	<.001
Sex	.050 (0.03)	.214	.055 (0.01)	<.001	.069 (0.04)	.068	.096 (0.01)	<.001
Education	.239 (0.04)	<.001	.061 (0.01)	<.001	-.193 (0.04)	<.001	-.144 (0.01)	<.001
	Adjusted r^2 = .083		Adjusted r^2 = .054		Adjusted r^2 = .053		Adjusted r^2 = .052	

Quality of life was worse in current smokers, mean CASP-19 scores (adjusted for covariates) were 39.31 (95% CI 37.47 – 41.14) vs. 41.70 (95% CI 41.04 – 42.36) for cancer survivors who smoke and non-smokers respectively ($p<.05$), and 40.73 (95% CI 40.29 – 41.16) for smokers and 43.23 (95% CI 43.03 – 43.42) for non-smokers in those with no cancer history ($p<.001$). Smoking had an unfavourable relationship with depressive symptoms, with significantly higher CES-D depression scores (after adjustment for covariates) in smokers 2.18 (95% CI 1.77 – 2.59) than non-smokers 1.64 (95% CI 1.47 – 1.82) in survivors ($p <.001$), and 1.90 (95% CI 1.80 – 1.99) for smokers and 1.39 (95% CI 1.35 – 1.44) for non-smokers in those with no history of cancer.

Discussion

This study provides evidence concerning three health-related behaviours in a cohort of older cancer survivors in England identified from a population-based national survey. The results highlight the prevalence of sub-optimal health behaviours (that is, low levels of physical activity and a significant minority continuing to smoke). Cancer survivors were more likely to be former smokers, but they had similar levels of alcohol consumption and current smoking, and they were less likely to be physically active than those with no history of cancer.

The comparable rates of smoking between cancer survivors and those without a history of cancer is in accordance with previous US samples (Bellizzi et al., 2005; Mayer et al., 2007) but in contrast with Blanchard et al (2008) who found lower rates of smoking among cancer survivors. Different again are results from an Australian study that found cancer survivors were more likely to be current smokers (Eakin et al., 2007). This variation may be explained by differences in sampling between studies. The current study and Bellizzi et al, Mayer et al, and Eakin et al's research used data from population samples. In contrast Blanchard et al (2008) surveyed cancer survivors identified through state cancer registries, achieving a 33% response rate. This sample may therefore be more likely to have a healthy response bias. Also, most of the difference in current smoking found in the Australian study was explained by higher rates in the younger (18-39 years) survivors. Similar results were found in a US sample with younger cancer survivors significantly more likely to be smokers than those without a history of cancer (Bellizzi et al., 2005). Younger cancer survivors are not included in the current study.

The greater proportion of former smokers in the cancer survivors group (52%) than among the rest of the sample (46%) is encouraging. Similar results were reported in an Australian population-based sample where cancer survivors were 30% more likely to be ex-smokers compared with non-cancer controls (Eakin et al., 2007). It is also consistent with a recent review that reported relatively high levels of quitting, particularly among survivors of smoking related cancers – at least in the short-term (Demark-Wahnefried & Jones, 2008). However, a worrying finding is that 15% continued to smoke. In chapter 1 I described the increased risk of various comorbid disease and second primary cancers among cancer survivors. Smoking is likely to increase this risk further.

There was no significant difference in alcohol consumption between cancer survivors and those with no history of cancer, confirming findings from similar studies in US population samples (Bellizzi et al., 2005; Coups & Ostroff, 2005) although direct comparison between studies is difficult because of differences in definitions. The studies from the US used total number of drinks consumed in a day, but in ELSA, alcohol consumption was only divided into drinking ≥2 drinks per day vs. less, which does not distinguish very heavy from moderately heavy drinkers.

Cancer survivors were significantly less active than those without a history of cancer independent of confounding factors including arthritis. Three population-based studies from other countries (Bellizzi et al., 2005; Courneya et al., 2008b; Eakin et al., 2007) have reported no difference in physical activity participation between cancer survivors and those with no cancer history, and one similar study (Coups & Ostroff, 2005) found cancer survivors to be 9% more likely to meet physical activity recommendations. Different definitions could be part of the explanation for this variation; previous studies used the relevant general population guidelines as a cut-off, whereas in the present analyses, active was defined as engaging in moderate or vigorous activity more than once a week, a much lower threshold.

When separately comparing cancer survivors who had received treatment within the last 2 years and those who had not, with individuals with no history of the disease, only those who had been recently treated were found to have lower levels of physical activity. This is in accordance with evidence discussed in chapter 1 that suggested physical activity was reduced soon after diagnosis but begins to recover after treatment completion. However these results should be interpreted with caution due to the small sample size.

Also discussed in chapter 1 was evidence that QoL impairments in cancer survivors can persist for several years after treatment completion. Results from the present study support this, finding cancer survivors to have a lower QoL than those without a history of cancer; however differences in scores were small. Some have argued that the continued impairment in QoL among cancer survivors is a result of ageing (Cimprich et al., 2002). However the lower QoL levels in this study were found even when controlling for age. Chapter 1 also discussed the evidence that physical activity has been consistently associated with higher QoL in cancer survivors and the results from this study support this. Smoking was also found to be negatively associated with QoL. This relationship has previously been reported in a large US sample (Blanchard et al., 2008), in head and neck (Duffy et al., 2002) and CRC survivors (Steginga et al., 2009).

Although depression scores were significantly lower among cancer survivors, differences in scores were small. We saw in chapter 1 that data on the prevalence of depression in cancer survivors is inconclusive. However it has been suggested that early studies that found higher rates of depression among cancer survivors compared to the general population may have been overestimated (Simon et al., 2007). In the current study depression was negatively associated with physical activity in cancer survivors and those without a history of cancer. This relationship seen among the group without a history of cancer is in accordance with previous literature in healthy populations (see Lawlor & Hopker, 2001 for a review). However evidence for an association between physical activity and depression in cancer survivors is mixed. The recent American College of Sports Medicine review found equivocal results. For example, of the seven studies investigating this association in post-treatment breast cancer survivors three found a positive association while four did not (Schmitz et al., 2010). However table 1.1

(chapter 1) described results from a recent meta-analysis that found a small to moderate negative effect (-0.39) of physical activity on depression in cancer survivors who had completed treatment (Speck et al., 2010).

This study has a number of limitations. Cancer survivorship was determined from self-report of a diagnosis and this may not be completely reliable although a recent study found reasonably good agreement with record data (Ferrante et al., 2008). Health behaviours were also self-reported, and this may have led to response biases such as over-estimation of physical activity and under-estimation of alcohol consumption. It would have been useful to be able to classify participants as meeting vs. not meeting physical activity recommendations in order to compare with previous studies.

The cross-sectional nature of the data means it is not possible to determine if the patterns of health behaviours were a result of change since diagnosis or maintained since before the diagnosis. These data were collected in 2002 and it is possible that awareness of the importance of health behaviours among cancer survivors has changed since that time. Finally sample size did not permit analysis for individual cancer sites. Evidence from previous population-studies suggests behaviours may differ between survivors of different cancers and it would have been of interest to examine this. Nonetheless, this study is a first step towards addressing the issue of health behaviours in cancer survivors in England.

Chapter 3

Study 2: Prevalence of health behaviours in colorectal cancer survivors

Introduction

As was clear from the previous chapter, recent population-based studies have made progress towards establishing the prevalence of health behaviours in cancer survivors. The English Longitudinal Study of Ageing analyses in study 1 are in an English sample but numbers were too small to allow analysis to be conducted on individual cancer sites. Some recent evidence suggests that there are differences in the prevalence of health behaviours across cancer sites (Bellizzi et al., 2005; Blanchard et al., 2008); therefore research focusing specifically on individual cancer groups is warranted.

Throughout the cancer survivorship literature, breast cancer survivors have received the majority of research attention leaving other cancer groups under-studied. Given that CRC is one of the most common cancers in western society with good survival rates, this is one such group for which more research is urgently needed.

Over 17,000 new cases of CRC are diagnosed each year in England and Wales and it is the second and third most common cancer in women and men respectively (Mitry et al., 2008). Incidence of CRC has remained fairly stable over the last decade, but 5-year survival rates have doubled in the last 30 years (Cancer Research UK, 2009) resulting in a growing population of CRC survivors. This is thought to be largely a consequence of improvements in treatment and advances in early detection. Advances in surgical techniques and developments in radiotherapy reduced the chance of recurrence and improve survival (Ko & Ganz, 2007). In addition, early diagnosis results in considerably higher survival rates: data from the Surveillance, Epidemiology, and End Results (SEER) program reported a 5-year survival of 65% for tumours diagnosed at stage III verses 90% for those diagnosed at stage I and II. Several US studies have reported increased detection of early stage disease through screening programmes (Kronborg et al., 1996; Mandel et al., 1993; Mandel et al., 2000). Similar results have also been reported in a pilot study in the UK which found a 15% reduction in mortality as a result of faecal occult blood screening (Hardcastle et al., 1996). More recently one-off flexible sigmoidoscopy was found to reduce mortality rates by 43% (Atkin et al., 2010). In addition to the contributions of detection and treatment to the rising number of CRC survivors, incidence of CRC increases with age. Almost 75% of CRC cancers in the UK are diagnosed in people over 65 years old and with an ageing population projections suggest an ever increasing rise in the number of survivors of this cancer.

The World Cancer Research Fund/American Institute of Cancer Research (WCRF/AICR)- Food Nutrition, Physical Activity and the Prevention of Cancer report, the most comprehensive review of lifestyle factors and cancer prevention available, concludes that “food and nutrition has a highly important role in the prevention and causation of cancers of the colon and rectum”(World Cancer Research Fund / American Institute for Cancer Research, 2007). This report summarised available evidence for the role of various lifestyle factors, classifying the strength of evidence as convincing, probable, limited/suggestive, limited/no conclusions, or substantial effect on risk unlikely. Evidence for the role of physical activity for reducing the risk of CRC was found to be convincing, revealing a dose-response effect. Convincing evidence for an increased risk due to red meat was also found with meta-analysis reporting a 15% increased risk per 50g/day consumed; the same was true for processed meat with a 21% increase in risk per 50g/day consumed. The evidence for consumption of alcoholic drinks increasing risk was found to be convincing for men and probable for women. Body fatness was also reported to be associated with CRC, with an increased risk of 15% for every 5kg/m^2. The report concludes probable evidence for a reduced risk with consumption of dietary fibre; a 10% decreased risk per 10g/day consumed. Evidence for consumption of F&V, while showing a generally consistent protective effect, was too limited to draw definitive conclusions. The same was true for the increased risk associated with consumption of animal fat.

These conclusions are supported by a recent study by Parkin et al (2009). The authors estimated the proportion of preventable CRC in the UK population based on adherence to five protective lifestyle factors; reduced consumption of red meat, increased F&V, exercising for 30 minutes 5 times a week, limited alcohol consumption (3 units a day for men, 2 for women), and weight control. They concluded that 31.5% of CRC in men and 18.4% in women could be avoided if these targets were met.

Given that there is such strong evidence for the role of lifestyle in CRC cause and prevention it is likely the same factors may play a role in outcomes and survival of those diagnosed with the disease. As we saw in chapter 1, promising evidence has recently been published suggesting that physical activity may be protective with regard to reduced recurrence and all-cause mortality (Meyerhardt et al., 2006a; Meyerhardt et al., 2006b). The same research group also reported higher intake of a western diet (characterised by high intakes of processed and red meats, refined grains and high fat dairy products) to be associated with higher risk of CRC recurrence and mortality (Meyerhardt et al., 2007). Additionally rates of comorbid conditions (potentially preventable though improved lifestyle) have been found to be high in this group with one study reporting 75% of CRC between 1-3 years of diagnosis reporting a major comorbid disease (Ko & Chaudhry, 2002). Possibly even more worryingly, 14% report diabetes, and survivors of CRC with diabetes have been found to have a 42% increased risk of death compared to those who had no history of the disease (Meyerhardt et al., 2003). Taken together the data present a strong case for examining the prevalence of health behaviours in CRC survivors, a group who stand to benefit from lifestyle interventions. To date there is no literature on the health behaviours of CRC survivors in a UK sample.

Study aims

The primary aim of this study was to examine the prevalence of several health behaviours including physical activity, F&V consumption, alcohol consumption, smoking status and BMI in a cohort of CRC survivors, in order to establish the need for lifestyle intervention. The secondary aim was to examine reported change in health behaviours since diagnosis.

Ethical approval

This study received favourable approval from the UCLH NHS Trust Clinical Research Ethics Committee. It has also been accepted by the UK National Cancer Research

Network (UKNCRN) Psychosocial Oncology Clinical Studies Group and added to the UKNCRN portfolio. See appendix 2 for approval letter.

Pilot

Once the design of the questionnaire was complete, it was administered to a convenience sample of seven individuals who had received a diagnosis of cancer within the last 7 years. Respondents were asked to comment on any questions they found confusing / difficult to understand or upsetting. Comments were also invited on ease of completion and layout of the questionnaire, and an open section was available to make any other comments.

On the whole, participants found the questionnaire was simple to complete, not overly burdensome, and intuitively presented. One individual commented that she found the question of recurrence a little unsettling. On completion of this pilot we concluded that no structural or content changes were necessary.

Methods

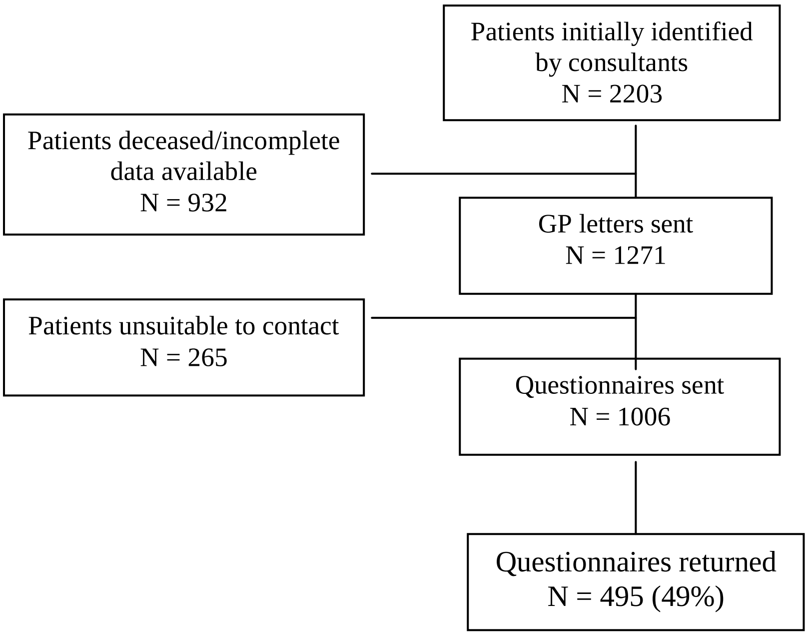
Recruitment and sampling

For the main study consultant oncologists based in the London area and specialising in CRC were identified either by previous collaboration or through the UKNCRN clinical studies lead directory. They were contacted by email, informed about the study and ask to respond if interested in collaboration. Three consultants (with access to patients at five hospitals) agreed to be involved.

Consultants identified all patients diagnosed with non metastasised (M0) CRC within 6-months to 5 years of diagnosis. The inclusion criteria of M0 diagnosis only was based on the poor prognosis of patients diagnosed with metastasised disease, thus minimising any outcome benefits that may be incurred through lifestyle changes. Only patients who were at least 6 months post-diagnosis were included in an effort to minimise the number of people contacted who were still undergoing primary treatment. Consultants also provided information on date of diagnosis and stage of disease.

On receiving patient lists, I manually checked hospital records in order to exclude any deceased persons and collate address details for patients and their general practitioner (GP). Letters were then sent to the GP of each patient informing them of the study and asking them to withdraw the patient if they deemed them inappropriate to contact, i.e. they were terminally ill, deceased, suffering severe cognitive decline, or would otherwise be distressed to receive a questionnaire. A response was also requested if the patient identified was no longer registered with their practice, these patients were also excluded as suitability is unknown. A questionnaire pack, including a letter of invitation (signed by the consultant oncologist) information sheet, two consent forms, questionnaire and self-addressed envelope was sent to all remaining patients. In order to maximise response rates a reminder was sent to those who did not respond within three weeks of sending the first questionnaire. See figure 3.1 for flow of participants.

Figure 3.1: Flow of Participants



Measures[3]

Physical activity: Physical activity was measured using the Godin Leisure-Time Exercise (GLEQ) Questionnaire (Godin et al., 1986). Independent evaluation found it to have favourable reliability and validity compared with nine other self-report measures based on various criteria including test-retest scores, objective activity monitors and fitness indices (Jacobs et al., 1993). This measure has been extensively used throughout

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[3] See appendix 3 for questionnaire used in Study 2

the survivorship literature (Courneya & Friedenreich, 1997c; Courneya et al., 2003; Jones et al., 2007; Karvinen et al., 2007a; Karvinen et al., 2007b; Rogers et al., 2006; Stevinson et al., 2007b; Valenti et al., 2008) and was recommended for use in this study on personal communication with Professor Wendy Demark-Wahnefried, a prominent academic in the field of health behaviours and cancer survivorship. Participants were asked to report the frequency with which they engaged in mild, moderate and strenuous intensity exercise for at least 15 minutes in leisure time during an average week. Unfortunately average duration of each exercise session was not recorded. Physical activity was categorised as taking part in five or more bouts of moderate/vigorous activity a week *vs.* fewer.

Fruit and vegetable intake: Fruit and vegetable (F&V) intake was assessed using a two-item frequency question. Participants were given examples of portion sizes and asked to report how many servings of F&V they usually eat in a day/week. Response items ranged from 0-2 a week to more than 5 a day. Participants were categorised into at least 5 vs. less than 5 portions a day. This measure has been used previously (Steptoe et al., 2004) and has shown adequate validity when compared to objective biological measures of F&V consumption (plasma ascorbic acid, plasma alpha-tocopherol, plasma beta-carotene and 24 hour urinary potassium exertion expressed as a total daily excretion (Cappuccio et al., 2003).

Smoking: Smoking status was established using a single item; “do you smoke cigarettes at all nowadays?” Those who responded positively are asked “how many cigarettes do you smoke a day?” Those who responded negatively are asked “have you ever smoked cigarettes regularly (at least 1 cigarette a day), if so, how many and when did you quit smoking?” resulting in classification of individuals as current smokers, ex smokers or never smokers. This measure of smoking status is adapted from the questions used in the Health Survey for England (Craig et al,. 2008).

Alcohol: Participants were asked if they drink alcohol nowadays. For those who answered yes, weekly intake is measured by asking respondents how many of the following do you usually drink per week; small glass of wine (125ml), half pint of beer/larger/cider, pub measure of spirits (25ml). This measure is based on the HSE.

Respondents were classified as either non-drinkers, moderate drinkers (weekly alcohol units >1 and ≤21 for men and >1 and ≤14 for women), or heavy drinkers (>21 units for men and >14 units for women).

Body mass index: Participants were asked to report their height (in centimetres or feet and inches) and weight (in kilograms or stones and pounds) to enable calculation of body mass index (BMI) (kg/m^2). Participants were classified as underweight (BMI $<18.5 kg/m^2$), normal weight (BMI ≥ 18.5 - <25 kg/m^2), overweight (BMI ≥ 25 - $\leq 30 kg/m^2$) or obese (BMI >30 kg/m^2).

Change in health behaviours: Respondents were asked if the level of each reported health behaviour is more than, about the same, or less than, before their cancer diagnosis. This measure was adapted from a previous study of lifestyle change after cancer diagnosis (Blanchard et al., 2003). To determine if smokers quit before or after diagnosis the self-reported quit date was subtracted from date of diagnosis.

Demographics: Participants were asked to report their age, sex, martial status and ethnicity. Socioeconomic status (SES) was indexed using a combination of material circumstances and education (car ownership vs. not, home ownership vs. not, university-level education vs. not). The sum of these items generated a score between 0 (no deprivation) and 3 (high deprivation), which for analyses was dichotomised into 0 vs. ≥1. This measure has been recommended when the majority of participants are retired and occupation and income are not as reflective of SES as in younger adults (Wardle et al., 1999).

Medical characteristics: Date of diagnosis was obtained from case records where available and was also self-reported. Comorbidities were assessed using a checklist option as used in the HSE 2005 - Health of older people (Craig & Mindell, 2007). Participants were asked to report if they were currently undergoing treatment. They were also asked if their cancer had recurred since the initial diagnosis.

Statistical analysis

Descriptive data are presented on the prevalence of health behaviours and reported behaviour change. Simple T-tests (for continuous measures) and chi square tests (for categorical measures) used to examine difference in health behaviours by demographics.

Results

Participant characteristics

A total of 1006 questionnaires were sent out and 495 returned (49% response rate), of which four were excluded for being incomplete, and 12 because the patient reported a cancer other than colorectal; final N = 479. The questionnaire included the consent form, and therefore no data were available on non-responders. The average age of respondents was 68 years (range 31-97), 59% were male, 90% were white, 20% had experienced a cancer recurrence, and 16% were currently receiving treatment (see Table 3.1).

Table 3.1 Sample characteristics

Characteristic	**Men (n=284)**	**Women (n=194)**
Age in years (SD)	66.75 (10.86)	69.37 (11.24)
Missing n=6		
Deprivation: N (%)		
0 (low)	153 (57)	74 (41)
1	66 (25)	69 (39)
2	40 (15)	27 (15)
3 (high)	8 (3)	9 (5)
Missing n = 33		
Ethnicity; N (%)		
White	257 (92)	174 (90)
None white	23 (8)	19 (10)
Missing n = 6		
Comorbidities: N (%)		
0	133 (48)	66 (36)
1	85 (31)	70 (39)
>1	60 (22)	46 (25)
Missing n = 19		
Time since diagnosis in years (SD)	2.06 (1.45)	2.15 (1.52)
Missing n = 0		
Recurrence: N (%)	66 (25)	30 (16)
Missing n = 20		
Receiving treatment: N (%)	50 (18)	23 (13)
Missing n = 26		

Prevalence of health behaviours

Table 3.2 presents prevalence of each health behaviour. More than half the respondents (58%) were consuming fewer than 5 portions of F&V a day, over half (58%) were overweight or obese, and the majority (82%) were not physically active. However, very few (6%) were current smokers or heavy drinkers (8%), and 27% were non-drinkers.

Those classified as active were younger (p = .023) and level of activity (i.e. number of bouts per week of moderate/vigorous activity) was higher among those with no markers of deprivation (p = .025). Consuming five portions of F&V a day was more common among women than men (p = .001). Moderate consumption of alcohol was more likely among those with some markers of deprivation (p <.001), among younger participants (p = .003), and women (p < .001). Former smokers were more likely to be older (p = .003) and men were more likely to be both current (p =.004) and ex smokers (p = .032).

Table 3.2: Prevalence of health behaviours

Health behaviour	**Whole sample N (%)**	**Men N (%)**	**Women N (%)**
Activity			
≥ 5 sessions per wk	84 (18)	56 (20)	28 (15)
< 5 sessions per week	372 (82)	214 (80)	157 (85)
Missing n = 23			
Fruit and vegetables			
≥ 5 portions of F&V a day	192 (43)	97 (36)	95 (52)
< 5 portions of F&V a day	260 (57)	171 (64)	88 (48)
Missing n = 27			
Smoking status			
Current smokers	28 (6)	24 (9)	4 (2)
Ex-smokers	220 (49)	141 (52)	78 (44)
Never-smokers	202 (45)	105 (39)	97 (54)
Missing n = 29			
Alcohol			
Non drinkers	118 (27)	54 (21)	64 (37)
Moderate drinkers	282 (65)	183 (70)	99 (58)
Heavy drinkers †	33 (8)	24 (9)	9 (5)
Missing n = 46			
BMI			
Underweight (<18.5kg/m^2)	8 (2)	3 (1)	5 (3)
Normal weight (<25kg/m^2)	179 (40)	108 (40)	71 (40)
Overweight (≥ 25 - <30 kg/m^2)	177 (40)	112 (42)	64 (36)
Obese (≥30 kg/m^2)	83 (19)	46 (17)	37 (21)
Missing n = 33			

† >21 units per week for men, >14 units per week for women

Health behaviour change

Table 3.3 presents data on behaviour change. Few respondents reported increasing their physical activity since diagnosis (8%), compared to half the sample who reported doing less physical activity. Similar proportions of cancer survivors increased F&V consumption (18%) as did decrease (15%). Nearly half of respondents reported reduced alcohol consumption since diagnosis and very few increased. Thirty eight percent of smokers quit after receiving a CRC diagnosis.

Table 3.3 Change in behaviour since diagnosis

Change in health behaviour	**N (%)**
Physical activity	
More	35 (8)
The same	191 (41)
Less	245 (52)
Missing n = 8	
F&V consumption	
More	83 (18)
The same	321 (68)
Less	70 (15)
Missing n = 5	
Alcohol consumption	
More	14 (4)
The same	200 (49)
Less	191 (47)
Missing n = 74	
Smoking	
Smokers who quit after diagnosis	17 (38)
Smokers who continue to smoke	28 (62)
Missing n = 2	

Discussion

In this sample of CRC survivors, smoking and heavy drinking were relatively infrequent, but fewer than 50% were consuming ≥ 5 portions of F&V a day, the frequency of physical activity was low, and prevalence of overweight was high.

To set these results in context, they were compared with population data for older adults from the recent Health Survey for England (HSE) 2008 (NHS information centre for health and social care, 2009). General population figures show that only 20% of men and 17% of women were physically active five times a week, which was strikingly similar to the 20% and 15% rates in this sample. However direct comparisons are not possible due to the different classifications used. It was also possible to compare results from the English Longitudinal Study of Ageing (ELSA) sample (presented in chapter 2). Using the same cuff-offs (moderate or vigorous activity at least once a week) reveal similar levels of physical activity, with 48% of the current sample meeting this criteria vs. 51% of cancer survivors in the ELSA. The other four health behaviours were broadly positive compared with the general population. The proportion meeting the 5-a-day target for F&V consumption was 42%, which was higher than the 30% of older adults in the HSE. Prevalence of smoking (6%) was considerably lower than in the ELSA sample where 15% were current smokers, and was also lower than in the general UK population at this age group (13%). Heavy drinking was infrequent compared with population levels, although 46 participants did not provide data on consumption levels. They may have been reluctant to report heavy drinking.

Comparing these results with findings from other CRC samples in Australia and the US revealed some similarities. Absolute rates of physical activity were higher in CRC survivors from Australia and the US (32% and 39%) (Blanchard et al., 2008; Lynch et al., 2007), but activity levels in the general populations are comparably higher there too (Armstrong et al., 2000). Smoking rates in CRC survivors in Australia (8%) and the US (9%) are also lower than in the respective general population (Blanchard et al., 2008; Hawkes et al., 2008), and in one of the few studies of alcohol consumption, CRC survivors in Australia also reported low consumption (Lynch et al., 2008). In contrast F&V consumption in the present study was higher than the 16% previously reported in a large US sample of CRC survivors (Blanchard et al., 2008), despite similar levels among the general population (Casagrande et al., 2007; Craig & Mindell, 2007).

The lower levels of smoking and alcohol consumption and higher F&V intake compared with the general population, may be because the survivors make positive lifestyle changes following diagnosis. A diagnosis of cancer has been described as a ‘teachable moment’, and early research suggested that cancer survivors often made changes to their lifestyle (see Demark-Wahnefried et al., 2005 for a review). Indeed, nearly half of respondents in this study reported a reduction in alcohol consumption since diagnosis (although data were missing for 74 cases) and 38% of smokers quit.

However, abstinence from alcohol may be the result of illness, rather than a conscious decision to make a healthful behaviour change. In addition, almost as many respondents reported reducing F&V consumption (15%) as reported increasing it (18%). This tends to implicate response bias or recruitment of a ‘healthier’ survivor sample.

The finding that 52% of participants reported doing less physical activity than before diagnosis is concerning and supports the suggestion that activity levels are lower among CRC survivors compared with the general population. Few comparable studies are available that examine change in physical activity after CRC and results are not consistent. For example, in a prospective study in a Norwegian sample there was no change in physical activity from pre-diagnosis to an average of 2.5 years post-diagnosis (Skeie et al., 2009). In contrast, a prospective study in a US sample found a significant increase in activity levels (Satia et al., 2004). In comparison, as discussed in chapter 1, there is evidence that physical activity levels are lower among breast cancer survivors compared to pre-diagnostic levels (e.g. Littman et al., 2010). In addition, investigating reasons why participants activity levels have reduced would shed light on this issue and may help design interventions to increase activity; analysis of barriers to physical activity are discussed later in chapter 7. Alternatively it may be reflection of age.

The findings of this study are limited by the fact that health behaviours and reported behaviour change are self-reported. Results are therefore likely to over-estimate physical activity and F&V consumption, and under-estimate alcohol and smoking. In addition the lack of data on duration of activity means the proportion of respondents meeting and not meeting the recommendation of 30 minutes of physical activity five times a week can not be calculated.

Conclusion

In conclusion, with the possible exception of physical activity, CRC survivors did not have poorer health behaviours than general population samples, but both physical activity levels and F&V intake were sub-optimal. Given that cancer survivors are at increased risk of diseases with an established behavioural aetiology and there is emerging evidence for a protective effect of health-related behaviours on cancer survival, multiple health behaviour change in the growing population of CRC survivors is an important area for research.

Chapter 4

Study 3: Health behaviours and quality of life in colorectal cancer survivors[4]

Introduction

Several studies have shown that physical activity is associated with a favourable quality of life (QoL) among colorectal cancer (CRC) survivors (Blanchard et al., 2004; Blanchard et al., 2008; Courneya & Friedenreich, 1999a; Lynch et al., 2007b; Lynch et al., 2008) and there is some evidence for a similar association with fruit and vegetable (F&V) intake (Blanchard et al., 2008) and not smoking (Blanchard et al., 2008), although there are no studies examining associations with alcohol consumption. Most of the previous studies in this area use generic (rather than cancer-specific) measures of QoL, making it difficult to draw conclusions about associations between health behaviours and cancer-specific symptoms such as fatigue, nausea, pain and sleep disturbances. In addition, there are no data available on the association between health behaviours and QoL in UK cancer survivors. The aim of this study was therefore to examine associations between health behaviours and QoL using a cancer specific measure; the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire, version C30 (EORTC-QLQ-C30).

Methods

Data for this study were drawn from the questionnaire survey discussed in chapter 3. Chapter 3 also describes the measures used to assess health behaviour practices.

Quality of life was measured using EORTC QLQ-C30 (Aaronson et al., 1993). The EORTC QLQ-C30 is a 30-item questionnaire and measures physical (five-items), role (2-items), emotional (four-items), social (two-items) and cognitive (2-items) functioning as well as global QoL (2-items) and three symptoms, fatigue (three-items),

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[4] A version of this results section has been submitted for publication in the Journal of Cancer Survivorship

pain (2-items) and nausea/vomiting (2-items). There are also six single items for dyspnoea, appetite loss, insomnia, constipation and diarrhoea, and financial difficulties. This scale has been previously used in numerous studies of cancer patients, including CRC survivors (Ulander et al., 1997). Aaronson et al (1993) reported acceptable to good reliability coefficients for the individual scales (cronbach's alpha = 0.65-0.92).

Statistical Analysis

Sample size was calculated statistical package G-Power. Based on a t-test to identify a 10 point difference in QoL (EORTC-QLQ-30) score, i.e. between those who do and do not meet government recommendations for each health behaviour using the. A 10 point change has been reported to be clinically meaningful (King, 1996; Osoba et al., 1998). Standard deviation scores were obtained from EORTC-QLQ-30 reference data. Using the standard deviation of 30.4; for 80% power 147 participants were required per group, resulting in a total sample target of 294.

Missing data on the EORTC-QLQ-C30 items were imputed using expectation-maximisation (EM) algorithm. EM is an iterative method that has two steps. Step 1 'expectation' involves estimating the expected value based on the observed values and current estimates. The estimates used here were items that were highly correlated with scales items, including other EORTC-QLQ-C30 items, comorbidities, activity, SES, marital status, current alcohol consumption status, self-rated health, life satisfaction. Step 2 'maximisation' performs a maximum likelihood estimation as though the missing data had been filled. Analysis of EM-imputed data is biased because error is not added to the imputed data (Graham et al., 2003), however the proportion of missing data was low (< 3% for each item), and therefore any bias is likely to be minimal.

Regression models were used to examine the dependence of QoL function subscales and fatigue on individual health behaviours (including body weight), adjusting for age, sex, socio-economic status (SES), comorbidities, recurrence, current treatment and time since diagnosis. Unstandardised regression coefficients were obtained to indicate the size of effects. QoL scores were not normally distributed and attempts to transform the data did not improve its distribution. Therefore, after receiving advice from the department statistician on the most appropriate analytic method, bootstrapping was used with 1500 replications to obtain reliable significance tests and confidence intervals (CI's) (Mooney, 1996). Adjusted means with standard errors (SE) and p values are presented. Scores on the symptom subscales (excluding fatigue) were very skewed with approximately half of respondents scoring 0. Therefore results were dichotomised into any vs. no symptoms. Logistic regressions, adjusting for covariates as above were used to assess whether symptom subscales differed for those engaging in healthful behaviours vs. not. Adjusted odds ratios (OR) with 95% CI's and P values are reported. Checks were made to ensure no multicollinearity was present.

A pragmatic health behaviour score was calculated by assigning one point for each of the following behaviours: not smoking, consuming ≥5 portions of F&V a day, being physically active, and having moderate alcohol consumption (Khaw et al., 2008). Regression analysis (with adjustment and bootstrapped p-values and CIs as above) examined associations between the health behaviour score and QoL subscales. Logistic regression was used to examine whether symptom subscales varied by health behaviour score, adjusting for demographic and medical covariates. I did not include weight in the health behaviour score because although it is influenced by energy balance, lower weight may be due to illness rather than lifestyle.

Results

Association between health behaviours and quality of life

Table 4.1 presents the association between health behaviours and QoL subscales and fatigue (effects not detailed in the table are non significant). Participants who were physically active had higher global (p = .003), physical (p= <.001), role (p = .007), cognitive (p = .037), and social QoL scores (p = .024), as well as lower fatigue (p = .004). Those who ate ≥5 portions of F&V a day had higher global (p = <.001), physical (p = .002), role (p = .021), and cognitive scores (p = 0.004). Effects were in the other direction for weight, with overweight survivors having higher cognitive scores (p =.032) and lower levels of fatigue (p = .039). Non-drinkers had lower physical (p = .030), role (p = .039), and social (p = .034) scores, and higher fatigue (p = .026) compared to moderate drinkers. There were no significant associations between QoL and either smoking or heavy drinking.

Table 4.1 Association between quality of life subscales and health behaviours

	Adjusted quality of life score (0-100) Means (SE)			
	Physical activity (n = 397)			
	≥ 5 sessions per week	**< 5 sessions per week**	**Regression coefficient (95% CI)** [a]	**p-value**
Global quality of life	77.34 (2.25)	70.36 (1.13)	6.98 (2.06 - 11.90)	.005
Physical function	90.11 (1.48)	81.77 (0.98)	8.34 (4.92 - 11.76)	<.001
Role function	87.87 (2.36)	81.82 (1.43)	6.04 (0.65 - 11.44)	.028
Social function	83.39 (2.98)	76.56 (1.46)	6.83 (0.30 - 13.37)	.040
Fatigue [b]	19.27 (2.49)	26.58 (1.18)	-7.30 (-12.67 - -1.92)	.008
	Fruit and vegetable intake (n = 395)			
	≥ 5 portions a day	**< 5 portions a day**		
Global quality of life	75.26 (1.37)	67.71 (1.47)	7.54 (3.61 - 11.48)	<.001
Physical function	85.88 (1.10)	80.18 (1.29)	5.70 (2.28 - 9.12)	.001
Role function	86.25 (1.70)	78.75 (1.83)	7.40 (2.61 - 12.38)	.003
Cognitive function	88.02 (1.28)	82.51 (1.37)	5.51 (1.73 - 9.29)	.004
Fatigue	22.85 (1.64)	28.34 (1.65)	-5.49 (-10.14 - -0.84)	.021
	Alcohol consumption (n = 352)			
	No alcohol	**Moderate alcohol intake** [c]		
Physical function	78.50 (1.98)	83.56 (1.07)	-5.07 (-9.65 - -.485)	.030
Role function	76.06 (3.28)	83.86 (1.57)	-7.80 (-15.20 - -.390)	.039
Social function	71.19 (3.51)	79.38 (1.51)	-8.18 (-15.73 - -.626)	.034
Fatigue	30.75 (2.71)	23.76 (1.32)	6.99 (.82 - 13.17)	.026

Adjusted for age, sex, SES, comorbidities, recurrence, current treatment and time since diagnosis [b] Higher scores of fatigue indicates a higher degree of that symptom. [c] Moderate alcohol intake: >1 and <14 units for women, >1 and <21 units for men.

Logistic regression was used to examine associations between health behaviours and symptoms. Respondents who were physically active reported less pain: 26% vs. 45% (OR = 0.41, 95% CI, 0.27-0.61; p < .001) and less sleep disruption; 39% vs. 52%; (OR = 0.45, 95% CI, 0.37-0.56; p < .001). Participants eating ≥5 portions of F&V a day had less constipation than those eating less; 20 vs. 30% (OR 0.50; 95% CI, 0.26 – 0.96; p = .039). Normal-weight individuals had more nausea than those who were overweight or obese; 21% vs. 16% (OR 2.12; CI, 1.33 - 3.36; p = .001), more loss of appetite; 21% vs. 17% (OR 2.02; 95% CI, 1.37-2.96; p <.001), and less dyspnoea; 31% vs. 41% (OR 0.70; 95% CI, 0.55-0.89; p = .005). Non-drinkers had more loss of appetite; 29% vs. 16% (OR 1.77; 95% CI 1.25 -2.51) and more diarrhoea 35% vs. 27% (OR 1.37; 95% CI 1.01 – 1.68) compared to moderate drinkers. There were no other significant associations with symptoms.

Associations between health behaviour score and quality of life

Only five respondents scored 0 on the health behaviour score therefore for analysis they were combined with those scoring one. Significant linear trends were found between the number of health behaviours and global QoL (p = .040) and physical function (p <.001), see figure 4.1. A significant negative linear trend was also found for fatigue (p =.001), see figure 4.2. The linear trend approached significance for role function (p = 0.06) but was not significant for other functional subscales. Logistic regression revealed that higher health behaviour scores were associated with less pain (OR 0.64 (95% CI 0.53-0.80) p = .001), less dyspnoea (OR 0.65 (0.55-0.80) p <.001) and less constipation (OR 0.76 (95% CI 0.60-0.96) p = .020).

Figure 4.1: Association between health behaviour score and quality of life

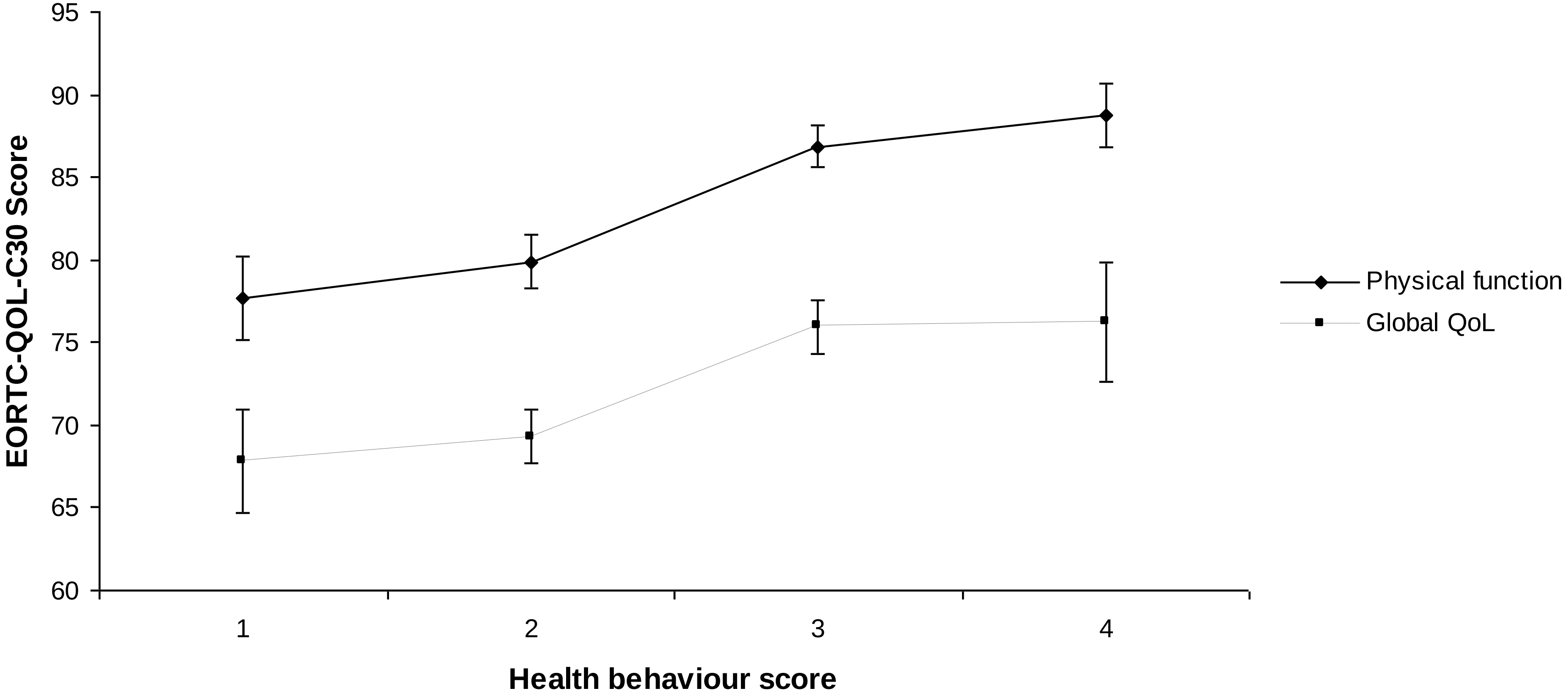
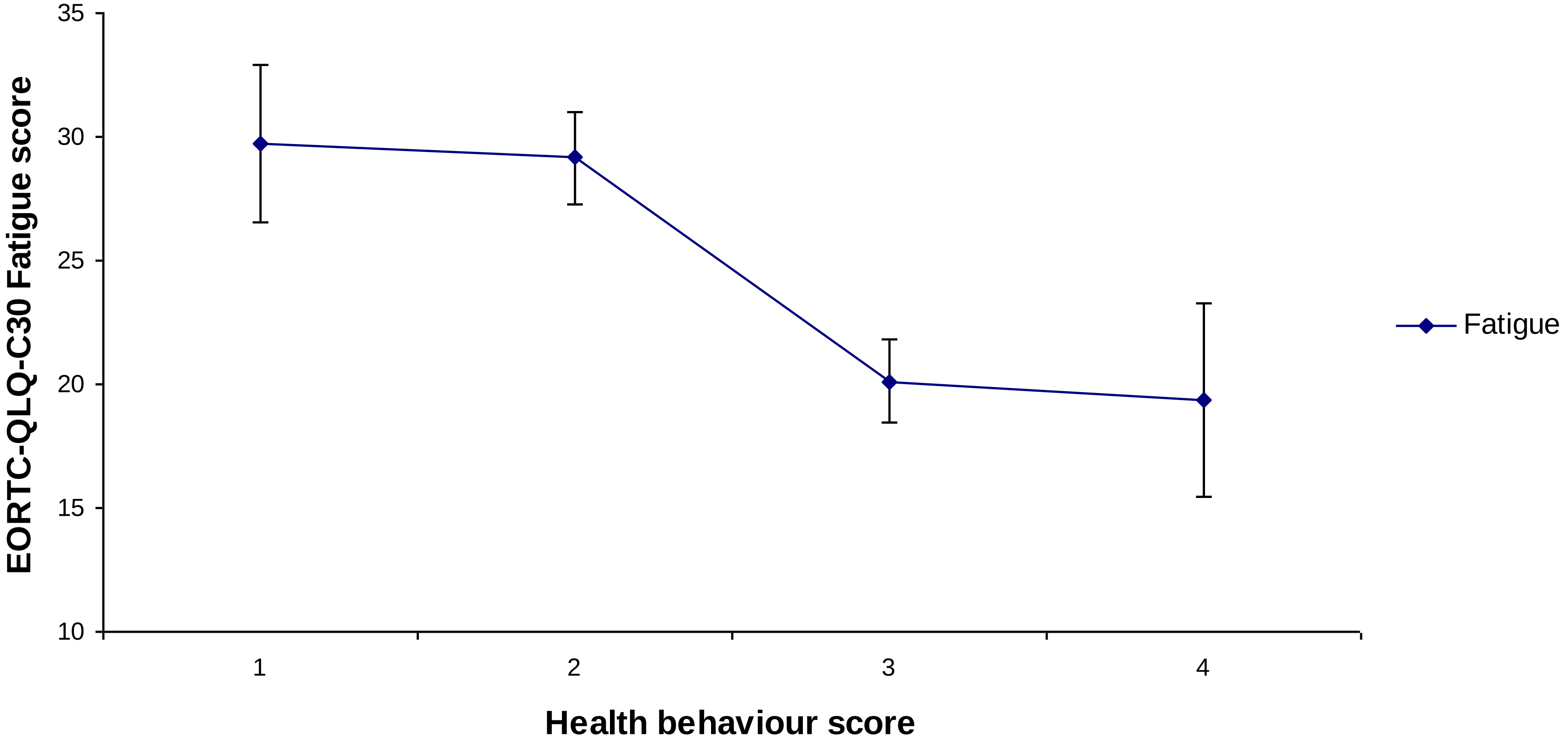


Figure 4.2: Association between health behaviour score and fatigue



Discussion

In this sample of CRC survivors, participation in more healthful behaviours was associated with better QoL across many different domains, and fewer cancer symptoms.

Quality of life scores were comparable to data from the EORTC Reference Value Manual for CRC survivors of a similar age group except that emotional function scores were 11 points higher in our sample (Fayers et al., 2002). This is above the cut-off of 10 points which has been deemed clinically meaningful (Yost et al., 2005) suggesting the sample used in the current study may have higher emotional function than the reference groups.

Survivors who were physically active had better scores for global QoL and physical, role and social function subdomains, as well as lower levels of fatigue, pain and insomnia. Previous studies have consistently shown a positive association between physical activity and general QoL (as discussed in chapter 1) across cancer sites. Two previous studies have examined the association between physical activity and QoL in CRC survivors as measured with a cancer specific QoL instrument; the FACT-C (Lynch et al., 2007; Steginga et al., 2009). Both of these studies failed to find an association between physical activity and social function. However being physically active was associated with less ‘colorectal cancer-specific additional concerns’ which include items such as diarrhoea and loss of appetite. Both studies also reported better functional wellbeing. One other study including CRC survivors provided data on QoL subdomains (Mosher et al., 2009). The authors measured QoL using the SF-36, rather than a cancer specific measure; however this included measures of pain and vitality. In accordance with results from the current study, physical activity was associated with less pain, greater vitality, physical QoL, physical and social functions.

F&V intake was also associated with better global QoL, physical, role and social function. This is in accordance with a large US study with 1918 CRC survivors (Blanchard et al., 2008) although the authors did not report on the various dimensions. The only other study to examine this relationship in a sample including CRC survivors found no such association (Blanchard et al., 2004). However the sample size was small and there may not have been sufficient power to detect an association. A number of studies have examined diet quality (as apposed to F&V consumption *per se*) and QoL in cancer survivors; although to my knowledge no such data are available among CRC survivors specifically. Data from the HEAL study revealed a direct association between diet quality and mental and physical function (as measured by the SF-36) with a stronger relationship for mental function (Wayne et al., 2006) among breast cancer survivors. In contrast, but in accordance with the current study, a study of long-term cancer survivors found a stronger association between diet quality and physical function (Mosher et al., 2009).

There was no association found between BMI and most QoL subscales, with the exception of cognitive function. Being overweight/obese was however associated with *better* cognitive function and *less* pain, nausea, loss of appetite, and fatigue. The seemingly protective effect most likely reflects lower weight being a consequence of symptoms and post-operative complications. Conversely, Mosher et al (2009) examined a sample of colorectal, prostate and breast cancer survivors and found higher BMI to be associated with worse QoL. However normal-weight survivors were excluded from the sample, so the observed differences came from comparisons of overweight and obese sub-groups. Similarly, a recent large (n = 3241) US study (Blanchard et al., 2010) presented data on CRC survivors and found healthy weight and overweight survivors to have similar physical and mental health scores (as measured by the RAND-36), but lower levels were seen in obese participants. In the current study overweight and obese participants were combined due to small sample size. Similar null findings have been reported elsewhere. In an Australian sample no significant relationships were found between BMI and total QoL, physical, social, emotional or functional wellbeing (Steginga et al., 2009). However there was a negative association between BMI and CRC specific additional concerns (as measured by the FACT-C). This sample were however assessed closer to diagnosis; this may explain the variation in results.

There was no significant association between smoking and QoL. Previous studies have found smokers to have worse QoL (Blanchard et al., 2008; Steginga et al., 2009), however there were too few current smokers in the present sample (n = 28) to have adequate statistical power. We also found no association between heavy drinking and QoL. Non-drinkers however had lower functional QoL and higher levels of fatigue compared to those who consumed a moderate amount of alcohol. Similar associations have been reported in healthy populations of older adults, (Chan et al., 2009; Lang et al., 2007) and in head and neck cancer survivors, with those consuming a moderate amount of alcohol having favourable QoL compared to those who abstain (Allison et al., 2002). However null results have also been reported among head and neck cancer survivors (Duffy et al., 2002; Duffy et al., 2007). I am not aware of other studies that have examined this relationship in CRC survivors.

A composite positive health behaviour score showed a clear linear relationship with global and physical QoL, with differences in scores defined as ‘moderate’ for effects observed in a clinical setting (Fayers et al., 2002; King, 1996). The health behaviour score also had a negative linear relationship with fatigue. Three other studies have found a similar cumulative effect of health behaviours on QoL in cancer survivors (Blanchard et al., 2004; Blanchard et al., 2008; Demark-Wahnefried et al., 2000) although to my knowledge no other studies have considered the relationship with cancer symptoms such as fatigue. The consistency of such an association supports the argument for investigating the value of multiple behaviour change among cancer survivors.

This study had a number of limitations. It was cross-sectional which made it impossible to draw casual inferences concerning the relationship between health behaviours and QoL but bidirectional effects are likely. For example there is considerable evidence from healthy populations that physical activity has favourable effects on wellbeing (see Bize et al., 2007 for a review), but at the same time, fatigue and pain are likely to be disincentives to activity. As previously mentioned, reliance on self-reported health behaviours is likely to over-estimate physical activity and F&V consumption, and under-estimate alcohol and smoking. Sample size also prohibited thorough investigation of associations between smoking and obesity and QoL. Imputation of missing QoL data and the use of bootstrapping may also have reduced the variance in scores.

On the positive side, it is the first UK study to investigate the association between health behaviours and QoL in CRC survivors, and one of only a handful to assess associations between multiple behaviours and QoL.

Chapter 5

Study 4 - Perceived causes of cancer and recurrence and associations with health behaviours

Introduction

Data from the current study and previous literature suggest that a cancer diagnosis motivates some individuals to make positive health behaviour changes. However this is not true of all cancer survivors. Determining what factors motivate people to make behavioural changes may help in the design of effective behaviour change interventions.

Leventhal’s common sense model (Leventhal et al., 2003) suggests that illness representations (i.e. beliefs regarding cause and controllability) may influence behaviour and behaviour change. Therefore variation in such cognitions may help to explain some of the differences in behaviour and behaviour change among cancer survivors. Previous research examining causal attributions of disease in cancer survivors has focused primarily on female breast and gynaecologic cancer survivors. In general, attributions of disease tend to be to uncontrollable factors such as stress, genetics, environment and hormones. It is likely that this is a self-protecting cognition as attribution to controllable factors such as lifestyle could result in feelings of guilt, blame and distress. Indeed, in a study of long-term gynaecologic cancer survivors, attributing cancer to lifestyle, diet, alcohol or tobacco was associated with higher levels of anxiety and recurrence worry (Costanzo et al., 2005). This association between stronger causal attributions and distress in consistently reported in the literature (e.g. Faller et al., 1995; Lowery et al., 1993). In contrast, studies that have examined cancer survivors’ perceptions of factors that may help prevent cancer *recurrence*, consistently report internal controllable factors such as diet, exercise and a positive attitude. These attributions may provide a sense of control over future health. There is also evidence that survivors are less likely to endorse any factor, external or internal as having had an influence on the development of their disease compared with preventing recurrence. In a long-term gynaecologic cancer survivors sample most factors were rated as somewhat to very important in preventing a cancer recurrence, but only around a third endorsed any factor as having been somewhat to very important in the development of their cancer (Costanzo et al., 2005).

In addition to the work among breast and gynaecologic cancer survivors, lung cancer survivors have also received some attention. Studies have however been small and predominantly qualitative, but the results suggest that this group commonly attribute the cause of their disease to a controllable factor, namely smoking (Berckman & Austin, 1993; Faller et al., 1995). It is likely that this is because of the widely recognised association between smoking and lung cancer, with 85% of lung cancers attributable to smoking. In contrast, the aetiology of breast and gynaecologic cancers is not as well understood. Despite this, survivors of these cancers appear to frequently assign attributions to the cause of disease. This is in accordance with Leventhal’s common sense model which suggests that individuals make such attributions in an attempt to make sense of their illness.

To date, only one study has examined causal attributions made by colorectal cancer (CRC) survivors (Wold et al., 2005). This was part of a study of the beliefs of 416 breast, 165 prostate and 89 CRC survivors. As with the breast cancer literature, survivors tended to attribute the cause of their disease to factors such as genetics, environmental factors and stress. In the light of evidence for a causal association with low fibre diets and CRC one might expect this to be acknowledged as a potential risk factor in this group (given the evidence regarding smoking and lung cancer survivors attributions) and a third of CRC survivors compared with less than 20% of the survivors of breast cancer endorsed this factor. However the sample of CRC survivors was small and the study did not examine beliefs about recurrence. Therefore one aim of the present study is to examine beliefs about the cause of disease and influences on recurrence in a large sample of CRC survivors.

In addition to descriptive data on attributions, a small number of studies have examined the association between attributions and reported change in behaviour since diagnosis. Again, most previous research has examined breast cancer survivors. For example, two studies in recently diagnosed breast cancer survivors, found that those who believed an unhealthy diet may have contributed to the development of their cancer were more likely to report positive changes to their diet (Costanzo et al., 2010; Rabin & Pinto, 2006). The same pattern was also seen for those who believed diet to be important in the prevention of a recurrence. However, no such association was found for physical activity.

Rabin and Pinto (2005) also examined attributions regarding alcohol consumption. No association was found between perceived importance of alcohol consumption in the cause of their cancer and reported reductions in alcohol consumption, but those who perceived alcohol consumption to be important in recurrence reported drinking less since diagnosis.

One study also examined this association among a group of long-term gynaecologic cancer survivors (Costanzo et al., 2005). In contrast to the data on breast cancer survivors, no association was found between attributions of their current diagnosis to diet and dietary changes. However, as in the breast cancer literature, perceived importance of diet in the recurrence of disease was associated with change in this behaviour. Also in accordance with the breast cancer literature attributions of physical activity in both the cause and recurrence of cancer were not associated with reported increase in physical activity.

In general, attributing a causal role to health behaviours tends to be associated with reported positive change in the corresponding behaviour (particularly for diet), although results are not entirely consistent. However, the existing literature has a number of limitations. All three studies described above focus solely on women and none of the studies examined associations between these attributions and reported behaviour (as opposed to change). Therefore the aim of this study was to examine the association between attributions regarding the cause and potential recurrence of cancer and both reported change in behaviour, and actual behaviour, in a large sample of CRC survivors. Analyses were also conducted separately by sex to provide data on a male sample.

Methods

Data for this study was drawn from the questionnaire survey discussed in chapter 3.

Chapter 3 also describes the measures used to assess health behaviour practices and behaviour change.

Perceived cause of cancer and perceived ability to prevent recurrence was measured by asking participants to rate how important a variety of factors were in the development of their cancer and in preventing the cancer from recurring. A 5-point response scale was used ranging from "not at all important" to "very important". The questions were introduced with the sentence "sometimes people have ideas about factors that played a role in the development of their cancer. Please rate how important you think each of the following were in the development of your cancer" and "sometimes people have ideas about what prevents cancer from coming back, please rate how important each of the following are to you in reducing the chance that your cancer will come back". This measure was adapted from similar measures previously used in studies of cancer survivors (Costanzo et al., 2005; Rabin & Pinto, 2006).

Statistical analysis

In order to compare results of the present study with the existing literature responses for perceived importance of various factors in the cause and recurrence of cancer were dichotomised with scores of 2-4 (from a likert scale of 0-4) categorised as positive endorsement of that factor vs. those who scored 0-1 who were categorised as perceiving little or no importance of that factor. Percentages for each cause and recurrence attribution are presented. Simple chi square tests were used to examine differences in attributions by sex. When results were significant ($p < 0.05$) logistic regressions were run controlling for medical and demographic covariates (age, SES, comorbidities, time since diagnosis, and current treatment). Odds ratio, 95% confidence intervals and p values are presented. Checks were made for multicollinearity. For analysis of attribution of recurrence, those who reported experiencing a cancer recurrence were excluded.

The relationship between attributions concerning cancer onset and recurrence and behaviour were examined. The covariates of age, sex, SES, comorbidities, time since diagnosis and current treatment were included in all analysis. As above, those who reported a cancer recurrence were excluded from analysis of attribution of recurrence. Regression analyses were used to determine whether behaviours differed between those individuals who perceived that behaviour to be of importance in the cause and recurrence of their cancer vs. those who did not see if as important. The distribution of physical activity and alcohol consumption were skewed, and transformations did not improve the distribution significantly. This violates the assumption of parametric tests which assume a normal distribution of the dependent variable. Regression analysis was therefore conducted in STATA and bootstrapping technique with 2500 repetitions was used in order to generate accurate p values and confidence intervals. Analysis was also conducted separately by sex. Regression coefficients, 95% confidence intervals and p values are presented.

Logistic regression analysis was used to determine the relationship between attributions and change in behaviour. Adjustment for covariates were made as above. Reported change in behaviour were dichotomised into those who reported a positive change (i.e. increase in physical activity and F&V consumption and reduction in alcohol consumption) vs. those who reported no change or a negative change (i.e. reduction in physical activity, F&V consumption or increase in alcohol consumption). Analysis was also conducted separately by sex.

Results

Cancer attributions

Table 5.1 shows the percentage of those categorised as perceiving each behaviour to be of some importance in the onset and potential recurrence of their cancer. Responses are rank ordered.

The most frequently endorsed factors for the development of cancer were uncontrollable in nature such as age, luck and genetics. Health behaviours were endorsed as potentially important by less than half of respondents with as few at 34% citing lack of physical activity. In contrast health behaviours were deemed to be of importance for prevention of recurrence of cancer among the vast majority of respondents (87% - 91%).

Logistic regression analysis revealed that men were more likely to endorse high fat intake as a possible contributor to the onset of their cancer; 52% vs. 40%; OR 1.61 (1.03 – 2.53); p = .039. They were less likely however to endorse several other factors including genetics; 51% vs. 62%; OR .503 (.315 - .804), p = .004, God's will; 29% vs. 42%; OR .558 (.366 – .945), p = .028, lack of physical activity; 29% vs. 42%, OR .548 (.340 – .882), p = .013, and hormones; 22% vs. 35, OR .457 (.271 - .772). Fewer differences were seen for attributions for recurrence. Men were however less likely to endorse the use of complementary therapies as a means of recurrence prevention, 22% vs. 37%, OR .486 (.270 - .809), p = .007.

Table 5.1: Rank order of participants' ratings of importance of various factors in the development and recurrence of their cancer.

Factors contributing to development	% (n)	Factors preventing cancer recurrence	% (n)
Age (n = 424)	67.2 (285)	Check ups (n = 463)	95.5 (442)
Luck/chance (n = 412)	65.3 (269)	Healthy weight (n = 450)	94.2 (424)
Family history (n= 422)	55.9 (236)	Positive attitude (n = 446)	94.6 (422)
Genetics (n = 400)	55.5 (222)	F&V (n= 439)	90.9 (399)
Stress (n = 408)	55.4 (226)	Not smoking (n = 433)	89.6 (388)
Pollution (n = 397)	51.1 (230)	Low fat diet (n = 443)	89.2 (395)
Lack of F&V (n = 408)	46.6 (190)	PA (n = 436)	88.5 (386)
High fat diet (n = 405)	46.6 (192)	Drinking (n = 457)	87.3 (399)
Smoking (n = 393)	41.7 (164)	Stress (n = 439)	85.9 (377)
Being overweight (n = 396)	40.2 (159)	Luck/chance (n = 404)	58.9 (238)
God's will (n = 383)	34.2 (131)	God's will (n = 379)	39.6 (150)
Alcohol (n = 424)	34.2 (145)	CMT (n = 415)	31.3 (130)
Lack of PA (n = 387)	33.6 (130)		
Infection (n = 404)	31.2 (126)		
Hormones (n =366)	27.0 (99)		
X-rays (n 385)	22.6 (87)		
Injury (n = 387)	14.7 (57)		

PA = physical activity
CMT = complementary therapy

Cancer attributions and health behaviour

Table 5.2 presents the association between attributions of cancer cause and behaviour. There were no significant associations between the perceived importance of any health behaviour and participation in that behaviour either for the whole sample or by sex. In contrast perceived importance of physical activity in recurrence was significantly associated with participation in more physical activity; however this was not the case when analysis was split by sex. Those who perceived F&V consumption to be important in recurrence were consuming more F&V than those who did not believe this to be important, this was also true when examined separately by sex. No association was found for alcohol (see table 5.3).

Table 5.2: Relationship between health behaviour and perceived importance in the cause of cancer

Attribution	**Level of behaviour**	**Regression coefficient (95% CI)[a]**	**p**	**Regression coefficient (95% CI) [b] Men**	**p**	**Regression coefficient (95% CI) [b] Women**	**p**
Physical activity	Bouts per week (SD)	N = 346		N = 215		N = 131	
Important in cause	2.44 (4.04)	-.137 (-.589 - .315)	.552	-.268 (-.844 - .309)	.362	-.083 (-.639 - .806)	.821
Not important in cause	2.31 (2.89)						
F&V	Portions per day (SD)	N = 356		N = 222		N = 134	
Important in cause (n = 179)	4.11 (2.29)	.064 (-.683 - .813)	.865	-.246 (-1.27 - .782)	.638	.493 (-.519 – 1.51)	.339
Not important in cause (n = 212)	4.25 (2.04)						
Alcohol	Units per week (SD)	N = 347		N = 219		N = 128	
Important in cause (n = 134)	7.50 (9.6)	1.29 (-.581 – 3.15)	.177	2.17 (-.511- 4.85)	0.113	.116 (-2.18 - 2.41)	.921
Not important in cause (n = 258)	5.81 (7.58)						

[a] Controlling for age, sex, SES, comorbidities, time since diagnosis, recurrence and current treatment

[b] Controlling for age, SES, comorbidities, time since diagnosis, recurrence and current treatment

Table 5.3: Relationship between health behaviour and perceived importance in the recurrence of cancer

Attribution	Level of behaviour	Regression coefficient (95% CI) ^{a}	p	Regression coefficient (95% CI) ^{b} Men	p	Regression coefficient (95% CI) ^{b} Women	p
Physical activity	Bouts per week (SD)	N = 379		N = 235		N = 144	
Important in recurrence	2.51 (3.45)	.961 (.226 – 1.70)	.010	.871 (-.284 – 2.02)	.140	.507 (-.702 – 1.72)	.441
Not important in recurrence	0.80 (1.55)						
F&V	Portions per day (SD)	N = 383		N = 236		N = 147	
Important in recurrence	4.28 (2.19)	.959 (.093 – 1.82)	.030	.544 (.220 - .870)	.001	.377 (.061 - .694)	.019
Not important in recurrence	3.24 (2.09)						
Alcohol	Units per week (SD)	N = 382		N = 236		N = 148	
Important in recurrence	6.93 (9.14)	-.700 (-3.79 – 2.39)	.657	-1.71 (-6.59 – 3.17)	.494	-.738 (-1.58 – 0.10)	.085
Not important in recurrence	6.35 (7.99)						

[a] Controlling for age, sex, SES, comorbidities, time since diagnosis, and current treatment

[b] Controlling for age, SES, comorbidities, time since diagnosis, and current treatment

Cancer attributions and reported behaviour change

Table 5.4 presents the association between attributions of cancer cause and reported behaviour change. No association was found between the perceived importance of physical activity and reported increase in physical activity since diagnosis. However group sizes were small and there was a trend for more positive change among those holding positive attributions. Attributions regarding F&V consumption however revealed those who perceived F&V consumption of some importance in the cause of their cancer were more likely to report increasing F&V consumption since diagnosis. Additionally, believing alcohol played a role in the onset on ones cancer was associated with a reported reduction in alcohol consumption since diagnosis. Examination of the relationship between attributions of recurrence and behaviour change (see table 5.5) revealed that 100% of those who reported believing physical activity is important in recurrence increased their physical activity since diagnosis, however only 28 individuals reported increasing their physical activity since diagnosis. No associations were found between perceived importance of F&V consumption or alcohol consumption and the associated behaviour; however, once again, group sizes were small.

Table 5.4: Relationship between change in behaviour and perceived importance in cause of cancer

Attribution	Reported change in behaviour (n %)	OR (95% CI) [a]	p	OR (95% CI) [b] Men	p	OR (95% CI) [b] Women	p
Physical activity		N = 352					
Important in cause	17 (13%)	1.97 (.814 – 4.77)	.133	NA		NA	
Not important in cause	12 (5%)						
F&V		N = 368		N = 229		N = 139	
Important in cause	44 (23%)	1.98 (1.08 – 3.53)	.021	1.51 (.728 – 3.12)	.269	3.18 (1.18 – 8.61)	.023
Not important in cause	29 (13%)						
Alcohol intake		N = 338		N = 224		N = 114	
Important in cause	71 (59%)	2.09 (1.29 – 3.36)	.002	2.05 (1.16 – 3.63)	.013	2.19 (.882 – 5.46)	.091
Not important in cause	104 (42%)						

[a] Controlling for age, sex, SES, comorbidities, time since diagnosis, recurrence and current treatment

[b] Controlling for age, SES, comorbidities, time since diagnosis, recurrence and current treatment

NA – Sample size did not permit analysis

Table 5.5: Relationship between change in behaviour and perceived importance in the recurrence of cancer

Attribution	Reported change in behaviour (n %)	OR (95% CI)[a]	p	OR (95% CI)[b] Men	p	OR (95% CI)[b] Women	p
Physical activity							
Important in recurrence	28 (10%)	NA		NA		NA	
Not important in recurrence	0 (0%)						
F&V		N = 387					
Important in recurrence	55 (18%)	.969 (.304 – 3.91)	.958	NA		NA	
Not important in recurrence	4 (14%)						
Alcohol intake		N = 355					
Important in cause	118 (46%)	1.20 (.564 – 2.56)	.633	NA		NA	
Not important in cause	14 (37%)						

[a] Controlling for age, sex, SES, comorbidities, time since diagnosis, and current treatment

[b] Controlling for age, SES, comorbidities, time since diagnosis, and current treatment

NA – Sample size did not permit analysis

Discussion

Data from the present study supports findings from breast and gynaecologic cancer survivors suggesting that survivors are more willing to identify behavioural factors as playing a role in cancer recurrence than in the origin of their disease. Uncontrollable/ external factors such as luck, genetics, stress and the environment were more readily acknowledged as possible causes of their disease than internal/controllable factors such as lack of physical activity and alcohol consumption, again; consistent with the existent literature. However almost half of the sample agreed that dietary factors may have played a role in the development of their disease (47% lack of F&V and a high fat diet) compared to 34% who thought lack of physical activity may have had a role to play. A similar pattern of results is seen in the previous literature with more (31-69%) endorsing dietary factors than physical activity (5-38%) in breast and gynaecologic cancer (Costanzo et al., 2005; Costanzo et al., 2010; Rabin & Pinto, 2006). A national survey in the UK examining public awareness of risk factors reported comparable results (Redeker et al., 2009) with more respondents believing that low F&V intake increased an individuals' risk of developing cancer than believed being physically inactive influenced risk. This suggests that both cancer survivors and the general population believe that diet is more important in development of cancer than physical activity.

Analyses from the current study revealed some sex differences with men being less likely to endorse genetics, God's will, lack of physical activity and hormones and more likely to agree that diets high in fat contribute to cancer development. It may be that women are aware of the genetic link associated with breast cancer and therefore are more likely to assume a genetic link with other cancers. The fact that men were less likely to endorse several factors suggests that they may be less inclined to endorse *any* factors in the development of cancer. Ancillary analysis comparing mean scores for perceived importance for all factors found lower scores among men for 12 of the 15 items, 8 of these being significantly different ($p <.005$) See appendix 4. Only one other study has included comparable data among a male sample of cancer survivors. Wold et al (2005) surveyed 89 colorectal and 165 prostate cancer survivors. They do not present any analysis on sex differences but rates are presented separately for men and women. In contrast to the present study, they found that more male CRC survivors endorsed behavioural factors as contributing to the developing of their cancer, although they were less likely to endorse genetic or environmental factors or stress. Data from the cardiac rehabilitation literature also indicates that there may be sex differences in illness representations. For example one study of acute coronary syndrome patients found men were more likely than women to perceive their disease as controllable compared to women (Grace et al., 2005).

The only sex difference in factors believed to be important in cancer recurrence was complementary therapies, with women more likely to endorse the use of complementary medicine than men. Previous literature has consistently reported a higher prevalence of complementary therapy use among female cancers survivors (Ferrucci et al., 2009; Fouladbakhsh & Stommel, 2010; Gansler et al., 2008; Kelly et al., 2007; Miller et al., 2008). It is important to note however that there was less variance in responses to the items referring to recurrence compared to cancer cause, with the majority of respondents believing most of the factors could play a part in the prevention of cancer recurrence.

The second aim of this study was to examine the association between attributions of cause and recurrence of disease and reported change in behaviour and actual behaviour. The results indicate a positive association between behaviour change and attributing health behaviours to cancer occurrence. This is in contrast to a lack of association between attributions and actual (as opposed to reported change in) behaviour. This discrepancy may be because those who reported a change in behaviour previously had poorer health behaviours than those that did not, and have improved their behaviours in line with the rest of the sample. Alternatively it may be that participants’ response to the attribution question influenced their response to the behaviour change item. However the questionnaire was ordered so that the attribution questions came after the behaviour change question to minimise the chance of this happening.

In contrast to the null findings on the association between attribution of cancer onset and behaviour, attributions on recurrence of disease were associated with healthful behaviours for F&V, physical activity. Associations between recurrence attribution and behaviour change also revealed a trend for positive behaviour change although small sample sizes prohibit reliable analysis. Ancillary analysis in the form of simple t-tests were conducted to examine mean scores in recurrence attributions (rather than a dichotomised variable) for those reporting a positive change vs. not. Attribution scores were significantly higher for all three behaviours among those who reported a positive behaviour change (see appendix 5).

Previous literature has focused on reported behaviour change (as opposed to actual behaviour) and association with attributions. In general there is greater support for the association between attributions and diet than for physical activity. One previous study provides partial support for the association between attribution of physical activity in cancer cause and behaviour change with respondents significantly more likely to report an increase in activity at 3 months post-treatment but not 3 weeks (Costanzo et al., 2010). A similar trend was seen among another breast cancer sample however results did not reach significance. This mirrors the non significant trend reported in the current study and suggests that the association between attributions of cancer cause and physical activity change may vary by time since diagnosis with positive associations more likely to be found several months (rather than weeks after diagnosis). No previous studies however have found a positive association between attributions of recurrence and increases in physical activity.

In accordance with data shown here two previous studies described a positive association between attribution of dietary factors in the cause of disease and positive behaviour change (Costanzo et al., 2010; Rabin & Pinto, 2006). Existing literature also supports a positive association between behaviour change and attribution of recurrence (Costanzo et al., 2010); a similar but non-significant trend is seen in the present study.

The present study found those who believed alcohol may have contributed to the onset of their cancer were more likely to report a reduction in alcohol consumption. This is in contrast to previous literature with two studies reporting no association (Costanzo et al. 2010, Rabin & Pinto, 2006). However in the present study this relationship was true for men and not women suggesting disagreement with the previous literature may be due to previous samples including only female respondents.

It is also possible that those who had made health behaviour changes were more likely to hold positive attributions as a result of this change, rather than such beliefs stimulating change in behaviour. The cross-sectional nature of this study means direction of causation can not be inferred.

In conclusion, it appears that there is a general trend towards positive attributions being associated with more healthful behaviours, particularly for diet, and there may be differences by sex.

Limitations of this study include the subjective measure of health behaviours and behaviour change as discussed previously. Prospective studies with objective measures would yield more reliable results. Also, the lack of variability in attributions of health behaviours to cancer recurrence (with over 90% holding positive attitudes) results in small sample sizes and therefore limits the interpretation of results.

Chapter 6

Study 5: Health professional lifestyle recommendations, behaviour and attributions

Introduction

Cancer survivors often ask what they can do to help stop their cancer recurring and improve their own health. Oncologists and other health professionals are in a favourable position to offer such advice and are patients' preferred source of information (O'Leary et al., 2007). An RCT examining the effect of a brief oncologist recommendation to exercise found it to be effective in increasing self-reported physical activity in breast cancer survivors (n= 450) (Jones et al., 2004). The intervention involved the oncologist saying "recent research has shown that some of the side effects you may experience during treatment may be controlled with a modest exercise program. I recommend trying to exercise for 20-30 minutes every day at a moderate intensity. Even less may be beneficial, but try to do something every day. Exercise such as brisk walking will meet these requirements". Those who received this advice were doing almost 30 minutes more moderate intensity physical activity per week at the six week follow-up than controls. This suggests that oncologists and other health professionals can be a powerful resource to motivate cancer survivors to make positive behavioural changes.

However health professionals appear to be reluctant to discuss the role of lifestyle factors in the onset or recurrence of disease. A national survey conducted among Canadian oncologists examined opinions towards recommending exercise to cancer patients (Jones et al., 2005). Although 43% said they tried to recommend exercise when appropriate, only 28% had done so in the last month. In another North American study, individuals with a history of cancer were asked if any health care professional had discussed lifestyle practices with them in the last year (Sabatino et al., 2007). Only 25% reported receiving advice on diet and 21% on exercise. In one of the few UK studies, a survey of oncologists and surgeons specialising in breast cancer examined whether exercise was routinely discussed with patients (Daley et al., 2008). Under half (44%)

said that they discussed exercise with their patients, and the response rate to the survey was only 14%, therefore this may be an optimistic estimate of the true picture.

One study has examined the association between receiving physical activity advice from a health professional and reported behaviour (Jones & Courneya, 2002). In a survey of 311 recently diagnosed prostate, breast, colorectal and lung cancer survivors, 28% recalled a oncologist initiated conversation encouraging exercise during cancer treatment. Those who recalled such advice reported doing more exercise during the course of treatment that those who did not. Another study examined the association between oncologists' lifestyle recommendations and a simple self-reported measure of behaviour change. Multiple health behaviours were considered including diet and exercise. The sample included 352 cancer survivors close to the point of diagnosis. Those who had received information about increasing fibre intake were five times more likely to report increasing fibre intake (OR 95% CI 5.48 2.91-10.33). A similar effect was found for exercise with those receiving a recommendation almost seven times more likely to report participating in more exercise since diagnosis (Blanchard et al., 2003).

These results are encouraging in suggesting that a simple recommendation from a health professional may result in improvements in health behaviours. However research to date suggests such recommendations are made infrequently. In addition, most research in this area focused on physical activity, with only one study examining the association between dietary advice and reported change, and no data available on the relationship between dietary advice and actual behaviour. Neither is there any evidence on the frequency with which reduction in alcohol consumption is discussed. Given that data from epidemiological studies suggest no safe level of alcohol consumption in relation to cancer risk, this is surprising.

As was seen in the previous chapter there is also evidence to suggest that cancer survivors who perceive health behaviours to be important in the cause of their cancer are more likely to change their health practices. This could present a mechanism by which health professional advice may lead to behaviour change. To my knowledge no published work as examined this association. Therefore the aims of this study were threefold; 1) to examine the frequency with which colorectal cancer (CRC) patients recall being given advice regarding health behaviours such as increasing F&V consumption, increasing physical activity and reducing alcohol consumption 2) to determine if recall of this advice is associated with reported change in behaviour or actual behaviour, and 3) to examine the association between recalled health professionals advice and perception of the role of health practices in the cause and recurrence of their cancer.

Methods

Data for this study was drawn from the questionnaire survey discussed in chapter 3. In order to determine the proportion of respondents recalling receipt of advice on lifestyle practices they were asked the following question: “at any time since your cancer diagnosis, did any health professional ever recommended any of the following”; stopping smoking, doing more exercise, reducing alcohol consumption, low fat diet, eating more F&V. If participants responded “yes” to any of these questions they were asked to give further details regarding what was discussed and with whom. Chapter 3 also describes the measures used to assess health behaviour practices and behaviour change. Continuous measures of physical activity (number of bouts of moderate/vigorous physical activity), F&V (number of portions per week) and alcohol (number of units per week) were used. Chapter 5 describes the measures used to examine perceived causes of cancer and recurrence. Continuous measure of perceived importance of cancer cause and recurrence were used in these analyses.

Statistical analysis

Participants were dichotomised into those who recalled receiving a recommendation to engage in each health behaviour vs. those who did not. Logistic regressions were run for each recommendation with age, sex, socio-economic status (SES), time since diagnosis, recurrence and current treatment as covariates. Simple T-tests were used to examine differences in levels of health behaviours between those who received advice vs. those who did not. The distribution of the physical activity and total alcohol intake variables were skewed, therefore analysis were repeated with non-parametric (Mann-Whitney) tests. Results of non-parametric tests are only presented if results differed from t-tests. Regression analysis were also run controlling for covariates of age, sex, SES, comorbidities, time since diagnosis, recurrence and current treatment (consistent with previous analysis). Bootstrapping with 2500 repetitions was used for analysis of physical activity and alcohol consumption due to their skewed distribution. Chi-square and logistic regression analysis were used to examine the relationship between recall of health professional recommendation (yes/no) and reported positive change in behaviour (positive change in behaviour vs. not) with the same covariates described as above. Checks were made to ensure there was no issue of multicollinearity. T-tests and regression analysis were also used to determine the association between health professional recommendations and perceived importance of that health behaviour in both the cause and recurrence of their cancer. Once again, covariates included as above. For all regression analysis unstandardised regression coefficients, 95% confidence intervals and p values are presented. For logistic regressions odds ratios and 95% confidence intervals are presented. For analysis of recurrence those who reported a cancer recurrence were excluded. STATA statistical software was used to analyse the data (STATA 11, 2009).

Results

Thirty percent (n = 132) of participants recalled receiving advice on physical activity, 35% (159) received advice on F&V consumption, and 19% (80) were advised to reduce alcohol intake. Table 6.1 presents logistic regressions examining predictors of health professional recommendations for each behaviour. Participants with more than one comorbidity were more likely to have received advice to increase physical activity than those with no reported comorbidities (35% vs. 23%, p = .014), and men were more likely to receive advice than women (33% vs. 25%; p = .012). Regarding advice to eat more F&V, men were more likely to have received advice than women (39% vs. 30%, p =.005), as were those not reporting a cancer recurrence (28% vs. 38%; p = .030). Finally, men were more likely to have received advice to reduce alcohol intake compared with women (23% vs. 12%, p = .003), as were those with some marker of social deprivation (24% vs. 13%, p = .002), and participants undergoing current treatment (25% vs. 18%; p = .038).

Table 6.1: Predictors of health professional recommendations

Increase physical activity (n = 387)	**OR (95% CI)**	**P**
Age	.988 (.963 -1.00)	.108
Sex (f=0, m = 1)	1.85 (1.15 – 3.00)	.012
SES (some deprivation = 1)	.789 (.505 -1.27)	.348
Comorbidities (yes = 1)	1.82 (1.13 - 2.93)	.014
Recurrence (yes = 1)	1.42 (.771 – 2.62)	.259
Time since diagnosis	1.01 (.862 – 1.18)	.924
Current treatment (yes = 1)	1.67 (.845 – 3.29)	.140
Increase F&V (n = 391)		
Age	.998 (.973 – 1.01)	.480
Sex (f=0, m = 1)	1.94 (1.23 – 3.08)	.005
SES (some deprivation = 1)	.712 (.457 – 1.11)	.135
Comorbidities (yes = 1)	.789 (.509 – 1.25)	.324
Recurrence (yes = 1)	.513 (.276 – .936)	.030
Time since diagnosis	1.07 (.923 – 1.24)	.374
Current treatment (yes = 1)	1.42 (.722 – 2.77)	.312
Reduce alcohol consumption (n = 372)		
Age	.987 (.957 – 1.01)	.982
Sex (f=0, m = 1)	2.55 (1.39 – 4.71)	.003
SES (some deprivation = 1)	2.45 (1.39 – 4.32)	.002
Comorbidities (yes = 1)	1.12 (.641 - .197)	.683
Recurrence (yes = 1)	.511 (.228 – 1.12)	.093
Time since diagnosis	.949 (.789 – 1.15)	.627
Current treatment (yes = 1)	2.29 (1.04 – 5.02)	.039

Relationship between advice and reported change in behaviour:

Table 6.2 presents chi-square and logistic regression analysis comparing reported change in behaviour with health professional recommendations. In the unadjusted analyses participants who had received a recommendation from a health professional to be more physical active were more likely to report an increase in physical activity since diagnosis. However after adjustment for age, sex, SES, comorbidities, time since diagnosis, recurrence and current treatment, this relationship was no longer significant. Those who received a recommendation to eat more F&V were almost twice as likely to report an increase in the amount consumed. No relationship was observed for advice on alcohol consumption but there was a relatively small number of respondents who reported an alcohol recommendation from a health professional, so this analysis was underpowered to detect an effect.

Relationship between advice and behaviour

T-tests and regression analysis examining the relationship between current health behaviour status and health professional recommendations found no associations for total physical activity, F&V consumption or alcohol intake (see Table 6.3).

Table 6.2: Association between health professional recommendation and reported change in behaviour

HP recommendation	Positive change in behaviour % (N)	Chi square	Odds ratio (95% CI) [a]	p
N = 382				
PA not recommended	6% (18)	χ^2 (1) 4.13. p = .042	1.00	
PA recommended	12% (15)		1.37 (.592 - 3.19)	.459
N = 390				
F&V not recommended	14% (41)	χ^2 (1) 5.81. p = .016	1.00	
F&V recommended	23% (37)		1.98 (1.13 – 3.46)	.017
N = 329				
Alcohol reduction recommend	45% (140)	χ^2 (1) 2.29. p = .130	1.00	.400
Alcohol reduction not recommended	56% (34)		1.30 (.705 – 2.40)	

[a] Adjusted for age sex, SES, comorbidities, time since diagnosis, recurrence, current treatment

Table 6.3: Association between recall of health professional advice and current behaviour

Health professional advice	**Behaviour (SD)**	**T-test**	**P**	**Regression coefficient (95% CI)[a]**	**p**
	Portions per day				
N = 376					
F&V advice	4.16 (2.4)	t (426) = -.109	.913	.073 (-.393 - .540)	.757
F&V no advice	4.14 (2.04)				
N = 373	Bouts per week				
Physical activity advice	2.42 (3.6)	t (422) = -.704	.482	.252 (-.493 - .996)	.508
Physical activity no advice	2.18 (3.1)				
N = 344	Units per week				
Alcohol advice	7.61 (10.3)	t (386) = -1.20	.232	-1.46 (-72.02 – 69.08)	.730
Alcohol no advice	6.30 (7.9)				

[a] Adjusted for age, sex, SES, comorbidities, time since diagnosis, recurrence, current treatment

Relationship between advice and perceived importance in cause and recurrence

Table 6.4 presents results from T-tests and regression analysis comparing level of perceived importance of each behaviour in the cause of their cancer (on a scale of 0-4) between those who did and did not receive a recommendation to change that behaviour. A recommendation to do more physical activity was associated with greater perceived importance of physical activity in the cause of cancer. A similar relationship was found for F&V consumption with results approaching significant in regression analysis. No such association was found for alcohol consumption.

The analysis conducted for perceived importance in cause of cancer was repeated for perceived importance in the recurrence of cancer. There were no significant associations between perceived importance of each health behaviour in the recurrence of cancer and health professional recommendation (see Table 6.5).

Table 6.4: Association between health professional recommendation and perceived importance in cause of their cancer

HP recommendation	Perceived importance in cause: Mean (SD)	T-test	p	Regression coefficient (95% CI)[a]	p
N = 328					
PA not recommended	.864 (1.21)	t (365) = -3.84	<.001	.562 (.248 - .875)	<.001
PA recommended	1.52 (1.49)				
N = 346					
F&V not recommended	3.04 (1.11)	t (418) = - 1.10	.272	.339 (-.006 - .684)	.054
F&V recommended	3.19 (1.12)				
N = 341					
Alcohol reduction not recommended	1.11 (1.32)	t (384) = -1.80	.074	.242 (-.148 - .631)	.223
Alcohol reduction recommended	1.43 (1.48)				

[a] Adjusted for age sex, SES, comorbidities, time since diagnosis, recurrence, current treatment

Table 6.5: Association between health professional recommendation and perceived importance in recurrence of their cancer

HP recommendation	Perceived importance in recurrence: Mean (SD)	T-test	p	Regression coefficient (95% CI)[a]	p
N = 363					
PA not recommended	2.93 (1.16)	t (410) = -1.35	.177	.089 (-.173 - .351)	.506
PA recommended	3.10 (1.19)				
N = 370					
F&V not recommended F&V	2.99 (1.11)	t (418) = -1.10	.272	.061 (-.183 - .304)	.625
recommended	3.12 (1.12)				
N = 351					
Alcohol reduction not recommended	2.83 (1.27)	t (396) = -1.27	.206	.181 (-.171 - .533)	.312
Alcohol reduction recommended	3.04 (1.23)				

[a] Adjusted for age sex, SES, comorbidities, time since diagnosis, current treatment

Discussion

These results suggest the number of participants who recall being given information or advice about health behaviours was comparatively low. Only 19% of respondents remembered discussions about alcohol consumption, 30% about physical activity and 35% about F&V intake.

In previous studies the proportion of cancer survivors reporting advice to increase physical activity ranged from 16% to 35% (Blanchard et al., 2003; Demark-Wahnefried et al., 2000; Sabatino et al., 2007). Interestingly a large US population-based study found CRC survivors were least likely to recall physical activity advice (16% vs. 22-26% among breast, prostate, cervical and uterine). The study with the greatest number of survivors reporting a physical activity recommendation (35%) was conducted in a mixed sample of breast and prostate cancer survivors (n=900). Sixty percent of this sample were participating in regular physical activity. This may suggest that such a recommendation had an impact on physical activity levels, or it may be that there is a healthy sample bias. Another explanation for the higher rates in the aforementioned study is that participants were recruited from a single Cancer Centre, which has been strongly associated with health behaviour research. Therefore health professionals there may be more engaged with the idea of health promotion.

Thirty five percent of the current sample recall being advised to increase F&V consumption at some point after their cancer diagnosis. This is slightly higher than that reported in most other studies with responses ranging from 16-25% (Blanchard et al., 2003; Demark-Wahnefried et al., 2000; Sabatino et al., 2007). The higher recall in the current study may be because F&V/fibre consumption has been implicated in the aetiology of CRC. However in a US study (Sabatino et al., 2007) CRC cancers were no more likely to recall dietary advice compared to breast, prostate, cervical or uterine cancers. However this item was not asking specifically about F&V or fibre, rather it asked; ‘within the prior year did a health care provider talk to you about your diet or eating habits’? Given that such advice could be delivered in the context of weight control, and higher weight has been implicated in the aetiology of many other cancers, this may explain why rates did not vary.

To my knowledge no other study has examined the extent to which cancer survivors are advised to reduce their alcohol consumption. Just 19% of respondents in this sample reported receipt of such advice. Given the low levels of heavy drinking in this study the low recall may be because health professionals did not think it was necessary.

Few studies have examined why there is reluctance to discuss lifestyle practices with cancer survivors. In a Canadian sample of oncologists, only 2% agreed that it would be easy for cancer patients to exercise during treatment (Jones et al., 2005). While it is not possible to extrapolate these findings to opinions about recommendations for cancer survivors at other points during the cancer experience, it is possible that oncologists are reluctant to provide advice as they do not believe patients would be capable of adhering to recommendations. This finding is echoed in a recent study of health care professionals in the UK (Miles et al., 2010). In this qualitative study of 23 cancer specialists, a common theme to emerge was a reluctance to provide advice on lifestyle change due to a lack of appropriate support for patients to make such changes. Another common reason was lack of clinic time.

Miles et al's (2010) study also indicated limitations in the health professionals' knowledge about prevention. There was scepticism and confusion concerning the behavioural literature, and risk factors well known to epidemiologists were not necessarily known or believed by health care professionals. Health professionals were also concerned about suggestions of blame or making patients feel guilty about their illness, particularly as it is not possible to determine one cause (behavioural or not) for a person's cancer. Such concerns may not be unfounded. As discussed in chapter 5, cancers survivors who attributed their cancer to controllable factors have been found to have greater depressive symptoms, intrusive thoughts, and recurrence worry (Costanzo et al., 2005).

Another aim of this study was to determine if advice from health professionals to modify behaviours was associated with either present behaviour or reported behaviour change. Results suggest that those who received advice to increase F&V intake were more likely to report a positive change in the amount of F&V consumed since diagnosis. A similar pattern was seen for change in physical activity behaviour;

however this was no longer significant after adjustment for covariates. Similar results were found in a mixed sample of US cancer survivors (Blanchard et al., 2003) with those reporting being advised to increase fibre consumption more likely to report a positive change in this behaviour. Comparable results were also found regarding exercise with recommendations associated with reported change in behaviour in univariate analysis but not after controlling for medical and demographic variables. Taken together these results indicate that a recommendation by a health professional to increase F&V consumption may be sufficiently powerful to result in change in that behaviour, but perhaps not for physical activity.

It is possible that other variables, such as age and comorbidities have a greater impact on the ability for survivors to increase physical activity. Contrary to this argument are results from an intervention showing a brief consultation to increase physical activity was sufficient to produce behaviour change (Jones et al., 2004). The lack of effect in this study may be due to the time since diagnosis. In Jones et al's study recommendations were given shortly after diagnosis. Health professional recommendations may have a greater power of persuasion at times closer to diagnosis. No data is available for the current study to suggest at what stage participants received advice. No other studies have explored this association.

However, no association was found between recommendations and actual behaviour for physical activity, F&V intake or alcohol consumption. This is in contrast to the results of the association with behaviour change. One explanation may be that those with prior lower levels of F&V consumption were more likely to get advice and they increased their consumption to levels comparable to the rest of the sample. It is also possible that reported behaviour change is a reflection of social desirability bias. No other studies have examined this relationship.

The final aim of this study was to examine the association between health professional recommendations and causal attributions of cancer onset and recurrence. No association was found between health professional recommendations and perceived importance for recurrence for any of the health behaviours. However recommendations to increase physical activity was associated with a greater perceived importance of physical activity in the cause of cancer. A borderline association was also found for perceived importance of F&V in the cause of cancer. There was no association for alcohol. This contrast in results across behaviours is interesting. It may be that survivors perceived their alcohol intake to be very low (as suggested by the prevalence data presented previously) and therefore unlikely to influence cancer occurrence, reducing any potential impact of health professionals' advice on attributions. Data from a qualitative study examining knowledge of cancer risk factors among a sample of healthy adults suggest a common perception that alcohol will only increase risk if you binge drink, or drink enough to feel drunk or unwell (Redeker et al., 2008).

Attributions of cancer onset to behaviour have been found to be associated with distress and depression (Costanzo et al., 2007). Therefore the suggested impact of health professional recommendations could be detrimental to cancer survivors. However there is also evidence from the previous chapter (and previous literature) to suggest that such causal attributions are associated with changes in behaviour. Additionally, such attributions were not found to be associated with distress if they were accompanied by behaviour change (Costanzo et al., 2007). These findings support the argument that health professional advice may be a useful catalyst for change, but this should be accompanied by support in making such changes.

In conclusion, these results suggest that relatively few cancer survivors recall recommendations to improve health behaviours. However such a recommendation may encourage survivors to improve their behaviours. It may also influence perceptions of cause of disease (or recurrence), which in study 4 was found to be associated with positive behaviour change.

There are a number of limitations to this study. As with the previous analyses, the cross-sectional design prohibits conclusions regarding direction of causation, in addition to the bias of self-reported health behaviour data (previously discussed). Also, it is not possible to be certain that health professionals were providing information in relation to respondents' cancer or to another comorbidity. Participants were given the opportunity to state who provided the advice they received and what was suggested. In general this item was poorly completed, however six respondents stated that such advice was given in relation to diabetes, cardiovascular health or cholesterol. Results on the proportion of participants receiving lifestyle recommendations may not be generalisable to the rest of the UK population. Consultant oncologists involved in the data collection for the present study had to agree to give their time to a survey interested in exploring lifestyle behaviours of cancer survivors (without incentive). It is therefore possible that they have a particular interest in the role of health behaviours and may be more likely to provide advice to their patients on the subject.

Chapter 7

Study 6: Perceived barriers and benefits to physical activity participation

Introduction

It is clear from results presented previously that few colorectal cancer (CRC) survivors are engaging in regular physical activity. Perceived benefits, defined as an ‘individual’s perception of the benefits that will accrue by engaging in a specific health action’ and perceived barriers; ‘a person's estimation of the level of challenge of social, personal, environmental, and economic obstacles to a specified behaviour or their desired goal status on that behaviour’ are cited by numerous social cognitive models of behaviour (e.g. the Health Belief Model, Theory of Planned Behaviour and Theory of Reasoned Action (Conner and Norman, 2005)) as important constructs in determining behaviour.

Understanding more about the specific perceived barriers to and benefits of physical activity for CRC survivors may help to design interventions that address the factors that inhibit physical activity participation and the salient beliefs about the benefits of this behaviour. For clarity, barriers and benefits to physical will be discussed separately.

Only two studies to date have explored perceived barriers to physical activity participation among CRC survivors. Lynch et al (2009) developed a measure of barriers to physical activity guided by an ecological model of health behaviour. This involved classifying barriers into three subscales: environment, social and personal domains. The 15 items that comprised the scale were drawn from studies with both general population and cancer survivor samples. The sample included 538 cancer survivors at 5 and 12 months post-diagnosis, who were asked to rate the extent to which each potential barrier ‘got in the way’ of their participation in physical activity. One strength of the study was its relatively large sample size. The fact that it did not ask respondents to recall barriers retrospectively (a feature of a lot of barrier research) was also an advantage. However restriction to predefined items may result in exclusion of important factors and it did not include many of the barriers identified in the only other study in this patient group (Courneya et al., 2005).

Acknowledging the limitation of using existing scales, Courneya et al (2005) assessed barriers to physical activity in a small (N=69) group of CRC survivors who were taking part in an intervention to increase physical activity. Participants were asked on a weekly basis to recall any barriers that prevented them from reaching their goals that week. Thirty six barriers were identified through the course of the study, although the generalisability of these results is questionable as participants were part of an intervention study and are therefore likely to be highly motivated. Both studies also examined only survivors who were within 12 months of treatment completion. Barriers to physical activity participation in the years following treatment completion may vary, as the acute effects of treatment subside. Qualitative data on a larger sample and over a longer time would add to the literature.

Currently few studies have examined the perceived benefits of physical activity in cancer survivors. The earliest research is this area involved Theory of Planned Behaviour (TPB) studies in CRC survivors who had recently completed cancer treatment. However the benefits elicited from these studies are likely to differ from the beliefs of survivors who are further on in the cancer experience. To my knowledge there are no data available among CRC survivors in the period after initial treatment completion. Therefore this study provides novel data that will help to understand CRC survivors’ motives to be active in the years following cancer treatment.

Methods

Data for this study were drawn from the questionnaire survey discussed in chapter 3. Chapter 3 also describes the measures used to assess physical activity. For this study physical activity was dichotomised into performing any (moderate of vigorous) physical activity vs. none.

Barriers and benefits to increasing physical activity were assessed with two open-response items; “what things would stop you from doing more physical activity?” and "what do you think you would gain from doing more physical activity". This item was developed specifically for this questionnaire.

Statistical analysis

Content analysis:

Content analysis (a form of thematic analysis) was used to analyse the responses (Joffe & Yardley, 2004). There are two methods of content analysis; deductive, where data is analysed for themes or codes drawn from existing research/theoretical ideas, and inductive, where themes are drawn from the data itself. Given the paucity of research in this area an inductive approach was used. Coding was exclusive (each coding unit can only be coded into one category), ensuring that clearly defined themes are identified and overlap between themes is minimised.

Content analysis has received criticism. It has been suggested that the method of numerically coding data can result in a 'realist view'. This has traditionally been associated with quantitative analysis which does not offer the same exploration of the personal perspective of the concept in question. However, unlike long transcripts from qualitative interviews brief bullet point responses given in this questionnaire survey lend themselves to a more quantitative approach.

Reponses to the open question were entered into SPSS. Numerical codes were then assigned to segments of text. In some cases respondents provided more than one barrier, and therefore each individual could be assigned several codes. For example, one respondent wrote '*feeling tired/unwell, cold weather, laziness';* in this case four codes were assigned. Codes were then grouped into themes, and themes into categories. A second researcher subsequently assigned themes to each coding unit in order to assess inter-rater reliability (Cohen's kappa (Landis and Koch, 1977)), which was found to be 0.77, p <.001 for barriers and 0.72, p <.001 for benefits.

Statistical analysis: As the aim of this study was to determine barriers and benefits to engaging in physical activity generally (and not meeting a certain level of activity), activity scores were dichotomised into any vs. no physical activity. Chi square and logistic regression was used to analyse the association between perceived barriers and benefits and physical activity. For continuity, the demographics/medical covariates included in the logistic regressions are the same as pervious analyses; age, sex, SES, comorbidities, time since diagnosis, currently receiving treatment, and recurrence. The analyses were run separately for each barrier/benefit category and to compare those who reported any barriers/benefit vs. those who reported none. Relationships with the barrier categories of bowel problems, poor condition or fear, and the benefit categories of protection from disease, hobbies/interests, appearance, and getting back to old self were not examined as numbers reporting these barriers were too small. Simple chi square tests were also run to explore the relationship between perceived barriers and an objective measure of that barrier where possible. This included examining the association between the perceived barrier of age and actual age, the barrier of comorbidities and self-reported comorbidities, and the perceived barrier of mobility and self-reported arthritis. For logistic regression analyses of these barriers, the objective variable was excluded as a covariate.

Results

Prevalence of perceived barriers

Table 7.1 presents the themes and categories that were defined and shows how often each category occurred (see appendix 6 for complete table include all coding units). The most commonly reported barriers related to cancer and its treatment, with 130 comments coded into this category. Ageing was the second most frequently mentioned barrier, with comorbidities and general barriers also commonly cited.

Table 7.1: Perceived barriers to physical activity

Categories **N = 379** ***Missing* = 100**	**N (%) of coding units in category**	**Themes**	**N**
Comorbidities	72 (18%)	COPD/breathlessness	36
		CVD/'heart condition'	11
		Other health problems (e.g. diabetes)	25
Mobility	43 (11%)	Arthritis	20
		Joint replacement (hip/knee)	6
		Lack of mobility	15
		Poor balance	2
Ageing	90 (24%)	Aches and pains	49
		Age	41
Treatment effects	127 (34%)	Tiredness/fatigue	50
		Cancer treatment	7
		Colostomy/illeostomy bag	17
		Hernia	14
		Nausea	2
		Neuropathy	6
		Feeling unwell	15
		Surgery	14
		Effects of radiation	2

	N (%) of coding units in category	**Themes**	**N**
Other commitments	48 (13%)	Family commitments	14
		Social commitments	7
		Work commitments	27
Bowel function	9 (2%)	Bowel problems	9
Fear	2 (0.5%)	Fear of infection	1
		Fear of falling	1
Poor conditioning	5 (1%)	Being overweight	2
		Poor fitness	3
General barriers	63 (17%)	Cost	2
		Inconvenience	1
		Lack of support	5
		Lack of time	31
		Bad weather	24
Lack of motivation	22 (6%)	No motivation	22

Association between perceived barriers and objective measures

Table 7.2 presents chi-square analysis comparing those who reported perceived barriers of age, comorbidities or mobility and an objective measure of this barrier. In all cases those who reported each barrier were more likely to have a corresponding objective measure of that barrier, i.e. those who reported a perceived barrier of age were more likely to be older (>65 years).

Table 7.2: Association between perceived barrier and objective measure of this barrier

Objective measure of barrier	Perceived Barrier % (n)	Chi-square
	Age	
≤ 65 years	10 (18)	χ^2 (1) = 14.71 p <.001
> 65 years	24 (68)	
	Comorbidities	
No comorbidities	6 (11)	χ^2 (1) = 20.80 p <.001
≥ 1 comorbidity	20 (55)	
	Mobility	
No arthritis	3 (11)	χ^2 (1) = 87.56 p <.001
Arthritis	34 (30)	

Association between perceived barrier to physical activity and actual behaviour

Logistics regressions were run to determine if there was an association between physical activity and each barrier category (Table 7.3). Those who reported any barrier were less likely to be active compared to those who reported no barriers. Those who perceived barriers of age and mobility were less likely to be active (p = .012 and .031 respectively). There were no significant associations for any other barriers.

Table 7.3: Association between physical activity and barrier categories

	Active (% n)	Chi square	OR (95% CI)	p
Age barrier				
No	52% (182)	χ^2 (1) = 8.99 p = .003	1.00 [a]	.012
Yes	33% (26)		.481 (.271 - .853)	
Comorbidities barrier				
No	50% (187)	χ^2 (1) = 4.31 p = .003	1.00 [b]	.575
Yes	36% (21)		.826 (.424 – 1.61)	
Mobility barrier				
No	51% (200)	χ^2 (1) = 12.25 p <.001	1.00 [b]	.031
Yes	21% (38)		.367 (.147 – .914)	
Cancer treatment barrier				
No	49% (162)	χ^2 (1) = .842 p .359	1.00 [c]	.240
Yes	44% (46)		.727 (.427 – 1.24)	
General barrier				
No	46% (172)	χ^2 (1) = 7.56 p .006	1.00 [c]	.210
Yes	66% (36)		1.53 (.788 – 2.97)	
Commitments barrier				
No	47% (188)	χ^2 (1) = 1.69 p .194	1.00 [c]	.472
Yes	56% (20)		.732 (.312 – 1.72)	
Any barriers				
No	62% (54)	χ^2 (1) = 8.45 p .004	1.00 [c]	.002
Yes	45% (154)		.390 (.218 – .698)	

[a] Adjusted sex, SES, comorbidities, time since diagnosis, recurrence, current treatment

[b] Adjusted age sex, SES, time since diagnosis, recurrence, current treatment

[c] Adjusted age, sex, SES, comorbidities, time since diagnosis, recurrence, current treatment

Prevalence of perceived benefits of physical activity:

Table 7.4 presents the themes and categories that were defined and shows how often each category occurred (see appendix 7 for complete table include all coding units). The most commonly reported perceived benefits were related to physiological changes with 223 comments coded into this category. Maintaining a healthy weight/loosing weight was the second most frequently mentioned benefit with improvements in feelings of wellbeing and psychological benefits also cited 47 and 32 times respectively. Interestingly, only 2% of the sample (N=8) made reference to the potential for physical activity to contribute to disease prevention, and more specifically its role in cancer prevention.

Table 7.4 Perceived benefits to engaging in physical activity.

Categories N = 291 *Missing* = 188	**N (%) of coding units in category**	**Themes**	**N**
Physiological benefits	223 (77%)	Improves bowel function	2
		Improves breathing	8
		Improves cardiovascular system	13
		Improve health	53
		Ease of ADL	5
		Improve sleep	3
		More energy/less tiredness	21
		Improve mobility	8
		Improve fitness	84
		Increase strength	26
Protection from disease	8 (3%)	Increase lifespan	2
		Reduce chance of cancer recurrence	2
		Ward off cancer	1
		Resistance to disease	3
Wellbeing	47 (16%)	Improve wellbeing	47
Hobbies/interest	19 (7%)	Get out of the house	5
		Socialising	2
		Relieves boredom	1
		Enjoyable	8
		Increase independence	2
		Provides an interest	1
Weight	78 (27%)	Maintain a healthy weight	10
		Lose weight	68

Appearance	7(2%)	Better figure/appearance	7
Get back to old self	2 (0.5%)	Get back to “old self”	2
Psychological/cognitive benefits	32 (11%)	Positive attitude	1
		Peace of mind	2
		Feel positive	1
		Self-satisfaction	2
		More alert	6
		Improves concentration	1
		Increases confidence	6
		Able to cope with more	1
		Reduce risk of depression	1
		Inner strength	1
		New outlook on life	1
		Relaxation	3
		Self-respect	1
		Decrease stress	5

Association between perceived benefits of physical activity and actual behaviour

Logistics regressions were run to determine if there was an association between physical activity and each benefit category (Table 7.5). After adjusting for covariates there were no associations between benefits and physical activity.

Table 7.5: Association between physical activity and perceived benefits

	Active (vs. no activity)	Chi square	OR (95% CI) [a]	p
No physiological benefits	52% (109)	χ^2 (1) = 9.52 p = .002	1.00	.432
Physiological benefits	48% (99)		1.21 (.756-1.92)	
No wellbeing benefits	47% (184)	χ^2 (1) = .803 p = .370	1.00	.798
Wellbeing benefits	55% (22)		1.11 (.510 – 2.40)	
No weight benefits	48% (175)	χ^2 (1) = .005 p .945	1.00	.533
Weight benefits	49% (33)		.824 (.449 – 1.51)	
No psychological benefit	48% (196)	χ^2 (1) = .000 p .998	1.00	.237
Psychological benefits	48% (12)		.580 (.219 – 1.54)	
No reported benefits	41% (70)	χ^2 (1) = 5.46 p .019	1.00	.741
Any report benefits	53% (138)		.921 (.567 – 1.50)	

[a] Adjusted age, sex, SES, comorbidities, time since diagnosis, recurrence, current treatment

Discussion

Barriers to physical activity

Data from this survey show that the most commonly reported perceived barriers to physical activity relate to cancer and its effects, most notably tiredness/fatigue and issues associated with colostomy/illeostomy bags. Ageing and aches and pains were the next most commonly reported barrier, followed by comorbidities such as heart and/or breathing difficulties. General barriers such as lack of time and bad weather also featured frequently. However, only the perceived barriers of age and mobility were associated with less participation in physical activity.

The association between the barrier of age and physical activity is not surprising given that age is negatively associated with activity in this sample and population-based surveys consistently report lower levels of physical activity among the older age groups. The association with perceived mobility restrictions is also intuitive; people suffering pain or limitations during movement being less likely to be active.

Ancillary analyses were conducted in order to try and unravel what aspects of ageing results in lower levels of physical activity. Even after controlling for covariates of comorbidities and mobility restrictions (such as arthritis), and measures of physical function (i.e. physical function QoL score), age had an independent negative association with activity. This suggests that older people feel less able to exercise, even in the absence of quantifiable physiological restrictions. It may be that this survey did not capture other aspects of ageing that might limit activity, or it could be that older people simply feel that being physically active is not feasible.

The barrier of age is reflected in the intervention literature in cancer survivors. A lifestyle intervention in older cancer survivors revealed that physical activity can slow decline in physical function (Morey et al., 2009), but this trial had huge problems with recruitment. Some 20,015 invitations were sent, with just 2156 expressing interest in the study (11%).

There is a sparse evidence base from which to compare the findings of this study. Some of the earliest work examined perceived barriers in the context of perceived behavioural control in studies examining the utility of the TPB in engagement in physical activity. The first such research included an elicitation study to determine the most salient control beliefs (barriers) in this population (Courneya & Friedenreich, 1997a). A subsample of the 110 participants were asked to recall factors that prevented them from exercising during their cancer treatment. The most commonly reported barriers were nausea, fatigue, lack of time, lack of support, pain and no counselling for exercise. There is some match here with the present findings with fatigue, lack of time and pain commonly cited. However lack of support and counselling were infrequently mentioned in the present study. It is important to note however that only 24 individuals were included in this study and participants were an average of 26 months post-diagnosis and were asked to recall retrospectively factors that inhibited them from being active during their treatment.

Three studies have used the questionnaire generated from Courneya and Friedenrich’s (1997) to examine predictors of exercise behaviour in cancer survivors and reported associations between control beliefs outlined above and behaviour. All asked about exercise behaviour during the treatment period. Two were retrospective and examined breast and CRC survivors (Courneya & Friedenreich, 1999b; Courneya et al., 2001). Only the barrier of time was found to be consistently correlated with exercise behaviour, and the barrier of lack of support was also associated with behaviour in the breast cancer sample. Conversely, in a prospective study of CRC survivors all but the barrier of time were correlated with exercise behaviour (Courneya et al., 1999). This is a more methodologically vigorous study and so may be a more accurate reflection, but replication of these findings is necessary. These results are in contrast to the present study which only found an association between age and mobility, factors not endorsed as barriers in the previous TPB literature. However the fact that previous studies have focused on exercise in the treatment period is an important distinction and means results are not directly comparable.

To my knowledge only two other studies have examined perceived barriers to physical activity among CRC survivors. One asked participants in an intervention study to state what factors prevented them from reaching their activity goals during the study (Courneya et al., 2005). The three most commonly reported barriers were lack of time, non-specific side effects of treatment, and fatigue. This is similar to the pattern seen in the present study. It is difficult to compare the category of non-specific side effects to the current data as examples are not given as to the type of comment included in this category. However the sample were within 3 months of surgery and it is likely that these factors differ from the ‘cancer and its treatment’ category describe here where participants are up to 5 years post-diagnosis and the most acute effects have likely subsided. It is also worth noting that one of the most frequently mentioned barriers of age was once again not cited in Courneya’s study. This may be due to differences in the characteristics of the sample and participants were taking part in an activity intervention for which the response rate was only 35%. Therefore those who believed they were “too old for exercise” may have chosen not to take part in the intervention. This is supported by the fact that 40% of the sample was under 60 years old. The difference in settings is an important distinction, as those involved in an intervention study are, by definition, motivated to increase their physical activity. The authors argue however that this is more likely to result in respondents providing real barriers to physical activity as opposed to excuses.

The only other published data on perceived barriers to physical activity in CRC survivors surveyed participants at 5 and 12 months post-diagnosis (Lynch et al., 2009). Participants were asked to report the extent to which a pre-defined list of barriers prohibited them from being physical active. Barriers were split into four categories; physical environment, social environment, personal attributes and disease-specific barriers. The disease specific barriers consisted on 3 items; difficulties with fatigue, not feeling well enough and incontinence/diarrhoea. At both time-points disease-specific barriers were the most frequently reported with fatigue endorsed by 40% of the sample, again, similar to the results of the present study. At five months those reporting physical, and social environment, and disease-specific barriers were less likely to be physically active. However at 12 months only disease-specific barriers were associated with activity and the association was positive with those reporting this barrier being *more* likely to be active. These results suggest a trend for barriers having less association with behaviour as time since diagnosis increases. This supports the lack of association found in the present study between treatment effects and behaviour in which participants were on average 2.4 years post-diagnosis. It could be that these barriers reported at a time closer to diagnosis present real obstacles to engaging in physical activity as the effects of disease and its treatment are acute. As survivors recover these barriers may be more reflective of excuses. However it is important to note that a lack statistical power in the present study meant that relationships may not have been detected. No other data is available in CRC survivors across the time period examined in this study.

Finally a study using data from the Health Survey for England, while not examining barriers to activity in cancer survivors, did examine this construct in a sample of older (60-69 years) adults (Chaudhry & Shelton, 2010). A number of similar barriers were recalled; these included lack of time and poor health. However the authors report that being employed (and therefore presumably having more leisure time in which to exercise) was in fact inversely associated with level of physical activity. This supports findings from the current study that reported barriers do not always present real obstacles to physical activity participation.

Conclusion

Results from the present study and the existing literature suggest that side effects of treatment are commonly cited as barriers to physical activity. However after the initial treatment phase this barrier does not appear to be associated with behaviour. On the whole, reported barriers show little association with actual behaviour, with the exception of age and mobility which are associated with participation in less physical activity; unfortunately these factors are not modifiable.

The current evidence is limited by small sample sizes and methodological and sample heterogeneity. The use of both retrospective and prospective studies, pre-defined surveys of barriers vs. open questions/qualitative format, and focus on both the treatment and post-treatment time periods makes comparison across studies difficult. In addition, few studies have examined a direct relationship between perceived barriers and physical activity. This study overcame a number of the short comings of previous work, avoiding retrospective recall, allowing respondents to report any barrier they deemed to be of importance and examining the association between perceived barriers and activity. However the study also has limitations. No data was collected regarding the frequency or intensity of the barriers reported. It has been argued that such information is required in order to weight a barrier so that both perceived strength and frequency of a barrier can be accounted for when trying to explain its impact on behaviour (Brawley, 1998). Also the method of data collection was such that reported barriers could not be explored in more detail. It would have been useful for example to ask those who reported age as a barrier to state precisely what it is about age that is restricting. Development of a well tested measure of barriers through extensive qualitative investigations is required. Testing this questionnaire among large samples of cancer survivors, gathering frequency and intensity information for each barrier, and examining the association with activity may provide greater insight into this area.

Benefits of physical activity

Of those who completed this item, the majority (77%) of respondents cited a benefit coded into the physiological category with the most common themes being improved health and improved fitness. Weight loss benefits were mentioned by 21% of respondents and psychological/cognitive benefits by 10%. Interestingly, only eight participants cited protection from disease, and just three suggested that physical activity may reduce the chance of cancer recurrence/occurrence. Sixty one percent of respondents made reference to at least one benefit, suggesting a generally positive perception of physical activity. However, none of the perceived benefits were associated with level of physical activity.

There are no published studies that examine perceived benefits to physical activity in CRC survivors although some studies that have used the TPB to predict exercise behaviour use measures of perceived benefits. The earliest TPB study in CRC survivors was conducted by Courneya & Friedenrich (1997a). As was the case for control beliefs, an elicitation study was conducted to determine the most salient behavioural beliefs. The most salient behavioural beliefs were: 1) take my mind off cancer and my treatment, 2) feel better and improve my wellbeing, 3) maintain a normal lifestyle, 4) cope with the stress of cancer and its treatment, 5) gain control over cancer and my life, 6) recover from surgery and treatment, and 7) control my weight. These beliefs vary considerably from those reported in the present study, most likely due to the fact that participants in the TPB study were asked to recall potential benefits of exercise during the treatment period, as opposed to during recovery. All but ‘get my mind off cancer’ and ‘control my weight’ were positively correlated with behaviour, however behavioural beliefs were not direct determinants of exercise behaviour. This suggests that holding positive beliefs about the benefits of physical activity alone is not sufficient in determining positive behaviour; this supports the null results in the present study.

A prospective study was subsequently conducted by the same research group (Courneya et al., 1999). Participants were recruited post-surgery and their physical activity monitored for four months (i.e. during or immediately after treatment). The authors noted that behavioural beliefs correlated with attitude but did not independently explain variance in intention or physical activity behaviour. They concluded that further research is required to identify more salient behavioural beliefs. It may however be that positive beliefs are not an important precursor for physical activity; perhaps because most people view physical activity as a good thing.

There is some evidence among breast cancer populations in post-treatment periods. In a study of 289 breast cancer patients (~25 months post-diagnosis) participants were asked to report on perceived benefits of physical activity throughout the cancer experience (Milne et al., 2007). The key themes to emerge were improvements in wellbeing, restoring a sense of normality, providing a feeling of control, and being a social activity. Only wellbeing overlapped with the present study. Associations with activity behaviour were not explored.

In a qualitative study, breast cancer survivors (1-5 years post-diagnosis) were asked to report on motivators and benefits for physical activity (Whitehead & Lavelle, 2009). Reported motivators for physical activity were categorised into four main themes: health (eg. physical activity does you good and fights the ageing process), weight loss and body image, a desire to carry on as normal, and enjoyment. Reported benefits were comparable with the key themes being improvement in wellbeing and energy levels, weight management, helping to carry out daily activities, and get out of the house and socialise. There is overlap with key benefits reported in the present study although activity as a means of socialising was mentioned by only a small number of respondents. Comparing qualitative interviews with a written open format is also difficult. In an interview study it is possible to prompt respondents to expand on what they meant, but in written format that isn’t possible.

Finally, one study used the TPB to examine motivational determinants to physical activity in a large (n = 354) sample of endometrial cancer survivors who were between one and ten years post-diagnosis (Karvinen et al., 2007a). The authors conducted an elicitation study in order to determine behavioural beliefs. No details were provided as to how this data was analysed, but 36% of respondents cited ‘lose weight’, 28% stated that physical activity made them ‘feel better about self’, and 26% that it helped them to ‘keep in shape’. As in the present study, the benefits of improvements in breathing, mental health and muscular strength were also reported.

Conclusion

In conclusion, the present study suggests that the perceived benefits to physical activity reported by cancer survivors tended to focus on general health, wellbeing and weight.

There was little mention of cancer specific themes. This is likely to be due to the fact that research in this area is relatively new and patients may not be routinely told about the possible benefits of engaging in regular physical activity after treatment (as was seen in chapter 6). Perceived benefits were not found to be associated with behaviour. Little data is available among this cancer site with the majority of research focusing on breast cancer survivors. Comparisons with other studies, which have been carried out with breast cancer survivors several years post-diagnosis, suggests some overlap with regard to beliefs on physiological benefits, but breast cancer samples also tended to cite ‘feeling normal’ and ‘social interaction’. This might be a gender effect or could be specific to breast cancer. As with the literature on perceived barriers, comparisons are difficult due to variations in study design and methodologies of analysis. Only studies using the TPB examined the association between behavioural beliefs and exercise levels. These studies concluded that such beliefs explain little of the variance in exercise behaviour. This may be due to the use of inappropriate items in the scales, or it could be because factors other than beliefs/attitudes have a larger effect on behaviour. This argument is supported by the lack of association found in the present study. More research in this area is warranted but it is likely that without knowledge of specific benefits to cancer outcomes, cancer survivors are not likely to see any more reason to be active than the general population.

Chapter 8

Pilot study for a multiple behaviour change intervention in colorectal cancer survivors

Introduction

The results presented in chapter 4 show that engagement in multiple healthy behaviours is associated with higher levels of quality of life (QoL) in colorectal cancer (CRC) survivors, and these findings are supported elsewhere in the literature. In addition the case for engagement in multiple health behaviours in relation to prevention of cancer and other chronic disease has already been discussed (see chapter 1). Given that the prevalence of healthful behaviours among CRC survivors in the UK population (presented in chapter 3) is low, particularly for physical activity and F&V consumption, there is a need to establish effective and acceptable interventions for behaviour change.

Multiple behaviour change interventions in cancer survivors

Seven studies have been published with the primary aim of achieving multiple behaviour change in adult cancer survivors (Anderson et al., 2010; Bloom et al., 2008; Demark-Wahnefried et al., 2003a; Demark-Wahnefried et al., 2003b; Hawkes et al., 2009; Snyder et al., 2008; von Gruenigen et al., 2008). They vary in terms of the methodological quality, cancer site being studied, time since diagnosis, intervention modalities used (telephone / face to face / group-based studies), duration of intervention, length of follow up, sample size, and specific behaviours that are targeted. Five of these studies were RCTs with either waiting list or attention control groups (Bloom J et al., 2008; Demark-Wahnefried et al., 2003b; Demark-Wahnefried et al., 2003a; Morey et al., 2009a; Snyder et al., 2008). The remaining studies were smaller feasibility trails that did not include control groups (Anderson et al., 2009; Hawkes et al., 2009).

Of the five RCTs, three focused on cancer survivors who were within five years of cancer diagnosis. Both Project LEAD (Demark-Wahnefried et al., 2003b) and FRESH START (Demark-Wahnefried et al., 2003a) included breast and prostate cancer survivors, with the former recruiting only older (>65 years) survivors. The other trial was in obese endometrial cancer survivors (von Gruenigen et al., 2008). The two other RCTs recruited long-term (> 5 years post-diagnosis) cancer survivors. The Reach out to ENhance Wellness (RENEW) trial was a study of 641 older, overweight, breast, prostate and CRC survivors (Snyder et al., 2009) and Bloom et al (2008) recruited a sample of 404 breast cancer survivors. All studies aimed to increase physical activity and make some sort of dietary change (e.g. increase F&V, reduce fat or improve diet quality). Intervention modalities varied across studies. Most used a distance-based approach, with written materials, telephone counselling or a combination of the two, although the study conducted exclusively among breast cancer survivors used group workshops (Bloom et al., 2008). Duration of the intervention varied from 3 months to one year with follow-ups typically conducted on completion of the intervention and two conducted a second follow-up several months later (Von Gruenigen et al., 2008; Demark-Wahnefried et al., 2003a).

FRESH START was a 10 month trial in which participants in the intervention arm were mailed personalised newsletters and workbooks and those in the control arm sent a series of non-tailored health brochures (Demark-Wahnefried et al., 2003a). Behavioural aims were to progress towards 30 minutes of physical activity five times a week, increase F&V consumption to ≥ 5 servings a day and reduced fat intake to ≤ 30% of total calories. Changes were seen in both groups, although improvements were significantly higher among the intervention group receiving tailored materials. Physical activity increased by 60 minutes a week (the biggest increase in physical activity amongst all intervention studies). There was also an increase in consumption of F&V (average 1 portion per day) and a reduction of percentage of calories from fat from 38 to 33% (Demark-Wahnefried et al., 2007). The other study to achieve change in diet and physical activity was the RENEW trial (Morey et al., 2009). This one year trial used a waiting list control. Participants in the intervention group received personalised workbooks of exercise and diet information, comparing current behaviours with population recommendations. They also received bi-weekly telephone counselling sessions for the first three weeks and monthly consultations there after. At the twelve month follow-up significant improvements were seen in the intervention group compared to controls for all targeted behaviours. Duration of endurance exercise increased by 36 mins.wk to 61mins.wk (p =.004), frequency of aerobic exercise increased from 1.6 to 3.2 sessions a week (p =.005), duration of strength training increased to 26mins.wk and frequency of 2 sessions a week (p's <.001), servings of F&V increased by 1.24 a week to 4.9 (p<.001), and fat consumption decreased by 3g a day (p <.002).

Despite some encouraging changes in behaviour, the proportion of individuals meeting the recommended guidelines by the end of the intervention was still small. Only 25% of the intervention group in FRESH START met two or more of the behaviour goals set (moderate activity ≥ 30 mins 5 times a week, consuming ≥ 5 servings of F&V a day, <30% of calories derived from fat). Even lower rates were reported in the RENEW trial with just 15% engaging in sufficient moderate physical activity, 16% eating enough F&V and 49% adhering to a low fat diet.

Of the three other RCTs which targeted multiple behaviour change two reported an increase in physical activity but no change in diet (Bloom et al., 2008; Von Gruenigen et al., 2008), and one (Project LEAD) found improvement in diet quality at the six months follow up, but no greater change in physical activity, and no greater change in either behaviour at 12 months follow-up compared to controls (Demark-Wahnefried et al., 2005b).

Two smaller studies were designed to determine feasibility rather than efficacy; but did present data on behavioural outcomes. Hawkes et al (2009) delivered a six week 'psychosocial and lifestyle' intervention in CRC survivors. The intervention involved weekly telephone consultations. The data presented on physical activity are difficult to interpret. The authors reported that fewer participants were classified as insufficiently active, but there was also a decrease in the number classified as sufficiently active. However there was an increase of approximately one portion of F&V a day and a reduction in weekly red meat intake. Anderson et al (2009) targeted overweight CRC survivors within one year of diagnosis. The response rate was good (71%), but there were negligible increases in physical activity at follow-up, although consumption of saturated fat reduced and an overall weight loss of 1.2 kg was reported.

An important question to pose is why some interventions were more successful than others in changing behaviour. The FRESH START trial produced the greatest increase in physical activity and was one of only two to change both physical activity and diet. Its success is unlikely to be related to intervention intensity (i.e. number of contacts with participants) as the programme involved receipt of only seven newsletters at 6-week intervals; fewer contacts than less successful interventions. Nor was it the longest in duration, at 10 months compared with 12 months in the RENEW trial. One explanation may lie in the characteristics of the sample. Participants were among the youngest (mean age 57 years) of all the studies. Studies involving older samples reported only small change in physical activity (RENEW), or no change at all (Project LEAD) and only modest change in diet. Participants in the FRESH START trial were also recruited at the most proximal time point to diagnosis (< 9 months post-diagnosis), when motivation to make changes is likely to be high. In addition only 27% of the sample received chemotherapy and consequently participants may have been suffering less adverse treatment-related affects than in other samples. Unfortunately other studies did not present this data in order to make comparisons. There are also several factors that suggest this was a highly motivated sample. The attention control arm reported improvements in all these health behaviours despite receiving non-tailored health-promotion print materials. The trial also had the lowest attrition rate (at just 4%), and one of the highest initial response rates (42%). This contrasts with the RENEW trial, which achieved an uptake rate of just 11%. It is also possible that the more successful interventions included participants who had less severe disease.

It is also possible that, despite a general consistency in the literature for interventions to included tailored written materials and/or telephone consultations, variation in the specific components of the intervention may have influenced the success of the study. Four out of the five RCTs reported using Social Cognitive Theory (SCT) as the conceptual framework for the intervention but the specific components/behaviour change techniques documented in each of the studies varied (see table 8.1).

Table 8.1. Behaviour change techniques employed in SCT intervention.

FRESH START (Demark-Wahnefried et al., 2003a)	**Project LEAD (Demark-Wahnefried et al., 2003b)**	**RENEW (Snyder et al., 2009)**	**Von Gruenigen et al., (2008)**
Set incremental goals	Set achievable goals	Set incremental goals	Goal setting
Feedback comparing behaviour with goal	Provide positive reinforcement	Provide reinforcement upon attainment of goals	Feedback
Log books to monitor behaviour	Monitor progress	Monitor progress	
Behavioural cues (pedometers, fat gram counters etc)		Behavioural cues (pedometers etc)	Behavioural cues (pedometer)
Guidance on overcoming barriers		Strategies to overcome barriers	Behaviour modification
Information on benefits of behaviour			

Only the FRESH START trial reported provision of information about the benefits of healthful behaviours, and only FRESH START and RENEW mentioned overcoming barriers to behaviour change. Three of the four mentioned self-monitoring, and all reported inclusion of goal setting and provision of reinforcement or feedback. However, despite some consistency in the components described there are subtle but important variations in what the technique entailed. For example, both FRESH START and RENEW stated that ‘incremental goals’ were set, dependent on baseline behaviour. This resulted in staged progress towards the ultimate behaviour goal. The other two studies simply state that ‘achievable’ goals were set, or simply ‘goal setting was used’. This provides the reader with little information on the exact nature of this technique. Similarly, FRESH START and RENEW provided information on the nature of the reinforcement or feedback provided, namely ‘feedback in which the participant’s behaviour is compared with the goal behaviour’ and ‘provide reinforcement upon attainment of behavioural goals’. This is different to Project LEAD which simply states ‘positive reinforcement’ was used. Also, von Gruenigen et al (2008) reported ‘behaviour modification’ were used, an ambiguous statement that gives no clue as to what strategies were involved. It appears that the most successful trials (i.e. RENEW and FRESH START) also provided the most comprehensive and clear details of the intervention. This may be a reflection of a more rigorous approach to the delivery of the intervention with a consistent use of well defined techniques.

The existing literature addressing multiple behaviour change interventions in cancer survivors is limited. People included in the studies tended to be high SES, white, and female with an over representation of breast cancer survivors. Only two studies provided comprehensive documentation of intervention components and behaviour change techniques. There was also almost no data on fidelity. Subsequently it is not known if those interventions that failed to affect behaviour did so as a result of intervention ineffectiveness, or because compliance with the intervention was inadequate.

In conclusion, the evidence base is too small to draw any definitive conclusions of the efficacy of multiple behaviour change. However results from two well conducted and documented trials are promising and it appears that tailored materials are better than standardised ones (as shown by FRESH START), and that interventions with telephone counselling show promise (Morey et al., 2009). Recruitment rates were also higher among those most proximal to diagnosis. More studies are clearly required to enhance our understanding of achieving successful multiple behaviour change in this population. It is important that these studies are clearly described in order to allow for a greater understanding of what components make a successful intervention. Data on fidelity should also be reported.

Multiple behaviour change interventions in colorectal cancer survivors

Only three of the multiple behaviour change studies have included CRC survivors. The RENEW trial (Snyder et al., 2009) included CRC survivors in a mixed sample (including breast and prostate). However recruitment was limited to older, overweight, long term survivors. The CanChange feasibility study was conducted exclusively in CRC survivors (Hawkes et al., 2009). However the small sample (n = 20) combined patients who were still undergoing treatment and who had completed treatment. There is evidence for variation in outcomes following physical activity interventions with a greater impact among those who have completed cancer treatment (see chapter 1). Therefore it is possible that cancer survivors at difference stages of the cancer experience will respond differently to behaviour change interventions, and combining the two groups could mask problems or effectiveness. This study was not designed to exclusively target health behaviours, and also included components of 'moving on after cancer, relaxation training, and coping with symptoms'. With such a short duration (six weeks) an ambitious number of factors were covered and with no reported improvements in heath behaviours.

Finally, a research group in Scotland conducted an intervention study in overweight CRC survivors with the aim of establishing the feasibility and acceptability of a 3-month personally tailored lifestyle intervention study in survivors who had recently completed treatment (Anderson et al., 2009). This was a well designed study and reported favourable results for recruitment, compliance and retention. However the intervention was restricted to overweight survivors and health behaviour change advice was directed specifically towards achieving weight loss. The intervention involved three personal visits to participants' homes, which overcomes the frequently reported barriers to participation in intervention studies of travel and time, but requires a substantial investment of time and resources which is unlikely to be feasible in a large sample or be conducive to translation into clinical practice.

Intervention timing

There is no consensus on the optimal time at which to promote behaviour change in cancer survivors (Rabin, 2009). The diagnosis of cancer has been described as a 'teachable moment'(Demark-Wahnefried et al., 2005a), a point at which many may evaluate their lifestyle and become motivated and interested in behaviour change. However promoting such behaviour change at the point of diagnosis may not be appropriate. Receiving a cancer diagnosis is a very stressful event and likely to result in adverse psychosocial responses. Treatment received also often results in adverse physiological side effects, both of which are likely to affect a person's motivation and ability to make healthful behaviour change. However it is possible that motivation to make such changes is high soon after treatment completion.

Following treatment, survivors interact with their medical team much less frequently, and while it is likely patients will be relieved that they have finished treatment, this transition from “patient” to “survivor” has been highlighted as a potential time of crisis. In a qualitative study, Arnold et al (1999) explored the psychosocial issues associated with completion of adjuvant cancer treatment. Fear of recurrence and a perception of reduced support were common themes. In a more recent study participants reported a feeling of being “pushed out” by the health care system and “losing control”; a need for information on “how to look after yourself” was also commonly expressed (Jefford et al., 2008). This supports data that consistently shows a preference for engaging in behaviour change immediately or soon after treatment. In a recent review of physical activity interventions more than 50% of respondents reported this preference. In addition, data from the questionnaire study conducted as part of this thesis, found that the vast majority (70%, n = 234) of participants would ‘definitely’ or ‘probably’ be interested in receiving lifestyle advice to improve health behaviours, with 48% preferring to receive such information within 6 months of treatment completion (with a further 36% stating ‘anytime’). It is possible that this preference is the result of a perception that engagement in such behaviour change may help restore some sense of control. Therefore CRC survivors who were within 6 months of treatment completion were recruited for this study.

As outlined in the opening chapter of this thesis, the National Cancer Survivorship Initiative has called for a cultural shift in cancer care, with a greater focus on recovery, health and well-being after cancer treatment (Department of Health & Macmillan Cancer Care, 2008). Clearly more research is required to determine feasible, low cost behaviour change interventions which could be applied in a clinical/community setting. The new Medical Research Council guidelines for developing and evaluating complex interventions (Craig et al., 2008) highlights the importance of pilot studies, identifying them as central to the development of effective behaviour change interventions. They note that large scale evaluations can be undermined by problems with recruitment, compliance, retention, acceptability and programme delivery. The rest of this chapter therefore describes a pilot study of a distance-based, personally-tailored multiple behaviour change intervention for CRC survivors.

Behavioural science and behaviour change interventions

Conclusions as to the most effective means to change behaviour are lacking not just among cancer survivors, but in the general population. This can in part be attributed to a lack of methodological clarity when designing and reporting such interventions, making it difficult to synthesise available evidence (Michie & Abraham, 2004). As a result researchers are being encouraged to design and report behaviour change interventions in a more consistent manner. Publication of both the Consolidated Standards of Reporting Trials (CONSORT) guidelines (Moher et al., 2001) to guide reporting of RCTs, and the Transparent Reporting of Evaluations with Non-Randomised Designs (TREND) statements (Jarlais et al., 2004), and the acceptance of these by journal editors, has provided some clarity by providing a consistent method of intervention design and reporting. In addition, Davidson et al., (2003) proposed an extension to these guidelines stating reports should include a) the content of the intervention and how it was delivered (e.g. oral communication, written material etc), b) who delivered it, c) methods of intervention delivery (e.g. telephone calls, face-to-face), d) the setting (e.g. school, workplace), e) the recipients, f) intensity (e.g. number of contacts), g) duration, h) fidelity (was the intervention delivered as intend). Despite these advancements many interventions continue to be published without such clarity.

There has also been a call for behaviour change interventions to be theoretically driven. This is based on the argument that interventions which target theoretically derived determinants of behaviour are more likely to be effective (Albarracin et al., 2005). As was seen in the previous overview of multiple behaviour change interventions in cancer survivors (chapter 6), most studies do specify a theory upon which the intervention is based (most commonly Social Cognitive Theory (SCT)). Somewhat paradoxically however less consistency exists with respect to the intervention components described in these studies. This is most likely due to these theories being developed in an attempt to understand behaviour, not change it, and therefore not specifying strategies or techniques to use in eliciting behaviour change. To overcome this, Abraham and Michie (2008) developed a taxonomy of behaviour change techniques used in interventions and mapped them onto existing theoretical frameworks (see also Michie et al., 2008). This is an important advancement in the field, standardising the vocabulary used to define intervention components. Therefore, if the development of new interventions is theory-based, includes theoretically-derived techniques, and provides clear descriptions of delivery, research can be synthesised and conclusions drawn regarding evidence-based best practice.

The theoretical framework used to guide the current intervention study is described below. In addition, an explanation of the intervention procedures is presented which addresses each of the eight points outlined by Davidson et al (2003).

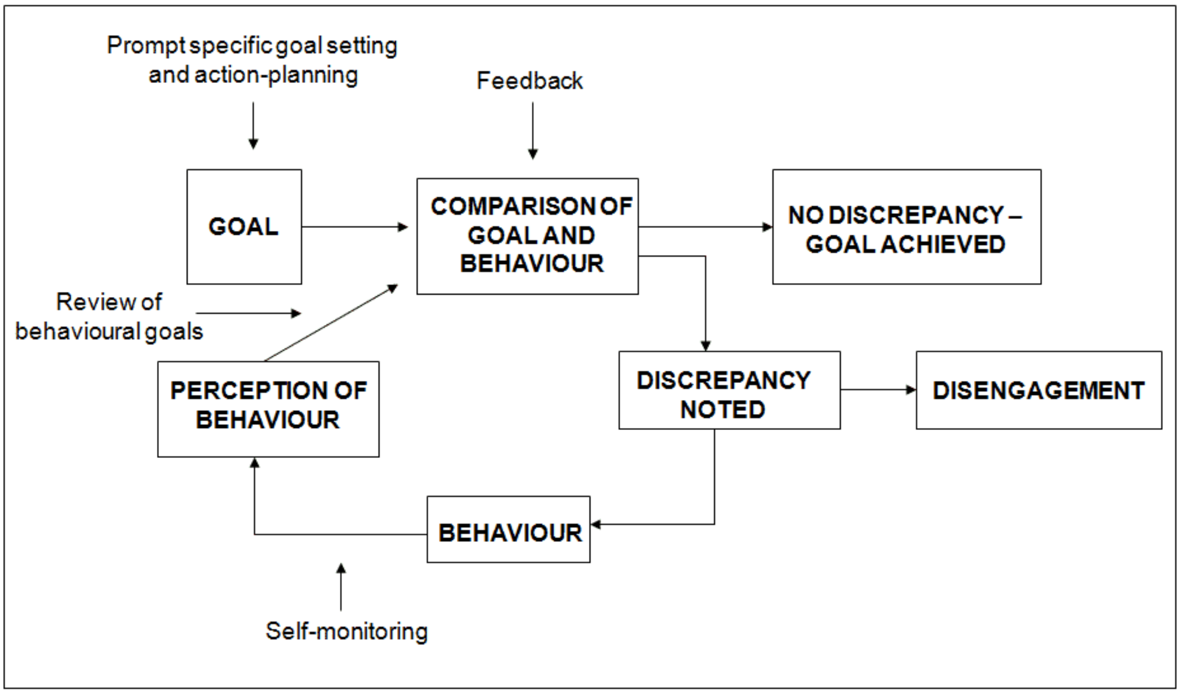
Theoretical underpinning

Michie et al (2009) published the first meta-analysis to examine the effectiveness of behaviour change techniques (classified using the Abraham and Michie's (2008) taxonomy) to change physical activity and diet. By conducting a meta-analysis and meta-regression the authors were able to determine the effects of individual techniques, and combination of techniques. The results showed that interventions which used self-regulation techniques derived from Carver and Scheier (1982) control theory (prompt intention formation or goal setting, specify goals in relation to particular actions, self-monitoring, feedback and review of previous goals) would be more effective than other interventions. The authors confirmed this hypothesis by reporting interventions that used self-monitoring and at least one other self-regulatory technique were significantly more effective than those not including these techniques. Given this, and the importance of using empirically supported change techniques, self-regulation was chosen as the theoretical basis for this behaviour change intervention. Also noteworthy is the techniques described above overlap with some of the techniques used in the most successful multiple behaviour change interventions to-date (RENEW and FRESH START), namely, goal setting, self-monitoring and review of previous goals.

There are a number of self-regulation models and it is beyond the scope of this thesis to review them in detail. However in essence they follow a feedback loop (Figure 8.1). An individual sets a behavioural goal and compares this with their current behaviour, if they notice a discrepancy (i.e." I aim to eat 5 servings of F&V a day but I am only eating 2"), then an action plan and a goal are developed to try to reduce this discrepancy. A new behaviour is performed which is compared with the goal behaviour;

the idea being self-regulation increases ones efficacy for regulating behaviour through the use of mastery experiences. As each goal is achieved and a new goal is made.

Figure 8.1: Self-regulation, including behaviour change techniques, adapted from Carver & Scheier (1982)



Theories of self-regulation focuses on volitional aspect of behaviour, assuming that positive attitudes and motivation to make behaviour change is already in place. Given that participants in this study are volunteering to take part in a lifestyle intervention, one might assume they hold positive attitudes towards health behaviours and are motivated to make changes. However, in an attempt to ensure motivation to change behaviour the intervention also included materials based on the TPB. These aimed to encourage positive beliefs about the value of consuming a diet high in F&V and low in red and processed meat and associated subjective norms. The third component of the TPB, behavioural control, is bolstered through the self-regulatory process and was therefore not included in the written materials.

In accordance with Abraham & Michie's (2009) taxonomy the following techniques were utilised in this intervention; 1) prompting specific goal setting, 2) prompting review of behavioural goals, 3), prompting self-monitoring of behaviour, and 4) provide feedback on performance. Theory of Planned Behaviour elements included: 1)

Providing information on consequences, 2) providing information about others' approval, and 3) prompt intention formation. More recently the taxonomy has been extended to 40 items (compared with the original 26) and now includes action planning (the "when, where and how" of goal setting), which is also relevant to self-regulation theory and is therefore included in this intervention (Ashford et al., 2009). Finally, although not specifically related to self-regulation or control theory, provision of social support was also incorporated into this intervention. This was deemed appropriate because social support has been consistently found to be related to positive behaviour change in cancer survivors (Park & Gaffey, 2007; Park et al., 2008).

Methods

Design

This was a small-scale, pre-post evaluation of a multiple behaviour change intervention which was designed to assess the feasibility and acceptability of delivering the intervention and provide an indication of behaviour change.

Recruitment

Participants were recruited from University College London Hospital (UCLH), Princess Alexandra Hospital (PAH), and North Middlesex Hospital. Recruitment strategies varied by site. At UCLH, I attended the weekly CRC clinics where a consultant identified any patients who were attending after their final cycle of chemotherapy or for their three month follow-up. During the consultation, eligible patients were asked by the consultant if they would be happy to hear about a lifestyle intervention study. If the patient agreed, the study was explained to them and an information sheet, reply slip and self-addressed envelope provided. Patients were told to take the information home and if they would like to take part, to call direct to the research office or return the reply slip. For the two remaining hospitals clinics were not held. Therefore collaborating consultants were reminded of the inclusion/exclusion criteria and asked to identify any eligible patients over the course of the recruitment period. A letter of invitation, signed by the consultant, information sheet and reply slip was sent to all eligible patients.

Patients who expressed interest in taking part in the study were contacted by phone to make an appointment at UCL. During this appointment participants had the opportunity to ask any questions about the study and if they were satisfied to sign the consent form.

Sample size

The recruitment target was 12. This was a pragmatic decision based on time and resources available.

Inclusion/exclusion criteria

Participants must have completed treatment for stage M0 (no metastasis) CRC and be over 18 years old. Spoken and written English was also a prerequisite as arrangements could not be made for none-English speakers due to resource constraints. Potential participants were excluded if they had mobility impairment that would restrict ability to be physically active (i.e. severe arthritis), significant cognitive impairment, or any other contraindication to physical activity. Patients were also excluded if they had a sub-total or total colectomy or ileostomy. Patients who had sub or total colectomy often experience gastro-intestinal problems when consuming fruit, vegetables and other fibrous foods, thus making it unethical to suggest doing so as part of the intervention.

Behavioural targets

The intervention focused on increasing engagement in moderate physical activity, increasing F&V intake and reducing red and processed meat consumption. These behavioural targets were chosen based on 1) the evidence that physical activity and healthy diets are associated with better QoL (see chapter 4), and 2) the role of these factors in the aetiology and/or outcomes in CRC (see chapter 3). The outcome goals were 1) to increase participation in moderate physical activity to at least 150 minutes of moderate intensity activity, or at least 75minutes of vigorous intensity activity per week, or equivalent combinations of the two, 2) to increase F&V consumption to $\geq$ 5 portions a day, and 3) limited consumption of red meat to 500g a week, and consume little or no processed meats. Other factors could also have been considered, such as alcohol or weight management, but attempting to change more than three behaviours over the course of a short intervention seemed over-ambitious. As this was a feasibility study, it seemed appropriate to consider the acceptability of addressing these behaviours in the first instance, and if successful, future studies can consider introducing other lifestyle factors.

Intervention materials and procedures

Participants attended a baseline assessment at UCL in which informed consent was given and the baseline questionnaire administered (see appendix 8). Height and weight were recorded (see measures section). This session was also used to build rapport with participants.

The intervention was 12 weeks in duration and consisted of two core elements; written materials (guided by the TPB) which were posted to participants, and telephone consultations which were guided by self-regulation theory. In general, telephone consultations were made to participants' homes at a time convenient to them. Telephone consultations were conducted once every two weeks (six in total). Details of these components are discussed below.

On completion of the intervention, participants returned to UCL for a follow-up assessment where the post-intervention questionnaire was administered (see appendix 9)[5], weight was recorded and a follow-up interview conducted (see appendix 10 for interview guide). In order not to bias responses, these interviews were carried out by a researcher who was not associated with the intervention, but had experience in conducting interviews in clinical populations. Participants were offered an end of study report detailing on completion of the intervention (appendix 11).

Written materials

Written information was presented in two sections, physical activity and diet (red and processed meats and F&V), see appendix 12. Both sections included two A4 pages of information (described in lay terms) on the association between each health behaviour and CRC risk, evidence for the role of health behaviours in the recovery from CRC, and protection from other comorbidities. This is in accordance with the technique outlined

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[5] Please note the only the scales and items not included in the baseline questionnaire are presented in the appendix

previously of ‘provide information on the consequences of behaviour’. Quotes from consultant oncologists and other cancer survivors, encouraging engagement in health behaviours were also included. This is in accordance with the technique of ‘provide information about others’ approval’. In addition to the diet information sheet, examples of red and processed meats, portion sizes, and a continuum of the least fibrous to the most fibrous foods was provided. The latter was deemed necessary as survivors recovering from treatment often experience digestive problems which can be aggravated by consuming foods high in insoluble fibre. To limit the chance of adverse events, participants were encouraged to start by consuming the least fibrous fruits and vegetables and work towards the more fibrous options. A pedometer was also provided and used as both a motivational cue and self-monitoring tool.

Written materials were developed specifically for this intervention and in consultation with a consultant oncologist, a senior physiotherapist and senior dietician, all specialising in CRC. In order to gain user input a CRC survivor also reviewed the materials and provided feedback.

Participants were provided with two logbooks, one for physical activity, the other for F&V and red and processed meats; these were used as a self-monitoring tool. There was space for participants to record their goals with associated action plans (see telephone consultation section). In the physical activity logbook participants recorded number of minutes of physical activity a day and number of steps per day. In the diet logbook, participants recorded portions of red and processed meat and F&V consumed at each meal time and as a snack. In both logbooks participants could record whether they had successfully reached their goal for that week, the rationale behind this was to encourage review of behavioural goals (see appendix 13 for examples).

Telephone consultations

Telephone consultations (which I delivered) took place once every two weeks. During the first consultations participants were provided with feedback about their current level of physical activity, F&V, red meat and processed meat consumption and how that relates to population guidelines. Discussions were then had regarding the aims of the telephone consultations, namely achieving guideline levels of each of these behaviours.

Participants were reassured however, that it was not expected that they reach these goals during the course of the intervention (particularly if baseline levels were very low), but any progress towards those goals would be a real achievement (this caveat was requested by the ethics committee). The importance of setting achievable incremental goals was discussed, and participants instructed how to use their logbooks and pedometer. Participants were then asked if they would prefer to start with changes to physical activity or diet.

Once progress had been made towards goals for the initial behaviour, the second behaviour was introduced. Each telephone consultation then followed the same structure; firstly, participants were encouraged to make a specific goal for behaviour change. An action plan was then formed in order to break down how this goal would be achieved. For example, if the goal was to eat one more portion of fruit a day, the action plan could be, when: every morning at breakfast time, where; at home, how; I will add a banana to my cereal. Participants were then reminded to fill in their logbook detailing the goal/s set, and to record their behaviour on a daily basis. Finally, they were encouraged to review their logbooks at the end of the week to see if they had achieved their goal/s. Encouragement was also given to engage in social support. For example, if the participant lived with a partner or spouse they were asked if they thought it might be helpful for them to be involved in the intervention to support the behaviour changes. At the start of the next consultation, progress made towards the goals previously set were reviewed and feedback provided on performance. If the goal was not achieved reasons why this may have been and possible solutions were discussed. The next behavioural goal was then set (in light of progress made so far), and the process repeated.

Ethical approval

This study was approved by The Joint UCL/UCLH Committees on the Ethics of Human Research (Committee Alpha). See appendix 14 for approval letter.

Outcome measures

Medical and demographic characteristics

Age, sex, treatment history, and date of treatment completion were reported by medical staff. Socioeconomic status was indexed using three items that reflect material circumstances and education (as used in the questionnaire study); car-ownership or not, home ownership or not, and some higher education verses none. Scores range from 0-3 with higher scores indicating no deprivation. Marital status was self-reported. Comorbidities were assessed using a checklist.

Feasibility and acceptability

A mixed methods process evaluation approach was used to evaluate the intervention, utilising both the follow-up questionnaire and post-intervention interview. Feasibility and acceptability were assessed.

Compliance

To assess compliance with written materials, participants were asked in the follow-up questionnaire if they had read the materials. For telephone consultations, the proportion of consultations delivered is presented. Compliance with the other behaviour change techniques i.e. prompt specific goal setting, prompt review of behavioural goals, prompt self-monitoring of behaviour and engage in social support was examined quantitatively in the follow-up questionnaire. Questionnaire items included ‘did you use the logbook to write down your goals for the week?’, ‘did you use the logbook to keep track of your physical activity and diet?’ and ‘did you use the logbook to check back on how you got on each week?’ and ‘did you get support from friends/spouse/partner during the study, i.e. to help you stick to your goals’. Response options were ‘no, none of the time’, ‘yes, some of the time’, ‘yes, all of the time’. Other items included were; 1) participants’ overall assessment of the intervention, 5-point response options ranged from ‘very poor’ to ‘excellent’, 2) if participants would recommend this programme to other CRC survivors, response options ‘definitely not’ to ‘definitely yes’, 3) if participants thought they made changes that have improved their lifestyle, response options as above, 4) if participants felt that they had made changes that have improved their QoL. Response options as above. Each behaviour change technique was discussed in the follow-up interviews in order to gain further insight into compliance.

Recruitment

Recruitment rates were calculated based on the number of participants approached, number of positive responses, and number who consented to take part in the study.

Acceptability

Motivation for taking part in the intervention was explored during follow-up interviews as was the perceived acceptability of the assessments and mode of delivery. Each of the behaviour change techniques were discussed in order to gain further insight into their acceptability. Acceptability of the timing of the intervention (in relation to cancer diagnosis and treatment), length of intervention and intervention format were also explored as well as perception of behaviour change and barriers to change. Finally, respondents were asked to make suggestions as to how the intervention could be improved.

The interviews also explored motivation to take part in the study, perceived change in behaviour, barriers to behaviour change and suggested improvements for the intervention.

Behavioural outcomes

Physical activity: Physical activity was measured using the modified version of the Godin Leisure Time and Exercise Questionnaire (Godin et al., 1986). The original questionnaire asked the frequency of bouts of vigorous, moderate and mild exercise lasting > 15 minutes during the last 7 days. The modified version also asks respondents to state average duration (in minutes) of these sessions. Total minutes spent in vigorous, moderate and mild activity can then be calculated. A pedometer (Yamex digiwalker SW-200), was used as an objective measure of physical activity. Convergent validity of this model has been confirmed against accelerometers (Tudor-Locke et al., 2002), and it has been endorsed for use in physical activity research (Schneider et al., 2004). Participants were asked to record total number of steps for three days (two weekdays and one weekend) at baseline (and follow-up) and an average was calculated.

F&V, red and processed meat: Consumption was assessed using a modified version of the Health Education Authority 3 (HEA3) food frequency questionnaire. Participants were asked to estimate the portion size i.e. (small, medium or large), number of days each week that food was consumed, and number of portions consumed on each day. Red meat items included ‘lean red meat (e.g. lean mince, beef, pork, lamb with fat removed)' and 'other red meats with fat (e.g. pork chops with fat, fatty minced meat). Grams per week were calculated. Processed meat consumption was measured with the item 'processed meats (e.g. sausages, burgers, ham, pate, salami)' and portions per week calculated. For F&V, the items included vegetables (fresh/frozen/tinned), salad, stewed/tinned fruit, fresh fruit, dried fruit and fruit juice (portions per day was calculated).

Weight status: Height was measured to the nearest 1cm using a Leicester stadiometer (Seca, Birmingham, United Kingdom) and weight to the nearest 0.1kg using the Tanita TBF-300MA Body Composition Analyser (Tanita Corporation, Tokyo, Japan). Although weight reduction was not a target of this intervention it is of interest to see if there were any suggestions that the intervention had an effect on participants' weight.

Attitudes

Theory of Planned Behaviour constructs: Each TPB construct, behavioural beliefs, normative beliefs, control beliefs, attitudes, perceived behavioural control (PBC), subjective norms and intention were measured in relation to physical activity and diet. Items were derived from reliable operationalisations in previous research, for physical activity this came from Courneya & Friedenreich (1997a) and Vallance et al (2007), for diet, items were derived from Blue & Marrero (2006), or were designed in accordance with TPB questionnaire guidelines (Conner & Sparks, 1996). Higher scores indicate stronger reporting of that cognition. Scales for attitude, PBC, subjective norms and intentions were consistent across both behaviours to allow comparisons. At the beginning of the TPB questions relating to diet, participants were informed that 'by "eating healthily", we mean eating a diet that is high in F&V and low in red and processed meat'.

Behavioural beliefs for physical activity: Behavioural belief items were preceded by the statement 'If I were to take part in regular physical activity over the next 12 weeks it would….' 12 items followed; 1) improve my fitness, 2) make me feel better about myself, 3) relieve stress, 4) help me cope with the stress of cancer, 5) make me feel more normal, 6) reduce the risk of my cancer returning, 7) keep my mind off cancer, 8), improve my energy levels, 9) help me recover from cancer treatment, 10), improve my immune system, 11) help me gain control over cancer and my life, 12) help me control my weight. Items were rated on a 5-point likert scale ranging from ‘extremely unlikely to extremely likely. Alpha coefficient for this scale was .918.

Control beliefs for physical activity: Control beliefs were measured with 10 items which followed the stem ‘How confident are you that, if you wanted to, you could take part in regular physical activity over the next 12 weeks if’……1) you had no counselling for exercise, 2) you had no support for exercise, 3) you had a cancer recurrence, 4) you were too tired/fatigued, 5) you don’t like exercise, 6) you experience pain or soreness, 7) you had additional family responsibilities, 8) you had no time to exercise/are too busy, 9) you had other health problems. A 5-point response scale ranging from ‘not at all confident’ to ‘completely confident’ followed. Alpha coefficient for this scale was .873

Behavioural beliefs for diet: Behavioural belief items were preceded by the statement ‘If you were to eat a healthy diet over the next 12 weeks it would; 1) improve my overall health, 2) control my weight, 3) prevent my cancer coming back, 4) improve the way I think about myself, 5) improve the way I look, 6) save me money, 7) be inconvenient, 8) result in my being hungry, 9) make me miss tasty foods I like, 10) improve my bowel function, 11) give me more energy. Items were rated on a 5-point likert scale ranging from ‘extremely unlikely to extremely likely. Items 7, 8, and 9 were reverse scored. Alpha coefficient for this scale was .669. This does not meet the criteria for an acceptable value (0.7-0.8) (Kline, 1999). Examination of the scale revealed an acceptable coefficient with removal of the item ‘save me money’; alpha coefficient .728, therefore analysis was run with this item deleted.

Control beliefs for diet: Control beliefs were measured with 11 items 1) I keep healthy foods available, 2) I have support for healthy eating from family and others, 3) I have the time to prepare foods that are healthy, 4) I am able to plan meals ahead of time, 5) I am able to keep track of my eating, 6) the cost of healthy foods is not a problem, 7) I am not able to choose healthy foods when eating outside the home, 8) I am not able to taste my favourite foods when I eat healthy foods, 9) I lack the will power to eat healthy

foods, 10) I find it hard to break eating habits, 11) It will upset my stomach. A 5-point response scale ranging from ‘strongly disagree’ to ‘strongly agree’ followed.
Items 7 – 11 were reverse scored. Alpha coefficient for this scale was .711

Perceived behavioural control: PBC was measured with four items: 1) If you wanted to, taking part in regular physical activity/eat healthily over the next 12 weeks would be….’ response items ranging from ‘extremely difficult’ to ‘extremely easy’. 2). If you wanted to, how confident are you that you would take part in regular physical activity/eat healthily over the next 12 weeks; response items range from ‘not at all confident’ to ‘extremely confident’. 3) If you wanted to, how much control do you feel you would have in exercising regularly/eating healthily over the next 12 weeks; response options ‘no control’ to ‘complete control’, 4) Whether or not you take part in regular physical activity/eat healthily over the next 12 weeks is completely up to me’ response items ‘strongly disagree’ to ‘strongly agree’. Alpha coefficient for this scale was .761 for physical activity and .734 for diet.

Attitudes: Attitude were measured using 6 items following the stem: ‘For you, would taking part in regular physical activity/eating healthily over the next 12 weeks be’. Items included ‘very harmful to very beneficial, very unnecessary to very necessary, very bad to very good, very unenjoyable to very enjoyable, very foolish to very wise, and very unpleasant to very pleasant. Items were rated on a 5-point likert scale. Alpha coefficient for this scale was .879 for physical activity and .873 for diet.

Subjective norms: Four items measured subjective norms. They followed the stem ‘Most people who are important to you….’ 1) would approve if you took part in regular physical activity/eat healthily over the next 12 weeks, 2) think you should, 3) would encourage you, 4) will take part in regular physical activity/eat healthily themselves. A 5-point response scale ranged from ‘strongly disagree to strongly agree’. Alpha coefficient for these scale were .970 and .899 for diet and physical activity respectively.

Intention: Intention was measured with three items 1) Do you intend to take part in regular physical activity/eat healthily over the next 12 weeks? 2) Do you want to take part in regular physical activity/eat healthily over the next 12weeks? Both questions had a 5 point response scale ranging from 'strongly disagree' to 'strongly agree' 3) How motivated are you to take part in regular physical activity/eat healthily over the next 12 weeks? This item had a 5-point response scale ranging from 'extremely unmotivated' to 'extremely motivated'. Alpha coefficient for this scale was .885 for physical activity and .894 for diet.

Normative beliefs: Five normative beliefs were assessed with the statement 'Would your [insert significant other] think you should take part in regular physical activity/eating healthily over the next 12 weeks? Items included oncologist, spouse/partner, friends, other CRC patients, and other family members. Items were rated on 5-point likert scale ranging from 'definitely not' to 'definitely yes'. Alpha coefficient for this scale was .873 for physical activity and .700 for diet.

Quality of life

Quality of life was assessed using the Functional Assessment in Cancer Therapy – Colorectal (FACT-C). The FACT-C is a 36-item questionnaire and consists of five subscales; physical (7 items), functional (7 items), social/family (7 items), emotional wellbeing (6 items) and colorectal cancer scale (CCS (7 items)); the two items relevant to stoma patients were not included. Respondents indicate how true each statement is for them during the last seven days, with a 5-point response scale ranging from 'not at all' to 'very much'. Scores range from 0-24 for the 6 items scales and 0-28 for 7 item scales. Total scores range from 0-136 with higher scores indicating better QoL. This measure has proven validity and reliability (Ward et al., 1999). Minimally importance differences (MID)/change range from 2-3 points for the CCS and 5-8 points for the FACT-C total score (Yost et al., 2005). MID has been defined as the ''smallest difference in score in the domain of interest that patients perceive as important, either beneficial or harmful, and that would lead the clinician to consider a change in the patient's management'' p. 377 (Guyatt et al., 2002).

Fatigue

Fatigue was measured using the Functional Assessment in Cancer Therapy – Fatigue Scale (FACIT) (Yellen et al., 1997). This is a 13-item scale with scores ranging from 0

– 52. High scores indicate greater fatigue. MID are defined as 3 points of this fatigue subscale (Cella et al., 2002).

Physical function

The physical function subscale of the SF-36 version 2 was used to measure functional status. This is a 10-item scale; scores are transformed with possible scores ranging from 0-100. High scores indicate better physical function. This is a validated and reliable measure (Ware & Sherbourne, 1992) which has been used frequently among cancer survivors e.g. (Demark-Wahnefried et al., 2003a; Snyder et al., 2009).

Perceived control

Perceived control over the outcomes of cancer was measured using the outcomes subscale of the Perceived Control Questionnaire, developed to measure multiple dimensions of perceived control in women with newly diagnosed breast cancer (Beckjord et al., 2009). Respondents were asked ‘how much personal control do you think you have over the outcomes of your cancer including, 1) recovering from your current cancer, 2) preventing your cancer from coming back. Responses were given on a 5 point scale ranging from ‘no control’ to ‘a great deal of control’. The Pearlin-Scooler Mastery Scale (Perlin & Scooler, 1978) was used to measure participants’ general sense of control. This is a 7-item scale with five positively orientated items and two negatively orientated items, the latter two are reverse scored. Scores range from 7-35 with higher scores indicating greater perceived control. This measure has been used previously among cancer patients (Ranchor et al., 2010).

Statistical Analysis

It was assumed that missing data for the FACT-C, TPB questionnaire, FACIT, physical function (as measured by the SF-36) and the Pearlin-Scooler Mastery Scale were equal to the average of those items that were complete for that participant and scale, so long as at least 50% of the other items were completed.

Descriptive statistics for recruitment and process evaluation are presented. Total scores at baseline (T0) and follow-up (T1) are presented for TPB components (including behavioural beliefs, normative beliefs, control beliefs, attitudes, PBC, subjective norms and intention), minutes of moderate and vigorous physical activity, average daily step counts, portions of F&V a day, grams of red meat a week, portions of processed meat a week, QoL, fatigue, physical function and control. Change scores were subsequently calculated (T1 – T0). Change in weight also presented. T-tests were used to examine mean change.

Qualitative interviews were recorded (with participants' permission), transcribed and key themes identified.

Results

Medical and demographic characteristics are presented in table 8.2. The average age of participants was 66.5 years, ranging from 61-78 years. The majority were female and white British. The average time since treatment completion was 2.8 months. All participants had undergone surgery and chemotherapy and one had also received radiotherapy. The majority (81%) were married, most had at least one marker of deprivation (60%) and average BMI was 26.9kg/m2 (±4).

Recruitment: Over a 4-month period 18 patients met the inclusion criteria and were invited to take part in the study; 11 were identified at Princess Alexandra, six at UCLH and one at North Middlesex. Thirteen responded to say they would be interested in taking part (72%) and appointments were scheduled to attend a baseline assessment at UCH. One patient was too unwell to attend her scheduled appointment and subsequently decided not to take part in the study.
In addition, one interested participant was already meeting all of the behavioural targets (i.e. physically active > 30mins 5 times a week, eating at least 5 portions of F&V a day and consumed little red or processed meat). He was therefore excluded from the study. Eleven patients (61% of eligible patients) finally consented to take part in the intervention; just short of the target of 12.

All six patients identified at UCLH agreed to be informed about the study in a face-to-face discussion and all of these patients agreed to take part in the study. Seven of the 12 patients identified at PAH / North Middlesex were contacted by letter and responded positively to their invitation. This may suggest that a face-to-face introduction to the study may be a more effective method of recruitment than contact by post. In addition, I know with certainty that all eligible patients were approached at UCLH as I was present at all weekly clinics. However at the two other sites, recruitment was dependent on consultants identifying all eligible patients. It was not possible to monitor this and given pressures on consultants' time it is possible that they did not identify all eligible patients. There was a suggestion of a biased approach at one site, with a consultant contacting me with details of an eligible patient, stating 'she likes to talk'.

Table 8.2: Demographic and medical characteristics

Characteristic	
Age in years (mean and range)	66.5 (61 – 78)
Sex (N %)	
Male	20% (2)
Female	80% (8)
Ethnicity (N %)	
White British	80% (8)
While French	10% (1)
Black Caribbean	10% (1)
Time since treatment completion (months)	2.8 (1-8)
Surgery	100% (10)
Chemotherapy	100% (100)
Radiotherapy	10% (1)
Marital status	
Married/living with partner	80% (8)
Single	20% (2)
SES	
No deprivation	40% (4)
Some deprivation	60% (6)
High deprivation	0% (0)
BMI (Kg/m2) (mean, SD)	26.91 (3.98)

Attrition*:* One participant withdrew from the study, citing 'personal problems'. All others completed baseline and follow-up assessment. Attrition rate of 9%.

Compliance with baseline and follow-up assessments, telephone consultations and behaviour change techniques*:* All participants were able to attended baseline assessments at UCL. However one was rescheduled three times. On the first occasion this was due to very cold weather aggravating side-effects of chemotherapy treatment including sore, watery eyes and neuropathy. Two other appointments were missed due to being unwell with viral infections. One participant was not able to attend the follow-up appointment at UCL as her mother was very unwell in hospital. The follow-up questionnaire was therefore sent by post and the interview conducted by telephone.

Of the 10 participants seven completed all of the scheduled telephone consultations and three each missed one consultation. Two of these were due to flight disruptions returning from holiday as a result of the eruption of Eyjafjallajökull volcano in Iceland. The other was due to a participant extending her holiday unexpectedly. A total of 95% of consultations were delivered.

One participant did not answer the questions in the follow-up questionnaire relating to compliance with behaviour change techniques. Of the remaining nine, 100% of respondents reported reading all of the written information provide, 100% reported using the logbooks for setting goals and for tracking behaviour, 77% (n = 7) reported using the logbook to review achievement of behavioural goals some of the time, and 22% (n = 2) reported doing this all of the time. Finally, 67% (n = 6) state they used social support for all parts of the intervention, 10% (n = 1) said they engaged in social support for some parts, and 20% (n = 2) said they didn’t have any social support.

Study evaluation: Evaluations of the study were very positive with 70% (n = 6) rating it as ‘excellent’ and 30% (n = 3) rating it as ‘very good’. In addition 90% said they would definitely and 10% would probably recommend the intervention study to others who are recovering from CRC. All reported that they had either definitely (90%, n = 8) or probably (10%, n = 1) made improvements to their lifestyle and QoL.

TPB constructs: Pre and post intervention scores on behavioural, control and normative beliefs, attitudes, PBC and subjective norms for physical activity are presented in table 8.3. Scores for all three belief scales increased, two significantly (p’s <.05). There was also an increase in attitudes which neared significance. Subjective norms and PBC remained stable.

Table 8.3. Changes in PBC constructs for physical activity

TPB construct - PA	T0 Mean (SD)	T1 Mean (SD)	Mean change (SD)	p
Behavioural beliefs (scores 12-60)	48.30 (8.12)	49.30 (5.69)	1.00 (7.61)	.688
Control beliefs (scores 10 – 50) Missing n = 1*	31.79 (6.35)	35.40 (7.25)	3.57 (3.45)	.015
Normative beliefs (scores 5 – 25)	21.6 (1.95)	23.70 (2.54)	2.10 (2.81)	.042
Attitude (scores 6-30)	24.2 (5.65)	27.10 (3.63)	2.90 (4.23)	.058
PBC (scores 4 – 20)	15.0 (2.31)	15.10 (3.60)	.104 (3.47)	.930
Subjective norms (scores 3-15)	13.00 (1.83)	13.00 (1.76)	.000	1.00
Intention (scores 3-15)	12.35 (1.29)	13.30 (1.63)	.952 (1.64)	0.100

*Participant had >50% of items missing

For diet, none of TPB scores changed significantly, although attitudes increased by almost 3 points, approaching significance (p = .058), see table 8.4.

Table 8.4 Changes in PBC constructs for diet

TPB construct – Diet	**T0 Mean (SD)**	**T1 Mean (SD)**	**Mean change (SD)**	**p**
Behavioural beliefs (scores 11-55)	37.48 (3.66)	38.20 (3.85)	.723 (3.82)	.564
Control beliefs (scores 11 – 55)	35.44 (4.35)	37.10 (2.08)	1.66 (3.91)	.213
Normative beliefs (scores 7 – 35) Missing n = 1*	32.78 (3.53)	32.87 (2.24)	.110 (4.21)	.998
Attitude (scores 6-30)	25.60 (4.01)	28.40 (2.12)	2.80 (4.08)	.058
PBC (scores 4 – 20)	16.20 (1.62)	17.40 (2.01)	1.20 (2.09)	.104
Subjective norms (scores 3-15)	12.50 (1.35)	13.60 (1.51)	1.10 (2.13)	.137
Intention (scores 3-15)	12.30 (1.34)	13.50 (1.44)	1.20 (1.99)	.089

*Participant had >50% of items missing

Behaviour change:

Physical activity: Data for baseline, follow-up and change in physical activity are presented in table 8.5. Baseline physical activity levels were low with participants engaging in an average of 32 minutes of moderate activity a week, and six out of ten being physically inactive. No participants reported taking part in strenuous activity. At T0 the average number of steps per day was 4830, however there were large individual differences with scores ranging from 833 to 9708. At follow-up there was a significant increase in moderate physical activity of 125 minutes (T (9) = 4.10, p = .003). In addition four participants were engaging in strenuous physical activity (t (9) = 2.07, p = .068). Seven of the ten participants were meeting recommended guidelines for physical activity compared to none at T0. Average number of steps increased by 1941 (T (8) = 3.45, p = .009), again variation was large ranging from a reduction of 520 to an increase of 4713. Follow-up step data was not available for one participant.

Table 8.5: Individual physical activity and step counts at T0 and T1

Participants	**T0 Moderate PA (mins.wk)**	**T1 Moderate PA (mins.wk)**	**Change (mins.wk)**	**T0 Strenuous PA (mins.wk)**	**T1 Strenuous PA (mins.wk)**	**Change (mins.wk)**	**T0 Steps (per day)**	**T1 Steps (per day)**	**Change Steps (per day)**
1	.00	30.00	30	.00	60.00	60	8703	12433	3730
2	70.00	40.00	-30	.00	60.00	60	833	missing	missing
3	120.00	225.00	105	.00	30.00	30	9708	11330	1621
4	60.00	280.00	220	.00	.00	0	2737	7450	4713
5	.00	140.00	140	.00	.00	0	1791	1643	-147
6	.00	225.00	225	.00	.00	0	3676	4899	1222
7	.00	270.00	270	.00	.00	0	7532	9288	1756
8	.00	30.00	30	.00	.00	0	8288	7768	-520
9	.00	160.00	160	.00	.00	0	3526	6353	2827
10	75.00	180.00	105	.00	120.00	120	1504	3774	2270
Average (mean)	32.50 (44.67)	158.0 (96.56)	125.5 (96.82)	.000	27.00 (41.10)	27.00 (41.10)	4830 (3362)	7323 (3721)	1941 (1690)

Fruit and vegetables: Data for baseline, follow-up and change in F&V are presented in table 8.6. At baseline, no participants were consuming the recommended five portions of F&V a day; mean total 3.37 (.81) portions per day. At follow-up, all participants exceeded the recommendation of five portions of F&V a day, average intake 6.59 (.85) portions per day, mean change 3.22 (1.06), T (9) = 9.62, p <.001.

Table 8.6 Individual consumption of F&V at T0 and T1

Participants	**T0 Portions F&V (per day)**	**T1 Portions F&V (per day)**	**Change (portions per day)**
1	2.58	7.15	4.57
2	4.15	6.72	2.57
3	4.43	8.15	3.72
4	3.00	6.29	3.29
5	4.43	6.43	2.00
6	2.43	6.43	4.00
7	4.00	5.15	1.15
8	3.00	7.29	4.29
9	2.43	5.59	3.16
10	3.29	6.72	3.43
Average (mean)	3.37 (.81)	6.59 (.85)	3.22 (1.06)

Red and processed meats: Ninety percent of participants (N=9) were consuming processed meats at baseline but intake was low (see table 8.7); average 1 portion a week (.67), with a significant reduction of -0.70 (.82) portions over the course of the intervention, T (9) = -2.69, p = .025. At follow-up, just two participants reported consuming any processed meat. At baseline, average intake of red meat was 245g (256g) per week; only two participants were eating more than the recommended 500g per week. At follow-up, one of these participants had reduced their intake to 350g, while the other changed little. Average reduction across the whole sample was significant; -69.7g (156); t (9) = 2.55; p .035, see table 8.7.

Table 8.7: Individual consumption of red and processed meat at T0 and T1.

Participants	T0 Red meat (g.wk)	T1 Red meat (g.wk)	Change (g.wk)	T0 processed meat (portions per.wk)	T1 Processed meat (portions per.wk)	Change (portions per.wk)
1	109	0	-109	1.00	.00	-1.00
2	72	0	-72	.00	.00	.00
3	216	144	-72	1.00	.00	-1.00
4	144	144	0	1.00	.00	-1.00
5	845	350	-495	2.00	.00	-2.00
6	545	525	-20	1.00	2.00	1.00
7	218	216	-2	.00	.00	.00
8	114	152	+38	1.00	.00	-1.00
9	189	224	+35	2.00	1.00	-1.00
10	0	0	0	1.00	.00	-1.00
Average (mean)	245 (256)	175 (167)	-69.7 (156)	1.00 (.67)	.30 (.67)	-.70 (.82)

Weight status: Seven out of ten participants were overweight (BMI ≥ 25 kg/m2) at baseline; there was no significant change at follow-up (see table 8.8). There was considerable variation in weight change over the course of the study, five participants gained weight (average +1.52kg), three lost weight (average -1.6kg), and one participants' weight remained stable. Data was not available for one individual as she did not attend follow-up. There does not appear to be an association with weight gain and F&V consumption.

Table 8.8: Individual weight at T0 and T1.

Participants	T 0 Weight (kg)	T1 Weight (kg)	Change
1	60.00	61.20	1.20
2	89.60	88.10	-1.50
3	62.00	63.00	1.00
4	63.00	64.70	1.70
5	94.00	94.00	.00
6	79.00	76.70	-2.30
7	58.00	57.10	-.90
8	61.00	missing	missing
9	76.00	78.10	2.10
10	68.00	69.60	1.60
Average (mean)	71.06 (12.90)	72.50 (12.64)	0.32 (1.57)

<u>Quality of life</u>

Table 8.9 presents FACT-C scores at baseline and post-intervention. Minimally important differences (MID) are only available for the CCS subscale and total scores. Three participants experienced improvements in CCS. Clinically meaningful improvements in total QoL scores were seen among four participants, one of whom reported a 17 point increase from baseline. However, one participant also experienced a significant reduction in total QoL (9 points). Three experienced reductions in CCS QoL, however two of these showed improvements in total QoL. There were no statistically significant increases in any of the QoL subscales, although mean change in total FACT-C score met the MID cut-off for improvements.

Table 8.9: Individual QoL scores at T0 and T1.

Participants	**T 0 PWB (0-28)**	**Change**	**T0 FWB (0-28)**	**Change**	**T0 SWB (0-28)**	**Change**	**T0 EWB (0-24)**	**Change**	**T0 CRCC (0-28)**	**Change**	**T0 Total (0-136)**	**Change**
1	23.00	5.00	25.00	2.00	28.00	.00	16.50	3.00	25.67	-2.67	92.50	10.00
2	21.00	-3.50	25.00	-8.00	22.40	-1.40	18.00	3.60	25.00	-4.00	86.40	-9.30
3	24.00	-1.00	21.00	5.00	28.00	.00	23.00	.00	22.00	3.00	96.00	4.00
4	22.17	-.17	17.00	4.00	7.00	8.17	19.50	1.50	18.00	.00	65.67	13.50
5	24.00	2.00	28.00	.00	24.00	1.00	24.00	.00	25.00	1.00	100.00	3.00
6	28.00	.00	26.60	.40	26.83	-2.83	22.00	2.00	24.00	2.00	103.43	-.43
7	20.00	6.00	23.00	2.00	24.00	2.00	21.00	.00	21.00	-3.00	88.00	10.00
8	26.00	1.00	26.00	.00	25.00	2.00	21.00	-1.00	24.00	2.00	98.00	2.00
9	25.00	2.00	20.00	8.00	28.00	-1.17	12.00	8.00	26.00	.00	85.00	16.83
10	27.00	.00	24.00	.00	26.60	.00	23.00	.00	24.00	.00	100.60	.00
Total (SD)	24.02 (2.57)	1.13 (2.78)	23.56 (3.36)	1.34 (4.21)	23.98 (6.28)	0.78 (3.0)	20.0 (3.65)	1.71 (0.84)	23.47 (2.47)	0.17 (2.35)	91.65 (11.10)	4.96 (7.72)
P*		.232		.340		.434		0.70		.829		.072

PWB = physical well being, FWB = functional well being, SWB = social well being, EWB = emotional well being, CCS = colorectal cancer scale.
Higher scores indicate better QoL.
T-tests were used to examine change in scores

Fatigue:

Table 8.10 shows scores of fatigue at baseline and post-intervention. When examining average scores, change in fatigue is minimal. However one participant reported an increase in fatigue of 24 points, bringing their total score to 37. This is above the cut-off for clinically significant fatigue of 34. This was the same participant who reported a significant reduction in QoL. Two participants reported clinically significant reductions in fatigue, and three report clinically significant increases.

Table 8.10: Individual fatigue scores at T0 and T1

Participants	T0 Fatigue	T1 Fatigue	Change
1	2.00	.000	-2.00
2	13.00	37.00	24.00
3	11.00	9.00	-2.00
4	6.00	9.00	3.00
5	10.00	3.00	-7.00
6	3.00	2.00	-1.00
7	19.00	14.00	-5.00
8	6.00	6.00	.000
9	5.00	3.00	-2.00
10	6.00	9.00	3.00
Average (mean)	8.10 (5.17)	9.20 (10.64)	1.10 (8.62)
P*			.696

*T-tests was used to examine change in scores

Physical function: Table 8.11 presents scores for the physical function subscale of the SF-36. As was seen in results for fatigue and QoL, one participant reported a significant decline in physical function from baseline to post-intervention. When excluding this participants' data from the analysis, mean change score was significant; 11.67 (13.46), p = 0.035. Considering results in relation to clinically meaningful change, a cut-off of 17 has been recommended (Ferguson et al., 2002). Therefore three participants reported a clinically significant change in physical function from baseline to post-intervention, and one clinically significant deterioration.

Table 8.11: Individual physical function scores at T0 and T1

Participants	T0- SF-36	T1 SF-36	Change
1	90.00	90.00	.000
2	72.22	25.00	-47.22
3	65.00	80.00	15.00
4	65.00	75.00	10.00
5	70.00	95.00	25.00
6	90.00	80.00	-10.00
7	75.00	75.00	.000
8	70.00	95.00	25.00
9	80.00	90.00	10.00
10	55.00	85.00	30.00
Average (mean)	73.22 (11.06)	79.00 (20.39)	5.78
P*			.438

*T-test was used to examine change in scores

Perceived control: Table 8.12 represents data on two items examining perceived control over cancer outcomes at baseline and post-intervention and scores from the Mastery Scale. In general participants perceived themselves to have more control over the outcome of their cancer than over preventing a recurrence at both time points. However, seven participants reported an increased sense of control over preventing cancer recurrence post-intervention. In addition there was a significant increase in mastery scores (T (9) = 3.21; p = .006).

Adverse events: One participant reported having an ‘upset stomach’ after consuming eight portions of F&V in one day.

Table 8.12: Individual perceived control at T0 and T1

Participants	Recovering from cancer (1-4)	Change	Preventing recurrence (1-4)	Change	Mastery Score (7-35)	Change
1	3.00	.00	2.00	1.00	22.00	3.00
2	5.00	-3.00	5.00	-3.00	24.00	1.00
3	3.00	1.00	3.00	1.00	25.00	4.00
4	3.00	1.00	2.00	2.00	28.00	-2.00
5	4.00	.00	1.00	3.00	26.00	2.00
6	4.00	-1.00	4.00	-1.00	25.00	6.00
7	4.00	-1.00	4.00	-1.00	28.00	1.00
8	4.00	.00	2.00	2.00	24.00	4.00
9	3.00	.00	1.00	2.00	28.00	7.00
10	1.00	4.00	1.00	4.00	28.00	3.00
Mean	3.4	0.10	2.5	1.00	25.80	2.90*
(SD)	(1.07)	(1.79)	(1.43)	(2.11)	(2.15)	(2.60)

* p = .006

Post-intervention evaluation

Below are results from the post-intervention interviews.

Motivation to take part

A mixture of motivating factors were reported. Feeling thankful to the hospital and the staff for the treatment they had received, and wanting to give something back and be helpful to others in the future was most frequently cited:

"They've done a lot for us and we'd like to put something back in again, because it was the only way we could think of to, you know, to return what people have done for us in the past" *Male, aged 78*

Several participants also reported thinking that it may improve their lifestyle and health:

"I thought, well, anything that would improve my life...." *Female, aged 64*

"I thought it might make me feel better, healthier" *Female, aged 62*

However it was more common for participants to reflect on personal benefits once they were engaged in the study:

"I realised it was for me once I started on it, that it was more for me, and what I found will probably help other people...rather than me doing it just for other people, it's been very helpful for me" *Female, aged 66*

One participant recalled a sense of responsibility to do what they could to improve their own health;

"Well you want to get better, you don't want things to go back as they were and all that; you have to help yourself" *Female, aged 69*

Few participants mentioned holding any reservations or perceived any demotivating factors about taking part. One found the length of the study off-putting, but was reassured by the information sheet stating that she could opt out at any time:

“The length of time, because it’s over 3 months, that was the main one [reservation]...as well, they said if you didn’t want to carry on you could get out of it, you know” *Male, aged 78*

Acceptability of assessments

Most participants were happy to attend appointments at UCL and complete the questionnaires, although some did state that they were long and repetitive:

“It took a little time to fill in all the bits and pieces, and I did think sometimes when I was filling it in that it did repeat itself a wee bit” *Female, aged 62*

One participant also had concerns about travelling to London, feeling that her immune system was low since completing treatment and was worried about infection:

“You’re in amongst people, and your immune system is crashing, you....you know, you meet the possibility of picking up infection, you know, it’s hard to avoid people on the tube!” *Female, aged 66*

Acceptability of delivery mode – telephone consultations

The telephone-based nature of the study was perceived to be appropriate:

“I think it [the telephone-based intervention] works very well....but I’m a very busy person, and to try and take any more time out to do it would have been intrusive and might have put me off’ *Female, aged 62*

Several participants remarked on the importance of meeting the person who was delivering the intervention at the baseline assessment in order to build a rapport:

“I think at the beginning it’s very necessary to have a face-to-face so you know who you’re dealing with” *Female, aged 68*

“I think possibly because if I hadn’t meet Chloe at first it might have been different. But I think going out for that first meeting helped the telephone because you had a face to face there, you know, I meet her, so I think that made the telephone calls that bit more personal” *Female, aged 66*

The motivational qualities of the telephone consultations were also recalled:

“Oh, I looked forward to those [telephone consultations], yes, well, it’s contact you see. You know, you’re not left on your own, you know someone is going to call you up and see how you’ve been getting on. Otherwise if you’d been left for the whole 12 weeks, after five or six, you’d say, ‘ahh, I’ve had enough of this’ like” *Male, aged 78*

Participants also commonly recount being motivated by not wanting to ‘let people down’:

“I did like having that outside help, and I don’t think I would have done all this on my own. When you know someone’s phoning, you know, you’ve got that sort of ‘oh I must do it!’, because I don’t want to let them down, and sometimes it needs quite a lot of discipline to do it on your own” *Female, aged 61*

Compliance with each behaviour change technique

Written information All participants reported reading the written information, although on the whole they felt that it reiterated advice that they had heard before:

“I’ve always known, you know, you should eat more fruit and veg and things like that” *Female, aged 64*

However, one participant said that he was not previously aware what constituted red and processed meat and what equated to a portion of fruit or vegetable:

“We didn’t realise that pork was a red meat....and what’s a portion [of F&V], like” *Male, aged 78.*

Others expressed scepticism about claims made regarding cancer prevention or cause, referring to numerous and conflicting claims in the wider media:

“You hear so many conflicting things, you know, one time coffee causes cancer according to the papers, and pepper, and stuff like that, you think, ‘yeah yeah’, it’s one of those things” *Female, aged 62*

“...I mean, in the course of a year they’ll tell you whatever you eat and drink will give you cancer” *Male, aged 63*

<u>Specific goal setting (using logbooks)</u> Some participants were happy to record goals and action-plans regularly even if they found it onerous:

“Yes, the goals were a good idea, otherwise you didn’t know where you were going really. The goals were.....achievable, you know, when you got there you thought ‘oh, that’s good’ and moved on. It was nice to have them” *Female, aged 66*

“Yes, I do write, you know, my goal was to eat more fruit, you know, try and eat a banana with breakfast, that sort of thing, but sometimes I found it a bit of a chore” *Female, aged 61*

However, others perceived it to be unnecessary towards the end of the study when they were maintaining their changed behaviours:

“Yeah, I wrote them down to start with, but towards the end it seemed a bit pointless because it was just repeating, you know, because I knew what my goals were” *Female, aged 69*

Also, one participant did not feel it was appropriate to set goals in advance due to unforeseen barriers:

“The only thing [improvement to the study] I can think of, with the log, try not to get you to make up your mind in advance....because circumstances change all the time, because a couple of times, I'd be enthusiastic at the beginning of the week, and then perhaps I'd be unwell, 2 or 3 days, and wasn't able to get out, you just can't plan in advance" *Male, aged 78*

There appeared to be a sense of disappointment when he failed to reach his goals.

Review of behaviour goals

Compliance with independent review of behavioural goals was mixed with some reporting referring back to previous behaviours:

"Yes, the diet ones, yes, referring back as well, you know, looking to see what we had last week, how many portions did we have last week" *Male, aged 78*

Where as others did not independently engage in this technique on a regular basis, particularly when behavioural targets were established and they were attempting to maintain behaviour:

"I didn't actually [look back at the end of each week to see how you got on]. I mean, I know I should be having my five-a-day and that sort of thing, so I just sort of moved forward" *Female, aged 62*

One participant made an active decision not to review behavioural goals, preferring instead to concentrate on the future. There was a suggestion that looking back was an unwanted reminder of previous "bad habits", and that concentrating on progress was more helpful:

"And I really didn't look at the first page until I'd finished the last page, and then I realised how far I'd come. And that was a conscious decision, not to look back. [Interviewer: 'What motivated that?'] Well, I felt if I kept looking back, it would, you know, sort of, I don't know, I felt like I wanted to go forward and not look back, I'm a great one for not looking back, it's training I've always adhered to, if you look back, um, there are things perhaps you don't want to dwell on, and it's better to go forward in a positive way, than look back and think 'oh dear'. *Female, aged 66*

Self-monitoring Compliance with self-monitoring was high with the vast majority of participants reporting routinely recording behaviours and finding it a very useful technique:

"Yeah! I completed them front to back, because it showed me that I was actually doing it, you know, it gives you quite a proud feeling really, you think 'yeah, I achieved that" *Male, aged 63*

"The fact that I had to write it down every day, and sort of face my demons! [laugh] I mean, if I had a day when I only had 3 [servings of F&V], I did feel a bit guilty" *Female, aged 62*

"The fact that you're logging everything you eat, meat and vegetable wise, again makes you aware 'oh, I better not eat that because it will go on my log" *Male, aged 78*

Participants were particularly motivated by the use of pedometers:

"You look and you put down whatever number is on there, and you think, 'oh dear, I didn't do much exercise yesterday', or 'oh, this is good, 7000! You know, you get a sense of achievement from it don't you" *Male, aged 78*

One participant however found the process of self-monitoring burdensome:

"The only thing is, it's a bit of a pain in the neck! [laughs] It's like going back to school, you have to do homework everyday, write down what you ate, what you did and all that, and if you're not a disciplined person, it's hard" *Female, aged 69*

Social support A number of participants recounted the benefits of social support. In the main this came from their partner/spouse. Several individuals also commented that they perceived their partner/spouse to have benefited from the intervention also;

“Yes, he’s [husband] been very very involved. In fact, when we were walking, we walked together so he was doing it as well as me, so he’s feeling fitter as well” Having a dog to walk was also viewed as a form of social support; *Female, aged 62*

“I go out every morning, and she [dog] asks for it, you know, she comes and sits by my computer and barks. So she’s been an inspiration, she loves going out” *Female, aged 66*

One participant however chose not to engage in social support as she was concerned her family would mock her:

“I was explaining once to Chloe, at one time they [weight loss programmes] used to say, ‘you need to weigh how much you eat’….and if they [her family] see me weighing what I am eating they will make fun of me, you know, ‘oh!! Mum is weighing her food!’ Because they know, I see food and I eat it! And um… so [laughs], I didn’t have to weigh or anything, but just say exactly what I’m doing. But I didn’t want any comments! [laughs]. Some people don’t mind, but I’m a little bit on the private side” *Female, aged 69*

Acceptability of timing of recruitment

The majority of participants thought the time at which they were invited to take part in the study was acceptable, with many believing it was important to approach survivors at a time proximal to treatment completion:

“I think it was a good time to start, and everything was fresh in our minds regarding...umm....what I’d been through”

[Interviewer; did you think it came at the right stage in your treatment?] “Yes, yeah, I did, particularly when you’ve been given good news, you think ‘right, I want to make sure’ you know, that I aid my own recovery, you know, get back to normal life” *Male, aged 78*

Another participant alluded to the concept of a ‘teachable moment’:

"It think you could leave it [recruitment] too long, I think there's a window there, while people are still interested in what they've been through, the surgery and all that, and to keep it rolling, like" *Male, aged 63*

However, one participant who was approached two weeks after completing treatment thought it was too soon. She had cancelled the first three appointments to attend UCL for her baseline consultation as she was still unwell:

"When I made the first appointment it was too soon, and the second I had an infection, and um, I think the third one, I spoke to Chloe and she said, 'no don't come', because I sounded so awful. Your energy level is so low, and your immune system is completely down, maybe three months afterwards would be better". *Female, aged 66*

Acceptability of length of the study

Twelve weeks was perceived as an appropriate intervention duration, being long enough to make changes but not so long that it became onerous:

"Twelve weeks is enough time to get you into habits. And I did get into the habits very quickly" *Female, aged 69.*

"It's long enough to get into your psyche, but not so long that it's going to become intrusive in your life". *Female, aged 62*

Perceived increases in physical activity

All participants perceived an increase in their activity levels. The majority mentioned being physically active before taking part in the study but not as regularly, or at a moderate intensity;

"Well, I did quite a lot of walking before, but not brisk walking, now at least three times a week I try and....because where we live there's a very steep hill, and when you get up the top of there you're really puffing! So at least three times I go into town and make a point of walking back up there". *Female, aged 64*

“I always used to think that gardening was enough, you know, a day in the garden...but sometimes a day in the garden would just be working in the greenhouse, or planting out, but now, we try to get a walk in, perhaps just to the newsagents, and by the time you get to the top there, your old heart starts to race a bit!” *Male, aged 78*

Walking was the most commonly chosen form of activity; however one participant started attending her local gym:

“I go to the gym for an hour, and do aerobics for one hour and the gym for one hour after that, that’s on a Monday, and on a Wednesday I do aerobics and yoga” *Female, aged 62.*

Perceived dietary changes

Perceived improvements to diet were commonly reported; both increasing F&V and reducing red and processed meat:

“When at one time I wouldn’t have considered twice getting bacon out for breakfast two or three times a week, that’s been cut down to once a week now, and we wouldn’t have considered that before” *Male, aged 78*

“I do try and have 5-a-day, and usually I do. You know, in the morning with breakfast, I’m in the habit of having something with that, and at lunchtime, and then at dinner, and then in the evening having some fruit. Before that I wasn’t really that bothered and I didn’t have much, maybe two a day, sometimes not even that” *Female, aged 61*

Barriers to changing behaviour

Barriers to achieving goals related to three main areas:

Effects of treatment:

“The tiredness....some days I feel really good and I do a lot of things....and some days I really can’t. If some days you don’t feel exactly yourself you tend to sit down and let yourself flop” *Female, aged 69*

"When I started getting treatment I got awful pains in my eyes, and this got very intense if I went out in the cold, it was very difficult to do it, to go out for periods of time when it's windy and cold, and this NE wind we had all winter was a real deterrent for me going out to do my exercise. And it carried on right until April, it was very difficult, so I'd wear my glasses and hats down over my eyes" *Female, aged 66*

Caring for elderly family members:

"That's [physical activity] really difficult because I have a lot of caring responsibilities for my mum. I've tried to do more but couldn't really"

"So I spent a lot of time rushing backwards and forwards to the hospital...and obviously when you're there you're sitting down and it's difficult to get any exercise....So I haven't been able to fit in any long walks at the weekends and that because of the circumstances" *Female aged 61*

Being on holiday:

"I had a fortnight in Cyprus, and you know, eating along with other people, so it you're invited out to a restaurant and you're eating out with other people, you're having to socialise, if I'm at home I can control what I eat, but if I'm out its more difficult" *Female, aged 64*

"Well, when I was on holiday, because you'd go around to a friends and have a barbeque, and there's always sausages and burgers on there....it's difficult, I mean, you can't just eat the chicken or whatever, if there's a burger there!" *Male, aged 63*

Recommendations for change:

In general participants were happy with the intervention and offered few recommendations for change. However one participant did report confusion about what constituted processed meat, despite the description in the written materials. This suggests a more detailed explanation should be provided in future:

"The only thing I had…I wasn't sure what processed meats were. I know some of them are listed, but now Chloe actually explained to me….that was the only thing…I was a bit confused about what actually was a processed meat and what wasn't" *Female, aged 64*

Another participant misinterpreted the information on fibre ratings, believing the list described healthy and unhealthy foods. Therefore this should also be more clearly explained:

"Because it's [list of fibrous foods] graded isn't it, down from what's good for you… from what's bad for you, to what's good for you" *Male, aged 78*

Also, one participant found the baseline questionnaires lengthy and tiring and suggested these are sent to participants to complete at home before they attend the appointment at UCL. No quote is available as this comment was made after the tape recorder had been turned off.

<u>Overall evaluation</u>:

The study was found to be helpful, providing a sense of awareness about lifestyle:

"We [participant and wife] did enjoy it, yes, no doubt about that. And it opened our eyes to diet and exercise, which if we hadn't come we wouldn't know about" *Male, aged 78*

Many participants also felt that their new behaviours had become habitual and they intended to continue in the future:

"It just comes naturally now, to look on the healthy side of things" *Female, aged 61*

"I couldn't walk past M&S without picking up a meat pie. Yes, it's done a lot of good, we won't go back now, no definitely not, we won't go back to how things were before, we're both converted!" *Male, aged 63*

Other points of interest:

It appears that the baseline assessment was an intervention in its own right, providing an opportunity for participants to reflect on their lifestyle:

“It’s an eye opener, I mean, when someone asks how much processed meat you eat, you think, maybe that’s not that good for you, you know, I think I have eaten healthier since” *Female, aged 62*

The intervention also provided some participants with a renewed sense of control over their lives which they had lost during their cancer treatment:

“When you’re coming out of it all [cancer and treatments] you feel like you’ve lost control of your life...A lot of it is about losing control, I mean, I said to my husband, in the last 12 months I’ve lost my hair, lost control of my bodily functions at different times, you just feel like you’ve lost complete control of everything. And just to gradually get the control back is a fantastic feeling” *Female, aged 66*

“Yeah, it definitely has mental benefits, you feel like you’re doing something, you’re in control, someone else isn’t controlling it for you” *Female, aged 68*

In addition a number of participants felt the study helped them to adapt from feeling like a patient to focusing on their own recovery:

“It gives you the chance to concentrate on something else, you know, if you’ve got a problem and are hospitalised for any length of time, you feel very remote from your situation, and uh, I feel the study has really helped get out of that” *Female, aged 69*

“You go from being frail and ill, and then suddenly, you’re treatment is over, you’re told you’re going to be ok, and psychologically you’ve got to get yourself back, and this has been a great help” *Female, aged 66*

Discussion

The primary aims of this study were to examine the feasibility, impact and acceptability of a personally-tailored, distance-based multiple behaviour change intervention in a sample of CRC survivors. Results indicate that the intervention was acceptable and feasible; it also resulted in behaviour change.

Recruitment was respectable (61%) suggesting a high level of interest in lifestyle interventions in this population. This recruitment rate was comparable to the only other intervention in CRC survivors to be conducted in the UK, which achieved a 65% recruitment rate (Anderson et al., 2009). Of interest was the variation in success of the two recruitment strategies used. There was a higher response from patients who were referred to me for a face-to-face discussion about the study by their consultant, compared to receiving an intervention by post. It may be that building a rapport with the programme deliverer resulted in a more positive response to the invitation. It is also possible that receiving a personal endorsement from the consultant was a powerful motivator. This concept was discussed in chapter 6 but briefly there is some evidence that a recommendation to change health behaviours by a health professional has been shown to be sufficient to initiate behaviour change (Jones et al., 2005). It is also possible that patients felt a sense of obligation as a result of the oncologists' endorsement. However the letter of invitation received by other patients was also signed by the consultant so both groups received such an endorsement.

It is interesting that many participants cited being motivated to take part in the study as a way of giving 'something back', having received an excellent standard of care from the hospital and staff. It was often not until they were taking part in the interventions that some reported becoming aware that the intervention may also help them. It is possible that such cognitions are self-protective, with participants reluctant to admit that they might benefit from behaviour change until they have experienced some success in making positive changes. Alternatively they may not have perceived health behaviour change to be of personal relevance.

The attrition rate was low (9%) and compliance with telephone consultations was high (95%). The study also received positive evaluation in the follow-up questionnaire and interview. Results from the post-intervention interviews suggested that participants thought the mode of delivery was appropriate and regular personal interactions during the telephone consultations helped maintain motivation and compliance.

Importantly only one adverse event was reported, that of digestive upset. However this occurred when the participant consumed eight portions of F&V in one day. This was not advised as part of the intervention, indeed participants were advised to increase F&V consumption slowly.

Compliance with the written materials was excellent with all participants stating they read all the materials. However, participants did not perceive them as offering any new information. It seems unlikely however that all participants would have been aware of the evidence for physical activity in combating cancer related fatigue for example. Therefore I cannot be sure that all the information presented was read and retained. A number of participants expressed a general scepticism towards claims in the media that various factors/behaviours cause cancer. Such scepticism is healthy given the magnitude of stories that reach the mass media, often including inaccurate of exaggerated claims of risk and failing to acknowledge study limitations. If the current study were to be repeated it may be worthwhile to discuss the importance of focusing on robust epidemiological evidence and being explicit about the strength of the evidence discussed in the written information. This may increase the credibility of the written materials. In addition it would be important to clarify the descriptions of red and processed meats and continuum of fibrous foods, points highlighted by participants during post-intervention interviews.

Compliance with the various behaviour change techniques associated with self-regulation theory was mostly good. There was particular enthusiasm for the use of self-monitoring, for both diet and physical activity. However one participant in particular found this technique burdensome. Follow-up interviews revealed the pedometer to be particularly popular as both a motivational cue and self-monitoring tool. The effectiveness of pedometers to promote increased physical activity in out-patients samples has been confirmed in a systematic review (Bravata et al., 2007), it has also been found to be effective among a sample of breast cancer survivors (Vallance et al., 2007).

Compliance with specific goal-setting was less consistent with most participants using the logbooks to review set goals ‘some of the time’. Data from the follow-up interviews suggested that some participants felt that the goal setting process was unnecessarily repetitive. My experience of delivering the telephone consultations was a sense of engagement with specific goal setting and action planning at the start of the intervention, with participants finding it helpful to start with small, manageable, and specific changes. However this engagement waned during the final weeks and it was difficult to prompt specific goal settings at this time. This tended to occur among those who felt like they were ‘already in the habit’ and were most often at the maintenance stage of behaviour change having previously met behavioural targets. If this study were to be repeated it might be specified that once participants reach behavioural targets, repetition of goal setting and action planning can be omitted.

Although participants did not always recall personally reviewing behavioural goals on a weekly basis, at the start of each consultation I asked how they had been ‘getting on’ over the last two weeks and encouraged every participant to refer back to their logbooks to recount the previous week’s behaviours. This ensured compliance with the technique of evaluating behavioural goals, even if this was not done independently. In addition, compliance with self-monitoring would have meant indirect review of goals on a daily basis as participants were aware of their goals when recording their behaviour.

There was a general consensus that the time at which participants were approached in relation to treatment completion was appropriate, with a sense that motivation to make behaviour changes would reduce as time elapsed. This is in accordance with the concept of cancer treatment and diagnosis presenting a ‘teachable moment’ for behaviour change. However one participant had to cancel three appointments for her baseline assessment, and another withdrew before consenting, citing side-effects of chemotherapy. Therefore acceptability of this timing is likely to be dependent on the extent to which survivors are adversely affected by the treatments they have received. It is also important to recognise that this positive response is biased by the fact that the comments were made by those who had successfully completed the study. One of the reasons for non-response may have been that the invitation was perceived to be too soon after treatment completion. Indeed, one eligible patient provided his reasons for not taking part in the study, stating that he had forthcoming appointments for “scans and blood tests” and did not feel well enough to travel to London.

Result from the post-intervention interviews suggest that for some participation in a behaviour change intervention provided a focus, a sense of purpose and a feeling of control. This was supported by increases in Mastery Scale scores reflecting an increased sense of general control. In recent years there has been growing interest in research examining adjustment to chronic illness in relation to perceived control. Perceived control has long been identified as an important determinant of health behaviour (e.g. King et al., 1984) and as such is included in a number of social cognition models i.e. the Health Belief Model and the Theory of Planned Behaviour (Conner & Norman, 2005). It is beyond the scope of this thesis to discuss this concept in great depth; however in general studies have shown an adaptive role of control beliefs when coping with cancer diagnosis and treatment (e.g. Barez et al., 2007; Henselmans et al., 2009). In addition, a recent prospective study examining changes in perceived control before and after diagnosis found that maintenance of control after diagnosis was associated with lower levels of psychological distress (Ranchor et al., 2010). It is possible therefore that behaviour change interventions may bolster general perceived control (perhaps as a result of participants perceiving such actions may improve their outcomes) and in turn have psychological benefits. To my knowledge no other health behaviour intervention study has examined changes in perceived control.

During the follow-up interviews, participants reported increases in activity levels and F&V consumption and reductions in red and processed meat intake. This was corroborated with outcome measures. Physical activity levels, as measured by the Godin LTEQ, showed all participants had increased activity levels at follow up with an average increase of over two hours of moderate intensity activity a week. Seven were meeting the recommended guidelines compared to none at baseline. It was also encouraging to see that three participants were engaging in strenuous physical activity on a weekly basis. These results compare favourably to previous multiple-behaviour change interventions in cancer survivors. The greatest increase in physical activity levels reported in the studies reviewed earlier was 53 minutes per week of moderate intensity exercise. However the follow-up assessment in this study was conducted two months after completion of the intervention. Activity levels tend to decline as time since intervention completion elapses; therefore it is likely that activity levels immediately after the intervention were higher. Comparing increases in self-reported physical activity to increases in steps per day (as measured using a pedometer) provides some insight as to the accuracy of self-reported activity levels. There is currently no reliable index for how many steps equate to a particular duration of activity, however Tudor-Lock et al (2002) estimate that the number of steps that equate to 30 minutes of at least moderate intensity activity fall between 3000-4000 steps. The average increase in minutes of moderate/strenuous activity per day in the current study was 22, and increase in steps was 1941. Therefore recorded changes in step counts are in accordance with self-reported increase in physical activity.

Average F&V consumption post-intervention was almost seven portions per day, with an increase of just over three portions per day across the group. Follow-up consumption of F&V intake after the FRESH START trial (Demark-Wahnefried et al., 2007a) was comparable (6.2 portions per day), however this equated to a 1.1 portion increase from baseline, similar to the 1.2 portion increase reported on completion of the RENEW trial (Morey et al., 2009a). One of the two participants who was exceeding recommended levels of red meat consumption at baseline had reduced their consumption to fewer than 500g a week at follow-up. The other participants' reduction was minimal.

Only two participants were exceeding the recommended intake of red meat at baseline and processed meat consumption was also low. However there were disparities between comments made during the follow-up interviews and self-reported baseline levels of red and processed meats. Two participants recount during the interview that they were now eating very little processed meat. When asked if this was a big change, they said yes, quantifying their statement with their estimation of pre-intervention intake. For one participant this reflected an under-estimation of two portions per week, for another the under-estimation was five portions a week. A similar pattern was seen in one participant regarding red meat consumption. The individual was eating >500g of red meat at both baseline and follow-up, but his perception was a large reduction. There are many possible explanations for this inconsistency. It may be that responses given during the baseline assessment was influenced by social desirability bias. Alternatively the low baseline levels may be a result of inaccurate recall and the exercise of self-monitoring consumption during the intervention made the participants' more aware of their actual consumption. Indeed, a recent study compared the validity of FFQ and 24-hour food diary with objective measures among participants in the WHEL study. The authors reported those in the intervention group had more accurate recall (Natarajan et al., 2010).

Although not statistically significant, there was a trend for improvements in QoL and physical function, with the exception of one participant who reported considerable reductions in QoL, physical function and fatigue at follow-up. This individual was suffering with a viral infection when she attended the follow-up assessment and this may account for these reductions in scores. Four participants reported a mean increase in total FACT-C scores of more than 5 points, exceeding the cut-off for minimally important differences (Yost et al., 2005). A previous multiple-behaviour change intervention study which also used the FACT to examine QoL found no notable change, however baseline levels were high suggesting a ceiling effect. In addition, the RENEW trial reported a slowing in the rate of decline in physical function (as measured by the SF-36) in their sample of older, long-term cancer survivors. Cross-sectional data represented in chapter 4 and reported in previous literature suggests a positive association between multiple health behaviours and QoL. Therefore the results of this study support the argument for promoting behaviour change in this population.

Limitations

This was a pilot study with numerous limitations. The study included only motivated individuals and it is not possible to speculate if compliance and attrition would be comparable in a less motivated group. The lack of control group means it is not possible to attribute any changes in behaviour to the intervention. Similar changes may have occurred regardless of the intervention as a function of time. This is also true for other outcome measures including QoL, physical function, fatigue and control. The study was also subject to limitations inherent in all self-reported measures of behaviour, that is, a tendency to over report healthful behaviours (i.e. F&V consumption) and under report unhealthy behaviours. The study would have benefitted from objective measures of outcomes measures, i.e. accelerometry and blood plasma levels of vitamin C, E, and beta-carotene. Excluding survivors who had a sub or total-illeostomy also limits generalisabiltiy to all CRC survivors.

However, this is the first distance-based multiple behaviour change intervention to be conducted in the UK and it shows promise in encouraging positive behaviour change in a vulnerable population of CRC survivors.

Chapter 9

General Discussion

Aims

The aims of this thesis were to examine the evidence for the role of health behaviours in improving outcomes among cancer survivors (chapter 1) and to investigate the extent to which cancer survivors in England adhere to healthful behaviours (study 1). The focus of the thesis then narrowed to colorectal cancer (CRC) survivors, with study 2 investigating health behaviours in this group. The relationship between health behaviours and quality of life (QoL) was examined (study 3), along with a number of other factors that may influence health behaviours, including attributions of disease (study 4) health professional advice (study 5), and perceived barriers and benefits (study 6). Having concluded that health behaviours among CRC survivors were suboptimal, that health professional advice on health behaviours would be welcomed, and that health behaviours were associated with better QoL, a distance-based behaviour change intervention was developed and its feasibility and acceptability examined in a pilot study (study 7).

Summary of findings and contribution to the literature

My research began with two studies of cancer survivors; one in a general population sample which included survivors of numerous cancers, and the second in a clinical sample of CRC survivors. Both were novel in being conducted in the UK. The subsequent publication of the English Longitudinal Study of Ageing (ELSA) study in the European Journal of Cancer represents an important contribution to the survivorship literature (Grimmett et al., 2009).

The first study found that cancer survivors had similar rates of alcohol consumption and current smoking levels than those without a history of cancer, but were less likely to be physically active and more likely to be ex-smokers. It appears that the smoking rates among UK cancer survivors are comparable to rates in the US and Australia (Coups et al., 2005; Bellizzi et al., 2005; Eakin et al., 2007). My results for physical activity indicated lower levels of physical activity than reported by previous studies (Coups et al., 2005; Bellizzi et al., 2005; Eakin et al., 2007), although in part this may be explained by the difference in measures of physical activity used. Use of a lower threshold may have some value given that the proportion of older adults in England meeting the recommended guidelines is so low; 31% of 55-64 year olds, 19% of 65-74 year olds, and 6% at age 75 and over (Craig & Mindell, 2007).

My finding that physical activity appeared only to be lower among those who reported receiving treatment for cancer in the last 2 years is interesting. It supports the notion that physical activity is often reduced shortly after diagnosis but recovers in the years following treatment completion (e.g. Hawkes et al., 2005). Unfortunately the sample size did not permit reliable analysis and it would be of interest to see if this finding was replicated in a larger sample.

I also found that physical activity was associated with lower levels of depression in cancer survivors. Few other population-based studies have examined this association, although a recent review found a small effect of physical activity on depression (Speck al., 2010). However studies may have been subject to a floor effect with depression levels already being low, leaving little room for improvement. Targeted interventions among those with high levels of depression may have a more potent effect. More research is clearly required in this area. Combined with the finding that depression scores were higher among cancer survivors who smoke, these observations provide additional support for the idea that health behaviours may be relevant to psychosocial outcomes.

In the large clinical sample of CRC survivors levels of physical activity were similar to those reported in study 1. In addition many survivors reported doing less physical activity at the time of the survey than before their cancer diagnosis. However this may be an ageing effect rather than being associated with cancer and treatment. F&V consumption was higher than population averages, and heavy drinking and smoking were also infrequent. Nonetheless, over half of respondents were still not meeting the recommended consumption of five portions of F&V a day, despite almost 20% reporting an increase in consumption since diagnosis.

In this clinical sample, I also found more healthful behaviours were associated with better QoL. Those who engaged in at least five bouts of moderate/vigorous physical activity per week had higher global, physical, role and social function than those who did not. Eating 5-a day was also associated higher global, physical role and cognitive function, and moderate alcohol consumption with better physical, role and social function compared to non-drinkers. There was a linear association between the number of healthful behaviours and global QoL and physical function. Physical activity, F&V consumption and moderate alcohol consumption were also associated with less fatigue. Those who were physically active also reported less pain and less sleep disruption. F&V consumption was associated with less constipation. Adherence to multiple behaviours was associated with less pain, less dyspnoea and less constipation. Alongside evidence that heath behaviours reduced the risk of recurrence, secondary primary cancers and comorbid disease, this adds to the case for health behaviour interventions in cancer survivors.

There was no association between BMI and global QoL in this study which was interesting given the consistent evidence of BMI on QoL in general population samples. However results from previous studies suggest these limitations may only be experienced in obese rather than overweight individuals. Given overweight and obese participants were combined in the present study (due to sample size limitations) I may have missed an important association. It would be of interest to explore this relationship in a larger sample.

The finding that non-drinkers had lower QoL than moderate drinkers was also of interest and has been noted in healthy population samples, but little comparable evidence is available among cancer survivors. It may be that individuals who abstain do so because of generally poorer health, or have been told to cut down due to other conditions such as diabetes, therefore explaining the lower QoL. Alcohol consumption may also be associated with socialising which may contribute to higher levels of QoL.

A strength of this study was its use of a cancer-specific measure of QoL which provided data on cancer related symptoms such as fatigue and pain; few other studies examine the relationship between physical activity and cancer related symptoms or subdomains of

QoL. Also, none have looked at the association between F&V or alcohol intake and subdomains of QoL or cancer-specific symptoms. This data supports two previous studies from the US which found favourable QoL scores among those adhering to numerous healthful behaviours (Blanchard et al., 2008; Demark-Wahnefried et al., 2000).

I also used data from the clinical sample to get some insight into cancer attributions, health professional advice and the associations with behaviour, as well as perceived barriers and benefits to physical activity participation.

The results showed that cancer survivors were reluctant to attribute the development of their disease to lifestyle factors. However participants frequently endorsed the role of health behaviours in preventing recurrence. This is in accordance with the previous literature (Rabin & Pinto et al., 2005; Costanzo et al., 2007; Costanzo et al., 2010). The lack of attribution for current diagnosis is consistent with the concept of avoiding self-blame, and endorsement of health behaviours for future health is consistent with increasing self-efficacy. Results also showed that men may be less likely to endorse any factor in the development of their cancer, with lower attribution scores on almost all items.

I found no association between attributions of cause of disease and behaviour. However a perceived importance in F&V and physical activity in preventing cancer recurrence was associated with higher rates of those behaviours. No association was seen for alcohol attributions and consumption. This may in part be explained by the generally low levels of alcohol consumption within this sample.

Perceived importance of F&V in disease development was associated with a greater likelihood of behaviour change. Almost a quarter (23%) of those who endorsed this factor reported increasing consumption since diagnosis, compared with 13% who did not perceive this to be important. However, when examining separately by sex this relationship was only seen among women. Reductions in alcohol consumption were also more prevalent among those who believed alcohol to be importance in cancer occurrence. There was a similar non-significant trend for physical activity but the sample size was very small and this analysis was underpowered and analysis by sex was not possible.

All those who reported increasing their physical activity level since diagnosis believed this factor to be important in cancer recurrence. No associations were found between increase in F&V consumption and perceived importance in recurrence. The same was true for alcohol reduction.

Together these results give some evidence that positive attributions towards healthful behaviours in cancer occurrence and recurrence may be associated with favourable behaviours and positive behaviour change. However the results were patchy and the retrospective nature plus the possibility that some changes were due to side effects of disease or treatment, meant that this are needs more attention.

I found that participants who recalled receiving health professionals’ advice to increase F&V consumption were more likely to report doing so. A similar trend was seen for the recommendation to increase physical activity. Recall of advice was also associated with perceived importance of that behaviour in the cause of cancer. This is an important contribution to the field, as the relationship between health professional advice and attribution of disease has not previously been examined. Given that such attributions may be associated with positive behaviour change this may present a way of motivating survivors to change their behaviour. It also provides support for the role of health professionals in promoting secondary prevention among cancer survivors. There is however a potential problem. Previous research has found that attribution of cancer to health behaviours is associated with feelings of blame, distress and depression (Costanzo et al., 2007). However this was not the case if the individual changed their behaviour. Therefore if health professionals are to be encouraged to promote behaviour change among cancer survivors, this should be thoughtfully considered and support for change offered whenever possible. Translating such recommendations into a clinical setting is far from straightforward. Until such a time those resources are in place, perhaps health professionals could be encouraged to refer patients to trustworthy sources of supports, such as Macmillian Cancer Care and Cancer Research UK who provide support and resources for positive behaviour change.

It should also be recognised that the proportion of health professionals who discuss secondary prevention with their patients was low. This is novel data to the UK and is an important part of addressing the provision of lifestyle advice among cancer survivors in this country. Further research examining the reluctance of health professionals to discuss these factors is warranted, as are investigations as to how health professionals may be encouraged to engage more readily in the promotion of secondary prevention.

It appears that perceived barriers and benefits to physical activity have little association with activity level among this population. Participants frequently cited cancer or treatment-related barriers to participation, which accords with previous studies. However these barriers have no association with reported levels of activity. No other studies have assessed barriers to physical activity among cancer survivors using such an open response format or examined the association with reported behaviour. While this study presented some insights into the perceived barriers to activity, few barriers were associated with actual behaviour, and those that were are not modifiable. This information does however hold practical implications. It suggests that when attempting to encourage activity in this group, promoters should acknowledge symptom/treatment related barriers and highlight the evidence that activity may ameliorate some of these factors.

It was also interesting to note that very few participants reported cancer-related benefits of regular physical activity. This is in accordance with the lack of information they appear to receive from health professionals as to the importance of such behaviours in relation to cancer. Given that a positive association was found between perceived cause of disease and behaviour change, and positive attributions were associated with health professional recommendations, it is possible that providing more information on the benefits of physical activity, as they relate to cancer aetiology, may help motivate cancer survivors to make positive behaviour changes.

My final study, the multiple behaviour change intervention was very well received and effective in producing behaviour change. It is also the first such intervention to be conducted in the UK. I approached 18 patients and 13 (72%) expressed interest in taking part in the study, suggesting a high level of interest among CRC survivors who have recently finished treatment. Attrition rate was low (9%) and compliance with the telephone consultations and behaviour change techniques were high, suggesting the study was both feasible and acceptable. However there was evidence of some reluctance to continue with goal setting and evaluation towards the end of the study when behaviours were perceived to be habitual. Changes in behaviours were also extremely promising, with an average increase of 125 minutes of moderate physical activity and 27 minutes of vigorous physical activity, all participants were exceeding the recommendation of five servings of F&V a day by the end of the study, consumption of processed meat was less than one portion a week, and only one participant was exceeding the recommended weekly consumption of red meat. There was also a trend for increases in QoL, physical function and feelings of general control.

In addition to its novelty this study had a number of strengths. A small number of multiple behaviour change interventions in cancer survivors have been previously published, however few are truly theoretically based. Most reported being guided by SCT but all vary in the behaviour change components described. By following the behaviour change techniques outlined by Abraham and Michie’s (2008) taxonomy, I explicitly stated the theoretical underpinning (self-regulation) of the intervention and the behaviour change techniques associated with this. Coupled with a comprehensive process evaluation this allowed for a greater understanding of the level of compliance with all of the behaviour change techniques and greater insight into what worked, and why. The low intensity (6 telephone consultations in 12 weeks) and the distance-based nature of the intervention also limited the burden on either the participant/s or the individual/s delivering the intervention. The intervention also requires minimal resources making it cheap to run. As such there is the potential for a similar intervention to be expanded to a larger trial and potentially applied to a clinical setting where financial and time resources are limited.

Limitations

The findings in this thesis are subject to a number of limitations.

Bias and inaccurate estimates: Data on health behaviours presented in my first two studies are likely to be biased by non-response. The ELSA sample, drawn from households who participated in the Health Survey for England, is representative of non-institutionalised people aged over 50 living in England. However, wave 1 achieved a household response rate of 70% and although the main reason for non-response was refusal some also report feeling too unwell (Marmot et al., 2003). Therefore there is the possibility of a healthy respondent bias. There is also potential bias from the response rates from the HSE surveys from which ELSA wave 1 is drawn (in 1998, 1999 and 2001) for which response rates were 74% to 76%. Similarly, the questionnaire survey in CRC survivors achieved a 49% response rate. Although this is respectable compared to similar studies, I have no data on non-responders and there was likely a healthy respondent bias. This may also be compounded by the fact that the questionnaire was entitled ‘health and lifestyle questionnaire’ and it was not possible to disguise the purpose of the survey. Consequently the true prevalence of health behaviours may be lower than the observed values.

Both studies also depend on self-reported behaviours, which often overestimate healthful behaviours such as F&V consumption and physical activity, and under-report unhealthy behaviours such as alcohol consumption and smoking. Given the increasing acknowledgement of the role of health behaviours in the aetiology of cancer, an additional social desirability bias may be present. Therefore it is possible that cancer survivors are even less accurate than healthy populations. As a result the difference in levels of physical activity participation found in the ELSA study may not reflect a true difference between these populations. Similarly, lifestyle behaviours are unlikely to be as healthy as data in studies 1 and 2 suggest.

In the study of CRC survivors I also asked participants to retrospectively recall health behaviours before their diagnosis. Not only is the recall of behaviour several years previous likely to be inaccurate, I was also asking participants to reflect on their lifestyle before a major life event.

Recall of health professional advice is also likely to be biased by recall error, particularly among those several years since diagnosis. This particular sample may have been more likely to have received this advice because the participants’ consultants had agreed to help with this study, suggesting an interest in the role of health behaviours among cancer survivors. Also, some of the health professional recommendations may have been related to other comorbidities, such as diabetes and cholesterol.

In addition, respondents were predominately white British and with higher than average SES and the sample only included those without metastatic disease, thus limiting generalisability.

Cross-sectional data: The cross-sectional nature of the data also means direction of causation cannot be inferred. For example, when interpreting the association between physical activity and QoL, I wanted to conclude that being physically active resulted in favourable QoL. However, when trying to explain the positive association between overweight and QoL, I wanted to attribute this association to overweight participants having less severe side effects of cancer and treatment, rather than assume being overweight resulted in higher levels of QoL. Similarly, in relation to my findings of attribution of disease and health professional recommendations; I was inclined to believe that favourable behaviour and behaviour change were due to holding positive attributions or being told by a health professional to change their lifestyle. However it is equally possible that, for example, when physically active participants are asked whether they think such a behaviour will prevent their cancer from returning, they may say yes, as it is comforting to perceive an existing behaviour to be benefiting future health. The same may be true for recall of health professional advice; those who did not make positive behaviour change may be less likely to acknowledge that they had previously been encouraged to do so.

Clearly prospective and controlled intervention studies are required to provide a more accurate picture of these associations; however the cross-sectional data presents a good starting point and highlights potentially interesting directions for future study.

Sample size: Although the ELSA study was conducted in a large population-based sample, sample size prohibited exploration of variation by cancer site, or time since treatment completion. In study 2, small sample size also inhibited reliable analysis of associations between smoking and heavy drinking and QoL, as well as between attributions or health professional advice and behaviour or behaviour change. There was also a significant amount of missing data on the attribution of physical activity and F&V and cause of disease. This may reflect a reluctance to attribute such causal factors to their disease and is likely to have biased the analyses examining associations with behaviour. There was also a lack of variance in responses to the items of prevention of cancer recurrence.

Questionnaire measures: The QoL measure used in this study, the EORTC-QLQ-C30, was developed for use in a clinical setting. It could therefore be argued that some items may have been unnecessary for otherwise healthy survivors. However, given that the effects of the disease and its treatment can persist for many years after treatment completion, using a more generic questionnaire, such as the SF-36, may have excluded important factors.

The ELSA study was also limited by a lack of dietary information. Similarly, in light of the evidence of its association with CRC occurrence, it would have been of interest to examine red and processed meat intake in the CRC sample.

Intervention study: My final study, a pilot study of a multiple behaviour change intervention was carried out in a very small sample. In addition, I do not know exactly how participants were selected by medical staff at two hospitals, although I did achieve a good response rate among those whom I was given permission to approach.

The study ideally would have included a control group, but it was beyond the scope of this PhD to recruit more participants. The lack of control group means that improvements in behaviours, QoL and control may have been a product of time rather than the result of the intervention. It would also have been an advantage to include objective measures of behaviour change such as actigraphs to measure activity and blood samples to determine changes in nutrient markers of increases in F&V consumption; but this was too costly for the current study.

The intervention failed to address weight loss among those who were overweight/obese. Given that the majority of participants were overweight, this may need to be considered if a larger trial were to be conducted. It would also have been advantageous to have a longer follow-up in order to gain some insight into whether behaviour changes were sustained in the months following completion of the intervention.

In addition, participation in the study was apparently often motivated by a desire to ‘give something back’ and contribute to research that may help others. Therefore it is not known how recruitment rates would be affected if a similar intervention was offered simply as a lifestyle programme for cancer survivors with no connection to science or research. Similarly, participants reported a motivation to adhere and comply with the intervention so as not to ‘let anyone down’; fearing discontinuation might affect the success of the study. In addition, given the difficulty experienced implementing specific goal setting and action planning towards the end of the study, quantitative data on compliance would have been of interest.

It would have also been useful to have Theory of Planned Behaviour questions specific to the dietary change, i.e. attitudes to increasing F&V and attitudes towards reducing red and processed meat. However the questionnaire was already long, taking at least 30 minutes to complete. Therefore the addition of more questions would have made completion burdensome to participants.

On a positive note, the intervention was feasible to deliver in the post-treatment context with reasonable recruitment rates, high compliance to telephone consultations and low attrition. Participation was associated with positive behaviour change suggesting behaviour change interventions using techniques derived from self-regulation theory hold promise in eliciting behaviour change in this population. Expansion of this trial to a larger RCT would address a number of the limitations described above, as well as allow the evaluation of the intervention in affecting behaviour change.

Future research

This thesis presents a number of interesting results and important contributions to this field of research. However the role of health behaviours in cancer survivors is a relatively new field of research and many questions have been raised that warrant future research.

More research is needed that examines the prevalence of health behaviours among survivors of cancers at other sites.

In the light of an association between attribution of disease and health behaviour practices, it would be interesting to investigate the association between attribution of disease and health behaviour practices in a larger sample and explore how such attributions are formed, whether they are amendable to change and what their associations are with behaviour. It would also be important to consider any negative implications of positive attributions of health behaviours to cause of disease and how this might be prevented. Similarly the potential role of health professionals in providing information regarding healthful behaviours is worthy of further investigation. Preliminary evidence suggests that health professionals may have an important role to play in advising cancer survivors on appropriate health behaviours. However little is known about the positive or harmful effects this information may have, or indeed the feasibility of engaging health professionals in this practice.

It appears that CRC survivors are receptive to, and engage with, a distance-based multiple behaviour change intervention, which may lead to positive behaviour changes. However, as already expressed, the study needs to be repeated in a larger sample and with objective measures of behaviour in order to confirm these results. I have been awarded funding from the World Cancer Research Fund to conduct such a study. Following on from this larger scale pilot would be a full-scale RCT in order to explicitly test the efficacy of such an intervention, and include longer follow-up in order to assess sustainability of behaviour change.

As mentioned in chapter 1 the National Cancer Survivorship Initiative (NCSI) was launched in 2008 to improve the care and support for those living with and beyond cancer. The NCSI recently published their “vision” document, providing an update of the first year of their work (Department of Health et al., 2010). One of the key findings from the mapping exercise was a lack of verbal and written information on areas such as diet, exercise and other potential beneficial lifestyle changes. They go on to describe the piloting of ‘Health and Wellbeing Clinics’. These clinics will be established in 10-15 NHS trusts across the UK with the aim of providing support to those who have completed treatment for cancer. This will include advice and information on healthful lifestyles. If results from a large RCT suggested that the intervention piloted in this thesis was successful in eliciting behaviour change, these clinics could present the perfect setting from which to deliver such an intervention on a national scale. In support of this argument a recent review of advising cancer survivors about lifestyle (conducted by the NCSI) concluded that information on the benefits of healthful lifestyle should become part of routine clinical care of cancer survivors, not just on completion of treatment, but encouraged at regular intervals during the cancer experience (Davies et al., 2010). It is therefore imperative that more research examines the most effective way of communicating this information, and how cancer survivors can best be equipped with the skills necessary to make positive behaviour changes.

Concluding remarks

I hope this thesis has succeeded in presenting an overview of the existing literature that suggests cancer survivors are likely to benefit from engagement in healthful behaviours. It also illustrates the scope for improvement in such behaviours among cancer survivors, and particularly CRC survivors, in England. Finally results from the evaluation of study 7 suggest a distance-based multiple behaviour intervention may hold promise in encouraging such behaviour change among this vulnerable population.

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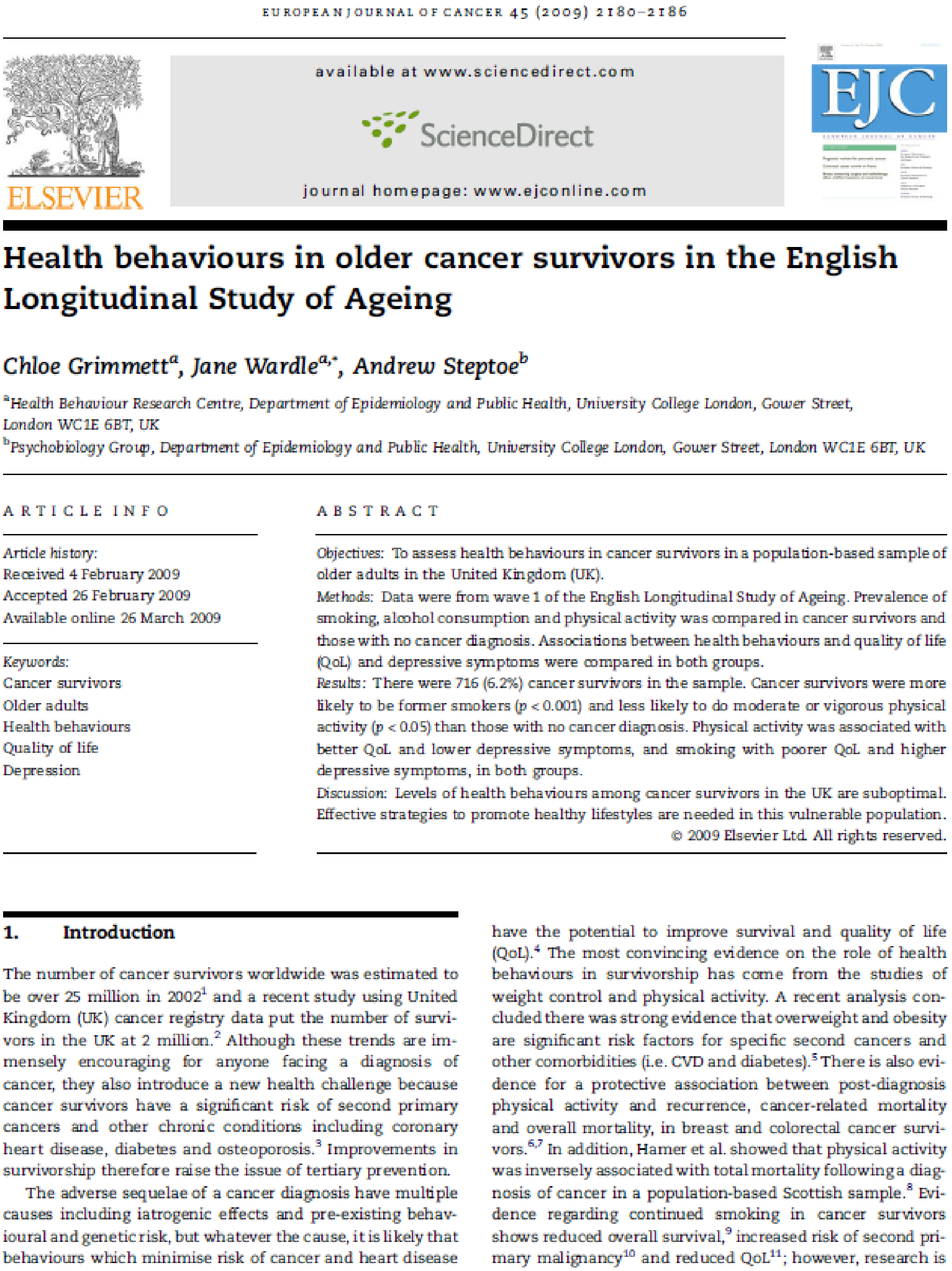
Appendices

Appendix 1: Published paper; health behaviours in older cancer survivors in the English Longitudinal Study of Ageing



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Health behaviours in older cancer survivors in the English Longitudinal Study of Ageing

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ABSTRACT

Objectives: To assess health behaviours in cancer survivors in a population-based sample of older adults in the United Kingdom (UK).

Methods: Data were from wave 1 of the English Longitudinal Study of Ageing. Prevalence of smoking, alcohol consumption and physical activity was compared in cancer survivors and those with no cancer diagnosis. Associations between health behaviours and quality of life (QoL) and depressive symptoms were compared in both groups.

Results: There were 716 (6.2%) cancer survivors in the sample. Cancer survivors were more likely to be former smokers ($p < 0.001$) and less likely to do moderate or vigorous physical activity ($p < 0.05$) than those with no cancer diagnosis. Physical activity was associated with better QoL and lower depressive symptoms, and smoking with poorer QoL and higher depressive symptoms, in both groups.

Discussion: Levels of health behaviours among cancer survivors in the UK are suboptimal. Effective strategies to promote healthy lifestyles are needed in this vulnerable population.

1. Introduction

The number of cancer survivors worldwide was estimated to be over 25 million in 2002[1] and a recent study using United Kingdom (UK) cancer registry data put the number of survivors in the UK at 2 million.[2] Although these trends are immensely encouraging for anyone facing a diagnosis of cancer, they also introduce a new health challenge because cancer survivors have a significant risk of second primary cancers and other chronic conditions including coronary heart disease, diabetes and osteoporosis.[3] Improvements in survivorship therefore raise the issue of tertiary prevention.

The adverse sequelae of a cancer diagnosis have multiple causes including iatrogenic effects and pre-existing behavioural and genetic risk, but whatever the cause, it is likely that behaviours which minimise risk of cancer and heart disease have the potential to improve survival and quality of life (QoL).[4] The most convincing evidence on the role of health behaviours in survivorship has come from the studies of weight control and physical activity. A recent analysis concluded there was strong evidence that overweight and obesity are significant risk factors for specific second cancers and other comorbidities (i.e. CVD and diabetes).[5] There is also evidence for a protective association between post-diagnosis physical activity and recurrence, cancer-related mortality and overall mortality, in breast and colorectal cancer survivors.[6,7] In addition, Hamer et al. showed that physical activity was inversely associated with total mortality following a diagnosis of cancer in a population-based Scottish sample.[8] Evidence regarding continued smoking in cancer survivors shows reduced overall survival,[9] increased risk of second primary malignancy[10] and reduced QoL[11]; however, research is mostly limited to head, neck and lung cancer survivors. Alcohol's role in survivorship is complex because it is associated with raised risk for certain cancers, but at the same time is cardio-protective in modest quantities[12]; nonetheless alcohol intake should clearly be modest at most. In addition to effects on morbidity and mortality, there is evidence that healthful behaviours in cancer survivors are related to better QoL[13] and lower depression,[14] giving an additional reason for promoting healthy lifestyles in this vulnerable group.

The recent review by the World Cancer Research Fund concluded that cancer prevention recommendations for the general population should also be applied to cancer survivors, including advice to maintain a healthy body weight, engage in regular moderate physical activity, eat at least five portions of fruit and vegetables a day, limit alcohol consumption and not to smoke.[1] The survivorship literature indicates that these recommendations may be even more important because of the raised risk of other adverse health outcomes in cancer survivors. Research to assess health behaviours in cancer survivors is therefore vital to identify the scale of the problem.

Large-scale, population-based studies have been conducted in the United States (US)[15,16] and Australia.[17] Generally they have found similar levels of physical activity, alcohol consumption and smoking in survivors as in the general population. To date, no studies of health behaviours in cancer survivors in England have been reported. The aim of the present analyses was to assess the prevalence of smoking, alcohol consumption and physical activity in older adults with a history of cancer compared with those with no cancer history using data from a population-based sample. We also assessed whether smoking and inactivity were related to poor QoL and greater depressed mood in the same way in cancer survivors as in people with no history of cancer.

2. Methods

2.1. Participants

Data for these analyses were from wave 1 of the English Longitudinal Study of Ageing (ELSA) carried out in 2002. This nationally representative, population-based sample was drawn from people aged 50 or over who had taken part in the Health Survey for England in 1998, 1999 or 2001. Data from 11,515 adults aged 50–99 are used for these analyses. Details of the ELSA methodology have been published previously,[18] but briefly involve a nurse assessment, an interview during a home visit, and a self-completion questionnaire to return by post which includes simple items on smoking, alcohol and physical activity, as well as established measures of depression and quality of life.

2.2. Measures

2.2.1. *Demographic*

Participants reported their gender, age, race/ethnicity (coded as white versus non-white) for these analyses and marital status (coded as married or cohabiting versus single, divorced, separated or widowed). Education was used as an indicator of socioeconomic status (SES). Participants were divided into three groups: higher education, intermediate qualification and no educational qualification.

2.2.2. *Health behaviours*

Smoking was assessed by asking participants if they smoked currently, were former smokers or had never smoked. Alcohol consumption was assessed by asking if they had consumed any alcohol in the last 12 months. Among those who reported having alcohol, respondents were divided into those who had two or more versus less than two drinks per day. Physical activity status was categorised as taking part in vigorous or moderate activity more than once a week versus once or less a week.

2.2.3. *Cancer history and arthritis*

Participants were asked if they had ever been told by a doctor or other health professional that they had 'cancer or any other kind of malignancy'. All those who answered yes were categorised as cancer survivors. This is in accordance with the National Cancer Institute's definition of a cancer survivor which states that from the time of diagnosis and for the balance of life, a person diagnosed with cancer is a survivor.[19] Those reporting a history of cancer were also asked to specify the kind(s) of cancer with which they were diagnosed and if they received treatment for their disease in the last 2 years. Arthritis was assessed as a confounder of opportunities for physical activity, and participants reported if they had ever been told by a doctor of other health professional if they had arthritis (including osteoarthritis and rheumatism).

2.2.4. *Quality of life and depression*

Quality of life was assessed using the CASP-19. This is a 19-item Likert-scaled index containing sub-domains from which the acronym is derived; control, autonomy, self-realisation and pleasure. The CASP-19 was developed specifically to assess the quality of life in early old age, and is based on a needs satisfaction perspective. Scores range from 0 to 57 with a higher score indicating higher QoL. The four sub-domains have shown good internal reliability (Cronbach's alphas between 0.6 and 0.8) in a non-institutionalised population of older adults. The scale correlates well with the Life-Satisfaction Index ($r = 0.63$, $p = 0.01$) demonstrating concurrent validity.[20]

Depressive symptoms were assessed using the Centre for Epidemiologic Studies Depression Scale (CES-D).[21] A shortened 8-item version with binary response options which was developed for the Health and Retirement Study (HRS) was used, as in several previous publications from ELSA and HRS.[22–25] Cronbachs α is 0.82, and the scale shows good sensitivity and specificity in comparison with the Short Form Composite International Diagnostic Interview clinical screener for depression.[22] Scores could range from 0 to 8, with higher scores indicating a greater number of depressive symptoms.

2.3. Statistical analysis

Demographic characteristics of cancer survivors and those with no cancer history were compared using t-tests for continuous variables and non-parametric methods for categorical variables. Results are also presented adjusting for age

and sex. Multiple logistic regression was used to assess whether health behaviours differed between cancer survivors and those with no cancer history. The three behaviours (smoking, alcohol consumption and physical activity) were modelled separately. For each behaviour, we first calculated the odds of engaging in the behaviour in cancer survivors versus those with no cancer history adjusting for age and sex, and then adjusted for additional variables that might affect health behaviour. For smoking and alcohol consumption, these models included age, sex and education. Since the number of ethnic minority cancer survivors was very small, ethnicity was not included as a covariate. Because physical activity may be impaired in people with mobility restrictions such as rheumatic conditions, the presence of arthritis was included as a covariate in the analyses of physical activity, along with age, sex and education. Adjusted odds ratios with 95% confidence intervals (CIs) are presented.

Relationships between physical activity or smoking and quality of life and depression were analysed using linear regression with the health behaviour as the independent variable, and including age, sex, education and arthritis (for the analyses of physical activity). Checks were made to ensure that no multicollinearity was present. R^2 for the regression analysis are presented, along with standardised regression coefficients (β) and standard error.

3. Results

3.1. *Sample characteristics*

There were 716 cancer survivors in the sample (6.2%) and 10,799 men and women who did not report a diagnosis of cancer. The most commonly reported cancer was breast (31.3%); 12.6% reported a diagnosis of colorectal cancer, 10.1% had skin cancer or melanoma, 3.6% had leukaemia/lymphoma, 2.2% had lung cancer and 40.2% had 'other' cancers. These results are comparable to prevalence rates reported in the cancer registry dataset for England.[2] Forty-three percent of cancer survivors had received treatment for cancer within 2 years of survey completion.

Cancer survivors were older ($p < .001$) and more of them were female ($p < .001$) than those without a history of cancer (Table 1). They did not differ from the rest of the sample with respect to marital status, ethnicity, education or the occurrence of arthritis, but they did have lower QoL ($p < .05$) after controlling for age and sex. Cancer survivors also had significantly more depressive symptoms ($p < .001$); however, both these differences were small.

3.2. *Health behaviours in cancer survivors*

Table 2 presents the prevalence of each health behaviour in cancer survivors and those with no history of cancer. Adjusted odds ratios for the association between cancer survivor status and health behaviours are also presented.

Overall, 15% of cancer survivors were current smokers compared with 18% of those with no history of cancer. This difference was not significant. However, cancer survivors were more likely to be former smokers (52% versus 46%), and this was significant after adjusting for age, sex and education (OR 1.20, CI 1.03–1.14, $p < .05$).

There was no difference in alcohol consumption; 66% of cancer survivors and 69% of those with no history of cancer reported drinking alcohol. Of those who drank, 8% of cancer survivors and 6% of those without a history of cancer reported ≥ 2 drinks per day. This difference was not significant after adjustment for covariates.

Fewer cancer survivors reported being moderately or vigorously active on more than one day per week compared to those with no history of cancer (51% versus 59%). The difference was significant after adjusting for age and sex ($p < .05$), and remained after additional adjustment for education and arthritis status (OR 0.82, CI 0.70–0.96, $p < .05$).

3.3. *Health behaviours, quality of life and depression*

The associations between health behaviours and QoL and depressive symptoms are summarised in Table 3. Physical activity was associated with better QoL in both cancer survivors and those with no history of cancer ($p < .001$). Mean scores on the CASP-19 (adjusted for covariates) were 43.11 (95% CI 42.15–44.07) versus 37.99 (95% CI 36.89–39.08) for active and inactive cancer survivors, and 43.49 (95% CI 43.25–43.73) versus 39.55 (95% CI 39.25–39.24) for those with no history of cancer. There was no interaction with cancer status. Physical activity was also negatively associated with depressive symptoms in both groups (both p's $< .001$). Adjusted depressive symptoms scores averaged 1.36 (95% CI 1.13–1.58) and 2.37 (95% CI 2.14–2.61) in active and inactive cancer survivors, and 1.37 (95% CI 1.32–1.43) and 2.05 (95% CI 1.99–2.16) for active and inactive individuals with no history of cancer. Among cancer survivors, QoL was better in women and those with more education, and worse in those with arthritis; the reverse associations for education and arthritis were observed for depressive symptoms. The same relationships were found for those with no cancer history with the addition of a negative association of age with QoL and greater depressive symptoms in women.

Quality of life was worse in current smokers, mean CASP-19 scores (adjusted for covariates) were 39.31 (95% CI 37.47–41.14) versus 41.70 (95% CI 41.04–42.36) for cancer survivors who smoke and non-smokers, respectively ($p < .05$), and 40.73 (95% CI 40.29–41.16) for smokers and 43.23 (95% CI 43.03–43.42) for non-smokers in those with no cancer history ($p < .001$). Smoking had an unfavourable relationship with depressive symptoms, with significantly higher CES-D depression scores (after adjustment for covariates) in smokers 2.18 (95% CI 1.77–2.59) than non-smokers 1.64 (95% CI 1.47–1.82) in survivors ($p < .001$), and 1.90 (95% CI 1.80–1.99) for smokers and 1.39 (95% CI 1.35–1.44) for non-smokers in those with no history of cancer.

4. Discussion

This study provides evidence concerning three health-related behaviours in a cohort of older cancer survivors in England identified from a population-based national survey. The results highlight the prevalence of suboptimal health behav-

Table 1 – Characteristics of sample. Percentage (n), mean (SD).

Characteristics	Cancer survivors	No cancer	P	P (adjusted for age and sex)
N	716	10,799		
Breast cancer	31.3% (224)			
Colorectal cancer	12.6% (90)			
Lung cancer	2.2% (16)			
lymphoma/leukaemia	3.6% (26)			
Skin cancer/melanoma	10.1% (72)			
Other cancer	40.2% (288)			
Age (years)	68.27 (10.55)	64.92 (10.44)	0.000	
Male	38.1% (273)	45.9% (4956)		
Female	61.9% (443)	54.1% (5843)	0.000	
Ethnicity (% minority)	1.4% (10)	2.9% (316)	0.018	0.059
Educational qualifications				
Higher education	24.3% (174)	22.0% (2372)		
Intermediate	32.1% (230)	35.5% (3823)	0.140	
No qualifications	43.6% (312)	42.5% (4573)		
Married (%)	62.0% (444)	66.9% (7220)	0.008	0.914
Arthritis (%)	32.5% (233)	28.5% (3079)	0.021	0.507
CES-D depression score (0–8)	1.87 (2.13)	1.57 (1.98)	0.000	0.009
CASP-19 quality of life (QoL) score (0–57)	41.36 (8.95)	42.57 (8.67)	0.001	0.011

Table 2 – Prevalence and adjusted odds ratios (ORs) for health behaviours by cancer survivors/no history of cancer. Percentage (n) and OR with 95% confidence intervals (CIs).

		OR (95% CI)^{a}	OR (95% CI)^{b}
	Former smoker (versus rest)		
No cancer	46.1% (4902)	1.00	1.00
Cancer Survivor	52.5% (368)	1.26 (1.08–1.47)**	1.24 (1.06–1.45)**
	Current smoker (versus rest)		
No cancer	18.0% (1919)	1.00	1.00
Cancer survivor	15.3% (107)	0.93 (0.75–1.15)	0.97 (0.78–1.20)
	Complete sample: any alcohol		
No cancer	68.8% (7318)	1.00	1.00
Cancer survivor	66.0% (463)	1.06 (0.90–1.25)	1.00 (0.85–1.19)
	Drinkers only: Two or more drinks per day		
No cancer	6.2% (457)	1.00	1.00
Cancer survivor	8.0% (37)	1.22 (0.86–1.73)	1.21 (0.85–1.75)
	Physical activity		
No cancer	58.8% (6355)	1.00	1.00^{c}
Cancer survivor	51.4% (368)	0.81 (0.73–0.99)*	0.81 (0.69–0.95) ^{c,*}

No cancer is reference category.
a Adjusted for age and sex.
b Adjusted for age, sex and education.
c Adjusted for age, sex, education and arthritis.
* $p < 0.05$.
** $p < 0.001$.

iours (that is, low levels of physical activity and a significant minority continuing to smoke) in this vulnerable population. Cancer survivors were more likely to be former smokers, but they had similar levels of alcohol consumption and current smoking, and they were less likely to be physically active than those with no history of cancer.

The greater proportion of former smokers in the cancer survivors group (52%) than among the rest of the sample (46%) is encouraging in terms of secondary or tertiary prevention. Similar results were reported in an Australian population-based sample[17] where cancer survivors were 30% more likely to be ex-smokers compared with non-cancer controls. It is also consistent with the studies of patients with cancer, who report relatively high levels of quitting – at least in the short term.[26] However, a worrying finding is that 15% continued to smoke despite their estimated twofold risk of develop-

Table 3 – Association between physical activity and smoking and quality of life (QoL) and depression.

Physical activity	Quality of life (CASP-19)				Depression (CES-D)			
	Cancer survivors		No cancer		Cancer survivors		No cancer	
	Regression coefficient β (SE)	p	Regression coefficient β (SE)	p	Regression coefficient β (SE)	p	Regression coefficient β (SE)	p
Physical activity	.283 (0.04)	<0.001	.220 (0.01)	<0.001	−.236 (0.04)	<0.001	−.169 (0.01)	<0.001
Age	.026 (0.04)	0.522	−.023 (0.01)	0.031	−.049 (0.04)	0.317	.007 (0.01)	0.714
Sex	.079 (0.03)	0.048	.081 (0.01)	<0.001	.053 (0.04)	0.147	.072 (0.01)	<0.001
Education	.198 (0.04)	0.001	.134 (0.01)	<0.001	−.160 (0.04)	<0.001	−.124 (0.01)	<0.001
Arthritis	−.167 (0.03)	<0.001	−.166 (0.01)	<0.001	.091 (0.04)	0.015	.156 (0.01)	<0.001
	Adjusted $r^2 = .183$		Adjusted $r^2 = .121$		Adjusted $r^2 = .108$		Adjusted $r^2 = .097$	
Smoking								
Current smoker	−.113 (0.04)	0.006	−.110 (0.01)	<0.001	.091 (0.04)	0.018	.098 (0.01)	<0.001
Age	−.067 (0.04)	0.112	−.092 (0.01)	<0.001	.030 (0.04)	0.451	.057 (0.01)	<0.001
Sex	.050 (0.03)	0.214	.055 (0.01)	<0.001	.069 (0.04)	0.068	.096 (0.01)	<0.001
Education	.239 (0.04)	<0.001	.061 (0.01)	<0.001	−.193 (0.04)	<0.001	−.144 (0.01)	<0.001
	Adjusted $r^2 = .083$		Adjusted $r^2 = .054$		Adjusted $r^2 = .053$		Adjusted $r^2 = .052$	

ing a second primary cancer compared to the general population[27] and the likelihood that smoking could increase this risk still further[28] as well as increasing the risk of other adverse health outcomes.[26] These observations suggest that smoking cessation interventions need to be more effectively targeted.

Public recognition of the smoking-cancer link is high in the UK.[29] However, in a recent study of cancer survivors, more than 75% believed smoking would cause the same type of cancer in other people, yet only 16% of former smokers and 29% of current smokers believed that smoking caused their own cancer.[30] Such a belief system may help to explain why some cancer survivors continue to smoke. Data on the efficacy of smoking cessation interventions in cancer survivors are limited (see de Moor et al., for a recent review),[31] therefore further research is needed to understand the determinants of continued smoking or relapse to smoking in cancer survivors, to help to design effective interventions.

There was no significant difference in alcohol consumption between cancer survivors and those with no history of cancer, confirming findings from similar studies in US population samples[15,16] although direct comparison between studies is difficult because of differences in definitions. The studies from the US used total number of drinks consumed in a day,[15,16] but in ELSA, alcohol consumption was only divided into drinking ⩾2 drinks per day versus less, which does not distinguish very heavy from moderately heavy drinkers. This issue deserves further investigation, and cancer survivors may look for guidance on the recommended level of alcohol intake to promote long-term health.

We found cancer survivors to be significantly less active than those without a history of cancer independent of confounding factors including arthritis. Three population-based studies from other countries[17,15,32] have reported no difference in physical activity participation between cancer survivors and those with no cancer history, and one similar study[15] found cancer survivors to be 9% more likely to meet physical activity recommendations. Different definitions could be part of the explanation for this variation; previous studies used the relevant general population guidelines as a cut-off, whereas in the present analyses, we estimated the proportion engaging in moderate or vigorous activity more than once a week, a much lower threshold. However, a lower threshold may have some value given that the proportion of older adults in the England meeting the recommended guidelines is so low; 31% of 55–64-year olds, 19% of 65–74-year olds and 6% of those aged 75 and over.[33]

It would have been interesting to explore the differences in the levels of physical activity between those diagnosed with cancer in the last 2 years versus longer survivors. Recent evidence suggests that physical activity is reduced soon after diagnosis but begins to recover (if not entirely) after treatment completion.[34] Unfortunately, the sample was not large enough to permit these analyses.

Impaired QoL at the time of diagnosis and treatment is well established, and recent evidence suggests that this can persist for several years.[35] Our results support the finding that cancer survivors have a lower QoL than those without a history of cancer. Physical activity is known to be associated with higher QoL in the general population, and our data suggest that this is also true for cancer survivors. This is in accor-

dance with the growing body of literature documenting the positive effects of physical activity on QoL in cancer survivors[13] and consistent with the idea that low physical activity could be contributing to poor QoL in cancer survivors. We also found a negative association between smoking and QoL, a relationship which has previously been reported in a small number of studies in head and neck cancer survivors.[14]

Physical activity was also associated with lower depressive symptoms. Given that we also found that smokers had higher depressive symptom scores than non-smokers, these observations provide additional support for the idea that health behaviours can improve psychosocial outcomes in cancer survivors. Alongside the evidence that physical activity after a cancer diagnosis has a protective effect on recurrence and mortality,[6–8] a strong case is emerging for supporting cancer survivors in engaging with healthy behaviours to improve both physical and psychosocial outcomes.

In conclusion, our results suggest that the prevalence of health risk behaviours is far from optimal in cancer survivors. With a current consensus that cancer survivors should follow recommendations for cancer and heart disease prevention in the general population, research into effective means of promoting healthy lifestyle in cancer survivors is required. A start has been made in the physical activity field (see Stevinson et al., for review)[36] but more work is needed to integrate effective behavioural interventions into the routine care of UK cancer survivors.

This study has a number of limitations. Cancer survivorship was determined from the self-report of a diagnosis and this may not be completely reliable although a recent study found reasonably good agreement with record data.[37] Health behaviours were also self-reported, and this may have led to response biases such as over-estimation of physical activity and under-estimation of alcohol consumption. The cross-sectional nature of the data means we are unable to determine if the patterns of health behaviours were a result of change since diagnosis or maintained since before the diagnosis. These data were collected in 2002 and it is possible that awareness of the importance of health behaviours among cancer survivors has changed since that time. Nonetheless, this study is a first step towards addressing the issue of health behaviours in cancer survivors in England. The prevalence of suboptimal health behaviours found in all the recent studies highlights the need for collaboration between researchers and health care providers to find effective strategies to improve psychological and physical wellbeing among the growing numbers of people who will survive a diagnosis of cancer.

Conflict of interest statement

None declared.

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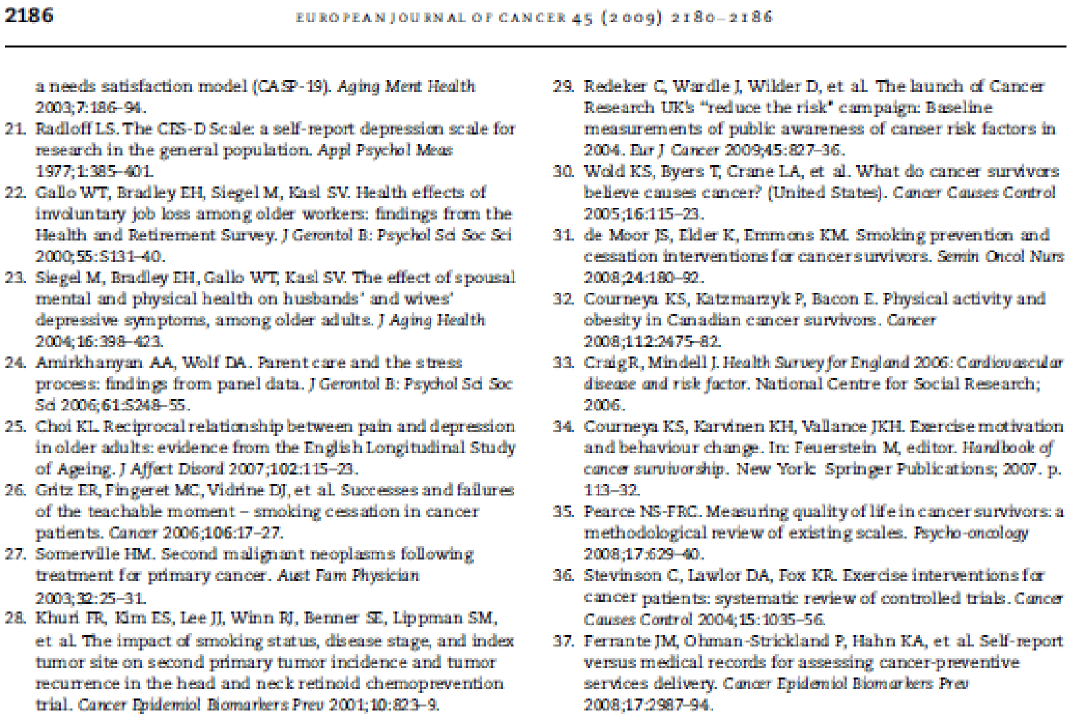

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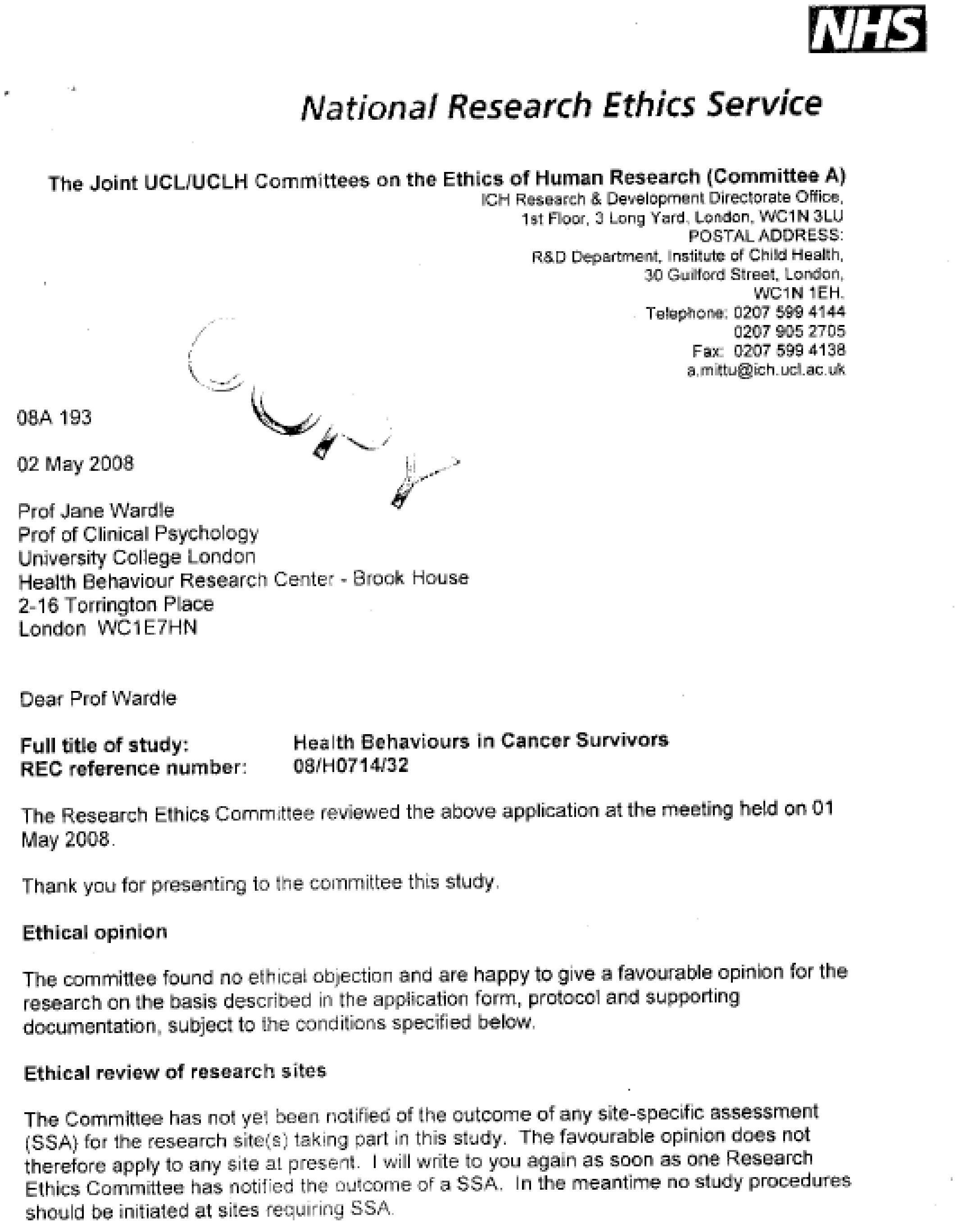
Appendix 2 Ethical approval letter; questionnaire study



NHS

National Research Ethics Service

The Joint UCL/UCLH Committees on the Ethics of Human Research (Committee A)
ICH Research & Development Directorate Office,
1st Floor, 3 Long Yard, London, WC1N 3LU
POSTAL ADDRESS:
R&D Department, Institute of Child Health,
30 Guilford Street, London,
WC1N 1EH.
Telephone: 0207 599 4144
0207 905 2705
Fax: 0207 599 4138
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Copy

08A 193

02 May 2008

Prof Jane Wardle
Prof of Clinical Psychology
University College London
Health Behaviour Research Center - Brook House
2-16 Torrington Place
London WC1E7HN

Dear Prof Wardle

Full title of study: **Health Behaviours in Cancer Survivors**
REC reference number: **08/H0714/32**

The Research Ethics Committee reviewed the above application at the meeting held on 01 May 2008.

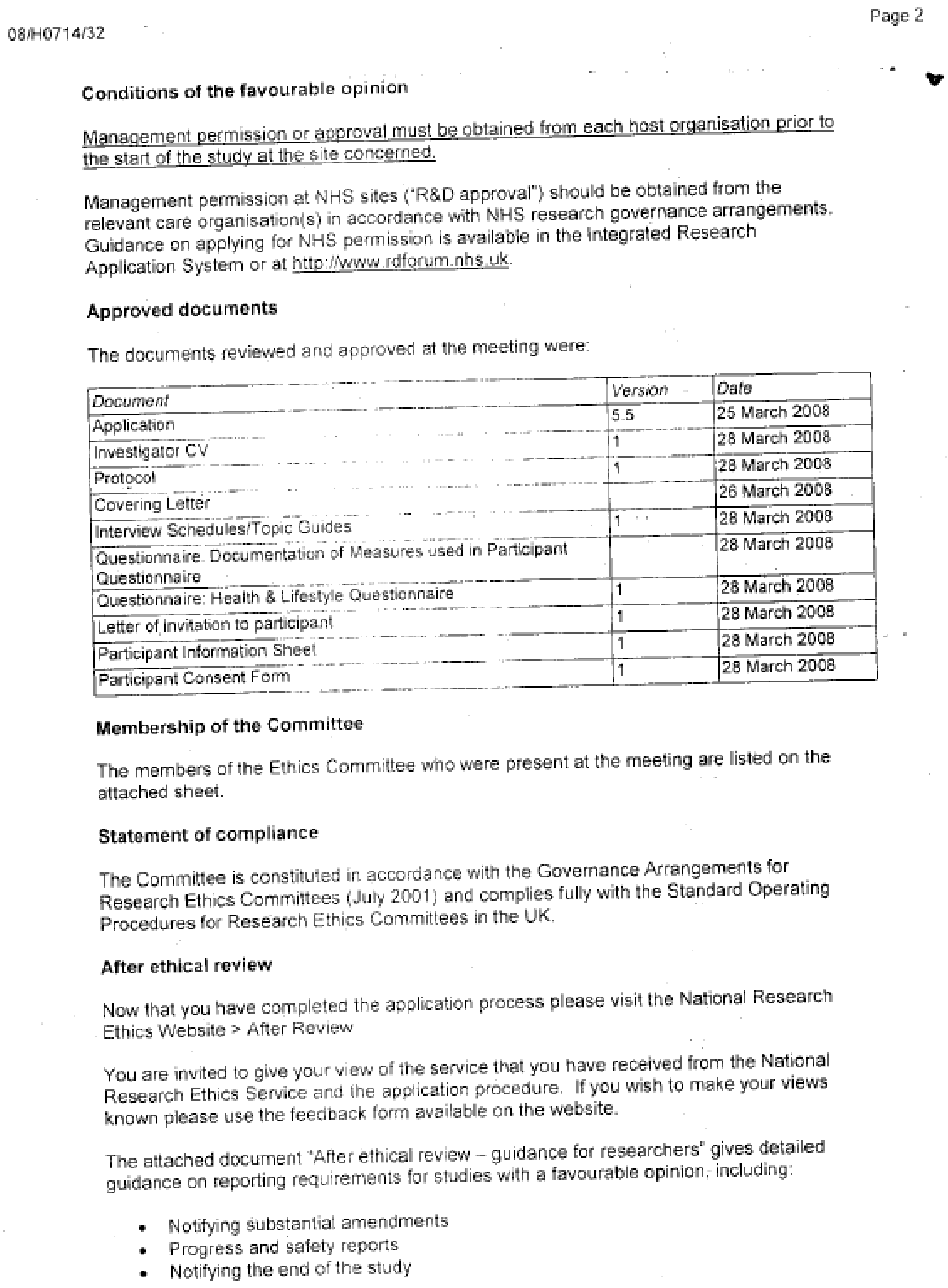
Thank you for presenting to the committee this study.

Ethical opinion

The committee found no ethical objection and are happy to give a favourable opinion for the research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the research site(s) taking part in this study. The favourable opinion does not therefore apply to any site at present. I will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at sites requiring SSA.



08/H0714/32

Page 2

Conditions of the favourable opinion

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Application	5.5	25 March 2008
Investigator CV	1	28 March 2008
Protocol	1	28 March 2008
Covering Letter		26 March 2008
Interview Schedules/Topic Guides	1	28 March 2008
Questionnaire. Documentation of Measures used in Participant Questionnaire		28 March 2008
Questionnaire: Health & Lifestyle Questionnaire	1	28 March 2008
Letter of invitation to participant	1	28 March 2008
Participant Information Sheet	1	28 March 2008
Participant Consent Form	1	28 March 2008

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

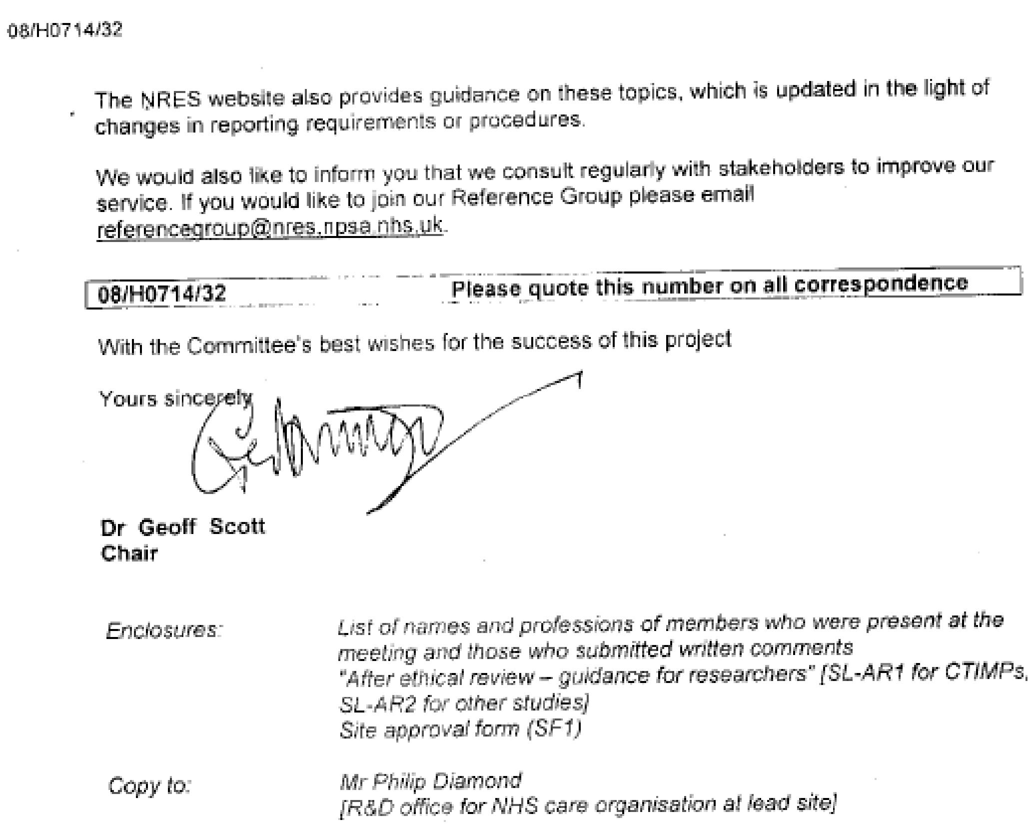
After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study



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The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H0714/32	**Please quote this number on all correspondence**

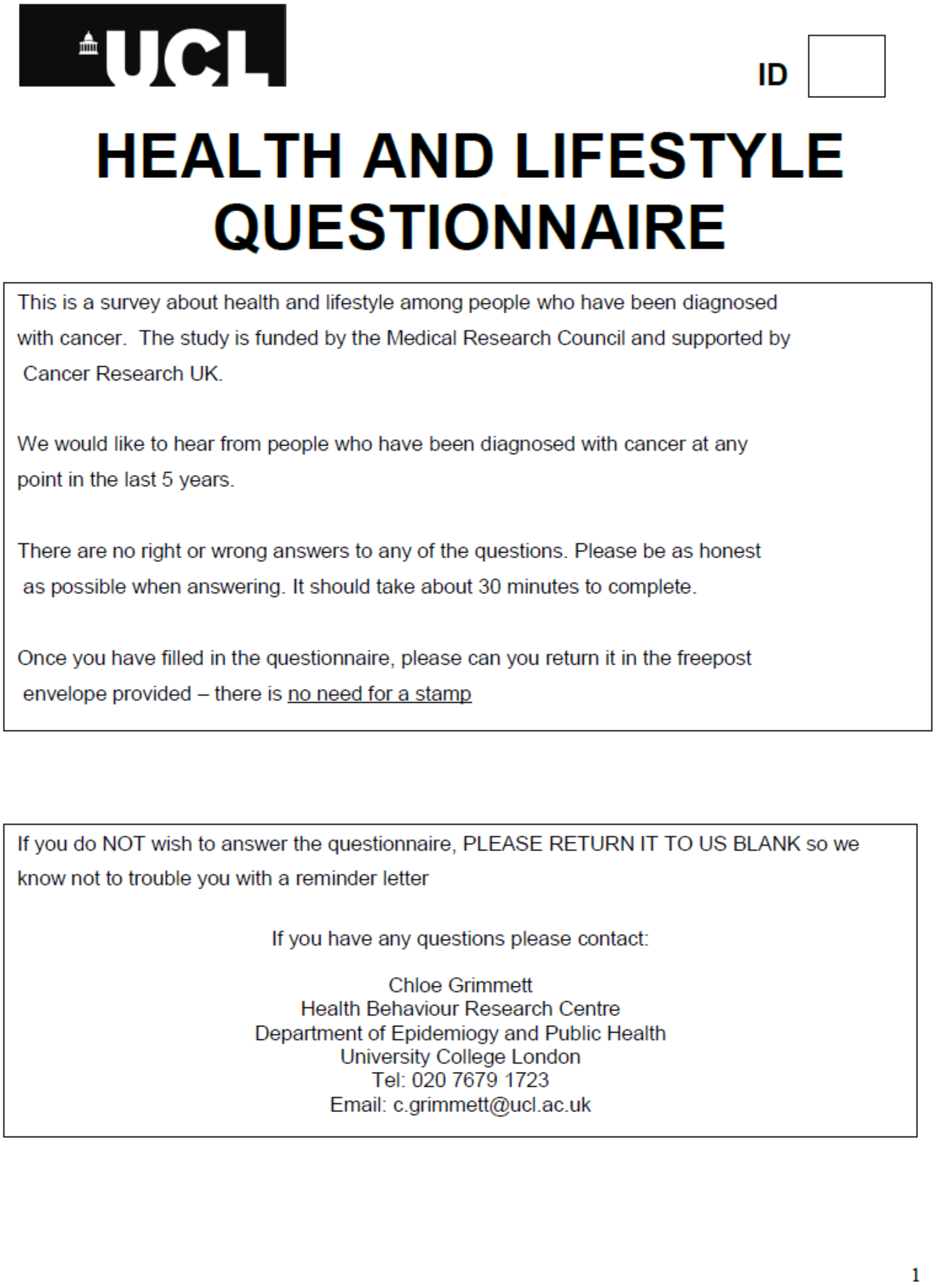
With the Committee's best wishes for the success of this project

Yours sincerely

Dr Geoff Scott
Chair

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments* *"After ethical review – guidance for researchers" [SL-AR1 for CTIMPs, SL-AR2 for other studies]* *Site approval form (SF1)*
Copy to:	*Mr Philip Diamond* *[R&D office for NHS care organisation at lead site]*

Appendix 3: Health and Lifestyle Questionnaire



UCL

ID

HEALTH AND LIFESTYLE QUESTIONNAIRE

This is a survey about health and lifestyle among people who have been diagnosed with cancer. The study is funded by the Medical Research Council and supported by Cancer Research UK.

We would like to hear from people who have been diagnosed with cancer at any point in the last 5 years.

There are no right or wrong answers to any of the questions. Please be as honest as possible when answering. It should take about 30 minutes to complete.

Once you have filled in the questionnaire, please can you return it in the freepost envelope provided – there is no need for a stamp

If you do NOT wish to answer the questionnaire, PLEASE RETURN IT TO US BLANK so we know not to trouble you with a reminder letter

If you have any questions please contact:

Chloe Grimmett
Health Behaviour Research Centre
Department of Epidemiogy and Public Health
University College London
Tel: 020 7679 1723
Email: c.grimmett@ucl.ac.uk

ABOUT YOUR HEALTH

1a When were you first diagnosed with cancer? ....month ....year

1b In what part of your body was the cancer found?...

2 What treatment/s have you had? Please tick any that apply

Surgery ☐ Hormone therapy ☐ None ☐

Chemotherapy ☐ Radiotherapy ☐ Not sure ☐

Other...

3 When did you finish treatment? Date................ Go to question 5

Still having treatment ☐ Go to question 4

4 What treatment/s are you having <u>at the moment?</u> Please tick any that apply

Surgery ☐ Hormone therapy ☐

Chemotherapy ☐ Radiotherapy ☐ Not sure ☐

Other...

5a Has the cancer come back (recurred) since your first treatment? Yes ☐ No ☐

5b If yes, in what part of the body? Please state..

6 Have you had any of the following health problems? Please tick any that apply

Osteoporosis ☐ Heart murmur ☐ Irregular heart rhythm ☐

Diabetes ☐ Stroke ☐ Any other heart trouble ☐

Asthma ☐ Heart attack ☐ Lung disease ☐

Arthritis ☐ Angina ☐ Parkinson's disease ☐

Emotional, nervous or psychiatric illness ☐

Other (please state)............................ ....

7 How is your health in general? Would you say it was:

Very good	Good	Fair	Bad	Very bad
☐	☐	☐	☐	☐

8 All things considered, how satisfied are you with your life as a whole?

Very satisfied	Moderately satisfied	Neutral	Quite dissatisfied	Very dissatisfied
☐	☐	☐	☐	☐

SECTION 2

ABOUT YOUR PHYSICAL ACTIVITY AND LEISURE TIME

1 During a typical 7-day period (a week), how many times on average do you do the following kinds of exercise for **more than 15 minutes** during your free time?

a **Strenuous exercise** (when your heart beats rapidly and you breath much faster)

e.g. running, jogging vigorous swimming, vigorous cycling. **Times per week**

……………..

b **Moderate exercise** (when you breath somewhat harder than normal)

e.g. brisk walking, easy cycling, easy swimming, dancing. **Times per week**

……………..

c **Mild exercise** (takes minimal effort)

e.g. easy walking, fishing, bowling. **Times per week**

……………..

d During a typical **7-Day period** (a week), in your leisure time, how often do you engage in any regular activity **long enough to work up a sweat** (heart beats rapidly)?

Often	**Sometimes**	**Rarely/Never**
☐	☐	☐

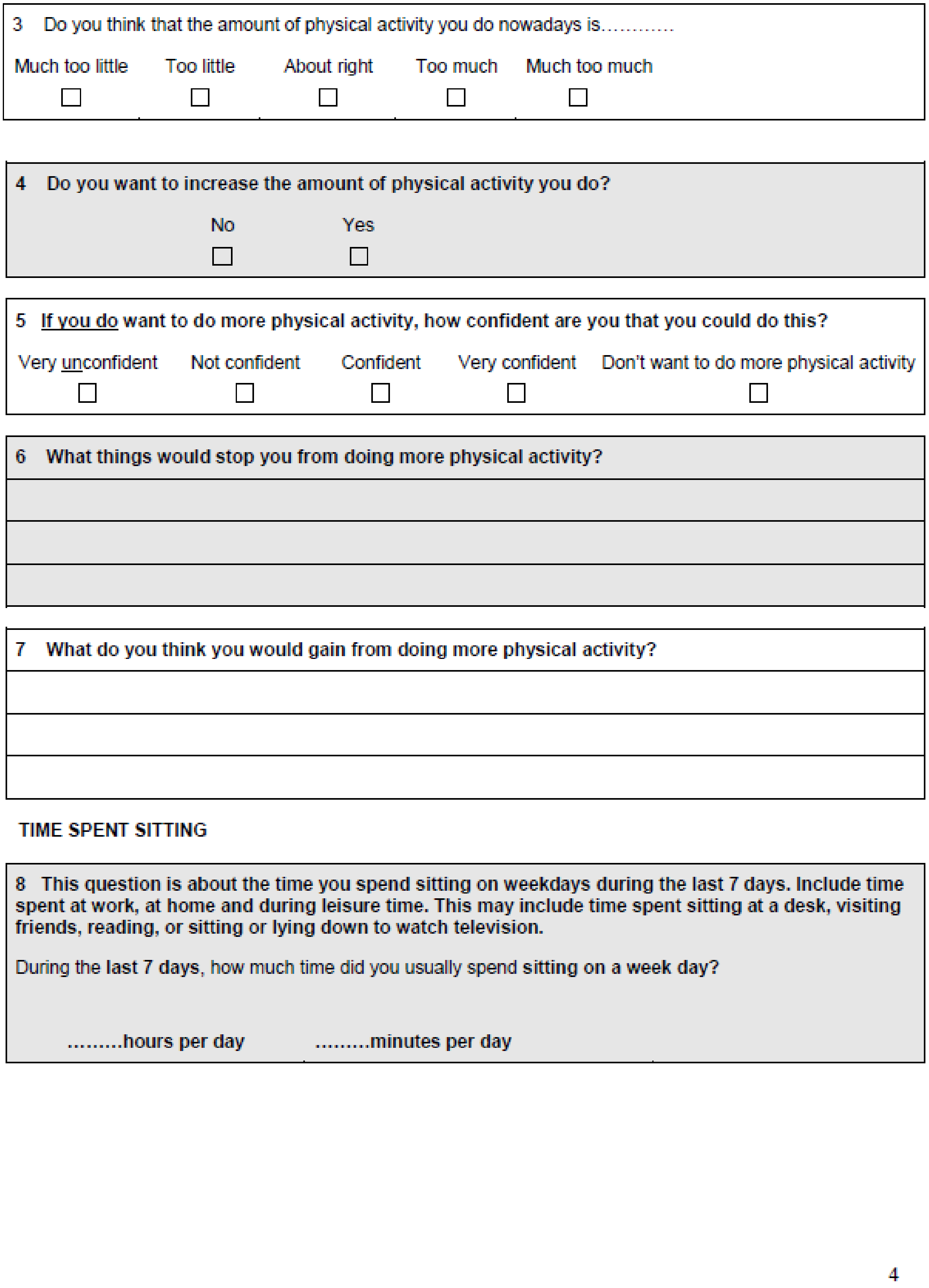
2 Is the amount of physical activity you do nowadays………

More than before your cancer diagnosis ☐

About the same as before your cancer diagnosis ☐

Less than before your cancer diagnosis ☐

3



3 Do you think that the amount of physical activity you do nowadays is…………

Much too little	Too little	About right	Too much	Much too much
☐	☐	☐	☐	☐

4 Do you want to increase the amount of physical activity you do?

No	Yes
☐	☐

5 If you do want to do more physical activity, how confident are you that you could do this?

Very unconfident	Not confident	Confident	Very confident	Don't want to do more physical activity
☐	☐	☐	☐	☐

6 What things would stop you from doing more physical activity?

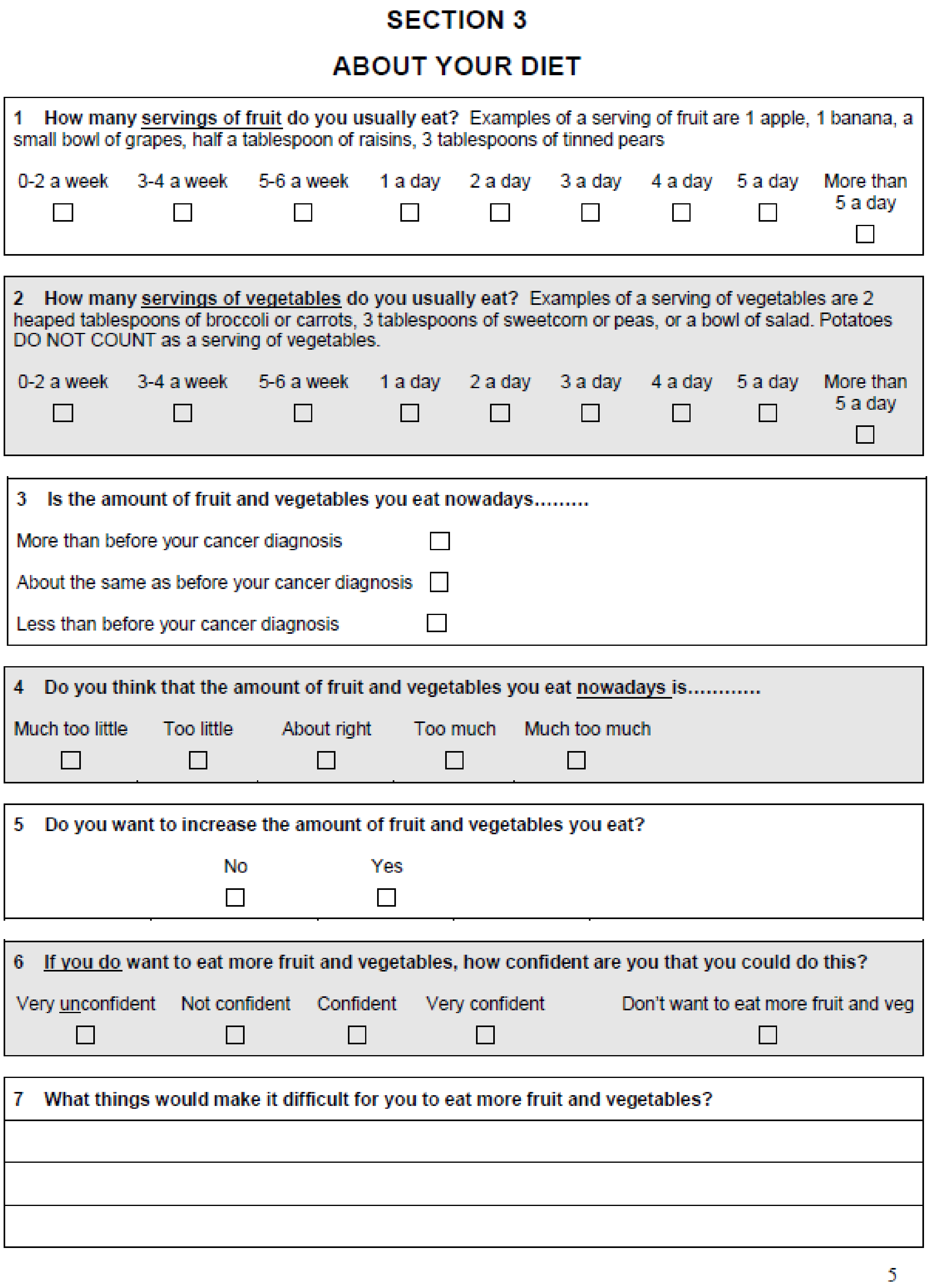
7 What do you think you would gain from doing more physical activity?

TIME SPENT SITTING

8 This question is about the time you spend sitting on weekdays during the last 7 days. Include time spent at work, at home and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

During the **last 7 days**, how much time did you usually spend **sitting** on a **week day?**

………hours per day **………minutes per day**



SECTION 3

ABOUT YOUR DIET

1 How many servings of fruit do you usually eat? Examples of a serving of fruit are 1 apple, 1 banana, a small bowl of grapes, half a tablespoon of raisins, 3 tablespoons of tinned pears

0-2 a week	3-4 a week	5-6 a week	1 a day	2 a day	3 a day	4 a day	5 a day	More than 5 a day
☐	☐	☐	☐	☐	☐	☐	☐	☐

2 How many servings of vegetables do you usually eat? Examples of a serving of vegetables are 2 heaped tablespoons of broccoli or carrots, 3 tablespoons of sweetcorn or peas, or a bowl of salad. Potatoes DO NOT COUNT as a serving of vegetables.

0-2 a week	3-4 a week	5-6 a week	1 a day	2 a day	3 a day	4 a day	5 a day	More than 5 a day
☐	☐	☐	☐	☐	☐	☐	☐	☐

3 Is the amount of fruit and vegetables you eat nowadays………

More than before your cancer diagnosis ☐

About the same as before your cancer diagnosis ☐

Less than before your cancer diagnosis ☐

4 Do you think that the amount of fruit and vegetables you eat nowadays is…………

Much too little	Too little	About right	Too much	Much too much
☐	☐	☐	☐	☐

5 Do you want to increase the amount of fruit and vegetables you eat?

No	Yes
☐	☐

6 If you do want to eat more fruit and vegetables, how confident are you that you could do this?

Very unconfident	Not confident	Confident	Very confident	Don't want to eat more fruit and veg
☐	☐	☐	☐	☐

7 What things would make it difficult for you to eat more fruit and vegetables?

5

8 What do you think you would gain from eating more fruit and vegetables?

9a About how many servings <u>per week</u> do you eat of the following foods?

	None	Less than 1 a week	1 to 2 a week	3 to 5 a week	6 or more a week
Cheese (any except cottage cheese)	☐	☐	☐	☐	☐
Beefburgers or sausages	☐	☐	☐	☐	☐
Beef, pork, or lamb (for vegetarians; nuts)	☐	☐	☐	☐	☐
Bacon, meat pie, processed meat	☐	☐	☐	☐	☐
Chicken or turkey	☐	☐	☐	☐	☐
Fish (NOT fried fish)	☐	☐	☐	☐	☐
ANY fried food; fried fish, chips, cooked breakfast, samosas	☐	☐	☐	☐	☐
Cakes, pies, puddings, pastries	☐	☐	☐	☐	☐
Biscuits, chocolates, or crisps	☐	☐	☐	☐	☐

9b MILK

About how much of the following types of milk do you yourself use <u>per day</u> for example, in cereal, tea, or coffee?

	None	Less than a quarter pint	About a quarter pint	About half a pint	1 pint or more
Whole milk	☐	☐	☐	☐	☐
Semi-skimmed milk	☐	☐	☐	☐	☐
Skimmed milk	☐	☐	☐	☐	☐

9c SPREADS

About how many rounded teaspoons per day do you usually use of the following types of spreads, for example on bread, sandwiches, toast, potatoes, or vegetables?

	None	**1**	**2**	**3**	**4**	**5**	**6**	**7 or more**
Regular margarine, butter, or **reduced fat spreads** such as sunflower or olive spread, Flora, Vitalite, Clover, Olivio, Stork, Utterly Butterly	☐	☐	☐	☐	☐	☐	☐	☐
Low fat spreads such as Flora light, St Ivel Gold, Half-fat butter, Olivite, Flora Pro-active, Light spread	☐	☐	☐	☐	☐	☐	☐	☐

9d What type of fat do you usually use for the following purposes?

	Butter, lard or dripping	**Solid cooking fat** (white flora, cookeen) **Half-fat butter, hard margarine** (stork)	**Soft margarine** (sunflower, soya) **Reduced fat spread** (olive, flora buttery, Olivio)	**Vegetable oil or low fat spread** (Flora light, St Ivel Gold, olive oil)	**No fat used**
On bread and vegetables	☐	☐	☐	☐	☐
For frying	☐	☐	☐	☐	☐
For baking or cooking	☐	☐	☐	☐	☐

10 Is the amount of fat in your diet nowadays………

More than before your cancer diagnosis ☐

About the same as before your cancer diagnosis ☐

Less than before your cancer diagnosis ☐

11 Do you think that the amount of fat you eat nowadays is…………

Much too little	Too little	About right	Too much	Much too much
☐	☐	☐	☐	☐

12 Do you want to reduce the amount of fat you eat?

No	Yes
☐	☐

13 If you do want to eat less fat, how confident are you that you could do this?

Very unconfident	Not confident	Confident	Very confident	Don't want to eat less fat
☐	☐	☐	☐	☐

14 What things would make it difficult for you to eat less fat?

15 What do you think you would gain from decreasing the fat in your diet?

SECTION 4

ABOUT SMOKING

1 Do you smoke cigarettes at all nowadays?

Yes ☐ No ☐

If Yes; About how many cigarettes do you smoke a day? ________

If No: Did you ever smoke cigarettes regularly? (e.g. at least 1 cigarette a day)

Yes ☐ No ☐

If Yes: How many cigarettes did you smoke per day? ________

When did you quit smoking? ________Month ______Year

2 Do you want to stop smoking?

No	Yes	I don't smoke (Go to question section 5)
☐	☐	☐

3 If you do want to stop smoking, how confident are you that you could do this?

Very unconfident	Not confident	Confident	Very confident	Don't want to stop smoking
☐	☐	☐	☐	☐

4 What things would make it difficult for you to stop smoking?

5 What do you think you would gain from stopping smoking?

SECTION 5

ABOUT ALCOHOL

1a Did you ever drink alcohol before your cancer diagnosis?

Yes ☐ No ☐

1b Do you ever drink alcohol nowadays?

Yes ☐ No ☐

1c If Yes, how many of the following do you usually drink per week?

Small glass of wine (125ml)	Half pint of beer/lager/cider	Pub measure of spirits (25ml)
________	________	________

2 Is the amount of alcohol you drink nowadays.........

More than before your cancer diagnosis ☐

About the same as before your cancer diagnosis ☐

Less than before your cancer diagnosis ☐

3 Do you think that the amount of alcohol you drink nowadays is…………

Much too little	Too little	About right	Too much	Much too much
☐	☐	☐	☐	☐

4 Do you want to decrease the amount of alcohol you drink?

No	Yes
☐	☐

5 <u>If you do</u> want to decrease the amount of alcohol you drink, how confident are you that you could do this?

Very unconfident	Not confident	Confident	Very confident	Don't want to decrease my alcohol
☐	☐	☐	☐	☐

6 What things would make if difficult for you to decrease the amount of alcohol you drink?

7 What do you think you would gain from decreasing the amount of alcohol you drink?

SECTION 6

HEIGHT AND WEIGHT

1 How much do you weigh? ……….kgs OR ……….stone ………pounds

2 How tall are you? ……….cms OR ……….feet ………inches

3 How would you describe your weight at the moment?

Very underweight	Slightly underweight	About right	Slightly overweight	Very overweight
☐	☐	☐	☐	☐

4 Is your weight nowadays………

More than before your cancer diagnosis	☐
About the same as before your cancer diagnosis	☐
Less than before your cancer diagnosis	☐

	No	Yes
5a Do you want to gain weight?	☐	☐
5b Do you want to lose weight?	☐	☐

6 <u>If you do</u> want to gain or lose weight, how confident are you that you could do this?

Very unconfident	Not confident	Confident	Very confident	Don't want to gain/lose weight
☐	☐	☐	☐	☐

7 What things would make maintaining a healthy weight difficult for you?

8 What do you think you would gain from maintaining a healthy weight?

SECTION 7

YOU AND YOUR HEALTH

		Not at all	A little bit	Quite a bit	Very much
1	Do you have any trouble doing strenuous activities like carrying a heavy shopping bag or suitcase?	☐	☐	☐	☐
2	Do you have any trouble taking a long walk?	☐	☐	☐	☐
3	Do you have any trouble taking a short walk outside the house?	☐	☐	☐	☐
4	Do you need to stay in bed or a chair during the day?	☐	☐	☐	☐
5	Do you need help with eating, dressing, washing yourself or using the toilet?	☐	☐	☐	☐
During the past week:		Not at all	A little bit	Quite a bit	Very much
6	Were you limited in doing either your work or other daily activities?	☐	☐	☐	☐
7	Were you limited in pursuing your hobbies or other leisure time activities?	☐	☐	☐	☐
8	Were you short of breath?	☐	☐	☐	☐
9	Have you had pain?	☐	☐	☐	☐
10	Did you need to rest?	☐	☐	☐	☐
11	Have you had trouble sleeping?	☐	☐	☐	☐
12	Have you felt weak?	☐	☐	☐	☐
13	Have you lacked appetite?	☐	☐	☐	☐
14	Have you felt nauseated?	☐	☐	☐	☐
15	Have you vomited?	☐	☐	☐	☐
16	Have you been constipated?	☐	☐	☐	☐
17	Have you had diarrhoea?	☐	☐	☐	☐
18	Were you tired?	☐	☐	☐	☐
19	Did pain interfere with your daily activities?	☐	☐	☐	☐
20	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	☐	☐	☐	☐

	During the past week:	Not at all	A little bit	Quite a bit	Very much
21	Did you feel tense?	☐	☐	☐	☐
22	Did you feel worried?	☐	☐	☐	☐
23	Did you feel irritable?	☐	☐	☐	☐
24	Did you feel depressed?	☐	☐	☐	☐
25	Have you had difficulty remembering things?	☐	☐	☐	☐
26	Has your physical condition or medical treatment interfered with your family life?	☐	☐	☐	☐
27	Has your physical condition or medical treatment interfered with your social activities?	☐	☐	☐	☐
28	Had your physical condition or medical treatment caused you financial difficulties?	☐	☐	☐	☐

For the following questions please tick the number between 1 and 7 that best applies to you

29 How would you rate your overall health during the past week?

Very poor						Excellent
1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

30 How would you rate your overall quality of life during the past week?

Very poor						Excellent
1	2	3	4	5	6	7
☐	☐	☐	☐	☐	☐	☐

SECTION 8

YOUR THOUGHTS ABOUT LIFESTYLE AND HEALTH

1 How important do you think the following behaviours are to your general health?

	Not at all important 1	2	3	4	Very important 5
Eating plenty of fruit and vegetables	☐	☐	☐	☐	☐
Having a diet that is low in fat	☐	☐	☐	☐	☐
Being physically active	☐	☐	☐	☐	☐
Not smoking	☐	☐	☐	☐	☐
Maintaining a healthy weight	☐	☐	☐	☐	☐
Drinking alcohol within the recommended limits	☐	☐	☐	☐	☐

2 Sometimes people have ideas about factors that played a role in the development of their cancer. Please rate how important you think each of the following were in the development of your cancer

	Not at all important 1	2	3	4	Very important 5
Genetic factors	☐	☐	☐	☐	☐
Family history of cancer	☐	☐	☐	☐	☐
Hormones	☐	☐	☐	☐	☐
Pollution or toxins in the environment	☐	☐	☐	☐	☐
Medical x-rays	☐	☐	☐	☐	☐
Bad luck/chance	☐	☐	☐	☐	☐
Stress	☐	☐	☐	☐	☐
God's will	☐	☐	☐	☐	☐
An injury	☐	☐	☐	☐	☐
Lack of physical activity	☐	☐	☐	☐	☐
Smoking	☐	☐	☐	☐	☐

	Not at all important 1	2	3	4	Very important 5
Drinking alcohol	☐	☐	☐	☐	☐
Lack of fruit and vegetables	☐	☐	☐	☐	☐
Having a diet high in fat	☐	☐	☐	☐	☐
Ageing	☐	☐	☐	☐	☐
Infections e.g. germs/viruses	☐	☐	☐	☐	☐
Being overweight	☐	☐	☐	☐	☐

Other (please state): ....

3 Sometimes people have ideas about what prevents cancer coming back (recurring). Please rate how important each of the following are to you in reducing the <u>chance that your cancer will come back (recur).</u>

	Not at all important 1	2	3	4	Very important 5
Medical check-ups/screening	☐	☐	☐	☐	☐
Luck/chance	☐	☐	☐	☐	☐
God's will	☐	☐	☐	☐	☐
Eating lots of fruit and vegetables	☐	☐	☐	☐	☐
Having a low fat diet	☐	☐	☐	☐	☐
Regular physical activity	☐	☐	☐	☐	☐
Reducing stress in your life	☐	☐	☐	☐	☐
Not smoking	☐	☐	☐	☐	☐
Maintaining a healthy weight	☐	☐	☐	☐	☐
Limiting alcohol consumption	☐	☐	☐	☐	☐
Having a positive attitude	☐	☐	☐	☐	☐
Using complementary therapies (e.g. massage, herbs, acupuncture)	☐	☐	☐	☐	☐

Other (please state):..

SECTION 9

HEALTH RECOMMENDATIONS

Below are a few questions about health professionals' recommendations for a healthy lifestyle.

1 Do you know how many servings of fruit and vegetables experts recommend that people eat PER DAY?

…………….**servings per day**

2 Do you know what the maximum number of units of alcohol <u>men</u> are recommended to drink PER WEEK? A unit is a small glass of wine, half a pint of beer or a 25ml measure of spirits

………………..units per week

3 Do you know what the maximum number of units of alcohol <u>women</u> are recommended to drink PER WEEK? A unit is a small glass (125ml) of wine, half a pint of beer or a 25ml measure of spirits

………………..units per week

4 Do you know how much MODERATE physical activity experts recommend people take? For example, brisk walking, leisurely cycling, dancing etc.

………….minutes per day on …………days per week

SECTION 10

SUPPORT FROM THOSE AROUND YOU

1 If you decided to make changes to your lifestyle (e.g. diet, physical activity etc)

	No help	A little	Moderate amount	Quite a lot	A great deal	Not applicable
How much help would you get from your family to make such changes?	☐	☐	☐	☐	☐	☐
How much help would you get from your friends or people you work with?	☐	☐	☐	☐	☐	☐
	Definitely not	Probably not	Don't know	Probably yes	Definitely yes	Not applicable
Would any member of your family try to make any changes with you?	☐	☐	☐	☐	☐	☐

	Definitely not	Probably not	Don't know	Probably yes	Definitely yes	Not applicable
Would your family encourage you to keep trying to make changes if the going got tough?	☐	☐	☐	☐	☐	☐
Would any of your friends or people you work with try to make any changes with you?	☐	☐	☐	☐	☐	☐
Would your friends or people at work encourage you not to give up if the going got tough?	☐	☐	☐	☐	☐	☐

SECTION 11

INFORMATION FROM HEALTH PROFESSIONALS

1a In the time since you were first diagnosed with cancer, did your oncologist or any other health professional (for example GP or nurse) ever recommend any of the following?

Stopping smoking?	No ☐	Yes ☐
Doing more exercise? (other than range of motion exercises after surgery)	No ☐	Yes ☐
Reducing the amount of alcohol you drink?	No ☐	Yes ☐
Eating a low fat diet?	No ☐	Yes ☐
Eating more fruit and vegetables?	No ☐	Yes ☐

1b If you answered <u>yes</u> to any of question 1 do you remember who gave you the information and what was suggested?

……

……

……………………………………………………………………………………

2 If you were given the opportunity to have further advice/support on making lifestyle changes would you take up the offer?

Yes definitely	Yes probably	Probably not	Definitely not	Not sure
☐	☐	☐	☐	☐

3 How interested would you be in the following?

	Not at all interested	A little interested	Somewhat interested	Very interested	Extremely interested
Advice/support that would help you to have a healthy diet	☐	☐	☐	☐	☐
Advice/support that would help you to maintain a healthy weight	☐	☐	☐	☐	☐
Advice/support that would help you increase your physical activity	☐	☐	☐	☐	☐
Advice/support to help you stop smoking	☐	☐	☐	☐	☐
Advice/support that would help you adopt an overall healthy lifestyle	☐	☐	☐	☐	☐

4 When do you think would be the best time to offer healthy lifestyle information to patients diagnosed with cancer?

At diagnosis or soon after	3-6 months after diagnosis	7-11 months after diagnosis	1-2 yrs after diagnosis	More than 2 yrs after diagnosis	Any time
☐	☐	☐	☐	☐	☐

5 If these options were available would you be interested in any of the following formats of advice/support about making lifestyle changes?

	Not at all interested	A little interested	Somewhat interested	Very interested	Extremely interested
Written material	☐	☐	☐	☐	☐
Internet information	☐	☐	☐	☐	☐
DVD/Video information	☐	☐	☐	☐	☐
A telephone call from a health professional	☐	☐	☐	☐	☐
A single individual session at the hospital	☐	☐	☐	☐	☐
A single group session at the hospital	☐	☐	☐	☐	☐
A multiple session group programme at the hospital	☐	☐	☐	☐	☐

SECTION 12

A FEW QUESTIONS ABOUT YOU

1 How old are you? ……….years

2 What is your sex? Male ☐ Female ☐

3 At what age did you leave full-time education? ………..years

4 What is the highest level of educational or professional qualification you have obtained?

GCSE/ School certificate/ O-level/CSE ☐
Vocational qualifications (e.g. NVQ1+2) ☐
A-level/Higher school certificate or equivalent (e.g. NVQ3) ☐
Bachelor Degree or equivalent (e.g. NVQ4) ☐
Masters/PhD/PGCE or equivalent ☐
Still studying ☐
No formal qualifications ☐
Other (Specify……………………..…….) ☐

5 Are you currently?

Employed full time ☐
Employed part-time ☐
Self-employed ☐
Unemployed and looking for work ☐
Looking after the home or family ☐
Full-time education ☐
Retired ☐
Disabled or too ill to work ☐
Voluntary work ☐
Other (please state)…..………………………………………….

6 What is your marital status?

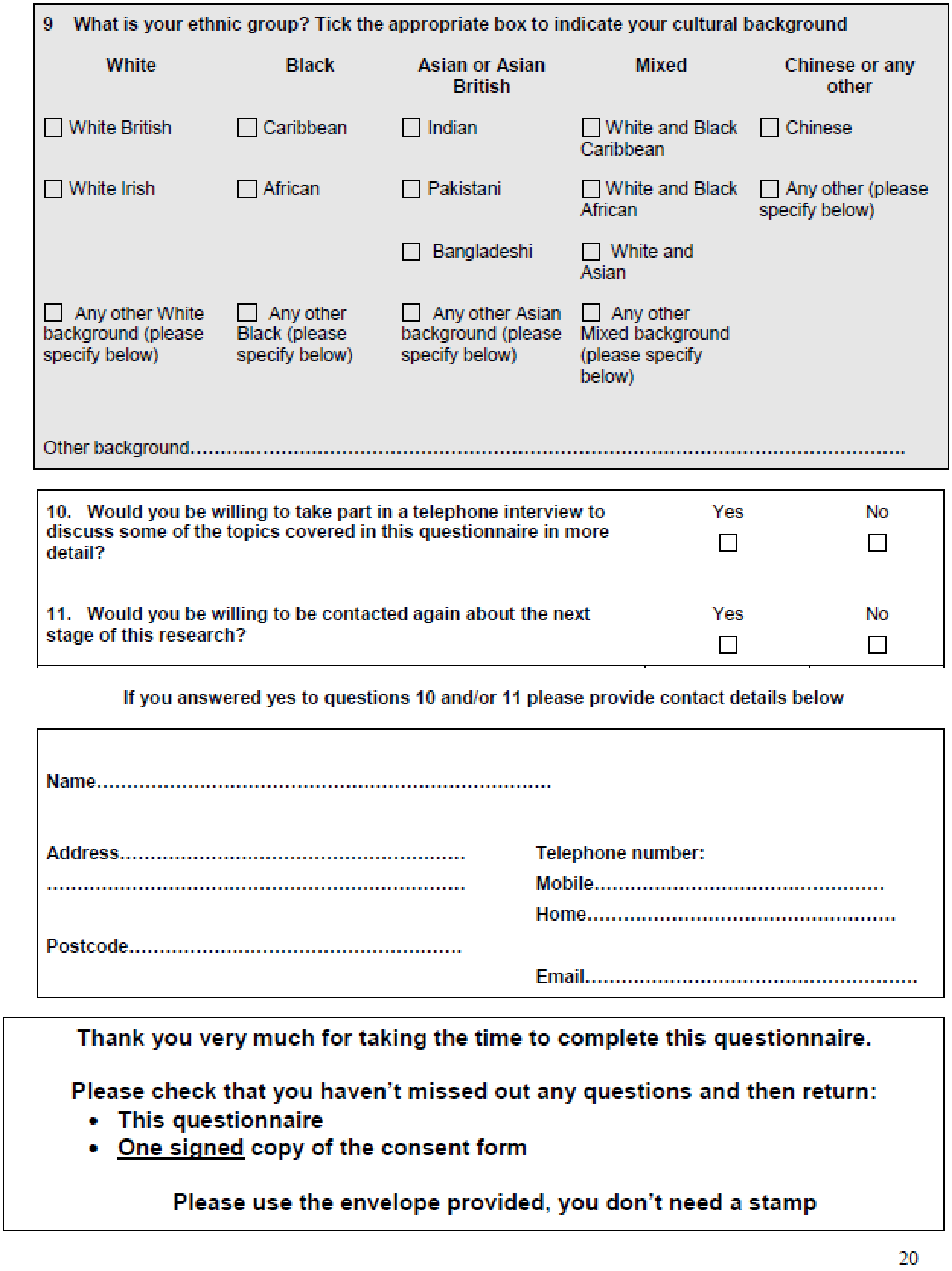
Married/Living with partner	Single	Divorced	Separated	Widowed
☐	☐	☐	☐	☐

7 Please tick the box which best describes your living arrangement:

Rent from local authority or housing association	Rent from private landlord	Own/buying own home	Live with parents/family	Other
☐	☐	☐	☐	☐

8 Does your household have a car or van? No ☐ Yes, one ☐ Yes, more than one ☐

PLEASE TURN OVER



9 What is your ethnic group? Tick the appropriate box to indicate your cultural background

White	**Black**	**Asian or Asian British**	**Mixed**	**Chinese or any other**
☐ White British	☐ Caribbean	☐ Indian	☐ White and Black Caribbean	☐ Chinese
☐ White Irish	☐ African	☐ Pakistani	☐ White and Black African	☐ Any other (please specify below)
		☐ Bangladeshi	☐ White and Asian	
☐ Any other White background (please specify below)	☐ Any other Black (please specify below)	☐ Any other Asian background (please specify below)	☐ Any other Mixed background (please specify below)	

Other background……………………………………………………………………………………………………

10. Would you be willing to take part in a telephone interview to discuss some of the topics covered in this questionnaire in more detail?	Yes ☐	No ☐
11. Would you be willing to be contacted again about the next stage of this research?	Yes ☐	No ☐

If you answered yes to questions 10 and/or 11 please provide contact details below

Name………………………………………………………………………

Address……………………………………………………

……………………………………………………………

Postcode…………………………………………………

Telephone number:

Mobile…………………………………………

Home…………………………………………

Email……………………………………………

Thank you very much for taking the time to complete this questionnaire.

Please check that you haven't missed out any questions and then return:

- **This questionnaire**
- **<u>One signed</u> copy of the consent form**

Please use the envelope provided, you don't need a stamp

Appendix 4: T-test to examine mean scores for causal attributions of cancer by sex

Attribution	Men	Women	t	p
Genetics	1.71 (1.60)	2.14 (1.64)	-2.58	.010
Family history	1.79 (1.61)	2.10 (1.63)	-1.96	.051
Hormones	0.70 (1.14)	1.08 (1.28)	-3.01	.003
Pollution	1.56 (1.53)	1.88 (1.48)	-2.00	.046
Xrays	0.75 (1.28)	1.03 (1.36)	-2.03	.043
Stress	1.65 (1.48)	2.01 (1.47)	-2.45	.015
God	0.93 (1.47)	1.31 (1.48)	-2.45	.015
Injury	0.38 (0.86)	0.58 (1.11)	-2.01	.045
Lack of physical activity	0.93 (1.32)	1.26 (1.32)	-2.27	.024
Smoking	1.46 (1.77)	1.63 (1.82)	-.882	.378
Alcohol consumption	1.64 (1.32)	1.03 (1.41)	.983	.326
Lack of F&V intake	1.49 (1.49)	1.49 (1.60)	.043	.969
Fat consumption	1.60 (1.51)	1.44 (1.54)	1.04	.301
Age	2.10 (1.42)	2.21 (1.38)	-.800	.424
Being overweight	1.26 (1.49)	1.39 (1.47)	-.819	.413

Appendix 5: T-tests to examine mean scores for behavioural attributions by change in behaviour

Behaviour change	Attributions of recurrence mean (SD)	T	p
Increased physical activity (n = 299)	3.50 (0.88)	t (325) = -2.16	.032
No increase in physical activity (n = 28)	2.95 (1.22)		
Increase in F&V consumption (n = 275)	3.36 (1.05)	t (332) = -2.07	.040
No increase in F&V consumption (n = 59)	3.03 (1.12)		
Reduction in alcohol intake (n = 130)	3.05 (1.19)	t (285) = -2.40	.017
No reduction in alcohol intake (n = 125)	2.69 (1.27)		

Appendix 6: Perceived barriers to physical activity

Categories **N = 379** ***Missing* = 100**	**N (%) of coding units in category**	**Themes**	**N**	**Coding Units**	**N**
Comorbidities	72 (18)	COPD/breathlessness	36	Shortness of breath	6
				Out of breath	5
				Breathlessness	11
				Asthma	3
				COPD	2
				Breathing problems	6
				Bronchitis	1
				Breathing	2
		CVD/’heart condition’	11	Heart failure	2
				Heart	2
				BP	3
				Irregular heart beat	2
				Heart problems	2
		Other health problems (e.g. diabetes)	25	Parkinsons	2
				Anaemia	1
				Diabetes	2
				Sciatica	2
				Panic attack	1
				CFS	1
				Key hole surgery	1

Categories	N (%)	Themes	N	Coding Units	N
				Aneurisms	2
				Polio	1
				Osteoporosis	3
				Physically unable	1
				DVT	2
				Blind	1
				Fractures	1
				Health	1
				Lung removed	1
				Awaiting op	1
				MRSA	1
Mobility	43 (11%)	Arthritis	20	Arthritis	18
				Arthritic knee	1
				Rheumatism	1
		Joint replacement (hip/knee)	6	Artificial knee	1
				Hip replacement	3
				Artificial hip	1
				Knee replacement	1
		Lack of mobility	15	Use crutches	1
				Semi paralysed	1
				Walking stick	1
				Losing use of limbs	2
				Leg trouble	1
				Hard to walk	1
				Can’t walk fast	1

Categories	N (%)	Themes	N	Coding Units	N
				Limited mobility	3
				Fall	1
				Unable to get about	1
				Agility	1
				Use wheel chair	1
		Poor balance	2	Knackered balance	1
				Impaired balance	1
Ageing	90 (24%)	Aches and pains	49	Joint pain	6
				Knee pain	5
				Aches and pains	4
				Painful muscles	1
				Back pain	10
				Joint aches	1
				Wear and tear of spine	1
				Pain	8
				Pains in stomach	2
				Joint problems	1
				Right side uncomfortable	1
				Uncomfortable to walk	1
				Sore feet	3
				Bad knee	1
				Stiff joints	2
				Discomfort	1
				Achy	1

Categories	N (%)	Themes	N	Coding Units	N
		Age	41	Aged 80	2
				Age	36
				81 years old	2
				Aging	1
Treatment and its effects	130 (34%)	Tiredness/fatigue	50	Tiring too easily	2
				Tiredness	29
				Feeling tired	1
				Getting over tired	1
				Lack of energy	3
				No energy	6
				Getting tired more quickly	3
				Feel weary	1
				Fatigue	2
				Excess tiredness	1
				Need more sleep	1
		Cancer treatment	10	Chemo	4
				Groshen line	1
				Treatment	4
				Dizzy from treatment	1
		Colostomy/illeostomy bag	17	Illiostomy	2
				Pouch anxiety	1
				Stoma	8
				Overactive stoma	1
				Colostomy	5

Categories	N (%)	Themes	N	Coding Units	N
		Hernia	14	Hernia	11
				Fear of damaging hernia repair	2
				Fear or hernia	1
		Nausea	2	Sickness	1
				Nausea	1
		Neuropathy	6	Neuropathy	3
				Lack of feeling in hands and feet	2
				Numbness in hands and feet	1
		Feeling unwell	15	Illness	7
				Serious illness	1
				Being unwell	4
				A decline in myself	1
				Weakness	2
		Surgery	14	Post surgery effects	1
				Scar tissue hampers me	1
				Getting over surgery	2
				Waiting for surgery	1
				Surgery	4
				Weak after stoma reversal	1
				Pain from surgery	1
				Surgery stopped play	1
				Discomfort from scar tissue	1

Categories	N (%)	Themes	N	Coding Units	N
				Weak after surgery	1
		Effects of radiation	2	Pain from radiation	1
				Bleeding from radiation	1
Other commitments	48 (13%)	Family commitments	14	Running after daughter	1
				Busy at home	1
				Leaving wife alone with MS	1
				Carer for wife	2
				Home commitments	2
				Household chores	1
				House to run	1
				Family commitments	2
				Visiting family	1
				Looking after grandchildren	1
				Home life	1
		Social commitments	7	Other things to do	1
				Other social activities	2
				Other interests	1
				Watching TV	1
				Catching up on travel	1
				Involved in other things	1
		Work commitments	27	Work	24
				Business commitments	1
				Secretary of block of flats	1
				Lots of meetings	1

Categories	N (%)	Themes	N	Coding Units	N
Bowel function	9 (2%)	Bowel problems	9	Anxiety with bowel	1
				Running to toilet	1
				Overactive bowel	1
				Need to go to toilet	2
				Loose bowel movement	1
				Lack of bowel control	1
				Bowel problems	1
				Diarrhoea	1
Fear	2 (0.5%)	Fear of infection	1	Risk of infection	1
		Fear of falling	1	Nervous of falling	1
Poor conditioning	5 (1%)	Being overweight	2	Overweight	2
		Poor fitness	3	Lack of fitness	1
				Stamina	2
General barriers	63 (17%)	Cost	2	Cost of fitness club	1
				Yoga is expensive	1
		Inconvenience	1	Convenience	1
		Lack of support	5	Lack of company	1
				Unsupervised, fear of doing wrong activity	1
				Can’t get out alone	2
				Loose interest if others not with me	1

Categories	**N (%)**	**Themes**	**N**	**Coding Units**	**N**
		Lack of time	31	Time	18
				Finding the time	2
				Time restraints	1
				Setting time aside	1
				Lack of time	3
				Time management	1
				Fitting it in	1
				Not enough hours in the day	2
				Too much else to do	1
				Busy life	1
		Bad weather	24	Cold weather	3
				Weather	12
				Bad weather	6
				Not much fun in winter	1
				Wet weather	1
				In winter, evenings are dark	1
Lack of motivation	22 (6%)	Motivation	22	Will power	1
				Laziness	7
				Don’t enjoy it	1
				Motivation	7
				Inclination	4
				Idleness	2

Appendix 7 Perceived benefits to engaging in physical activity

Categories **N = 291** ***Missing* = 188**	**N (%) of coding units in category**	**Themes**	**N**	**Coding Units**	**N**
Physiological benefits	223 (77%)	Improves bowel function	2	Not running to toilet	1
				Good for bowel	1
		Improves breathing	8	I wouldn't get out of breath	1
				Breathing	1
				Breathing would improve	4
				Deep breathing	1
				Better breathing	1
		Improves cardiovascular system	13	Improve circulation	2
				More oxygen	1
				Lower BP	3
				Better lung function	1
				CV exercise	1
				Benefits of getting HR up	1
				Strengthened CV system	1
				Stronger heart	2
				Improve heart	1
		Improve health	53	General health would improve	2
				Better health	19
				Healthy lifestyle	4
				Physical health	2

Categories	N (%)	Themes	N	Coding Units	N
				Be healthier	8
				Healthier life	1
				Feel healthier	4
				Good for my health	3
				Better physical and mental health	3
				General health	2
				Mental health	1
				Healthier body	1
				Be healthy	1
				More responsive body and mind	1
				Improved overall lifestyle	1
		Ease of ADL	5	Everyday activities	1
				I would be able to follow my interests	1
				It would make things like gardening easier	1
				Physically better to perform more active pursuits	1
				Carry out more activities	1
		Improve sleep	3	More sleep	1
				I would sleep better	1
				Better sleep	1
		More energy/less tiredness	21	More energy	14
				More vitality	1
				Tiredness	1
				Boost energy levels	1
				Less tired	2
				More lively	1
				Energise body and mind	1

Categories	N (%)	Themes	N	Coding Units	N
		Improve mobility	8	More agility	3
				Mobility	2
				Easier movement	1
				More mobile	1
				More joint movement	1
		Improve fitness	84	Regain stamina	1
				Greater fitness	5
				Fitter	29
				Physically fit	3
				Better/improved fitness	23
				More stamina	8
				Get heart rate down	1
				Feel fitter	7
				Keep fit	3
				General fitness	2
				Keep fit for longer	1
				Maintain fitness	1
		Increase strength	26	Stronger muscles	1
				Firmer muscles	1
				(body) strength	7
				Feel stronger	4
				Be stronger	3
				Strength in my muscles	3
				Stronger body function	1
				Muscle growth	1

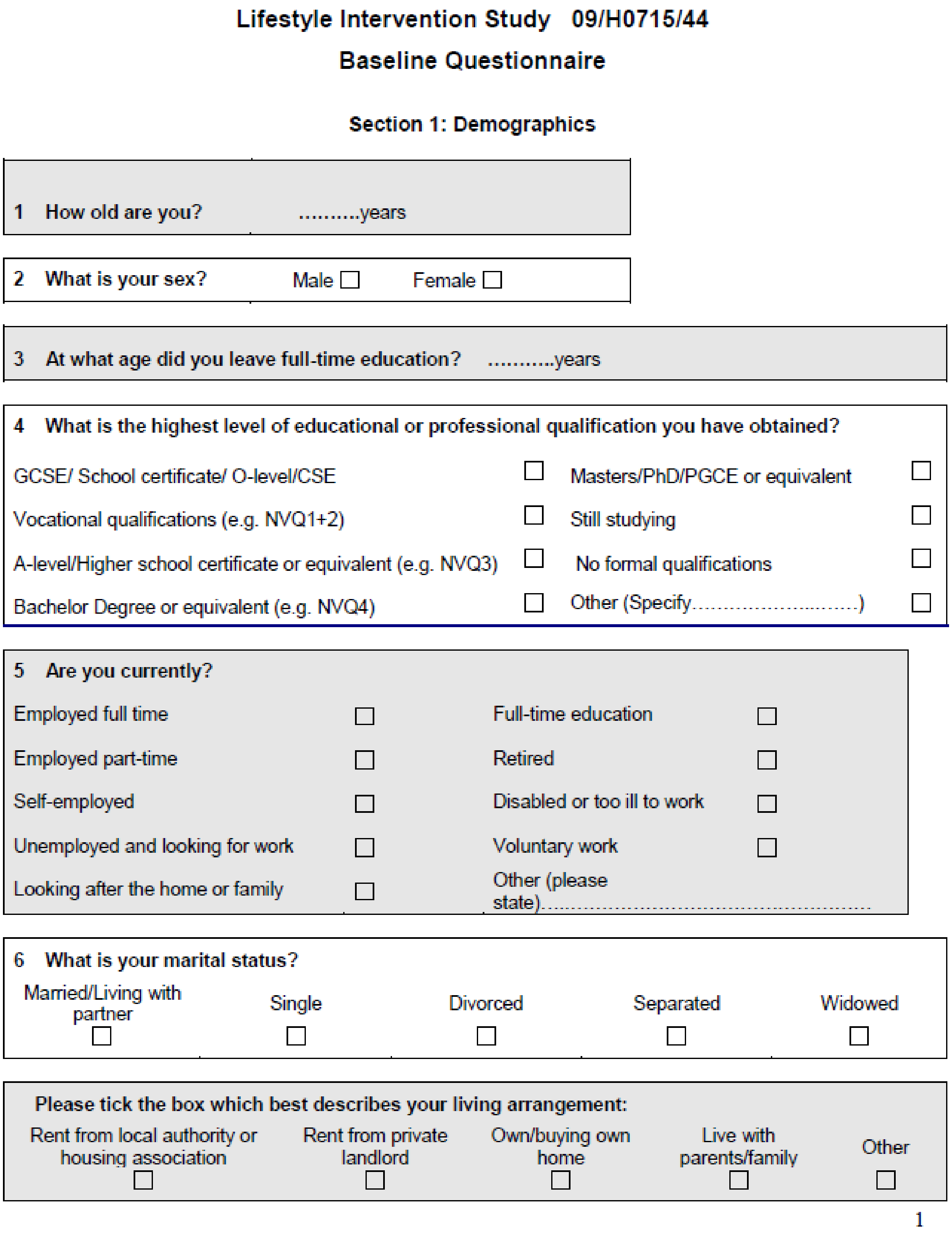
Categories	N (%)	Themes	N	Coding Units	N
				Better muscle tone	2
				Regain muscle	1
				All-round strength	1
				Stronger in old age	1
Protection from disease	8 (3%)	Increase lifespan	2	Prolonged life	1
				Live longer	1
		Reduce chance of cancer recurrence	3	Reduce risk of recurrence	1
				Ward off cancer	1
		Resistance to disease	3	Resistance to ill health	1
				Less chance of CV problems	1
				Greater resistance to all forms of illness	1
Wellbeing	47 (16)	Improve wellbeing	47	Feel better	20
				Feeling/sense of well being	18
				Feel good	3
				Feel at ease	1
				A better life	2
				Mental and physical well being	1
				Mental health	1
				Feel good factor	1
Hobbies/interest	19 (7%)	Get out of the house	5	Fresh air	2
				Getting out a bit more	2
				I could go out	1

Categories	N (%)	Themes	N	Coding Units	N
		Socialising	2	Better social life	1
				Socialising	1
		Relieves boredom	1	Less boredom	
		Enjoyable	8	Pleasure	4
				Enjoy life more	1
				Enjoyment of activities	2
				Fun	1
		Increase independence	2	Feeling independent	1
				Independence	1
		Provides an interest	1	A more interesting life	
Weight	78 (27%)	Maintain a healthy weight	10	Sensible weight	1
				Keep weight down	1
				Reduce weight gain	1
				Maintain weight	1
				Prevent weight gain	2
				Weight control	2
				Help weight	1
				Keep slim	1
		Lose weight	68	Lose weight	62
				Lose fat	1
				Less weight	1
				Less weighty	1
				Thinner	1
				Slimmer	2

Categories	N (%)	Themes	N	Coding Units	N
Appearance	7 (2%)	Better figure/appearance	7	Better physique	1
				Better figure	2
				Look better	3
				Better posture	1
Get back to old self	2 (0.5%)	Get back to “old self”	2	Feel like old self	
				Develop muscles back to pre- cancer condition	
Psychological/cognitive benefits	32 (11%)	Positive attitude	1	Positive attitude	1
		Peace of mind	2	Peace of mind	2
		Feel positive	1	The knowledge I am doing the best I can	1
		Self-satisfaction	2	Self-satisfaction	2
		More alert	6	More alert	3
				Feeling of alertness	1
				More focused	2
		Improves concentration	1	Better concentration	1
		Increases confidence	6	Confidence	3
				Confidence in the way I look	1
				More confident	2
		Able to cope with more	1	Able to cope with more	1

Categories	N (%)	Themes	N	Coding Units	N
		Reduce risk of depression	1	Reduce risk of depression	1
		Inner strength	1	Inner strength	1
		New outlook on life	1	New outlook on life	1
		Relaxation	3	Relaxation	1
				More relaxed	2
		Self-respect	1	Self-respect	1
		Decrease stress	5	Swimming de-stresses me	1
				Get rid of working stress	1
				Forget my problems	1
				Less stress	1
				No stress	1

Appendix 8: Intervention baseline questionnaire



Lifestyle Intervention Study 09/H0715/44

Baseline Questionnaire

Section 1: Demographics

1 How old are you? ……….years

2 What is your sex? Male ☐ Female ☐

3 At what age did you leave full-time education? ……….years

4 What is the highest level of educational or professional qualification you have obtained?

GCSE/ School certificate/ O-level/CSE ☐
Vocational qualifications (e.g. NVQ1+2) ☐
A-level/Higher school certificate or equivalent (e.g. NVQ3) ☐
Bachelor Degree or equivalent (e.g. NVQ4) ☐
Masters/PhD/PGCE or equivalent ☐
Still studying ☐
No formal qualifications ☐
Other (Specify…………………...……) ☐

5 Are you currently?

Employed full time ☐
Employed part-time ☐
Self-employed ☐
Unemployed and looking for work ☐
Looking after the home or family ☐
Full-time education ☐
Retired ☐
Disabled or too ill to work ☐
Voluntary work ☐
Other (please state)…………………………………………………

6 What is your marital status?

Married/Living with partner	Single	Divorced	Separated	Widowed
☐	☐	☐	☐	☐

Please tick the box which best describes your living arrangement:

Rent from local authority or housing association	Rent from private landlord	Own/buying own home	Live with parents/family	Other
☐	☐	☐	☐	☐

1

8 Does your household have a car or van? No ☐ Yes, one ☐ Yes, more than one ☐

9 What is your ethnic group? Tick the appropriate box to indicate your cultural background

White	**Black**	**Asian or Asian British**	**Mixed**	**Chinese or any other**
☐ White British	☐ Caribbean	☐ Indian	☐ White and Black Caribbean	☐ Chinese
☐ White Irish	☐ African	☐ Pakistani	☐ White and Black African	☐ Any other (please specify below)
		☐ Bangladeshi	☐ White and Asian	
☐ Any other White background (please specify below)	☐ Any other Black (please specify below)	☐ Any other Asian background (please specify below)	☐ Any other Mixed background (please specify below)	

Other background…………………………………………………………………………………………………

10 Have you had any of the following health problems? Please tick any that apply

Osteoporosis ☐
Diabetes ☐
Asthma ☐
Arthritis ☐

Heart murmur ☐
Stroke ☐
Heart attack ☐
Angina ☐

Irregular heart rhythm ☐
Any other heart trouble ☐
Lung disease ☐
Parkinson's disease ☐

Emotional, nervous or psychiatric illness ☐

Other (please state)………………………… ……………………………………………………………………

11 Weight? ……….kgs

12 Height? ……….cms

} To be taken by researchers

Section 2: Physical Activity

1 During a typical 7-day period (a week), how many times on average do you do the following kinds of exercise for **more than 15 minutes** during your free time?

a **Strenuous exercise** (when your heart beats rapidly and you breath much faster)

e.g. running, jogging vigorous swimming, vigorous cycling. .... **Times per week**

On average, how long were these sessions of exercise? .... **Minutes a session**

b **Moderate exercise** (when you breath somewhat harder than normal)

e.g. brisk walking, easy cycling, easy swimming, dancing. .... **Times per week**

On average, how long were these sessions of exercise? .... **Minutes a session**

c **Mild exercise** (takes minimal effort)

e.g. easy walking, fishing, bowling. .... **Times per week**

On average, how long were these sessions of exercise? .... **Minutes a session**

During a typical **7-Day period** (a week), in your leisure time, how often do you engage in any regular activity **long enough to work up a sweat** (heart beats rapidly)?

Often	Sometimes	Rarely/Never
☐	☐	☐

Section 3: Confidence

How sure are you that, if you wanted to, you could………

	Very sure	Sure	Somewhat sure	Unsure	Very unsure
1 Do moderate intensity exercise for at least 30 minutes a day on at least 5 days of the week?	☐	☐	☐	☐	☐
2 Eat at least 5 servings of fruit and vegetables a day?	☐	☐	☐	☐	☐
3 Eat unprocessed cereals/grains (such as wholemeal bread, brown rice and brown pasta)?	☐	☐	☐	☐	☐
4 Limit the amount of red meat (beef, lamb, pork and veal) you eat to 500g a week?	☐	☐	☐	☐	☐
5 Avoid processed meats such as ham, bacon, sausages, pate, salami, tinned meat and corned beef?	☐	☐	☐	☐	☐

Section 4: Attitudes towards physical activity

Below are some questions about your attitude towards taking part in regular physical activity. By "regular" we mean several times a week, and by "physical activity" we mean activities such as brisk walking.

If I were to take part in regular physical activity over the next 12 weeks it would……

	Extremely unlikely	Unlikely	Neither likely nor unlikely	Likely	Extremely likely
1a Improve my fitness levels	☐	☐	☐	☐	☐
1b Make me feel better about myself	☐	☐	☐	☐	☐
1c Relieve stress	☐	☐	☐	☐	☐
1d Help me cope with the stress of cancer	☐	☐	☐	☐	☐
1e Make me feel more normal	☐	☐	☐	☐	☐
1f Reduce the risk of my cancer returning	☐	☐	☐	☐	☐
1g Keep my mind off cancer	☐	☐	☐	☐	☐

	Extremely unlikely	Unlikely	Neither likely nor unlikely	Likely	Extremely likely
1h Improve my energy levels	☐	☐	☐	☐	☐
1i Help me recover from cancer treatment	☐	☐	☐	☐	☐
1j Improve my immune system	☐	☐	☐	☐	☐
1k Help me gain control over cancer and my life	☐	☐	☐	☐	☐
1l Help control my weight	☐	☐	☐	☐	☐

	Definitely not	Probably not	Neither yes nor no	Probably yes	Definitely Yes	N/A
2a Would your oncologist think you should take part in regular PA over the next 12 weeks?	☐	☐	☐	☐	☐	☐
2b Would your spouse/partner think you should take part in regular PA over the next 12 weeks?	☐	☐	☐	☐	☐	☐
2c Would your friends think you should take part in regular PA over the next 12 weeks?	☐	☐	☐	☐	☐	☐
2d Would other colorectal cancer patients think you should take part in regular PA over the next 12 weeks?	☐	☐	☐	☐	☐	☐
2e Would other family members think you should take part in regular PA over the next 12 weeks?	☐	☐	☐	☐	☐	☐

How confident are you that, if you wanted to, you could take part in regular physical activity over the next 12 weeks even if.....

	Not at all confident	Somewhat Unconfident	Neither confident nor unconfident	Confident	Completely confident
3a You had no counselling for exercise	☐	☐	☐	☐	☐
3b You had no support for exercise	☐	☐	☐	☐	☐
3c You had a cancer recurrence	☐	☐	☐	☐	☐

	Not at all confident	Somewhat Unconfident	Neither confident nor unconfident	Confident	Completely confident
3d The weather is bad	☐	☐	☐	☐	☐
3e You were too tired/fatigued	☐	☐	☐	☐	☐
3f You don't like exercise	☐	☐	☐	☐	☐
3g You experience pain or soreness	☐	☐	☐	☐	☐
3h You had additional family responsibilities	☐	☐	☐	☐	☐
3i You had no time to exercise/are too busy	☐	☐	☐	☐	☐
3j You had other health problems	☐	☐	☐	☐	☐

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
4a Do you intend to take part in regular physical activity over the next 12 weeks?	☐	☐	☐	☐	☐
4b Do you want to take part in regular physical activity over the next 12 weeks?	☐	☐	☐	☐	☐
	Extremely unmotivated	Unmotivated	Neither motivated nor unmotivated	Motivated	Extremely motivated
4c How motivated are you to take part in regular physical activity over the next 12 weeks?	☐	☐	☐	☐	☐

5 For you, would taking part in regular physical activity over the next 12 weeks be.....

Please tick one number per line

	1	2	3	4	5	
Very Harmful	☐	☐	☐	☐	☐	Very Beneficial
Very unnecessary	☐	☐	☐	☐	☐	Very necessary
Very Bad	☐	☐	☐	☐	☐	Very Good

	1	2	3	4	5	
Very Unenjoyable	☐	☐	☐	☐	☐	Very Enjoyable
Very Foolish	☐	☐	☐	☐	☐	Very Wise
Very Unpleasant	☐	☐	☐	☐	☐	Very Pleasant

Most people who are important to you ….

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
6a Would approve if you took part in regular physical activity over the next 12 weeks	☐	☐	☐	☐	☐
6b Think you should take part in regular physical activity over the next 12 weeks	☐	☐	☐	☐	☐
6c Would encourage you to take part in regular physical activity over the next 12 weeks	☐	☐	☐	☐	☐
6d Will take part in regular physical activity themselves over the next 12 weeks	☐	☐	☐	☐	☐

	Extremely difficult	Difficult	Neither easy nor difficult	Easy	Extremely easy
7a If you wanted to, taking part in regular physical activity over the next 12 weeks would be…..	☐	☐	☐	☐	☐
	Extremely unconfident	Somewhat Unconfident	Neither confident nor unconfident	Somewhat Confident	Extremely confident
7b If you wanted to, how confident are you that you could take part in regular physical activity over the next 12 weeks	☐	☐	☐	☐	☐
	No control	Little control	Moderate control	A lot of control	Complete control
7c If you wanted to, how much control do you feel you would have in exercising regularly over the next 12 weeks	☐	☐	☐	☐	☐

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
7d Whether or not I exercise regularly over the next 12 weeks is completely up to me	☐	☐	☐	☐	☐

Section 5: Attitudes towards healthy eating

Below are some questions about your attitude towards eating a healthy diet. By "healthy eating" we mean eating a diet that is high in fruit and vegetables and low in red and processed meats.

1 If I were to eat a healthy diet over the next 12 weeks it would…….

	Extremely unlikely	Unlikely	Neither likely nor unlikely	Likely	Extremely likely
1a Improve my overall physical health	☐	☐	☐	☐	☐
1b Control my weight	☐	☐	☐	☐	☐
1c Prevent my cancer coming back	☐	☐	☐	☐	☐
1d Improve the way I think about yourself	☐	☐	☐	☐	☐
1e Improve the way I look	☐	☐	☐	☐	☐
1f Save me money	☐	☐	☐	☐	☐
1g Be inconvenient	☐	☐	☐	☐	☐
1h Result in me being hungry	☐	☐	☐	☐	☐
1i Make me miss tasty foods I like	☐	☐	☐	☐	☐
1j Improve my bowel function	☐	☐	☐	☐	☐
1k Give me more energy	☐	☐	☐	☐	☐

	Definitely not	Probably not	Neither yes nor no	Probably yes	Definitely yes	Not applicable
2a Would your spouse/partner think you should eat a healthy diet over the next 12 weeks?	☐	☐	☐	☐	☐	☐
2b Would your oncologist think you should eat a healthy diet over the next 12 weeks	☐	☐	☐	☐	☐	☐
2c Would your children think you should eat a healthy diet over the next 12 weeks	☐	☐	☐	☐	☐	☐
2d Would your friends thinks you should eat a healthy diet over the next 12 weeks	☐	☐	☐	☐	☐	☐
2e Would other colorectal cancer patients think you should eat a healthy diet over the next 12 weeks	☐	☐	☐	☐	☐	☐
2f Would other family members thinks you should eat a healthy diet over the next 12 weeks	☐	☐	☐	☐	☐	☐
2g Would people you work with thinks you should eat a healthy diet over the next 12 weeks	☐	☐	☐	☐	☐	☐

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
3a I keep healthy foods available	☐	☐	☐	☐	☐
3b I have support for healthy eating from family and others	☐	☐	☐	☐	☐
3c I have the time to prepare foods that are healthy	☐	☐	☐	☐	☐
3d I am able to plan meals ahead of time	☐	☐	☐	☐	☐
3e I am able to keep track of my eating	☐	☐	☐	☐	☐
3f The cost of healthy foods is not a problem for me	☐	☐	☐	☐	☐
3g I am not able to choose healthy foods when eating outside my home	☐	☐	☐	☐	☐

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
3h I am not able to taste my favourite foods when I eat healthy foods	☐	☐	☐	☐	☐
3i I lack the will power to eat healthy foods	☐	☐	☐	☐	☐
3j I find it hard to break eating habits	☐	☐	☐	☐	☐
3k It will upset my stomach	☐	☐	☐	☐	☐

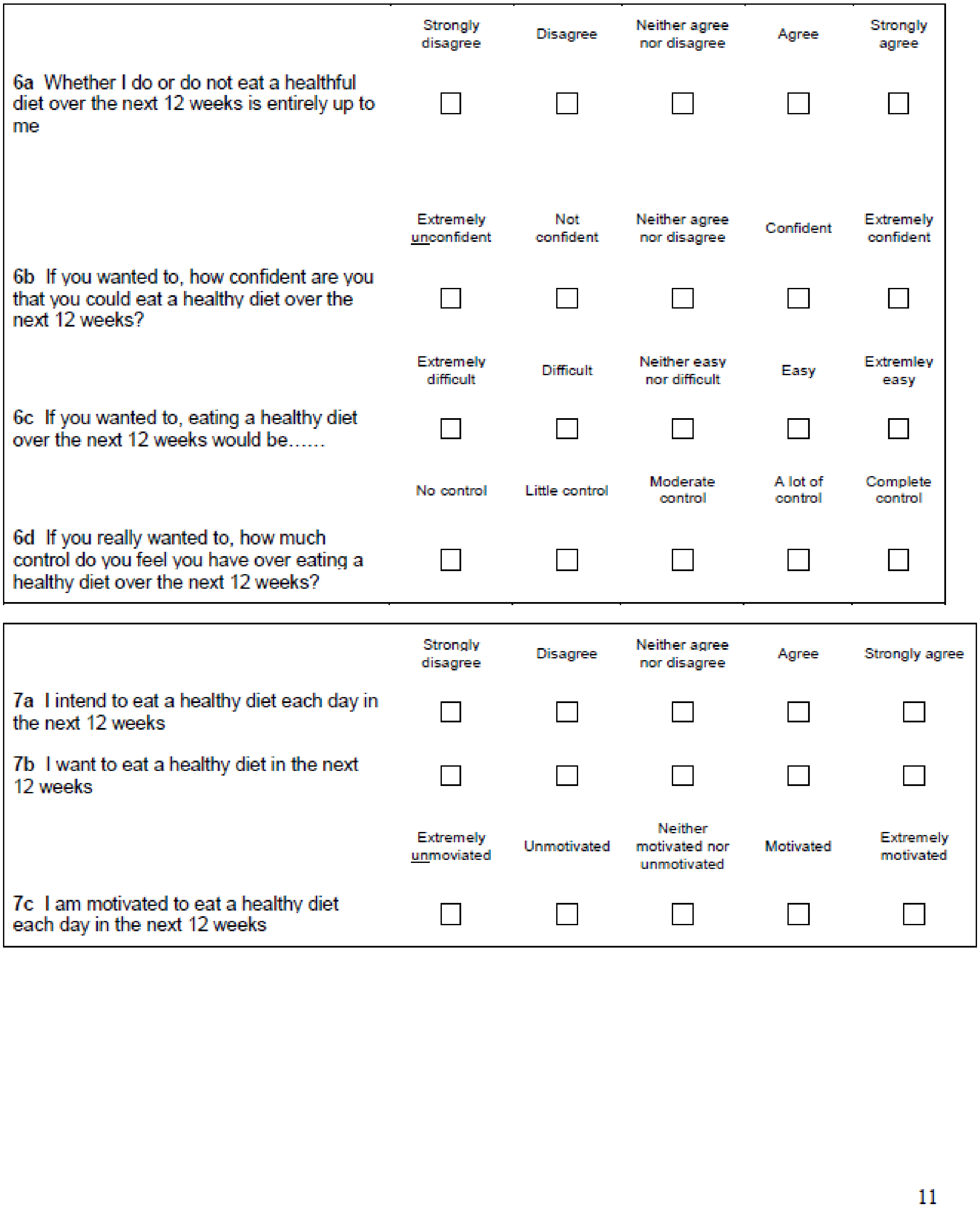
5 Eating a healthful diet over the next 12 weeks would be .....

Please tick one number per line

	1	2	3	4	5	
Very unpleasant	☐	☐	☐	☐	☐	Very pleasant
Very foolish	☐	☐	☐	☐	☐	Very wise
Very unenjoyable	☐	☐	☐	☐	☐	Very enjoyable
Very bad	☐	☐	☐	☐	☐	Very good
Very unnecessary	☐	☐	☐	☐	☐	Very necessary
Very harmful	☐	☐	☐	☐	☐	Very helpful

5 Most people who are important to you would.....

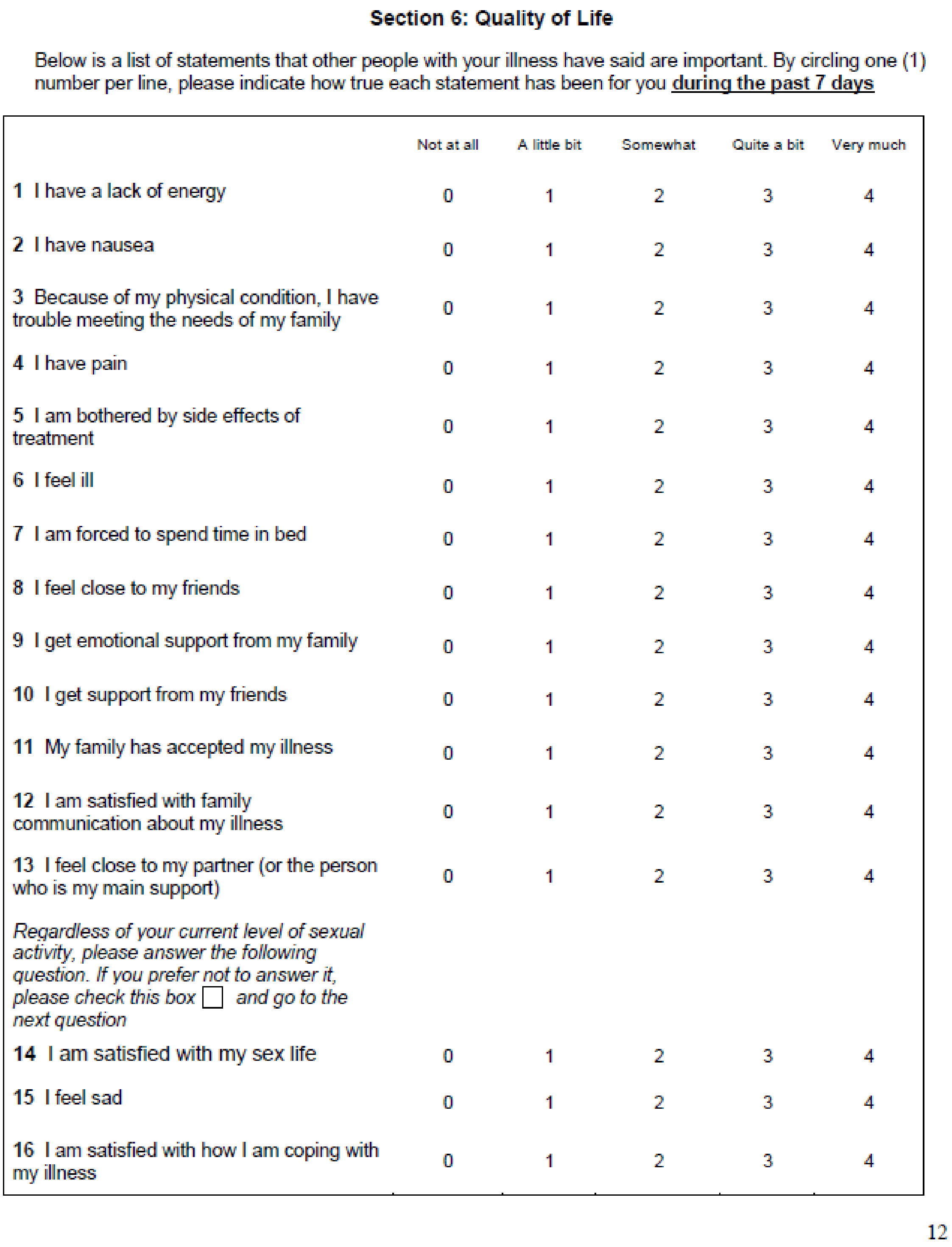
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
5a Approve if you ate a healthy diet over the next 12 weeks	☐	☐	☐	☐	☐
5b Think you should eat a healthy diet over the next 12 weeks	☐	☐	☐	☐	☐
5c Will eat a healthy diet themselves over the next 12 weeks	☐	☐	☐	☐	☐
5d Will encourage your to eat a healthy diet over the next 12 weeks	☐	☐	☐	☐	☐



	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
6a Whether I do or do not eat a healthful diet over the next 12 weeks is entirely up to me	☐	☐	☐	☐	☐
	Extremely unconfident	Not confident	Neither agree nor disagree	Confident	Extremely confident
6b If you wanted to, how confident are you that you could eat a healthy diet over the next 12 weeks?	☐	☐	☐	☐	☐
	Extremely difficult	Difficult	Neither easy nor difficult	Easy	Extremley easy
6c If you wanted to, eating a healthy diet over the next 12 weeks would be……	☐	☐	☐	☐	☐
	No control	Little control	Moderate control	A lot of control	Complete control
6d If you really wanted to, how much control do you feel you have over eating a healthy diet over the next 12 weeks?	☐	☐	☐	☐	☐

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
7a I intend to eat a healthy diet each day in the next 12 weeks	☐	☐	☐	☐	☐
7b I want to eat a healthy diet in the next 12 weeks	☐	☐	☐	☐	☐
	Extremely unmoviated	Unmotivated	Neither motivated nor unmotivated	Motivated	Extremely motivated
7c I am motivated to eat a healthy diet each day in the next 12 weeks	☐	☐	☐	☐	☐

11



Section 6: Quality of Life

Below is a list of statements that other people with your illness have said are important. By circling one (1) number per line, please indicate how true each statement has been for you **during the past 7 days**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
1 I have a lack of energy	0	1	2	3	4
2 I have nausea	0	1	2	3	4
3 Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
4 I have pain	0	1	2	3	4
5 I am bothered by side effects of treatment	0	1	2	3	4
6 I feel ill	0	1	2	3	4
7 I am forced to spend time in bed	0	1	2	3	4
8 I feel close to my friends	0	1	2	3	4
9 I get emotional support from my family	0	1	2	3	4
10 I get support from my friends	0	1	2	3	4
11 My family has accepted my illness	0	1	2	3	4
12 I am satisfied with family communication about my illness	0	1	2	3	4
13 I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box ☐ *and go to the next question*					
14 I am satisfied with my sex life	0	1	2	3	4
15 I feel sad	0	1	2	3	4
16 I am satisfied with how I am coping with my illness	0	1	2	3	4

12

	Not at all	A little bit	Somewhat	Quite a bit	Very much
17 I am losing hope in the fight against my illness	0	1	2	3	4
18 I feel nervous	0	1	2	3	4
19 I worry about dying	0	1	2	3	4
20 I worry that my condition will get worse	0	1	2	3	4
21 I am able to work (include work at home)	0	1	2	3	4
22 My work (include work at home) is fulfilling	0	1	2	3	4
23 I am able to enjoy life	0	1	2	3	4
24 I have accepted my illness	0	1	2	3	4
25 I am sleeping well	0	1	2	3	4
26 I am enjoying the things I usually do for fun	0	1	2	3	4
27 I am content with the quality of my life right now	0	1	2	3	4
28 I have swelling or cramps in my stomach area	0	1	2	3	4
29 I am losing weight	0	1	2	3	4
30 I have control of my bowels	0	1	2	3	4
31 I can digest my food well	0	1	2	3	4
32 I have diarrhoea	0	1	2	3	4
33 I have a good appetite	0	1	2	3	4
34 I like the appearance of my body	0	1	2	3	4
35 Do you have an ostomy appliance	Yes ☐	No ☐			

If yes, please answer the next two items

36 I am embarrassed by my ostomy appliance	0	1	2	3	4
36 Caring for my ostomy appliance is difficult	0	1	2	3	4

Section 7: Fatigue

Below is a list of statements that other people with your illness have said are important. By **circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
1 I feel fatigued	0	1	2	3	4
2 I feel weak all over	0	1	2	3	4
3 I feel listless (“washed out”)	0	1	2	3	4
4 I feel tired	0	1	2	3	4
5 I have trouble starting things because I am tired	0	1	2	3	4
6 I have trouble finishing things because I am tired	0	1	2	3	4
7 I have energy	0	1	2	3	4
8 I am able to do my usual activities	0	1	2	3	4
9 I need to sleep during the day	0	1	2	3	4
10 I am too tired to eat	0	1	2	3	4
11 I need help doing my usual activities	0	1	2	3	4
12 I am frustrated by being too tired to do the things I want to do	0	1	2	3	4
13 I have to limit my social activity because I am tired	0	1	2	3	4

Section 7- Physical Function

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
1 **Vigorous activities,** such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
2 **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
3 Lifting or carrying groceries	☐	☐	☐
4 Climbing **several** flights of stairs	☐	☐	☐
5 Climbing **one** flight of stairs	☐	☐	☐
6 Bending, kneeling, or stooping	☐	☐	☐
7 Walking **more than a mile**	☐	☐	☐
8 Walking **several hundred yards**	☐	☐	☐
9 Walking **one hundred yards**	☐	☐	☐
10 Bathing or dressing yourself	☐	☐	☐

Section 8 - Control

How much *personal* control do you think you have over the outcomes of your colon cancer, including....

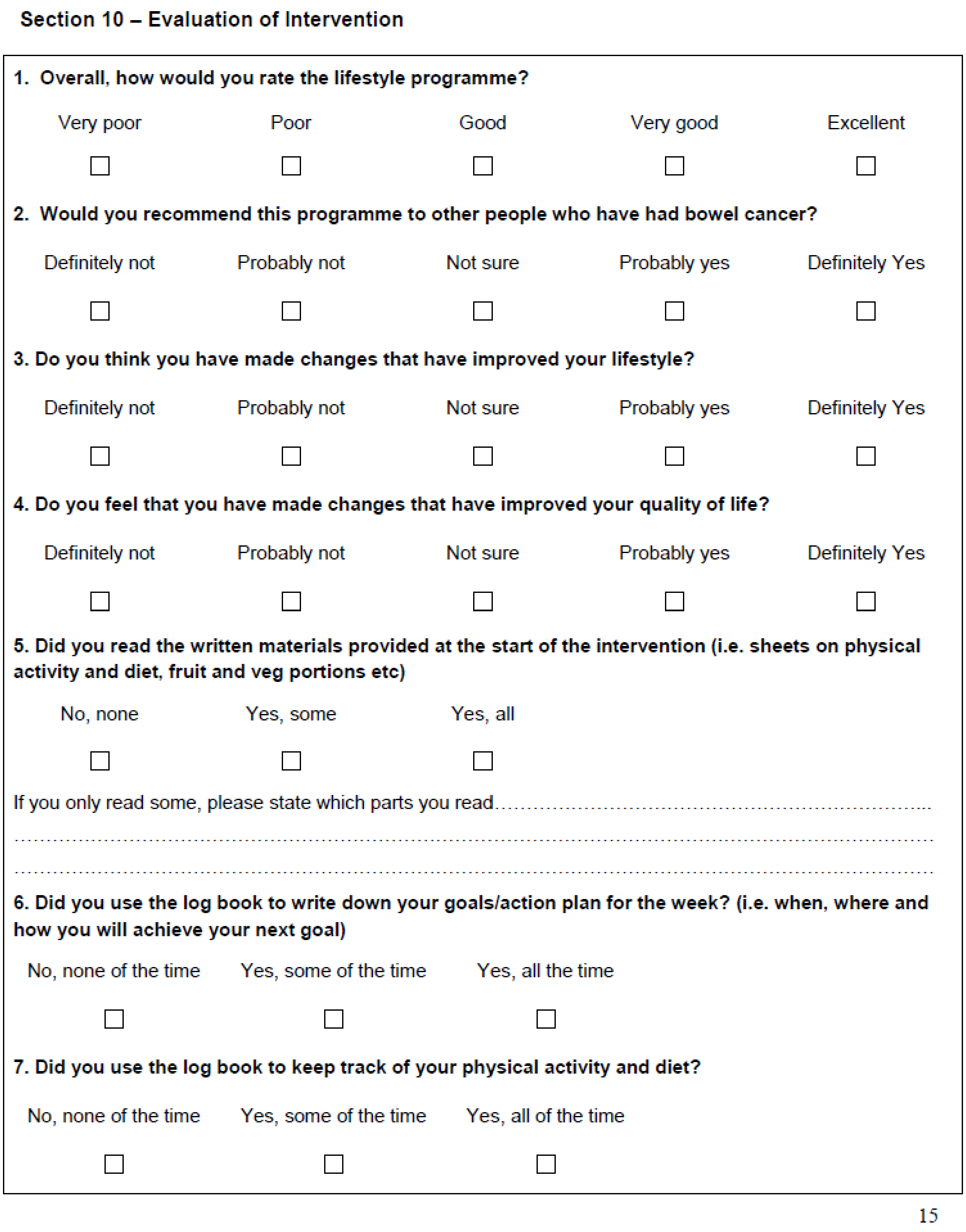
	No control	A little bit of control	A moderate amount of control	A great deal of control	Does not apply to me
1 Recovering from your current cancer?	1	2	3	4	5
2 Preventing colon cancer from coming back?	1	2	3	4	5

15

Please tick the response that indicates how strongly you agree or disagree with each statement.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1 I have little control over the things that happen to me.	☐	☐	☐	☐	☐
2 There is really no way I can solve some of the problems I have	☐	☐	☐	☐	☐
3 There is little I can do to change many of the important things in my life	☐	☐	☐	☐	☐
4 I often feel helpless in dealing with the problems of my life	☐	☐	☐	☐	☐
5 Sometimes I feel that I'm being "pushed around" in life	☐	☐	☐	☐	☐
6 What happens to me in the future mostly depends on me	☐	☐	☐	☐	☐
7 I can do just about anything I really set my mind to do	☐	☐	☐	☐	☐

Appendix 9 Intervention follow-up questionnaire



Section 10 – Evaluation of Intervention

1. Overall, how would you rate the lifestyle programme?

Very poor	Poor	Good	Very good	Excellent
☐	☐	☐	☐	☐

2. Would you recommend this programme to other people who have had bowel cancer?

Definitely not	Probably not	Not sure	Probably yes	Definitely Yes
☐	☐	☐	☐	☐

3. Do you think you have made changes that have improved your lifestyle?

Definitely not	Probably not	Not sure	Probably yes	Definitely Yes
☐	☐	☐	☐	☐

4. Do you feel that you have made changes that have improved your quality of life?

Definitely not	Probably not	Not sure	Probably yes	Definitely Yes
☐	☐	☐	☐	☐

5. Did you read the written materials provided at the start of the intervention (i.e. sheets on physical activity and diet, fruit and veg portions etc)

No, none	Yes, some	Yes, all
☐	☐	☐

If you only read some, please state which parts you read……………………………………………………………

……

……

6. Did you use the log book to write down your goals/action plan for the week? (i.e. when, where and how you will achieve your next goal)

No, none of the time	Yes, some of the time	Yes, all the time
☐	☐	☐

7. Did you use the log book to keep track of your physical activity and diet?

No, none of the time	Yes, some of the time	Yes, all of the time
☐	☐	☐

8. Did you use the log book to check back on how you got on each week (i.e. if you meet your goals)

No, none of the time	Yes, some of the time	Yes, all of the time
☐	☐	☐

9. Did you get support from a friend/spouse/partner during the study, i.e. to help you stick to your goals?

No, not at all	Yes, for some parts	Yes, for all parts
☐	☐	☐

If you involved a friend/spouse/partner for some of the study, please could you state which parts

……

……

……

Appendix 10 Topic guide for follow-up interviews

Lifestyle intervention after colorectal cancer

Follow-up Interview

Topic guide

This topic guide is intended to ensure key aspects are covered during the interview. However a respondent-sensitive approach will be taken, allowing deviation from the order of the questions and raising additional issues if desired.

Introduction

Introduce researcher.

Purpose of the interview: ‘explore the participant’s experience of the study’

Introduce tape recorder and ask permission to record the conversation.

Assure confidentiality and that names will not be used when this is written up.

Motivating factors

- What was your main reason for taking part in the study?
  Probe: to improve lifestyle, reduce the chance of cancer recurrence, to ‘give something back’, avoid displeasing consultants
- Was there anything that made you think twice about taking part?

Initial response

- What were your first thoughts when approached about the study/received a letter?
- What did you think the main purpose of the intervention was?

De-motivating factors

- Did you perceive any initial drawbacks/did anything put you off?
    - Probe; anything in the letter/way you were approached? Not wanting to think about condition etc

Response to baseline assessment

- How did you find the baseline assessment (first visit to UCL with CG?)
    - Prompt; travelling, length of session, length of questionnaire

PA aspects:

- Compared to the start of the study (not before diagnosis), do you feel like you are doing more PA?
- Did you understand what you were expected to do regarding increasing PA?
- What part of the intervention was most helpful for making change to PA?
    - Prompt; log book, pedometer, written materials, telephone calls
- What made it difficult for you to increase your PA?
    - Prompt; problems associated with cancer, i.e soreness from surgery, time, practical issues, motivation etc

Diet aspects:

- Compared to the start of the study (not before diagnosis), do you feel like you have made changes to your diet?
    - Prompt; specifically fruit and veg, and red and processed meat.
- Did you understand what you were expected to do regarding changing your diet?
- What part of the intervention was most helpful for making change to your diet?
    - Prompt; log book, written materials, telephone calls
- What made it difficult for you to change your diet?
    - Prompt; problems associated with cancer, i.e. soreness from surgery, time, practical issues, motivation etc

- How did you perceive the knowledge/skills/approach of CG (who delivered the intervention)?

<u>Specific components</u>

Written information:

- Did you read the written materials?

  - Prompt – these were the laminated sheets sent at the beginning of the study

- Did you find them useful?
- Did they tell you anything you didn't already know?
- Did you feel differently about diet/physical activity after reading the materials?
- Is there anything else you would have liked included in the written information?

Log books:

- Did you write down your goals after each consultation?
- Did you fill them in on a daily basis?
- Did you look back over your log book to see how you got on each week?
- Did you find the log books helpful?
- Would you change anything about the log books?

Pedometer:

- Did you use your pedometer?
- Did you find it helped you to increase your physical activity?

Telephone consultations:

- What did you think of the telephone calls?
- Was the goal setting process helpful?
- Did you find there was enough detail? Where the goals specific enough?
- Was reviewing your progress over the last few weeks helpful?
- Would you have liked any other information/talk about anything else?

Social support:

- Did you involve anyone else, friend/partner/spouse in the study; i.e. did anyone make changes with you or encourage you to stick to your goals?

Timing of the intervention

- What did you think of the timing of the study in relation to your cancer treatment?

  - Probe; was it too soon after treatment completion?
- When would you recommend approaching patients if we did the study again?

Contact structure and telephone calls

- Did you like the telephoned-based nature of the study or would you have preferred consultations face-to-face/group discussions?
- What did you think about the number of contact periods?
  - Probe; were there too many, would you have preferred more?
- Did the advice have credibility? Or would you have preferred a nurse/health professional to have delivered the intervention?

General reflection on the study

- What is your general reflection on the study?
- Did you enjoy it?
- How do you feel in yourself now compared to the start of the study?
- Would you recommend it to other people who have had bowel cancer?
  - Prompt; are there some bits you would recommend over others?
- Would you have made changes to your diet/PA had you not taken part?
- Do you feel as though you have benefitted from taking part?
  - Prompt; do you feel any different in yourself? Or feel differently about your cancer?
- What would you change about the study?
  - Prompt: would you like to add anything extra, such as walking groups etc.
- Do you think you will continue with the changes you have made?

Additional comments

- Is there anything else you would like to say about the study?

Concluding comments

- Thank participant for their time on the study and during the interview
- State that this is the end of the study and there will be no further contacts from CG/UCL
- Ask if they would like a copy of the log books to continue the goal setting/self-monitoring; CG can send those through
- Also ask if they would like a report at the end of the study, CG can send that to them. It will be in about 5 month's time.
- Thanks them again, and state that if they have any further comments/questions to call CG at any time

Appendix 11: Example of end of study report

DEPARTMENT OF EPIDEMIOLOGY & PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE

Results from the lifestyle intervention study after colorectal cancer

Participant characteristics:

Individuals who had recently completed treatment for colorectal cancer were identified from three London Hospitals; University College London Hospital, Princess Alexandra and North Middlesex.

A total of 18 people were invited to take part in the study and 13 expressed interest (72%). One of these individuals was already exercising for 3 hours a week, eating at least five servings of fruit and vegetables a day and eating very little red or processed meat. He was therefore excluded from taking part in the study but received a telephone consultation regarding health behaviours after colorectal cancer. Another participant was too unwell to attend her first appointment at UCL and subsequently decided not to take part.

Eleven participants were finally enrolled on the lifestyle intervention study. One participant withdrew mid-way through the intervention due to personal circumstances, therefore ten completed the study. The rest of this report presents your results and those from the nine other participants who completed the lifestyle study.

The average age of participants was 66 years, eight were female and two were male. On average participants were enrolled on the study 3 months after they had completed treatment.

Physical activity:

The graph below (Figure 1) describes the change in moderate intensity physical activity over the course of the study. The red bars represent the average of all participants in the study; the blue bars are your own results.

On entry to the study the average level of moderate physical activity was 32 minutes per week, however most (six out of ten) people were not doing any activity. You were doing [insert] moderate intensity activity. At the end of the study the average amount of moderate physical activity being performed was 158 minutes per week. You were performing [insert] minutes per week.

Figure 1: Change in moderate intensity physical activity

[INSERT FIGURE COMPARING AVERAGE AND PERSONAL CHANGE]

No participants were performing vigorous physical activity at the start of the study. By the end of the study [x] were engaging in an average of [x] minutes of vigorous physical activity per week. You were performing [x] minutes. See figure 2.

Figure 2: Change in vigorous intensity physical activity

[INSERT FIGURE COMPARING AVERAGE AND PERSONAL CHANGE]

You may remember I asked you to record the number of steps you took (using a pedometer) for three days, at the beginning and end of the study. Figure 3 below describes the average number of steps taken each day at the start and end of the study. You were taking [x] steps at the start of the study, the average was 4,830. You increased/decreased your steps to [x] per day by the end of the study; the average was 7,323 steps per day.

Figure 3: Change in steps walked per day

[INSERT FIGURE COMPARING AVERAGE AND PERSONAL CHANGE]

Diet

The average intake of fruit and vegetables on entry to the study was 3.4 portions per day, this increased to 6.6 portions per day. You were consuming [x] portions per day at the start of the study and increased/decreased this to [x] portions per day (see figure 4).

The average intake of red meat at the start of the study was 245g per week; you were consuming [xg] per week. By the end of the study the average intake had reduced to 175g per week and you increased/reduced your intake to [xg] (see figure 5).

Figure 4: Change in fruit and vegetables consumption

[INSERT FIGURE COMPARING AVERAGE AND PERSONAL CHANGE]

Figure 5: Change in red meat consumption

[INSERT FIGURE COMPARING AVERAGE AND PERSONAL CHANGE]

Quality of life

You may remember that you also answered some questions about your quality of life. Responses to these questions were used to calculate a quality of life score. Scores range from 0 – 136 with higher scores indicating a higher quality of life.

The average score for quality of life at the start of the study was 92. Your score was also [xx]. Average scores on completion of the study were 97. Your score had increased/decreased to [xx]. Scientists have calculated something called ‘minimally important differences’ (MID). This refers to the minimum change in score on a scale that result in a change large enough for individuals to feel the difference. For the quality of life measure used here, the MID is 5 points. On average participants’ scores increased by 5 points, your score increased by [xx] points (see figure 7).

Figure 7: Change in quality of life scores

[INSERT FIGURE COMPARING AVERAGE AND PERSONAL CHANGE]

End of study interview

All participants kindly look part in an end of study interview. This allowed a more in-depth analysis of what people thought of the study and how it might be improved.

In general participants enjoyed taking part in the study. All were happy with the length of the study, the number of contact periods and the fact that it was phone based. A number of participants felt that this distance-based approach was more practical than regular meetings at UCL, particularly if they had work or family commitments. The face-to-face meeting at the start of the study was also seen to be important. Many felt that knowing who was on the end of the phone made the calls feel more personal.

Most of those who took part in the study were aware of the benefits of eating well and taking regular physical activity but felt that they would not have made changes were it not for their involvement in the study. Everyone made improvements to their diet and increased their activity levels over the course of the study

.

The logbooks were seen to be useful, making people more aware of what they ate on a day to day basis and where there might be room for improvement. However some did find filling them out every day a little burdensome. In general the pedometer was perceived as the most helpful tool, both to keep track of how much activity they were doing, and as a motivator to reach their weekly exercise goals.

In general the timing of the intervention was deemed appropriate in relation to completion of treatment. A number of individuals felt that in the period shortly after completing treatment they were motivated to make lifestyle changes. Some felt that this motivation may have waned over the following few months. Others however did feel that a little more time to recover from treatments would have been beneficial.

Most participants were motivated to take part in the study as it presented an opportunity to give something back to those who had helped them. However once involved in the study many also began to feel that the study was likely to help them also.

Once again, thank you very much for your help with the study, without which we would not have been able to continue with this very important research. I really enjoyed meeting and working with you and wish you all the very best for the future.

Very best wishes

Chloe

Appendix 12: Physical activity and diet information sheets

Physical activity - Getting started

The goal of this part of the study is to help you get back on track after cancer treatment and incorporate physical activity back into your daily life. We will talk about the benefits of physical activity and the things that can make it tricky to stay active. We will set gradual targets over the next 12 weeks to help you build activity into your routine and I will give you tips on how to keep going when other things (like tiredness or bad weather) get in the way.

Physical activity is just one of many factors that may be associated with your health and recovery from cancer, but is an area that has received a lot of research interest in recent years.

How can physical activity help me?

Physical activity can reduce tiredness

A review of 28 studies using 2083 participants found that physical activity can help reduce fatigue (tiredness) that patients often feel after cancer treatment[1].

Physical activity can improve quality of life

Studies have also found that those people who are active after their colorectal cancer treatment have a better quality of life than those who were not active. For example, a study of 1966 participants found those who were active had an 18% better quality of life than those who didn't do any physical activity.[2]

Physical activity can improve physical function

Cancer patients often experience a decline in physical function during and after their treatment. This means they may find it hard to carry out the everyday activities and leisure pursuits that they took part in before their cancer. Studies have shown that cancer patients who take part in regular physical activity have less of a decline in physical function, finding it easier to carry out everyday tasks such as shopping, walking up stairs, and playing with children/grandchildren[3].

Other reasons to be active

Being physically active can reduce the chance of:
- Developing heart disease
- Developing diabetes
- Becoming overweight

This is why experts recommended that people who have had cancer should try to be physically active

You don't have to do loads of activity to feel the benefits! Gradually building physical activity, like brisk walking, gardening or climbing the stairs for 10 minutes each day will help and you will feel yourself getting stronger as the weeks go on.

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[1] *Cramp, D. Exercise for the management of cancer-related fatigue in adults (Review).2009. The Cochrane Library; Issue 2.*

[2] *Lynch et al. Prospective relationship of physical activity with quality of life among colorectal cancer survivors. 2008. Journal of Clinical Oncology; 26 (27) 4480-448*

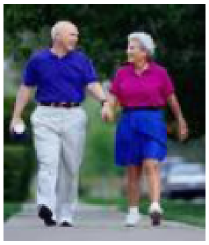
What do cancer specialists think?

Here is what some oncologists in London have to say about physical activity after colorectal cancer:

"A balanced lifestyle with regular exercise and a healthy diet are important for maintaining good health and good quality of life. Since patients can actively contribute to this aspect of their wellbeing I recommend to them that they stay active and ensure that they have a healthy diet".

Dr Astrid Mayer
Consultant in Medical Oncology
Royal Free Hospital, London

"Being physically active is important for anyone who has been diagnosed with cancer. Evidence is increasing to suggest physical activity can improve patients overall health and quality of life. Patients should try some form of physical activity as often as they feel able. If patients are not used to regular activity they should begin slowly and build up gradually".



Dr John Bridgewater
Consultant in Medical Oncology
University College Hospital, London

What do other cancer patients think?

Other cancer patients recommend being physically active too!

Below are some comments from cancer patients who took part in a similar physical activity study in Canada

"Sometimes I think a lot about the cancer I had. Sometimes I also don't feel very healthy. But exercise allows me to feel like I am doing something positive for my well being. Also, getting out to do my exercise helps me physically and mentally"
Jo (Age 59)

"Exercise is great for me! It gets me out and I feel that I am doing something constructive, not only for health reasons, but it keeps my spirits up. I feel more positive. Exercise definitely helped me beat my cancer"
Beverly (Age 72)

IMPORTANT! A word of caution....

If you experience any of the following symptoms stop your activity and call your GP:

- Chest pain
- Dizziness, blurred vision or fainting
- Joint or bone pain (besides the usual everyday aches and pains you might feel)
- Difficulty breathing
- Extreme tiredness
- Nausea

---

[3] *Stevinson et al., Exercise interventions for cancer patients: Systematic review of controlled trials. 2004. Cancer Causes and Control; 15:1035-1056*

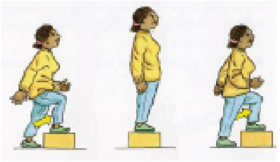
Example Exercises

Below are some examples of exercises you can do at home. If you find any of these uncomfortable – **stop!** And stick to the ones that don't cause you discomfort. Start off by doing these exercises once a week, performing each exercise 5 times. You can increase this as you get stronger.

Gentle warm up

1. Marching on the spot:

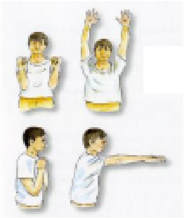
- With your feet shoulder width apart start a walking action on the spot – continue this for about 1 minute
- Carry on marching but now start to swing your arms up and down – continue this for another minute



2. Step-ups:

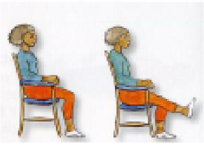
- Pick a step or your bottom stair
- Step up and down on the step making sure your foot is flat on the step and lift your weight onto the step until your leg is straight
- Repeat this 5 times leading with one leg, then another 5 times leading with the other leg

Seated exercises



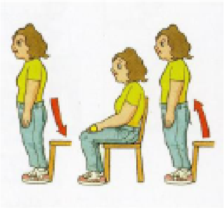
3. Arm raises:

- Lift both arms straight above your head and then straight out in front
- Repeat this 5 times



4. Single leg lifts:

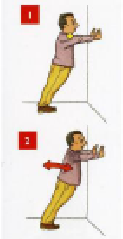
- Pull your toes up towards your shins and tighten your thigh muscles
- Now straighten your knee bringing your foot out in front
- Hold this for a count of 3 then lower your foot to the floor
- Repeat 5 times for each leg



5. Sit to stand:

- Sitting on a chair with your hands on your lap or crossed over your chest
- Now stand up and then slowly sit down, repeat this 5 times
- If you find this hard work, use your hands to help you

Standing exercises



6. Wall press:

- Stand facing a wall. Place your hands on the wall, slightly wider than shoulder width apart and move your feet back until you are about 2 meters from the wall
- Slowly bend you arms so your shoulders move towards the wall
- Then slowly push away from the wall, be careful not to lock your elbows – repeat this 5 times

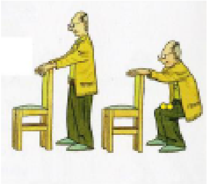
7. Knee lifts:

- Face the wall, about 1 metre away and place your hands on the wall at about shoulder height to support you
- Balance on one leg and pull the other knee towards your chest
- Only lift your leg as high as is comfortable.

8. Arm curls:

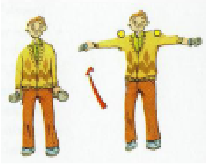
- Start with some light weights (a can of beans or small water bottle) in each hand
- Hold the weights in your hands and keep your elbows tucked into your sides
- Lift the weights towards your chest, count to 2, then lower the weights – repeat this 5 times

9. Knee bends:



- Hold onto the back of a sturdy chair with your feet a little more than hip width apart and your feet pointing forwards
- Keep your back straight and suck your tummy in
- Now with your hands still on the chair bend your knees, imagining you are sitting down and then straighten again
- Repeat this 5 times

10. Arm raises:



- Using the same weight you had for the arm curls, hold the weights by your side with your palms facing down
- Gently raise your arms out to the side to shoulder height, then lower
- Repeat this 5 times

11. Side leg raises:

- Stand side on to a wall for some support
- Move the leg that is furthest from the wall away from the other leg and up from the ground
- Keep both your feet pointing forward
- Repeat 5 times on each side

IMPORTANT! A word of caution….

If you experience any of the following symptoms stop your activity and call your GP:

- Chest pain
- Dizziness, blurred vision or fainting
- Joint or bone pain (besides the usual everyday aches and pains you might feel)
- Difficulty breathing
- Extreme tiredness
- Nausea

A Healthy Diet - Getting Started

Cancer and its treatment often affect what patients can and want to eat. The aim of this part of the study is to help you get back on track with eating a balanced diet. You will not be given a strict diet to follow, but we will suggest some foods that it is good to eat more of and some foods it's best to limit. We will set gradual targets during the study to help you to build these changes into your everyday diet.

Your diet is just one of many things that contribute to your health and your recovery from cancer but is an area that has received a lot of research interest. It is also an area patients often want to know more about.

Why change my diet?

Research suggests that having a healthy diet may:

- Help prevent the development of a new cancer
- Help stop the development of heart disease
- Help you maintain a healthy weight

Fibre and fruit & Veg

A huge international study called EPIC looked at the links between diet and cancer in 10 European countries. This study found that eating foods that are high in fibre can reduce the risk of colon cancer[1]. Fruit and vegetables also contain lots of different vitamins and minerals and researchers are trying to find out if any of these reduce cancer risk.

What is fibre?

Dietary fibre (or roughage) is the part of plants that cannot be digested. The fact that it can't be digested is what makes fibre important. It absorbs water as it passes through the bowel providing bulk which helps with healthy bowel movement.

The Science Bit – How does it work?

Experts have suggested a number of reasons why fibre might reduce the risk of colon cancer. Fibre increases the weight of the stool and reduces the time it takes for the stool to pass through the bowel; this means there is less time for the chemicals in the stool to be in contact with the bowel.

Another possibility is that eating fibre produces a chemical called butyrate, this may help stop the growth of cancer cells and help to kill them off

Red and processed meat

There is strong evidence that eating lots of red and processed meat increase the risk of colon cancer, experts believe it is likely that eating less red and processed meat could reduce the chance of getting colon cancer again.

What are red meats?	What are processed meats?
• Beef • Pork • Lamb	Meats that are preserved by smoking, curing or salting, or adding preservatives: • Ham • Bacon • Sausages

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[1] Peters et al. Dietary fibre and colorectal adenoma in colorectal cancer early detection programme. 2003. Lancet; 361 (9368): 1496-1501

In 2007 the World Cancer Research Fund looked at all the studies on diet and cancer risk. There were 147 studies on red and processed meat and nearly all of them showed an increased risk of colon cancer with higher intake. Processed meats increased cancer risk more than red meats.

The Science bit - How does it work?

Experts aren't certain about how red and processed meats might influence cancer risk. It could be to do with the way the meat is cooked. Cooking meat at high temperatures (such as frying and barbequing) increases the amount of a chemical called heterocyclic amines (HCA). Higher levels of HCA's have been linked to higher rates of colon cancer.

Another possibility is that red and processed meats increase the amount of a substance called N-nitros compounds (NCO's) in your body. NCO's have been linked to an increased risk of colon cancer.

A study in colorectal cancer survivors

One study has looked at the relationship between diet and survival in colon cancer patients. The study included 1009 people who had been diagnosed with stage III colon cancer. They found that over 5 years those with the highest intake of what the researchers called a "western diet", which included high intake of meat, fat and desserts, were almost 3 times more likely to experience a recurrence than those at the lowest end of this category[2].

This is still a very new area of research and more studies are need before we can know for sure what effect diet has.

Variety is the spice of life!

You definitely don't need to change your diet overnight! Making small and gradual changes will all add up, and trying new foods can make meals more interesting. We can all get a little bored of cooking and eating the same old meals, buy a new fruit or vegetable every week and look up some fun recipes.

What do other cancer patients think?

"I love to eat more fruit and vegetables because they contain lots of vitamins that are good for my body. My digestive system feels good and they improve my health"

"They give me extra vitamins, more energy, I look healthier, my nails are stronger, hair shinier and I feel mentally more alert"

A word from a specialist

"Diet plays a key role in everyone's health, and this is particularly true for patients who have had colorectal cancer. Red and processed meats should be avoided and fiber should be increased. There is strong evidence to suggest that this can protect against further occurrence of colorectal cancer".

Dr John Bridgewater, Consultant oncologist. University College Hospital

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[2] Meyerhardt et al. Association between dietary patterns with cancer recurrence and survival in patients with stage III colon cancer. 2007. JAMA; 298 (7):754-764

What is a portion of fruit?

1 Apple	
1 handful of grapes	
1 medium banana	
2 kiwi fruits	
1 tablespoon of sultanas	
2 halves canned peach (or 7 slices)	
1 150mil glass of fruit juice	

What is a portion of veg?

2 spears of broccoli	
3 heaped tablespoons of carrots	
8 Brussel sprouts	
3 heaped tablespoons of peas	
1 tomato (or 7 cherry tomatoes)	
½ an avocado	
1 large parsnip	

Foods high in fibre

It is important to add fibre to your diet very gradually. Introduce a new high fibre source every few days.

Ensure you drink plenty of fluids, as fibre absorbs water, so it is important to stay well hydrated.

It is best to start with foods that are the least bulky (soluble fibre), and move on to more bulky foods later (insoluble). The less bulky fibrous foods will absorb water to form a gel, which can help prevent diarrhoea.

Below is a list of fibrous foods starting with the least bulky to the most bulky.

Least bulky

Apples (just the pulp with skins removed)
Bananas (ripe)
Stone fruits like peaches, nectarines and plums (just the pulp with skins removed)
Carrots
Broccoli
Swede
Parsnip
Potato (without skin)
Avocado
Oats
Grapes
Berries
Kiwi fruits
Cabbage
Raisins
Brussel sprouts
Sweetcorn
Aubergine
Green beans
Broad beans
Brown rice
Weetabix
Wholegrain bread

Most bulky

What is a portion of meat?

3 ounces of meat is a portion. This is about the same size as a pack of cards

Try to limit the red meat intake to three or four times a week

You can swap red meat for:

- Chicken
- Turkey
- Fish
- Meat alternatives such as quorn or tofu

An example of a meal plan

Breakfast:

- Glass of fruit juice
- Porridge oats with sliced banana

Mid-morning snack:

- Apple

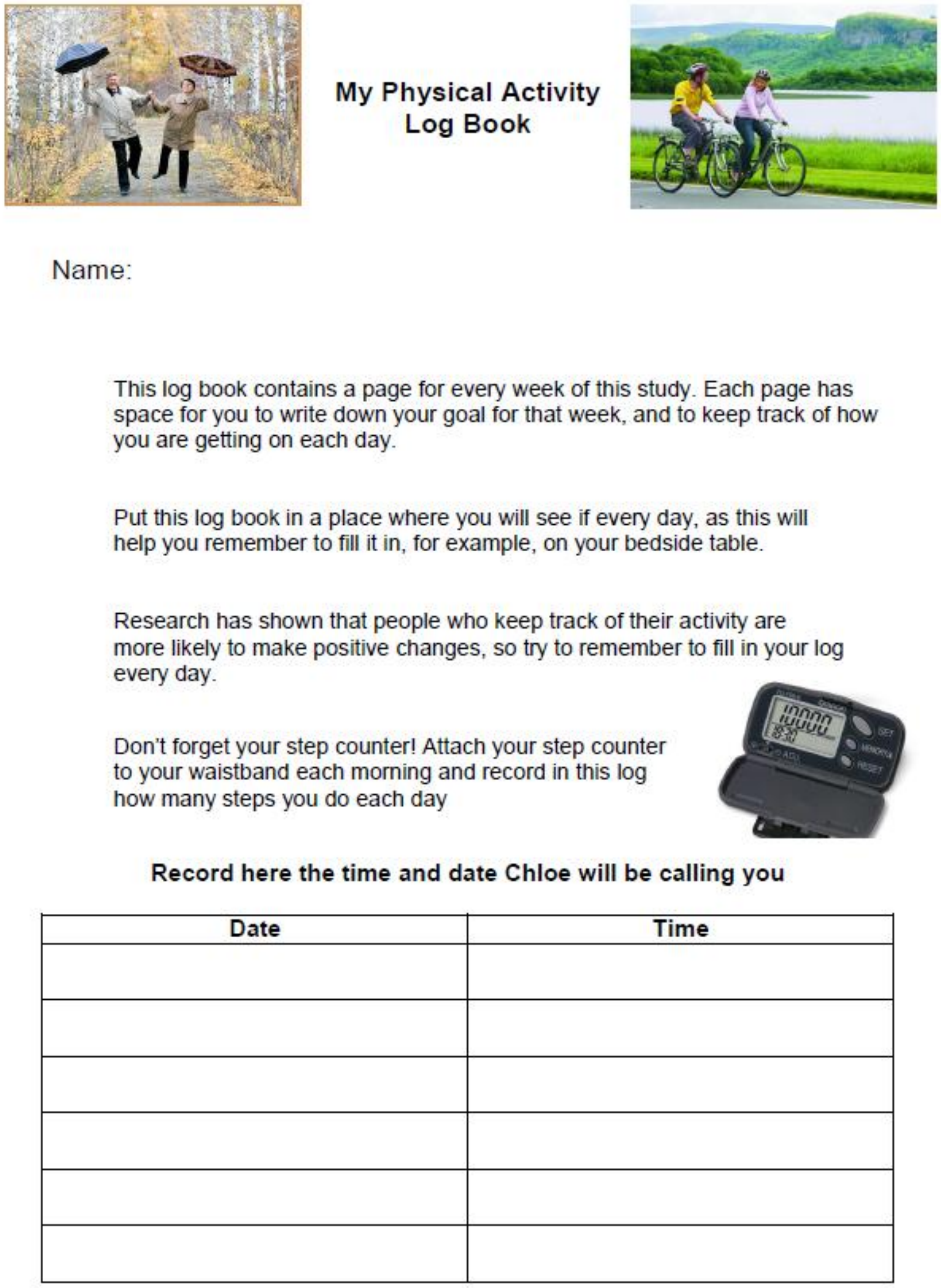
Lunch:

- Cheese and salad sandwich (brown bread)
- Low fat yoghurt with fruit

Dinner:

- Baked salmon with a jacket potato (leave the skin if necessary)
- Serving of broccoli and carrots

Appendix 13 Physical activity and diet logbooks



My Physical Activity Log Book

Name:

This log book contains a page for every week of this study. Each page has space for you to write down your goal for that week, and to keep track of how you are getting on each day.

Put this log book in a place where you will see if every day, as this will help you remember to fill it in, for example, on your bedside table.

Research has shown that people who keep track of their activity are more likely to make positive changes, so try to remember to fill in your log every day.

Don't forget your step counter! Attach your step counter to your waistband each morning and record in this log how many steps you do each day

Record here the time and date Chloe will be calling you

Date	Time

How to fill in your log

Each week write down your goal for that week. Remember you also need to be specific about when, where and how you will carry out your goal. Here's an example:

My goal this week

I aim to do 10 minutes of physical activity 3 times in the next week

Be specific!

When? On Tuesday, Thursday and Sunday after breakfast

Where? To the corner shop

How? I will wear comfortable shoes and walk as if I'm late for an appointment

Use your step counter

The step counter can help motivate you to increase your activity. Write down how many steps you walked at the end of each day, add them up at the end of the week and see if you can do better next week.

Day	Goal	How many minutes did you do?	Did you meet your goal?	How many steps?
Monday				3450
Tuesday	10 min brisk walk	10	Yes!	4100
Wednesday				2963
Thursday	10 min brisk walk	10	Yes!	3900
Friday				3507
Saturday				3248
Sunday	10 min brisk walk	None	No	2458
			Total Steps	**23, 356**
		Total minutes of activity		**20**

Did you reach your goal this week? I was too tired to manage any activity on Sunday

How have you been? I felt quite well most of the week but was feeling very tired over the weekend

Diet Log Book

Name:

This log book contains a page for each week of the study. Each page has space for you to write down your goals for that week, and to keep track of how you are getting on each day.

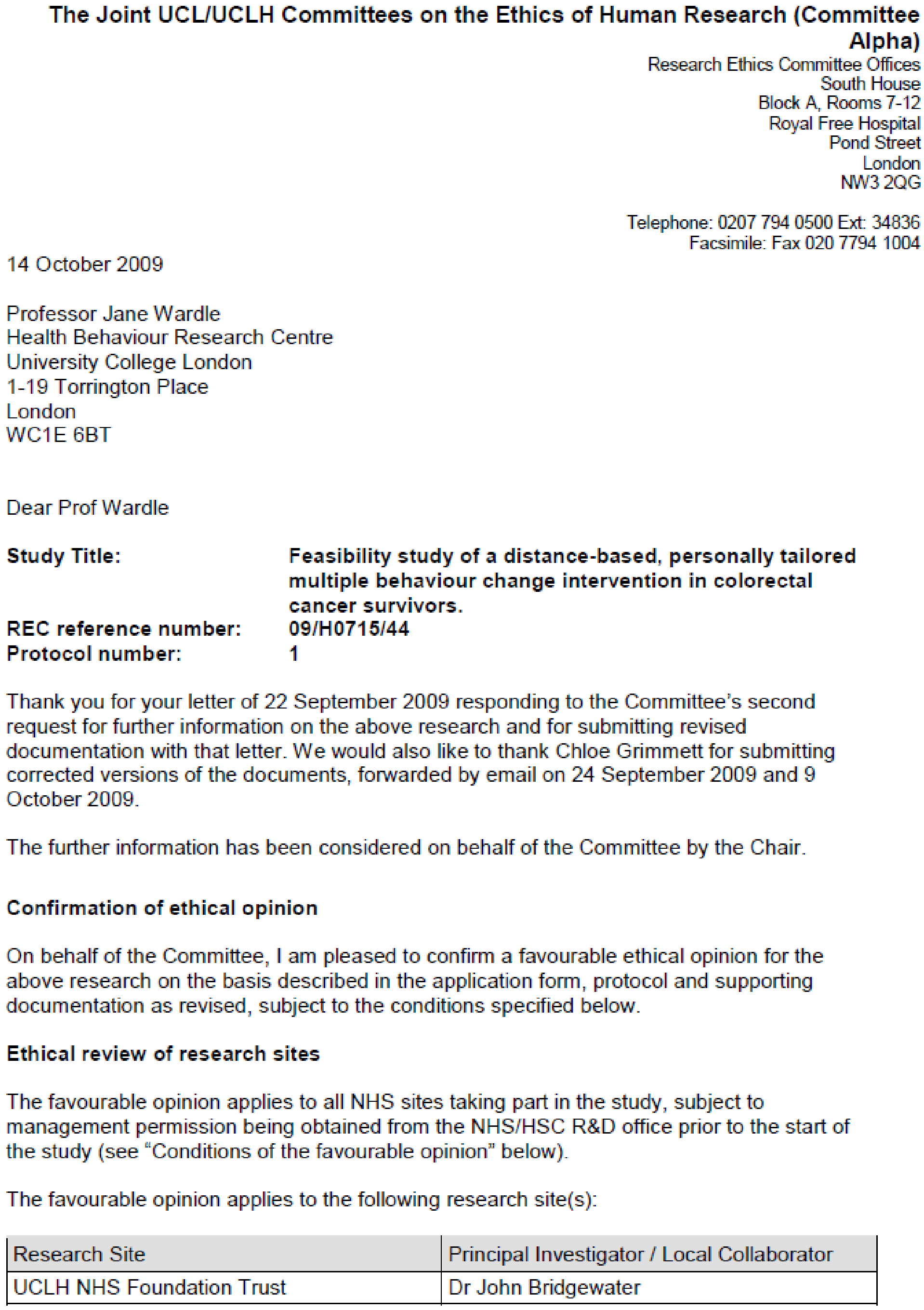
Put this log book in a place where you will see it every day; this will help you remember to fill it in, for example, on your bedside table.

Research has shown that people who keep track of their activity are more likely to make positive changes, so try to remember to fill in your log every day.

Record here the time and date when Chloe will be calling you

Date	Time

Appendix 14 Ethical approval letter; intervention study



The Joint UCL/UCLH Committees on the Ethics of Human Research (Committee Alpha)
Research Ethics Committee Offices
South House
Block A, Rooms 7-12
Royal Free Hospital
Pond Street
London
NW3 2QG

Telephone: 0207 794 0500 Ext: 34836
Facsimile: Fax 020 7794 1004

14 October 2009

Professor Jane Wardle
Health Behaviour Research Centre
University College London
1-19 Torrington Place
London
WC1E 6BT

Dear Prof Wardle

Study Title:	**Feasibility study of a distance-based, personally tailored multiple behaviour change intervention in colorectal cancer survivors.**
REC reference number:	**09/H0715/44**
Protocol number:	**1**

Thank you for your letter of 22 September 2009 responding to the Committee's second request for further information on the above research and for submitting revised documentation with that letter. We would also like to thank Chloe Grimmett for submitting corrected versions of the documents, forwarded by email on 24 September 2009 and 9 October 2009.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

The favourable opinion applies to the following research site(s):

Research Site	Principal Investigator / Local Collaborator
UCLH NHS Foundation Trust	Dr John Bridgewater

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Email with attached submission		22 September 2009
Response to Request for Further Information	2	22 September 2009
Covering Letter		22 September 2009
Scientific evidence to support information sheet content		22 September 2009
Participant Information Sheet: A Healthy Diet - Getting Started [With incorrect version number and date]	1	30 July 2009
Participant Information Sheet: Physical Activity - Getting Started [With incorrect version number and date]	1	30 July 2009
Participant Information Sheet: Information about the research	3	22 September 2009
Covering Letter [Email]		24 September 2009
Participant Information Sheet: Physical Activity - Getting Started	2	22 September 2009
Participant Information Sheet: Sample Exercises	2	22 September 2009
Covering Letter [Email]		09 October 2009
Participant Information Sheet: A Healthy Diet - Getting Started	2	22 September 2009

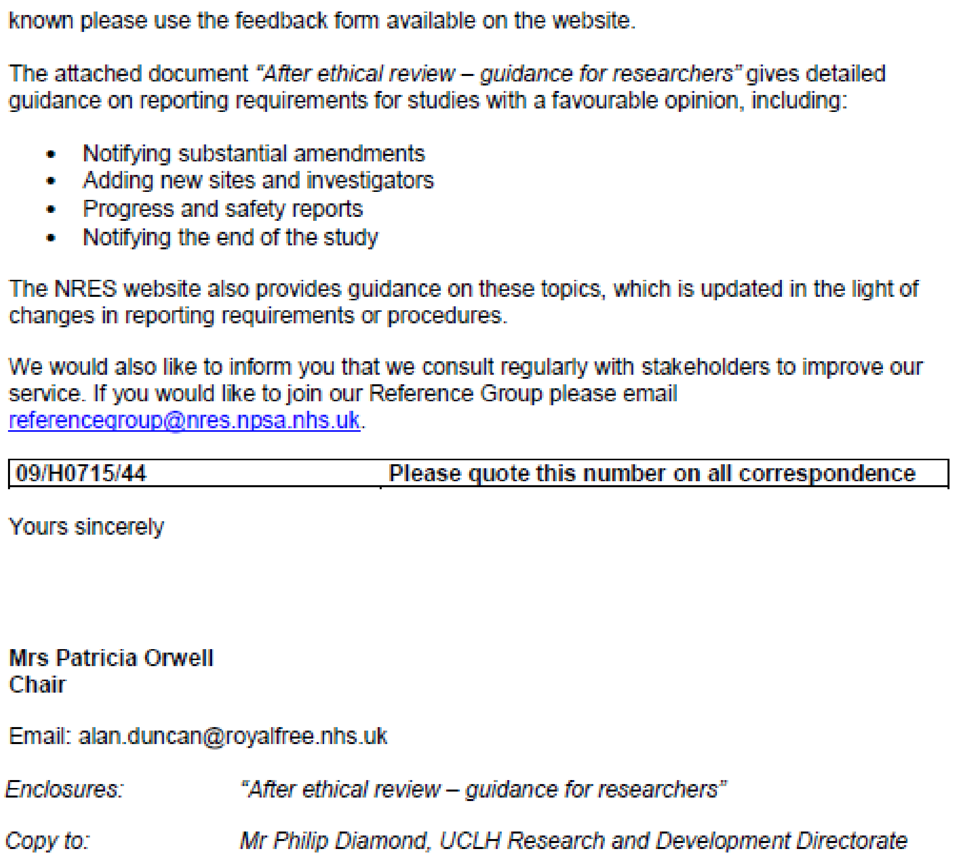
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views



known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0715/44	**Please quote this number on all correspondence**

Yours sincerely

Mrs Patricia Orwell
Chair

Email: alan.duncan@royalfree.nhs.uk

Enclosures:	*"After ethical review – guidance for researchers"*
Copy to:	*Mr Philip Diamond, UCLH Research and Development Directorate*