Risk, Colon Cancer & Physical Activity: A Qualitative Exploration in Older Adults

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Abstract

Rationale and Objectives

There is convincing evidence that physical activity (PA) reduces risk of colon cancer (CC) and may improve survival after cancer, although few older adults achieve recommended PA guidelines. Numerous barriers to participation exist, though few studies focus on socio-cultural influences. This study explores barriers specific to individuals at elevated risk of CC following screening colonoscopy, as well as how health professionals or a 'diagnosis' may provide additional motivation to change.

Methods

Interviews were conducted with colonic polyp patients and CC survivors over 60 years old, selectively sampled from a feasibility study for a randomised controlled PA intervention. Narrative accounts enabled discussion of influences on health behaviour throughout participants' lifetimes, the impact of their recent 'diagnosis', and attitudes towards PA. Interviews and focus groups were conducted with health professionals to triangulate data collection.

All interviews were transcribed verbatim and a constructivist grounded theory approach to data analysis was followed.

Findings

Despite not meeting current PA guidelines, participants perceived a lifetime of 'natural' PA. CC survivors were more inclined to initiate PA engagement to improve their health; conversely, elevated risk individuals were often not aware of their change in health status, leading them to conclude that no lifestyle change was necessary.

Professionals confirmed that no PA guidance is currently offered to screening patients, but believed that there may be scope to implement health promotion advice. Barriers towards this however, are complex and numerous.

Conclusions

The 'meaning of PA' is situated and understandings may differ. Despite reporting perceptions of high PA, this study sample did not seem to understand what constitutes *sufficient* PA to elicit a positive health response.

Risk status awareness and the benefits of PA is lacking in elevated risk individuals. For the screening setting to be utilised, questions around 'why', 'when' 'who' and 'how' health promotion should be delivered, need to be addressed.

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Abbreviations

- ALP Active Lifestyle Programme
- BB Baby Boomer
- BMI Body Mass Index
- CC Colon Cancer
- CGT Constructivist Grounded Theory
- CRC Colorectal Cancer
- CRP C-Reactive Protein
- ESRC Economic and Social Research Council
- FOBT Faecal Occult Blood Test
- **GP** General Practitioner
- HBM Health Belief Model
- HCE Health Certificate Effect
- HINTS Health Information National Trends Survey
- HP Health Professional
- HR Hazard Ratio
- MOVE Motivation for Exercise
- NHS National Health Service
- NHS BCSP National Health Service Bowel Cancer Screening Programme
- NSAID Non-Steroidal Anti-Inflammatory Drug
- PA Physical Activity
- PARC Physical Activity and Risk of Cancer
- RCT Randomised Controlled Trial
- SCT Social Cognitive Theory
- SN Staff Nurse
- SSP Specialist Screening Practitioner

- TM Teachable Moment
- UKTRC United Kingdom Transport Research Centre
- WCRF World Cancer Research Fund
- WHO World Health Organisation.

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Introduction

'Risk, Colon Cancer & Physical Activity: A Qualitative Exploration in Older Adults'

This thesis explores the socio-cultural influences on physical activity (PA) participation in a population of individuals over the age of 60 years who had all recently attended a bowel cancer screening colonoscopy and been identified at elevated risk of developing colon cancer (CC) in the future. Following on from the emergent findings from the first few elevated risk patient interviews, the decision was made to interview CC survivors (who are also at elevated risk of cancer due to recurrence) to identify whether their motivations for PA were comparable or different from that of the original elevated risk sample. Finally, health professionals (HPs) within the bowel cancer screening setting were interviewed to determine whether a potential opportunity for health promotion is being missed at this time, and if so, what barriers are to be overcome so that this may be a possibility in the future.

The UK is populated by an increasingly ageing population where 80% more individuals are now over the age of 65 than in 1951 (Rutherford and Socio, 2012). With life expectancy also on the rise, a greater dependence on the National Health Service (NHS) as well as a rise in annual health care costs may be foreseen (Fahy, 2011). With this in mind, it is therefore a priority for us to find ways in which the older population may not only live longer, but also healthier lives.

A recent UK report suggests that up to 46% of total NHS costs were related to treating disease (such as certain types of cancer) which may have been prevented by changing lifestyle factors (Scarborough, 2011). Alongside this, with the aforementioned increasing age of the population, GLOBOCAN has predicted 21.4 million new cases of cancer by the year 2030 (World Health Organisation, 2008). Colorectal Cancer (CRC) (cancers of the colon *and* rectum) is the third most common cancer worldwide in both males and females (Ferlay 2010). This study specifically focuses on colon cancer (CC) due to its high prevalence in individuals over the age of 60 years, and the evidence that engaging in the recommended levels of PA; 150 minutes of moderate to vigorous intensity activity per week (O'Donovan, 2010), reduces an individual's relative risk of developing CC by 24% (Wolin, 2009).

Considering these statistics, the objectively measured figures for PA participation are extremely low with 6% and 4% of men and women respectively achieving the recommended levels. This percentage drops even lower to 3% in men and women over the age of 65 years (Craig, 2007), and given the potential for CC risk reduction, something must be done to try and understand the reasons why so few individuals within this population are achieving the current guidelines.

Previous research suggests that currently no lifestyle advice is provided to individuals at elevated risk of developing CC following their NHS bowel screening colonoscopy (Stead, 2012). Although the barriers given by professionals pertaining to health promotion in the primary care setting are numerous, there is less research in the secondary care setting. Therefore, this research also seeks to understand whether there is a health promotion opportunity currently being missed within the screening setting for behaviour change, by exploring this idea with both patients *and* professionals.

This thesis is split into eleven chapters over four parts. Part one (chapters 1 to 5), outlines the background and rationale for this research, as well as the existing literature relevant to the topic. *Chapter three* details how risk; especially in relation to cancer, is perceived *and* managed throughout the population in a number of quantitative and qualitative studies. Alongside this, the concepts of the teachable moment and health certificate effect are outlined as possible

motivators or barriers for behaviour change. *Chapter four* follows on from the concepts derived in the previous chapter by focusing on the influence a HP has on a patients understanding of their health status and also the opportunities available to them for health improvement. This chapter also briefly touches upon the numerous barriers for health promotion cited within the literature to date. Finally *chapter five* introduces the many psychological and social factors to consider within this older and elevated risk sub-set with regards to PA participation, as well as touching on the lesser studied cultural barriers within this population, which may have impacted upon health behaviour throughout their lives.

With that in mind these are the aims and objectives this thesis hopes to address;

- To contribute more fully to the understanding of socio-cultural influences in PA participation in a population of older adults
- To identify the impact of an 'elevated risk' cancer diagnosis on attitudes towards future health and health promotion behaviours with emphasis on PA
- To compare and contrast the motivations and barriers for PA between elevated cancer risk patients and CC survivors
- To examine the issue of providing health promotion within the cancer screening setting from the perspectives of patients and health professionals

Part two of this thesis describes and discusses in some detail the research methodology, with *chapter six* outlining the history of the methodology selected, key choices made and the rationale for those decisions. *Chapter Seven* provides examples of how the methodology has been used in practice, alongside the presentation of demographic tables, analytical flowcharts and thematic maps, and concludes with guidance on how to best interpret the findings presented within part three.

Chapter Eight, Nine and *Ten* are the findings chapters which focus more closely on the analytically derived findings of the three populations under study within this research. Beginning first with a chronological look into the PA experiences and influences encountered throughout the participants lives and to the present day. Secondly, focusing on the impact of a diagnosis on motivation for PA participation in both elevated risk and cancer survivor participants, and finally concluding with an exploration of the potential to utilise the screening setting as a place for health promotion.

Finally part four (*chapter eleven*), presents a discussion and interpretation of the findings in light of the existing literature and concludes the thesis with limitations and thoughts for future research.

Chapter One

This chapter outlines the background of the research and the rationale for the study with particular focus on the increasing age of the world's population. Alongside this, the cost afforded to treating illness which may have been prevented by reducing exposure to certain lifestyle factors is explored. The chapter concludes by introducing CC, discussing prevalence within the United Kingdom, summarising the National Health Service Bowel Cancer Screening Programme (NHS BCSP) and the lifestyle factors associated with increased CC risk.

1. Background and Rationale

The United Kingdom has an increasingly ageing population where 80% more individuals are now over the age of 65 than in 1951 (Rutherford and Socio, 2012). With life expectancy also on the rise, a shift from four people of 'working age' for every individual in the over 65 age group at present, to just two by the year 2060, is predicted due to advances in treatment and later life care (Fahy et al., 2011). In turn this may encourage a greater dependency upon the National Health Service (NHS) and care services, as well as a marked rise in annual health care costs as illnesses associated with ageing become increasingly common (Caley and Sidhu, 2011). This rise in the life expectancy of populations at large, is feared to increase current health care expenditure by between 15 and 40% throughout Europe (Fahy et al., 2011). It is therefore important for us to find ways in which the older population may not only live longer but healthier lives, so that they maintain good health and functional independence for longer.

The most recent UK report suggests that up to 46% of total NHS costs were related to treating and curing disease which, in the majority of cases, could have been prevented through changing lifestyle factors (Scarborough et al., 2011). Obesity-related ill health alone, in conditions such as heart disease and type II diabetes cost the NHS approximately £5 billion in the year 2006-07. In 1980, 8% of women and 6% of men were classified as obese in England, these figures increased to 25% in women and 24% in men by the year 2012 (a percentage increase of 213% and 300% respectively) (Health and Social Care Information Centre, 2014) and this trend shows no signs of slowing. The increasing age of the world's population will also have a profound effect on the total number of cancer cases, with GLOBOCAN predicting 21.4 million new cases by 2030 (Ferlay et al., 2010). The World Health Organisation (WHO) (World Health Organisation, 2008) has identified cancer as one of four leading threats to human health and development, but proposed that this 'global burden' could be reduced and controlled by focusing on three main, evidence based strategies. The first would be to prevent cancer occurring in the first place, secondly to ensure that cancers are detected early and thirdly successfully managing and treating those diagnosed with cancer.

Colorectal cancer (CRC) (cancers of the colon *and* rectum) is the third most common cancer worldwide with approximately 1.24 million new cases diagnosed in 2008 (Ferlay et al., 2010). The incidence rates vary markedly between countries however, with rates per 100,000 as low as 4.1 in India to 59.1 and 61 in the Czech Republic and Slovakia respectively (the UK value is around 43 per 100,000). This is further supported by many registries, which show higher incidence rates in Europe, North America and Oceania (Center et al., 2009). This suggests that urbanised countries with more 'westernised' cultures are at a higher risk of developing CRC with the highest risk emerging in countries within a transitional phase of economisation (Center et al., 2009). When considering mortality rates, CRC is the fourth largest cause of cancer death, however trends show that between the years 1985 and 2005 mortality rates due to CRC have decreased in both males and females (Ferlay et al., 2010) This is thought to reflect improvements in education acting to enhance current knowledge of the known risk factors, and advances in screening procedures and symptom recognition, aiding in the early detection of such cancers. Despite these medical advances and our increased knowledge it has been suggested that an estimated 33% and 53% of female and male CC cases respectively could be avoided by reducing exposure (or increasing participation in the case of PA), to certain unhealthy lifestyle risk behaviours (rectal cancer prevalence has been shown to be less effected by exposure to lifestyle factors) (de Vries et al., 2010). These potentially avoidable cases of CC are estimated to cost the NHS £65 million per annum (Scarborough et al., 2011).

1.1 Pathophysiology of Colon Cancer

Benign tumours of the gastrointestinal tract which often project above the surrounding mucosa are known as polyps (Fearon, 2011). The majority of colorectal polyps are purely hyperplastic (an abnormal increase in cells causing a small growth) and are not therefore considered to be a precursor to CC, whereas many cancers (between 70 and over 90%), develop from benign *adenomatous* polyps lining the walls of the bowel (Jass, 2007). An adenoma is a benign (non-cancerous) tumour, whereas an adenocarcinoma is a malignant (cancerous) tumour originating within the glandular tissue, such as that of the large bowel (Boyle and Leon, 2002).

It is now thought that up to 95% of CC cases are sporadic (scattered or isolated), with only 15-30% of these arising through a major hereditary component such as occurrences within a first or second degree relative (Fearon, 2011). Therefore, it is thought that up to 75% of all diagnoses are in patients with no familial risk factors (Cunningham et al., 2010). Within the UK, the lifetime risk of being diagnosed with CC is approximately 1 in 18 for males and 1 in 20 for females (Hewitson et al., 2008b). This incidence however increases dramatically as we age with 80% of cases occurring in individuals over the age of 60, (Hewitson et al., 2008b) and 40% of people within this age bracket possessing a colonic adenoma (Levine and Ahnen, 2006). More than 90% of these adenomas will not progress to cancer and for those which do progress the process can takes years to decades. Despite this, it is currently impossible to identify which lesions pose the greatest threat (Levine and Ahnen, 2006), and therefore there is a higher risk of CC in individuals whose adenomas are not removed at the earliest stage of detection (Fearon, 2011).

1.2 Early Detection and Elevated Risk Status

Since 2006 there has been a 12.5% increase in CRC incidence rates in those aged 60 – 69 years of age within England (Office for National Statistics, 2011). However, despite this, survival rates in individuals with CRC have increased substantially in the past few years (Cunningham et al., 2010). These figures can almost certainly be attributed to the introduction of the NHS BCSP, targeting this 'at risk' age group, which started in England in 2006 (Office for National Statistics, 2011). The aim of screening for CRC is to prevent the development of advanced cancers by detecting smaller localised cancers, or indeed premalignant adenomas, from which at least 80% of cancers are thought to arise (Cunningham et al., 2010).

The programme offers screening via a faecal occult blood test (FOBT) every two years to all men and woman over the age of 60 with the aim of detecting small amounts of blood within the stool; a result which would elicit an 'abnormal' test result. Individuals with an 'abnormal' test result are then invited to their local hospital for a colonoscopy investigation (Hewitson et al., 2008b). Figure 1.1 illustrates the pathway taken by each patient attending the NHS BCSP as well as the differing types of HP who they will speak to at each stage; for example specialist screening practitioners (SSPs), staff nurses and endoscopists.



Figure 1.1: Patient Pathway through Bowel Cancer Screening

Norfolk has one of the greatest return rates for FOBTs in the UK with 65.4% of patients sending the testing packs back for analysis in 2013. During this colonoscopy the surgeon will examine the lining of the large bowel for the presence of polyps and remove any which exist using a wire loop. These samples are then sent off for tissue analysis, with 1 in 10 colonoscopy patients having cancerous cells detected (Hewitson et al., 2008b).

Of the other 9 out of 10 patients, five will have a 'normal result' with no polyps being detected and the other four will have a 'polyps detected' diagnosis. These patients are then split into categories based upon their future risk of developing further polyps; 'low risk' – meaning one or two small polyps were detected during the first screening, 'intermediate risk' – following the removal of three to four small polyps or one large polyp, and 'high risk' – five or more small polyps or three or more large polyps (Hewitson et al., 2008b). It is these low, intermediate and high risk screening outcomes, alongside a cancer survivor population (who are incidentally at elevated risk of cancer recurrence), which form the 'elevated risk' study population within this research project.

1.3 Risk Factors for Colon Cancer

The most common risk factor for CC is age, with 75% of CC cases presenting in individuals with no other comorbidities that may have an influence on their likelihood of developing the illness, such as irritable bowel syndrome or Crohn's disease (Cunningham et al., 2010). With regard to gender, studies suggest that men are more likely to have colonic neoplasms, and are also twice as likely to have advanced lesions up to the sixth decade of life (when focusing on colon *and* rectal cancers) (Grahn and Varma, 2008). However, it is thought that this may be due to less women agreeing to screening or opting out due to a lack of adequate information on the procedure (Etzioni et al., 2004). This difference between sexes becomes insignificant however, if one looks purely at CC, where incidences are equally common in both males and females (Hewitson et al., 2008b).

Cancer is caused by an interaction of both internal (genetic susceptibility) and external (lifestyle and environmental) factors (Soerjomataram et al., 2007). This is supported by the work of Lichtenstein, Holm et al. (2000) who studied the incidence of cancer in twins, which can, not only point to hereditary effects, but also estimate the magnitude of the genetic effect, therefore determining if cancer is more likely caused by heritability or a shared environment. Among 9512 pairs of twins at least one cancer occurred in 10803 individuals; for CC, a statistically significant 35% of the risk (95% CI 10-48%) could be attributed to heritable factors – resulting in shared and non-shared environmental factors being associated with around 65% of the risk (Lichtenstein et al., 2000).

1.3.1 Lifestyle Risk Factors

Worldwide it is clear that the majority of CCs are most prevalent in industrialised countries due to increasingly westernised lifestyle choices (Chan and Giovannucci, 2010). This is supported by migration studies showing high lifetime incidence of CC in immigrants after moving from their native, low risk countries to higher risk counterparts (Chan and Giovannucci, 2010). One of the first studies to report this was conducted by Haenszel et al. (1968) who established that the risk of CC in Japanese migrants moving to the USA had risen to almost equal that of Caucasian American nationals. The importance of early detection through screening for adenomatous polyps is essential; however education to improve the understanding of modifiable risk factors may inform primary prevention strategies and indeed, by adopting appropriate changes, improve the overall health of the population in the future (Chan and Giovannucci, 2010).

1.3.1.1 Dietary Risk Factors

Many dietary components are thought to have a substantial influence on CC risk. Eating a fibre rich diet is thought to have a risk-reducing effect, with a recent meta-analysis conducted by the World Cancer Research Fund (WCRF) (World Cancer Research Fund, 2007) suggesting a 10% (95% CI: 3–16%) risk reduction per 10g/day increment when pooling together eight studies. One theory for this effect is that fibre dilutes faecal carcinogens, and exerts anticarcinogenic effects through a reduced transit-time within the gastrointestinal tract (Kritchevsky and Bonfield, 1995). Alongside this, both calcium (when coupled with high levels of vitamin D) (Martinez and Willett, 1998) and dietary folate (World Cancer Research Fund, 2007) are also thought to reduce the risk of CC. Both of these dietary components at recommended daily levels are believed to have an effect on cell growth, with calcium and vitamin D directly reducing cell proliferation and inducing apoptosis (cell death) of normal as

well as colorectal tumour cells (Lamprecht and Lipkin, 2001) and folate potentially suppressing initial tumour formation within the early stages of carcinogenesis (Kim, 2003).

Possibly the most studied dietary association with CC risk is red meat intake. The WCRF (2007) stated that sixteen cohort studies and seventy-one case control studies had been conducted prior to their 2007 report. A meta-analysis conducted by Larsson and Wolk (2006) also explored this association in fifteen prospective cohort studies and reported an increased risk of 28% when comparing the highest to the lowest intake of red meat (with the cut off for total intake at 500g per week). Similarly, excessive consumption of processed meat is thought to increase CC risk with a meta-analysis of five studies estimating an elevated risk of 21% between the highest and lowest intakes (World Cancer Research Fund, 2007). There is also evidence to suggest that polyp recurrence is also increased with greater intake of red and processed meats (Martínez et al., 2007). It has been proposed that meat intake has more of an effect on progression from polyps to carcinoma (the adenoma-carcinoma sequence) than the transformation from normal to neoplastic mucosa (Tantamango et al., 2011).

Although the mechanisms associated with this link are less understood (Chan and Giovannucci, 2010), some believe that processed meats are thought to contain carcinogenic N-Nitroso compounds (Huang, 2003). Alternatively elevated iron levels, associated with large intakes of red meat may activate oxidative responsive transcription factors, inflammatory cytokines and produce iron-induced hypoxia signalling (Huang, 2003), all associated with carcinogenesis.

However, the NHS have recognised the potential for interactive effects between various dietary components, rather than the specific macronutrients or micronutrients, grouping together items which may contribute to a far greater risk profile (Chan and Giovannucci, 2010). The western diet is energy dense; becoming increasingly dominated by processed foods such as baked goods, pastries and confectionary (Prentice and Jebb, 2003) and therefore

associations have already been drawn between this diet and conditions such as type II diabetes and cardiovascular disease (World Cancer Research Fund, 2007). Analysis of data from the French European Prospective Investigation into Cancer and Nutrition (EPIC) cohort, showed significant associations between two western dietary patterns and increased risk of CRC. The first pattern included high levels of cereal products, processed meat, potatoes, eggs, sweets, butter, pizza and pastry and showed a 39% increase in risk. The second was a 'drinker' pattern and included processed meats, sandwiches, snacks and excess alcohol; this was associated with a 42% increase in risk (Kesse et al., 2006).

1.3.1.2 Alcohol Consumption

The relationship between consumption of alcohol and risk of CC has been widely studied with mixed results. However, the majority of evidence indicates that a higher intake of alcohol is linked to a greater risk of CC (Cho et al., 2004). One study, which pooled the data from eight cohort studies (accounting for over 475,000 participants), showed an elevation in CC risk of 41% in individuals consuming 45g or more of ethanol per day (equivalent to 225ml of wine), in comparison with the lowest intake (Cho et al., 2004). However a similar meta-analysis conducted by the WCRF (2007), pooling data from six cohort studies, showed no elevated risk. It is believed that alcohol may induce folate deficiency by reducing its absorption into the colon, therefore, through mechanisms described above, increasing one's risk of developing CC (Kim, 2003).

1.3.1.3 Tobacco Smoking

The positive link between smoking and other non-pulmonary cancers, such as cancer of the kidney and pancreas, has been evident for many years. Despite controversial evidence for the

link between smoking and CC since the 1970's, the majority of studies with substantial followup have supported this association (Liang et al., 2009).

Liang et al. (2009) pooled data from 36 prospective cohort studies, including over three million participants in total. For 'current' compared to 'never' smokers, CC risk was non-significantly increased by 10% (95% CI: 0.89-1.36). When looking at dose response analysis of daily cigarette consumption and CC incidence, eleven studies were included. An increase of twenty cigarettes per day led to a 17.5% increase in CC risk, whereas an increase to 40 cigarettes per day led to a 38% increase in relative risk of CC, both of which were highly significant (p < 0.0001). Tobacco contains a large number of carcinogens which may cause irreversible genetic damage by binding to DNA within the normal mucosa of the bowel. As well as this, tobacco smoke contains pro-carcinogens, which may form DNA adducts, induce mutations and initiate carcinogenesis after metabolic activation (Wogan et al., 2004).

1.3.1.4 Body Composition

Recent studies conclude that CC risk is related to determinants of the metabolic syndrome, such as obesity, abdominal adiposity and physical inactivity (Bassett et al., 2010). It is however difficult to distinguish the effects of these separately due to their interrelated nature. In general, physical inactivity increases with increased body mass index (BMI). However, increased levels of PA do not always lead to weight reduction in an overweight population (de Vries et al., 2010), therefore it is hard to separate the independent impact of each risk factor on CC risk.

1.3.1.4.1 General Adiposity

Excess body weight is a risk factor for CRC and this is caused by imbalances between energy intake and energy expenditure – whether that be through excess dietary intake, lack of PA or in some cases a genetic predisposition to weight gain. It has been estimated that the attributable risk of CRC due to being overweight was 10.9% (95% CI: 9.59 - 12.24%) for males and 2.6% (95% CI: 0 - 5.5%) for females (Renehan et al., 2010).

The most recent large scale meta-analysis on general adiposity was published by the WCRF (World Cancer Research Fund, 2007), stating that, to date, 60 cohort studies and 86 case control studies have investigated body fatness (as measured by BMI) and cancers of the colon *and* rectum. Of these, 32 showed statistically significant elevated risks across both colon and rectal cancer. A meta-analysis was able to be conducted on 28 of the cohort studies and the summary effect estimate was 1.03 (95% CI: 1.02 - 1.04) per Kg/m² with an increased risk of 15% for each 5 kg/m², assuming a linear dose response relationship (World Cancer Research Fund, 2007).

1.3.1.4.2 Central Adiposity

Visceral abdominal fat, usually measured by the waist to hip ratio or waist circumference, seems to be a stronger predictor of CRC risk than general body fatness. As women gain weight they tend to accumulate *less* abdominal fat than their male counterparts, and this central adiposity is linked to insulin resistance, therefore many think this is the reason behind the slightly decreased risk of CRC in females, as suggested by the figures in the general adiposity section above.

Of the six cohort studies investigating waist-to-hip ratio, all showed an increased CRC risk with increasing ratios, a finding which showed statistical significance in five of the six studies in the WCRF expert review (World Cancer Research Fund, 2007). More specifically, a meta-analysis was possible on five studies, showing a 30% (95% CI: 17-44%) increase in risk per 0.1 waist-to-hip ratio increment.

1.3.1.4.3 Body Fatness and Adenoma Risk

A comprehensive meta-analysis of 36 studies was recently completed, investigating the relationship between body fatness and colorectal adenomas (Wei et al., 2012). A total of 29,860 cases of colorectal adenomas were included through 16 case control, 13 cross sectional and seven cohort studies. When controlling for confounders such as PA, smoking, energy intake, alcohol use and Non-Steroidal Anti-Inflammatory Drug (NSAID) use, a significantly increased risk of adenoma equating to 19% (95% CI: 13-26%) remained per 5 unit increase in BMI. Further analysis suggested that patients with an 'overweight' BMI ($25 \ge$ BMI <30) had a similar risk of adenoma compared to those of normal BMI, however, obese patients (BMI \ge 30) had a 31% (95% CI: 17-48) increased risk in colorectal adenoma when compared to normal weight individuals.

This chapter has introduced the prevalence of CRC cancers worldwide, the NHS BCSP within the UK and illustrated the evidence that the incidences of colon and rectal cancers could be decreased by reducing exposure to a number of lifestyle factors (World Cancer Research Fund, 2007). The next chapter will focus on PA more specifically in relation to CC incidence, and present the convincing evidence alongside current PA guidelines and statistics detailing adherence within the whole population.

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Chapter Two

Chapter two discusses in more detail the lifestyle risk factor for CC which has most relevance within this study in particular, namely physical activity (PA). The association between PA and CC risk *and* recurrence is explored and explained, and the current guidelines and levels achieved are defined. To conclude, the lay understanding of these guidelines, as suggested by previous literature, is examined.

2. Physical Activity and Colon Cancer

Alongside urbanisation and industrialisation, PA levels have dramatically decreased and while some people may engage in occasional recreational PA, on the whole, the population remains largely inactive. This transformation is thought to be due to the change in mainly hand-based labour to professions that have been replaced by machinery, as well as the increased prevalence of motorised transport and televisions in the second half of the 20th Century (see section 5.1.5 – Cultural Factors) (World Cancer Research Fund, 2007).

Studies examining the association between CC and PA have been ongoing for three decades. Garabrant (1984) was the first to propose such an association by establishing a consistent inverse relationship between levels of occupational PA and CC risk. Evidence supporting this inverse association has continued to accumulate since the early 1990's, irrespective of other potentially confounding factors such as body composition (World Cancer Research Fund, 2007). To date, three comprehensive meta-analyses have been published specifically investigating this relationship (Samad et al., 2005, Harriss et al., 2009, Wolin et al., 2009). Wolin (2009) evaluated all case control and cohort studies separately, and where possible separated the results for men and women and occupational versus leisure time PA to gain greater insight into this complex relationship. After excluding non-human studies and those where PA was used only as a covariate, a total of 60 studies remained. Six exclusions were made to delete studies which did not present data for CC separately (as opposed to CRC) due to the lack of association presented between PA and rectal cancer in previous studies (Harriss et al., 2009). A final exclusion was made for those studies which did not allow for relative risk or confidence interval calculations, leaving a total of 24 case control and 28 cohort studies.

Significant heterogeneity was found across all studies (p = < 0.0001), with no evidence to indicate publication bias using a funnel plot. When comparing the most to the least active individuals a significant 24% (95% CI: 19-28%) reduced risk of CC was found. Similar results were observed for men and women, (24 and 21% respectively). Of the 24 case control studies, 17 provided separate data for occupational PA and ten for leisure time PA, whereas for the 28 cohort studies these numbers were 15 and 16 respectively. Occupational PA was associated with a significantly reduced risk of 22%, similar to the 23% reduction in risk associated with increased leisure time activity (Wolin et al., 2009). Although this evidence seems convincing, there are certainly difficulties in measuring the threshold for effect with regard to PA and CC risk reduction. This is due to the variety of activities which can constitute PA, the intensity at which these are performed, and the way in which these levels are measured - either subjectively (and thus measured by self-report) or objectively (through a device such as an accelerometer). Within Wolin's study there is actually no mention about how PA was measured in any of the 52 studies included, or the thresholds for most and least active individuals suggesting that more standardised research is needed if accurate guidance of risk reduction is to be provided in the future.

Given the huge potential for risk reduction, the detection of possible illnesses early and education regarding prevention strategies is of upmost importance. This is especially significant for those falling into an 'elevated risk' population. Such goals have important public health implications, therefore achievable strategies must be put in place by both the clinician and patient in order to provide a successful outcome, including positive changes in lifestyle, or increased level of screening (Zlot et al., 2012).

2.1 Secondary Prevention

Individuals diagnosed with CRC remain at increased risk of secondary cancers, cancer mortality and CRC recurrence (Vrieling and Kampman, 2010). There are various methods of treatment which can influence cancer prognosis, however, there are also large differences in the clinical outcome of individuals with seemingly identical cancers receiving similar therapeutic strategies – this variation may be due to differing lifestyle factors.

In a 2006 study by Meyerhardt et al. (2006) 573 CRC patients were assessed within the Nurses' Health Study, and it was established that those in the highest quintile for leisure time PA compared to those in the lowest quintile had a much lower hazard ratio (HR) for CRC specific mortality (HR = 0.39, 95% CI: 0.18-0.82). The findings were echoed in a later Meyerhardt study (2006) where 661 male CRC survivors with the highest compared to the lowest quintile of PA were shown to have less chance of CRC specific mortality (HR = 0.47, 95% CI: 0.24-0.92).

Meyerhardt (2006) also established a lower risk of recurrence and mortality six months after chemotherapy when comparing patients in the highest and lowest PA quintiles (HR = 0.55, 95% CI: 0.33- 0.91). Furthermore, it was suggested that female cancer patients who increased their

levels of PA post-diagnosis were at significantly lower risk of CRC and all cause mortality than those who did not change (HR = 0.48, 95% CI: 0.24- 0.97).

2.2 Physical Activity and Adenomatous Polyps

Numerous studies have examined the link between PA and development of colonic adenomas, however to date only one comprehensive meta-analysis has been conducted (Wolin et al., 2011). Wei (2009) established the importance of this association as a public health issue because those with improved lifestyle have decreased risk of CC, even after their screening colonoscopy.

Wolin (2011) searched the literature surrounding this topic, and included the three previous reviews on this specific subject (Samad et al., 2005, Lee and Oguma, 2006, World Cancer Research Fund, 2007) resulting in a yield of 89 potential articles. After exclusions for non-human studies, studies without colon polyps as an outcome, studies where PA was only included as a covariate, and studies where no metric effect estimate was presented, the remaining studies were combined with searches from the reference sections of manuscripts and previous reviews, giving 20 original texts.

Significant heterogeneity was determined within the results (p<0.01) which reported an estimated risk reduction of 16% (95% CI: 8-23%) when comparisons were made between the most and least active individuals in each study. These risk reductions were similar for men and women (19% and 13% respectively) and remained stable when limiting studies to those defined as using the 'best approach'. Similar to the metaanalysis conducted by Wolin in 2009 (as described above), it is also incredibly difficult to measure the threshold for effect with regards to PA participation and reduced adenoma risk. Wolin (2011) also does not go on to

describe the ways in which PA was measured in the 20 manuscripts included within the metaanalysis and, as previously explained, the difficulties with providing standardised guidelines for PA is incredibly difficult with varying types of activity and differing intensities at which PA can be performed.

2.3 Body Composition and Physical Activity Mechanisms for Risk Reduction

To identify the exact mechanisms as to why both decreased body composition and increased PA have a positive effect on CRC risk is extremely difficult as several of the proposed mechanisms are interrelated. Therefore, to try and disentangle the relationships of single biological mechanisms can, in many cases, prove too complex (Friedenreich et al., 2010).

Physical inactivity and central adiposity are both associated with insulin resistance – leading to hyperinsulinaemia which may influence the growth of colorectal tumours (Chao et al., 2004). Increased PA, combined with positive changes in body composition may also play a key role in reducing systemic inflammation through a reduction in pro-inflammatory factors, such as C-reactive protein (CRP), interleukin – 6 (IL-6), tumour necrosis factor α (TNF- α) and an increase in anti-inflammatory factors, such as adiponectin (II'yasova et al., 2005).

The immune system is suggested to have a role in reducing cancer risk however this hypothesis has been largely untested. One proposed theory is that PA could improve the numbers and/or function of natural killer (NK) cells and macrophages which represent the first line of defence against the spread and development of cancerous malignancies (Friedenreich et al., 2010). PA alone has been proven to enhance numbers of these specific cells with a two-fold increase in circulation immediately after partaking in a vigorous intensity exercise session (Nieman and Pedersen, 1999), therefore, due to increased numbers there is the possibility that detection of any abnormal cells could be achieved far more easily alongside tumour suppression.

Another of the proposed mechanisms associated with an increase in PA and decreased cancer risk is related to the increased water intake when doing exercise. Many believe that this increases gut motility therefore providing a decreased stool transit time resulting in less interaction between colon mucosa and potentially harmful carcinogens which may give rise to CC (Chao et al., 2004).

Alongside many of these factors demographic contributors such as age and gender play an important role as well as PA specific factors such as type of exercise, duration, frequency and intensity (McTiernan, 2008).

2.4 Physical Activity Guidelines and Current Levels Achieved

It is estimated that physical inactivity is directly responsible for approximately 35,000 deaths each year within the United Kingdom, costing the NHS around £1.06 billion (Scarborough et al., 2011). Guidelines surrounding the levels needed to benefit an individual have varied throughout the last 20 years. It was believed during the 1990's that moderate intensity aerobic activity – activity which heart rate and breathing rates are raised but conversation remains comfortable (O'Donovan et al., 2010) offer substantial benefits to a person's health (Pate et al., 1995). However, US guidelines have proposed a mixture of both moderate and vigorous intensity activity – activity in which heart rate is higher, and breathing is heavier, could be coupled to achieve PA goals (United States Department of Health, 1996). Following a review current guidelines suggest that adults aged 18-65 years, and older adults, over the age of 65 years, should aim to participate in a minimum of 150 minutes of moderate intensity aerobic activity, or 75 minutes of vigorous intensity aerobic activity each week (O'Donovan et al., 2010). In terms of duration, aerobic activity should be performed for a minimum of 10 minutes each time, and should take place on five or more days per week to achieve positive health benefits (Haskell et al., 2007). Despite the unresolved issue of a dose response relationship between cancer risk and exercise it would be safe to assume that any exercise is better than none and therefore should be encouraged where possible.

With regard to those identified as an 'elevated risk' population; i.e. individuals with increased risk of cardiovascular disease, type II diabetes and cancer, available evidence suggests positive health benefits by going *above* the recommendations for healthy adults, to eventually work towards meeting the guidelines of 'conditioned individuals'. These levels are set at approximately 300 minutes or more, moderate to vigorous intensity aerobic activity per week (O'Donovan et al., 2010).

In terms of participation and adherence levels, individuals who were classified as obese (Zaninotto et al., 2009) or those suffering from a chronic disease (Stamatakis et al., 2007) were much less likely to achieve current PA guidelines. More specifically the results of the 2008 Health Survey for England suggests 39% of men and 29% of women aged 16 and over meet the minimum recommendations for PA. When we compare these self-reported values to objectively measured PA levels obtained through accelerometry data, these figures become much more revealing with percentages as low as 6% for men and 4% for women.

Activity changes, however small in the early stages, could still bring health benefits; therefore initially our focus must be given to supporting changes in activity patterns, setting achievable goals and increasing motivation. This illustrates that much improvement could be made, especially within the older population who have the lowest recorded PA throughout the lifespan (Craig et al., 2009).

2.4.1 Perceptions and Understanding of Physical Activity Guidelines

Trying to understand perceptions around PA in a general population is extremely complex. Despite health behaviour models rising in number and popularity (such as the 'social cognitive theory' and 'health belief model' as discussed later within the thesis) many fail to reflect the actual views and lay understandings of PA in the individuals who are currently not participating (Prior et al., 2014). Therefore it is this knowledge, or lack thereof, which needs further exploration to enable the design and implementation of more successful behaviour change strategies.

Despite this increased need to understand the knowledge and perceptions around PA in older people in England, very few studies to date have actually examined this with Chaudhury et al (2010) being the first to study a nationally representative sample. As suggested by Evans et al (1999) 'there is no segment of the population that can benefit more from exercise than the elderly', and this was further supported by Cassel (2002) who argued that regular PA participation may be 'the best treatment for ageing'. Byberg et al (2009) also discovered that those who increased PA levels between 50 and 60 lived for as long as individuals who were already exercising in middle age regularly; a further incentive to encourage PA participation within an older population. Although *purposeful* PA participation still declines as one ages (Chaudhury and Shelton, 2010), and despite retirement allowing for increased leisure time in many older adults, it has been suggested that the leisure time PA reported by individuals is insufficient to compensate for the loss of activity when one leaves work (Berger et al., 2005).

It is, however, the interaction of a number of complex motives and deterrents which determines whether or not a person chooses to participate in PA. Nies et al (1999) noted the importance of both internal and external – cultural or social influences, as well as exercise

history, exemplified often by older adults who speak of active childhoods and the translation of these internally programmed behaviours from an early age into their retirement years. These active lifestyles, however important to each individual, may still not be reaching the current guidelines for PA in an older person as suggested by Chaudhury (2010). Among survey respondents 23% of men and 32% of women believed they knew the current PA recommendations for adults (far from the truth in which only 3 and 7%, respectively, did) with three quarters of respondents either under-estimating them or not knowing them at all. On the same survey over half (57%) thought they could incorporate enough PA into their daily lives without attending a public gym or structured class, and 77.5% of individuals when questioned, believed they were more physically active when compared to others of their own age.

A possible explanation for these statistics is given by Lewis et al (1997) who found discrepancies between cultures as to what did or did not classify as adequate PA. For example, Italians defined the term 'exercise' as a deliberate form of activity, and housework as natural or part of a person's lifestyle, this was in contrast to the views of Jewish and Greek groups who would count work around the home as actual PA (Lewis et al., 1997). These differences highlight the need for more research into how different people, whether from different cultures, or age groups, perceive 'sufficient PA' levels. Along similar lines, there are common misconceptions held by a number of people that PA has to be strenuous or uncomfortable to elicit any positive health outcomes (Lee, 1993), which in turn may dramatically reduce a person's motivation to become more active.

Achieving the PA guidelines as outlined in the previous section, may prove extremely difficult for an older person with potentially lower initial fitness levels or other existing health restrictions (Brawley et al., 2003c). Maintaining adherence levels can also be a challenge to older individuals due to lowered motivation levels and slow progression. Therefore when
designing a suitable PA intervention for individuals of an older age group, it is essential to remember that they are not a homogenous group (Moore et al., 2014). Whilst lack of good health can contribute to sedentary lifestyles, it is also cited as a key motivator in people's choices to becoming physically active in an older population (Belza et al., 2004). Belza et al (2004) suggested that a change in health status, such as an elevated risk result from a cancer screening examination, may serve as a cue to adopt a more healthy lifestyle. However it is essential that the individual understands this novel diagnosis, and is aware of the risk it may pose to future health.

Chapter Three

As defined by the Oxford Dictionary of English (2010), *Risk* is 'the possibility that something unpleasant or unwelcome may happen' with the key determinant of risk being uncertainty, and therefore the possibility for change in the form of increasing or decreasing one's risk. This study focuses on two parameters of risk; the *perception* of an elevated risk 'diagnosis' following a screening colonoscopy for cancer, *and* the impact this aforementioned elevated risk status may have on deciding to partake in a risk reducing behaviour, namely PA, for risk *management*.

3. Risk Perception and Risk Management

It could be assumed that a person's perceived vulnerability to an illness, and therefore how 'at risk' they feel, may determine their levels of motivation to partake in protective health behaviours such as exercise in a linear fashion. However research suggests this is often not the case, as humans do not always behave rationally with their best interests in mind for a number of reasons (as discussed in section 3.6 'The Rationality of Health Behaviour'). Therefore, it is extremely important for HPs in particular, to understand how the general public understand the term risk, and also how beliefs are constructed regarding an illness such as cancer (Lipworth et al., 2010).

The majority of research within the domain of cancer risk perception has been quantitative using surveys to examine cancer related knowledge and health beliefs. However, more recently qualitative investigations have been implemented to determine lay understandings and experiences of risk in much greater detail (Lipworth et al., 2010). Many now argue that qualitative research in this field of study has much worth as it offers a unique insight into the minds of the participants through the use of inductively derived concepts; an essential element as risk is very difficult to measure and differs from person to person; (Lipworth et al., 2010).

This chapter will explore both quantitative and qualitative research in the area of cancer risk perception, and then go on to the domain of risk management by exploring the Health Belief Model (HBM) (Rosenstock, 1966), the potential impact of a change in health status by exploring the 'teachable moment' (TM) (McBride and Ostroff, 2003) and 'health certificate effect' (HCE) (Tymstra and Bieleman, 1987) and conclude with the rationality of living a healthy lifestyle.

3.1 Quantitative Studies

In Britain, 17% of older adults aged between 55 and 64 estimated their risk of developing CRC as 'lower than average' (also known as 'unrealistic optimism' – so called because of the higher risk faced by individuals falling into an older age group) (Weinstein, 1980)) with a mere 9% of these 'elevated risk' (due to age) individuals rating their risk at above average (Robb et al., 2007). This may be due a number of factors such as complex and confusing health messages or a feeling hereditary factors play a large part in cancer risk with no family history (both mentioned later on in the chapter). Additionally, data from a UK pilot study of bowel screening (Wardle et al., 2000) showed that over a quarter (26%) of 'optimists' (those who perceive their risk as lower than average) claimed that they were not interested in attending a screening examination; compared to 2% of pessimists, who believe their risk to be 'higher than average'. A study conducted by Robb et al. (2004) examined whether this 'unrealistic optimism' (Weinstein, 1980) is justified by looking at the objective results of flexible sigmoidoscopy

screening across both 'optimistic' and 'pessimistic' groups. A modest, yet significant relationship, was found between risk perceptions and screening outcome, with optimists having less chance of an adenoma compared to pessimists (11.2 versus 13.7% respectively) and a higher percentages of a screening with no abnormalities (76.8 versus 71.1% respectively). This research therefore suggests that having a positive attitude towards future health can improve the chance of leading a life free from health concerns. However, it does raise an important concern; people who feel they are at a lower risk of having an adverse health event, may in turn, be less inclined to engage in risk reducing behaviours such as attending screening or initiating PA (Robb et al., 2004).

Judging by these statistics and hypotheses it would seem necessary that interventions to modify this unrealistically positive risk perception are needed – although previous studies suggest there has been limited success in this field (Brewer et al., 2004).

Much of the confusion surrounding these low levels of risk perception may be due to conflicting health messages as briefly touched upon, a theory supported by Niederdeppe and Levy (2007). In this study information from the Health Information National Health Trends Survey (HINTS) (Nelson et al., 2004) found that almost half of the respondents (47.1%) agreed that *'it seems almost everything causes cancer'*, over one quarter (27%) of participants believed *'there's not much people can do to lower their chances of getting cancer'* and 71.5% of respondents agreed that *'there are so many recommendations about preventing cancer it's hard to know which to follow'*.

The 'Common Sense Model' tries to group the ways in which people think about an illness, including strategies for testing, preventing or treating the conditions and perhaps most importantly an individual's representation of the illness in question (Leventhal et al., 1980). Within this model there are five categories; 1) identity – what is cancer?, 2) cause – why do

people get cancer?, 3) timeline – *is cancer an acute or chronic problem*?, 4) consequences – *how painful is cancer?*, and 5) controllability – *can cancer be prevented*? (Sullivan et al., 2010). With regard to health behaviours, one's impressions regarding *controllability*, are the most predictive of health outcomes. Therefore, this factor is essential when developing health promotional messages or interventions (Hagger and Orbell, 2003).

More recently a study by Sullivan (2010) examined this relationship further using the HINTS Survey (2004) to look at views surrounding the *controllability* of three types of cancer, colon, lung and skin. They discovered that there were significantly fewer CC respondents who disagreed with the statement 'there is not much you can do to prevent CC' compared to respondents for both lung and skin cancer (F = 6.05, p = .005). Similarly this result was echoed by CC patients who were less likely to believe that a poor lifestyle behaviour may cause cancer, (F = 108.93, p = <.001). These results suggest that those opting to attend screening for CC do so purely as a preventative mechanism as opposed to using the opportunity to engage in other healthy lifestyle choices.

A study by McCaffery et al. (2003) identified that knowledge on cancer risk factors was very low across study respondents aged 16-74 years. 58% of participants could not list any CC cancer risk factors, with only 4% of respondents stating old age as a risk factor. Although knowledge was higher among older adults (p = <0.0001) results still suggested 38.7% of participants over the age of 65 had low knowledge (with little or no knowledge of correct risk factors). Regarding knowledge surrounding the use of PA specifically as a risk reducing health behaviour for CC, results are just as concerning. Keighley et al. (2004) investigated the responses of over 20,000 respondents from 21 European countries and established that the percentage of adults believing CC could be due to a low levels of PA was as low as 12% in the Netherlands and 15% in Britain. This is also supported by findings from Coup et al.'s study (2008) in which only 15% of respondents within this investigative survey were aware of the risk reducing effects of PA in relation to CC, a figure which further decreased in those over the age of 50, and those with a sedentary lifestyle (12% and 7.3% respectively).

3.2 Qualitative Studies

A large meta-analysis of 87 qualitative studies examining the topic of CC risk perception was published recently by Lipworth (2010). Combining the analyses, it was established that discussing risk with an individual can evoke extremely strong emotions of apprehension, guilt and sometimes shame surrounding the stigma of being at increased risk due to lifestyle choices. These mixed emotions were found to have a profound effect in both negative and positive ways depending on an individual's emotional wellbeing. For example, in many cases these overwhelming feelings would act as encouragement to engage in risk reducing behaviours (as explained in section 3.4 - 'The Teachable Moment') whereas on the other hand they may manifest as denial in avoiding the realisation of risk status. One's perception of risk also appears to be highly influenced by personal experiences, and in most cases the more traumatic or disruptive the experience the greater the awareness of risk, and the more likely the individual would try to prevent the likelihood of the disease occurring, (by attending screening for example). It was also established that the way an individual analyses their own risk status is defined using a number of cognitive processes. These include constant internal comparisons aiming to justify and rationalise choices to engage in certain behaviours despite the knowledge of potentially negative consequences. As previously mentioned in Sullivan's (2010) study, experiencing a sense of control was hugely important to avoiding fatalistic ideologies, so that they could 'continue with their lives' and 'put their mind to rest'. Unfortunately, where this could be portrayed as advantageous when referring to potentially protective behaviours such as PA, it was actually discovered that in some cases people played down their hereditary cancer links (an unmodifiable risk factor) in acts of denial, or indeed felt a sense of not needing to take control as there was no genetic history of cancer. Finally many people, exemplified through Weitzman et al.'s study (2001) had strong beliefs that if they were asymptomatic, there was no need for heightened concern or need to screen for early detection, potentially illustrating a form of 'self-serving bias' in these individuals (Cameron et al., 1997).

All of these findings point towards the increased need for both targeted and individualised education in those most vulnerable to CC as a 'one size fits all' approach may not be optimal. Results from qualitative investigations not only highlight the unique experiences of individual patients but also draw upon clear similarities which can be grouped into clearly defined categories to better understand a person's perception of risk.

3.3 The Application of the Health Belief Model

Motivation to reduce a perceived threat of disease is a common coping response (Folkman and Moskowitz, 2000) and may trigger single or even multiple lifestyle changes, providing the threat is large enough to elicit a protective response (McBride and Ostroff, 2003). The HBM (Rosenstock, 1966), although one of many 'expectancy-value' approaches (Biddle, 2008) to motivation, is particularly relevant to this research as it focuses upon an individual's personal assessment on their level of vulnerability to an illness, as well as their ability to cope if this illness was to arise. This perception on coping ability, may in turn, encourage or discourage motivation to engage in behaviour change (Rogers, 1983). Therefore this may provide an indication as to the reasons for certain health behaviours in a person at elevated risk of a disease, such as the participants at elevated risk of developing CC within this thesis due to their screening result.

The HBM assesses the interaction between factors such as the *seriousness of an illness, perceived susceptibility of a particular illness* and the *benefits which may arise from engaging in health behaviour,* and therefore may provide some answers to behaviour initiation in a clinical, or risk setting. As well as these three factors, *perceived barriers* to engaging in health behaviour are some of the most influential parameters, as they may motivate or discourage participation regardless of clear direction to do so from a trusted person, such as a health care professional. A combination of these four factors have been found to be associated with the formation of a *perceived threat* of disease, and the consequences (known as outcome expectancies) for not engaging in a health protective behaviour (Nutbeam et al., 2010) (see figure 3.1).



Figure 3.1: 'Health Belief Model' (Munro et al., 2007)

To determine the likelihood of behaviour change, the combination of these complex beliefs could read like a mathematical sum in a person's mind whereby the perceived benefits minus the perceived barriers would directly influence the choice to engage in health promoting behaviours such as PA (Biddle and Nigg, 2000). For example, high perceived threat, coupled with high perceived benefits and low barriers which may otherwise inhibit behaviour change, increase the likelihood of engagement (Munro et al., 2007).

Previous research into the HBM has had limited success in the area of PA initiation, however it has proven extremely useful with regards to screening behaviours (Nutbeam et al., 2010) and providing clear and understandable predictions to levels of inactivity in an individual (Biddle and Nigg, 2000). Also, a major review by Janz and Becker (1984) concluded that 'the HBM has continued to be a major organising framework for explaining and predicting acceptance of health recommendations' (p.1). Therefore, with an increasing recognition of PA as a health behaviour and perhaps reinforced by 'exercise on prescription' schemes (Thurston and Green, 2004), the HBM may form an appropriate framework in a clinical health promotion setting.

'Self-efficacy', defined as the situation-specific confidence that one can execute behaviour to achieve a desired outcome (Bandura, 1986), was found to be highly predictive of intentions to exercise (Wurtele and Maddux, 1987, Godin, 1994). It was therefore suggested in 1988 that self-efficacy be added to the HBM to provide a more comprehensive model to explain a person's choice to initiate and maintain behaviour change (Rosenstock et al., 1988).

However comprehensive, many social cognitive theories and continuum models, like the HBM, suggest that a person's intentions to act are the most successful predictors of behaviour change (Schwarzer, 2008). However these predicted outcomes are often based upon a *consciously* derived decision, and often people do not behave in accordance to their intentions for a variety of social, psychological and cultural reasons (known as the intention-behaviour gap), or rationally in accordance with the rationality of human behaviour models discussed within section 3.6 (Sniehotta et al., 2005).

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For this reason, it is essential when studying a person's risk awareness, and attitudes towards risk management, that a 'one size fits all' approach is avoided, and instead the whole picture, from a more qualitative perspective needs be understood by taking account of the uniqueness of individual experience in informing choice to engage in a behaviour.

3.4 The Teachable Moment

Knowledge surrounding the importance of healthy lifestyle choices and CC risk has been shown to be weak among the general population. Clearly health promotion strategies are not as effective as they could be with regards to education surrounding the importance of a balanced diet or regular exercise and this could be due to a number of complex contributing factors. This case can be further complicated when we consider much of the population whom we try to advise will simply choose not to act upon the suggestions. Therefore it is of paramount importance we target the correct patient group at a time when they may be most receptive to guidance, and present the advice in a way that patients are likely to take it on board, and act.

Much the same as the diagnosis of an illness can be thought of as a catalyst for health behaviour change, many believe the circumstances of a screening examination can provide a unique platform for health promotion to target those at increased risk of cancer. This incentive for change is known as a 'teachable moment' (TM) and is defined as 'naturally occurring life transitions or health events that have the potential to motivate individuals to spontaneously adopt risk-reducing or health-protective behaviours' (McBride and Ostroff, 2003).

A great proportion of the literature surrounding the term 'TM' is focused upon the notion of an opportune moment for teaching or learning, especially in children within the educational system (Lawson and Flocke, 2009). Unfortunately, with this type of TM, unpredictability plays a large part and therefore this 'serendipitous event' cannot be counted upon in all cases (Kittleson, 1994). In the health promotion setting this level of uncertainty is not ideal to elicit a positive response, nevertheless within this branch of the literature another key theme emerges surrounding the need for the 'educators' to provide a knowledgeable and trustworthy support system when trying to exploit this TM in order for it to be acted upon successfully (Lawson and Flocke, 2009). Therefore in relation to our field of study, this statement alone emphasises the importance of trusted and well respected HPs in the delivery and maintenance of lifestyle advice – something that will be discussed in greater detail in chapter four: 'The Influence of Health Professionals'.

The second type of literature using the term TM is highly transferable to our study population as it suggests that a particular event may be marked by increased capacity for some sort of change (Lawson and Flocke, 2009). Elser and Bock (2004) established that patients attending a hospital emergency department for non-cardiac chest pains were far more likely to make health behaviour changes 'during a key time when their attention is focused on their health' (p. 267). This may provide some explanation as to why a screening examination increases a patient's receptivity to health advice.

One of the first people to examine this link was Glasgow et al. (1991) who demonstrated that smoking cessation was statistically higher amongst those who had previously been hospitalised when compared to the general population. Glasgow proposes that this hospitalisation creates a temporary disruption to one's usual activity creating a unique 'window of opportunity' (p. 29) in which to engage the patient in motivational advice. The difficulty of maintaining this behaviour change and adhering to a new lifestyle choice is a further challenge which many individuals fail to successfully complete, as suggested by Judge et al. (2005) who found that 75% of people relapse back to smoking within 12 months of cessation. A further interesting examination is that patients are twice as likely to recall health behaviour advice if they are currently suffering health behaviour related illness, such as cardiovascular disease or diabetes (Flocke and Stange, 2004). This further highlights the benefit of focusing advice upon those told they may be at elevated CC risk after screening when providing health promotional information.

The final and least documented use for the TM is a relatively new concept and involves the practice of 'modelling' the TM (Lawson and Flocke, 2009). This suggests not only can a personal change in health status act as a cue to action, a TM may also occur in an individual if a friend or family member has a change in health status. Although the evidence within this field is highly limited it is also extremely exciting as it proposes that a TM may not be an unpredictable event, but instead something which may be effectively created through interactions with others (McBride and Ostroff, 2003).

Whether the event forms a TM strong enough to elicit behaviour change is thought to depend on how the situation is interpreted in the eyes of each individual. For a change in lifestyle to occur, it is believed that three factors must be analysed first, starting with the *significance* of the event in question, the *cause* of the situation and finally what the event *means* to the individual – similar to the parameters outlined within the 'common sense model' as described previously (Fife, 2005).

A review of the literature surrounding the concept of a TM formation within the context of screening programmes was conducted by Senore et al. (Senore et al., 2012). From the extensive literature search, nine randomised lifestyle interventions were found to be applicable with one examining fruit and vegetable intake during an educational intervention (Baker and Wardle, 2002), three assessing the impact of smoking cessation counselling (McBride and Ostroff, 2003, van der Aalst et al., 2010b, Clark et al., 2004) and the remaining five reporting multiple health related behaviour such as alcohol intake and PA (Emmons et al., 2005, Caswell et al., 2009, Robb et al., 2010, Craigie et al., 2011, Chellini et al., 2011). Within the studies, two intervention intensities were implemented; either minimal contact or an

intensive programme. However, regardless of how much contact was established throughout, all participants randomised to the intervention group were offered personalised programmes to achieve the desired change. The lower intensity approaches involved obtaining baseline assessments and then mailing programmes along with guidelines out to each participant (Baker and Wardle, 2002, Clark et al., 2004, Robb et al., 2010, van der Aalst et al., 2010a) whereas the remainder opted for greater contact either through personal meetings (Caswell et al., 2009, Craigie et al., 2011, Chellini et al., 2011) or telephone conversations (McBride et al., 1999, Emmons et al., 2005).

A minimal contact intervention had positive effects with regard to the proportion of people meeting their recommended fruit and vegetable intake during follow-up at six weeks (Baker and Wardle, 2002) and at six months (Robb et al., 2010), however similar results were not observed within smoking cessation or PA. On the other hand, the more intensive interventions were associated with a significant increase in the proportion of people changing multiple healthy behaviours at three months (Emmons et al., 2005) and eight months (Caswell et al., 2009). Additionally, findings concluded that 90% of participants at elevated risk of developing CRC within an intensive intervention, found the additional material and counselling as 'helpful' or 'very helpful' (Emmons et al., 2005). If we consider this alongside additional findings among UK breast cancer screening attendees stating UK women would welcome having diet and exercise advice, it seems that screening may provide the perfect opportunity for health promotion (Fisher et al., 2007). Although the above findings appear promising, conclusions from a recent qualitative investigation highlight problems with the general population's current perception of risk status after adenoma removal (Stead et al., 2012). As part of an ongoing randomised controlled trial known as the BeWEL Study (Craigie et al., 2011), potential participants were identified for four focus groups from hospital records based on their history of having adenomas removed through colonoscopy in the past 3 months. After screening for eligibility and accounting for attrition, a total of twelve males and five females were invited to take part in one of four focus groups to discuss a wide range of topics surrounding their experiences of adenoma diagnosis and treatment. From their responses, it was apparent that general knowledge surrounding adenomas was lower than expected, with most considering them a minor health problem and many unaware of their potential link to the development of CC. This lack of knowledge was seemingly reinforced throughout discussions with HPs (during and after the treatment process), who would frequently give reassurance of an 'all clear' message, which in turn was received as a validation to continue with current lifestyle habits a phenomenon known as the 'Health Certificate Effect' (HCE) which is described in more detail in section 3.5. The proposed lack of knowledge surrounding the possible causes for their adenomas seemed also in part due to a lack of information provided during initial and subsequent interactions with HPs; "They sent you a leaflet to give you an idea what a polyp was and that was about it. They never said what caused it." (Group 4 Participant cited in Stead et al. 2012). The suggestion that changing ones' lifestyle may improve future health outcomes formed a high level of scepticism from many participants due to the apparent contradiction after their 'clean bill of health' and many dismissed lifestyle change due to the advice being inconsistent; "if you read the newspapers you realise that whatever you do is bad for you" (Group 1 Participant, cited in Stead et al. (2012). There was also a clear link between the age of the participants and unrealistic lifestyle goals with many people believing it was too late to change habits "at our age". This link has also been documented throughout quantitative investigations such as Clipp et al. (2004) who established less motivation to succeed at lifestyle adaptation within the elderly due to vulnerabilities in other aspects of their lives. Furthermore, Mcbride et al. (2008) were surprised to discover that during Project PREVENT those participants displaying the greatest amount of risk factors, for example the elderly, the overweight and the sedentary, had diminished motivation to adjust current behaviours. These

findings are indeed concerning as research suggests small changes in lifestyle behaviours regardless of age, are beneficial in treating various chronic conditions and improving quality of life variables (Lorig et al., 2001). There were however positive responses to the suggestion of lifestyle advice within the screening setting. Some believed that it was the perfect time for HPs to provide suggestions as they were not only relieved upon getting an 'all clear' diagnosis, but open to advice surrounding how to prevent similar circumstances in the future; *"I think if somebody suggested to me that if you did this, or you didn't do that I would...you know take it seriously."* (Group 1 Participant cited in *Stead et al.* 2012).

The findings of this paper suggest the need for increased education in those at risk, especially the elderly, if we are to expect screening to create a 'TM'. In the case of diseases such as lung cancer many people are aware of the links between their lifestyle choices such as smoking, and that their choice to partake in such behaviour may increase risk status. Therefore, with increasingly more positive evidence surrounding lifestyle choices, specifically PA and the number and size of adenomatous polyps (Wolin et al., 2011), it would appear necessary to gain further understanding surrounding why this information is not being readily provided to participants in need by HPs.

3.5 Health Certificate Effect

The opposite effect to the TM is described as the 'health certificate effect' (HCE) and this can be established when a participant believes a negative screening result, for example one where no cancer is detected, as verification to continue with their usual lifestyle patterns (Tymstra and Bieleman, 1987). Despite the screening procedure seemingly acting as a perfect platform where patients are likely to raise questions regarding a relationship between their current lifestyle choices and subsequent effects on their health; it is always more difficult to motivate and introduce guidelines for change amongst people who feel they are in good health, especially if they feel a negative screening result translates to a message of good health (Senore et al., 2012)

The first to document this phenomenon were Tymstra and Bieleman (1987) in a study examining the experiences of men undergoing cardiovascular disease screening and their views on the subsequent diagnosis. Despite a mixed response to the results (ranging from indifferent to astonished) out of the males who received a test result pertaining to elevated risk, such as high cholesterol, less than one quarter (23%) said their first reaction was that changes to their lifestyle must be made. Despite this statistic, of these participants, 82% followed up their diagnosis with a visit to their GP and subsequently made changes to their behaviour such as lowering fat intake and increasing PA. On the other hand, of those participants who received a negative diagnosis i.e. no risk factors established, almost half (44%) of questionnaire respondents stated that the 'favourable result' acted as a verification for current lifestyle choices despite the fact there was no significant differences in lifestyle between both groups.

This model has been further applied to type II diabetes within qualitative research showing similar effects (Adriaanse and Snoek, 2006). Within Adriannse and Snoek's study, interviews were conducted with 40 participants who had previously undergone diabetes screening tests due to elevated risk status, twenty of whom were classified as diabetic, the other twenty non-diabetic. Although the questions were slightly altered within each interview, the main topics covered were the experiences of screening and personal thoughts with regard to their individual diagnosis. Despite 75% of participants expressing concern at the screening outcomes *prior* to testing, and then subsequent relief after their diagnosis, 100% of the non-diabetics were fully reassured and saw no reason to change their lifestyle. Adriaanse and Snoek concluded that the response given emotionally to a diagnosis is largely determined by one's

perceived seriousness of threat (as suggested within the HBM (Becker et al., 1974)). However, upon further analysis, prior to the diabetes screening, only 1.4% of the participants stated that diabetes was not a serious disease (the remainder thought it moderate to very severe), which would suggest other variables were 'buffering the emotional impact' (Adriaanse and Snoek, 2006). The reason for this speculation is that despite all participants being selected on the basis of their elevated risk status, little concern for lifestyle change was portrayed in the nondiabetic group. This was further reinforced as only 20% of these participants planned to check their glucose levels in the future despite potential impaired glucose tolerance leading to diabetes in 30% of this population (Griffin et al., 2000). When considering all of the evidence, this again may be due to GP reassurance; downplaying the potential for diabetes or other medical problems such as cardiovascular disease (CVD) later in life if they were not to consider lifestyle alterations (a factor discussed again in Chapter four).

More recently, this effect was examined in participants undergoing CC flexible sigmoidoscopy screening by Larsen et al. (2007). Responses to a validated health questionnaire taken directly before the procedure and again three years later as a follow up measure (including dietary habits, PA levels, BMI and smoking), were analysed against matched control subjects who did not attend a screening procedure and were approached via mail. Baseline measures indicating a number of lifestyle variables from each group did not show statistically significant differences when compared, however the screening group displayed slightly higher levels of PA and a greater intake of berries, vegetables, boiled potatoes and oily fish. After adjustment for confounding variables, on average the screening group gained 0.2 kg more than the control group (p = 0.023, 95% CI: 0.04-0.45) and screening attendance was also an indicator of less improvement in exercise levels (p = 0.003).

If we are to look at all of the evidence over the previous two sections it paints a clear picture that more could be done, not only to increase awareness of risk in all individuals, but also enhance current knowledge in elevated risk patients about the potential future health consequences of having an adenoma. On the other hand, many may agree that the health service is turning relatively 'healthy' people into patients earlier and earlier, taking the view that it is unnecessary to identify an 'elevated risk status' as a '*diagnosis*' per se, especially when there is no guarantee that an individual will go on to develop the condition (Aronowitz, 2009).

Therefore more data needs to be collected on the views of 'elevated risk' patients and health promotion messages received and delivered within the screening setting, as well as the thoughts of HPs regarding their views on whether healthy lifestyle promotion within this population is possible, or perhaps more importantly, even needed.

3.6 The Rationality of Health Behaviour

The previous section demonstrates that, regardless of knowledge around the benefits of leading a healthy lifestyle, often individuals choose to behave in ways which would appear irrational, especially if they are considering future health as their main priority.

A 'risk behaviour' is defined as one which deviates from the 'norm', as judged by the wider society, or policy, and constitutes an acceptable moral standard of acting. These behaviours are often also said to have a negative effect on a person's future health status. However, when it comes to sedentary living, despite being associated with numerous health conditions, can we actually regard it as a *risky* behaviour? As so few adults, especially in the older age group, participate in the recommended amount of PA as suggested by policy makers, a strong argument can be made that it is more *normal* to be inactive than active, in today's society. With only 24 hours in a day in which to split our time into four different pursuits; working for pay, housework, being physically active in leisure time, or alternatively spending that leisure time in sedentary pursuits, people will inevitably only exercise when it is the best use of their time – however irrational this may seem to active observers of an individual (Cawley, 2004).

The theory of rational choice assumes 'an individual will always choose according to his own self-interest, and that so-choosing is the essence of rational behaviour' (Douglas, 1992)(p.102). This theory, alongside the HBM (Rosenstock, 1966), also suggests that health protective behaviours will *only* be undertaken if the perceived benefits of engaging in said behaviour outweigh the negative costs associated with participation (see section 3.3 - 'The Application of the Health Belief Model'). It is also thought that if a behaviour is presented in a more favourable image (for example, the huge advertising campaigns for fast-food companies), individuals tend to accept the costs of that behaviour taking place (however negative), as opposed to fearing the consequences (Reyna and Rivers, 2008). Therefore this notion of rational choice can often become blurred, with individuals having to decipher between often contradictory consumption options, all claiming 'rational' arguments and health benefits at a fraction of the effort as attending a gym e.g. weight loss products (Maziak and Ward, 2009).

The concept of 'situated rationality' (Lawson, 1997) takes a more socially orientated approach, taking account of the context of behaviour and stating that risk is not a constant measure but is determined by a person's current situation. Therefore a person's motivation to engage or disengage with certain health related behaviours can differ within an individual depending on time and place, and may be altered in the presence of a significant health event – as suggested by the *'Teachable Moment'* (Rhodes, 1997). Regardless of health status however, when it comes to healthy lifestyle choices such as eating more healthily, or engaging in more PA, the targets laid down through current guidelines may be seen as too difficult to achieve (suggested in section 2.4.1 - 'Perceptions and Understanding of Physical Activity Guidelines') and

therefore they may actually cause frustration, alienation from, and distrust in, mainstream public health messages (Maziak and Ward, 2009).

Despite acknowledging the active decision making tasks an individual faces when deciding whether or not to partake in a risk reducing behaviour, the concept of *situated rationality* of risk does not account for the often 'habituated nature' and frequent patterns of activity (often sedentary) which are regularly performed with little thought of consequence to health. *Phenomenological theories* of risk attempt to explain these shortfalls by stating that choice to engage in risky behaviours (such as inactivity) may be a result of a decision making process (as suggested in the HBM, and situated rationality) *or* habitual, and therefore less within a person's control (as proposed in the cultural theories of risk).

Therefore, while attempting to understand the varying theories of risk with the hope of determining why a person seemingly acts *without* their best interests in mind, it would seem most sensible to allow for all of the theories to interact, such that they may apply to different individuals at different time points. Decisions around behaviour change, although often influenced by a person's awareness of risk, are more frequently shaped by an individual's preferences, and therefore behaviours which give the greatest pleasure or reward with the least amount of effort are frequently chosen (Cawley, 2004). The influence of a trusted HP in the domain of increasing risk awareness and encouraging health behaviour change, often appears to be underutilised (Stead et al., 2012) and should not be underestimated, as will be discussed in the next chapter.

Chapter Four

The following chapter looks at the influence a health professional may have on an individual's choice to initiate and engage in positive lifestyle behaviours. The previous literature explores patient preference for receiving advice, whether the guidance is currently provided and the effectiveness of said advice. As well as this, the debate around which type of professional is best suited to providing this advice and the common barriers to providing this advice within the care setting are explained.

4. The Influence of Health Professionals

As has become clear in the literature review so far, an individual's awareness of their risk of developing a disease, and subsequently the behaviours which may reduce this level of risk, may provide a cue to action and initiate a lifestyle change if motivation levels are great enough (Munro et al., 2007). However, as has also been discussed, individual's may not engage on active lifestyle changes *despite* awareness of risk as their own perception of level of risk may differ, when considering their situated sense of rationality, to that that may be externally observed. Leaders within the health care setting are highly respected, and therefore the attitudes and opinions around the promotion of lifestyle behaviours, such as PA, may have a considerable influence on the choice to engage within the general public (Vuori et al., 2013).

Within the older age group and in the domain of PA behaviour the aforementioned concept of situated rationality is often present whereby there is frequently a paradoxical relationship between awareness of the benefits of PA in disease risk reduction, and the often unpleasant physiological outcomes associated with partaking in exercise (such as nausea and fatigue) which, in turn, may discourage participation. Therefore, the need for increased education and guidance from trusted professionals pertaining to the 'normal' responses to exercise, is of paramount importance (Brawley et al., 2003c).

The significance of a confidential and supportive environment when discussing health concerns with any medical professional is hugely influential on a patient's relationship with their primary health care provider and therefore their likelihood of adhering to any recommendations, whether that be during medical intervention or behaviour change (Bastiaens et al., 2007). This care and sensitivity is of paramount importance to developing a strong patient-practitioner relationship. However, in settings where the illness is often considered self-inflicted (for example in lung cancer where smoking is a recognised risk factor), greater empathy is often required to reduce feelings of stigmatisation and blame (Chapple et al., 2004).

4.1 Patient Preference for Advice

Booth et al (1997) conducted a survey outlining PA preferences, including over 2000 Australian adults aged 18 to 78. According to the results, the most preferred source of help regarding PA behaviour was from a doctor or other health professional (38% of all respondents) rising to 50% of respondents aged 60 and over (compared to only 22% of the youngest age group, aged 18-39 years, p = <0.01). This is further supported by Hirvensalo et al (1998) who incidentally found that those given orders by a doctor or other trusted HP, were far more likely to initiate PA behaviour, and Schofield (2005) who established that general practitioners (GPs) are the most trusted source of PA guidance in individuals of an older age group, or with chronic disease.

Many patients speak favourably about receiving lifestyle advice, especially if risk of further disease or illness is likely to be reduced (Calderón et al., 2011), however this positivity is often coupled with the need for sensitivity and awareness of each patient's 'concrete life situation'. (Walseth et al., 2011). Promoters need to be aware of other comorbidities and personal socio-economic status before giving potentially unattainable lifestyle recommendations (Calderón et al., 2011).

Preference for professional advice over, for example, information found on the internet, was also explored in a qualitative study by Bowes et al (2012). Findings suggest that although many patients research their illness online and often present these findings to their GP during their consultation, the opinion of the professional was regularly held in greater regard, and trusted more widely.

4.2 The Effectiveness of Health Professional Advice

A trusted HPs advice (whether positive or negative) does appear to have an important influence on the behaviour of patients, especially within the older age group (Baert et al., 2011). Giving this advice in a personalised and tailored format also appears to reflect enhanced memory for recall within older patients which, in turn, may result in greater levels of adherence and maintenance (Posma et al., 2009).

In a study where GPs provided patients with oral and written guidance on PA, energy expenditure in patients increased by 9.4kcal/kg/week (p=<0.001) and leisure exercise by 34 minutes/week (p = <0.04) when compared to individuals in the usual care (or no PA guidance) group (Elley et al., 2003). In a more recent study by Josyula *et al.* (2013) the effects of providing exercise as prescription alone, versus the same exercise prescription alongside an exercise 'tool kit' which each person was able to take home, showed that additional support

(in the form of the toolkit) was more beneficial on PA levels over three months (p = <0.01). These findings support those of Smith *et al. (2000)* who found that coupling a PA prescription with verbal encouragement was more successful at eliciting behaviour change short term than prescription alone. Another study examining the difference in recall and behaviour change when comparing endorsement by a HP alongside 'take home' educational materials as opposed to no professional endorsement, was conducted by Kreuter *et al.* (2000) with similar findings. Results suggested that those patients who received both the face to face endorsement as well as the educational materials had a greater recall of the lifestyle information, and were also more likely to state a positive change in their PA behaviour (OR = 1.51, 95% CI: 0.95-2.40).

A review by Stead *et al. (2008)* examined the level of detail needed on lifestyle promotion (namely smoking cessation) within the health setting. When results were pooled, perhaps unsurprisingly, there was a small but significant advantage of more intensive advice over minimal lifestyle advice interventions (RR 1.37, 95% CI: 1.20-1.56). More reassuringly however, those who received a brief advice intervention versus those who received no advice at all also significantly increased quit rate over 17 trials as well (RR 1.66, 95% CI: 1.42-1.94.). Kerse *et al. (2005)* studied the change in PA levels when *specific*, tailored information around type and frequency was provided by the GP. The proportion of participants achieving adequate levels of PA rose from 0.14 to 0.31, and within the intervention group there were significantly lower rates of hospitalisation during the following year compared to the control group, highlighting the positive impact increased PA may have on future health.

4.3 Is the Advice Given?

Older patients personally describe their age cohort as 'belonging to a generation who easily accept the authority of a doctor' (Bastiaens et al., 2007), therefore the need for HPs to provide the necessary information regarding healthy lifestyle behaviours is of paramount importance, especially given the high success rate of PA counselling interventions as discussed in section 4.2 – 'The Effectiveness of Health Professional Advice'.

Despite these results, findings from a study by Buman et al. (2010) identified a distinct lack of support and encouragement for PA within primary care by physicians (a factor which will be hypothesised in section 4.7 - 'barriers to providing advice'), suggesting that a professional's interest in giving health promotion is crucial alongside patient acceptance of advice. Although studies examining PA recommendations from HPs within the older generation are relatively few (Hinrichs et al., 2011) a small number of studies have suggested figures from as high as 76% (Damush et al., 1999) and 67.2% (Hinrichs et al., 2011), to a lower 38% (Balde et al., 2003) of older adults *not* receiving any guidance in the form of PA from a trusted source, despite physicians in primary care having optimum exposure to the general public (Schutzer and Graves, 2004).

A study by Stermer *et al.* (2004) examined potential shortfalls in the management and provision of services given to individuals at elevated risk of developing CRC due to family history. Findings suggest that the delivery of advice around risk reducing behaviours, such as PA, and encouragement to attend surveillance screenings are often inconsistent and frequently confusing, especially where conflicting advice is provided. This study emphasises the need for clarity in the role of primary care physicians as well as improved follow up and support of these elevated risk individuals. Although not specifically generalisable to this study's elevated risk population who do not all have a family history of CC, the findings may be

applicable, and showcase potential shortfalls in the delivery of guidance and support throughout the elevated risk population.

4.4 Secondary Prevention

Despite evidence suggesting the beneficial effects of leading a healthy lifestyle in relation to cancer risk and recurrence (Holmes et al., 2005), public awareness still remains especially low, particularly in relation to alcohol intake, body weight and PA (Redeker et al., 2009). Furthermore, awareness of these positive behaviours appear to be no higher in cancer survivors than in individuals who have never been diagnosed with cancer (Lykins et al., 2008), with many people believing their own poor lifestyle habits are *not* to blame for their diagnosis (Wold et al., 2005).

A randomised trial conducted by Jones *et al.* (2002) established that a brief prompt by an oncologist increased PA in newly diagnosed cancer patients, further highlighting the 'instrumental gatekeeper role' clinicians may have in facilitating behaviour change (Daley et al., 2008). However, little research has been conducted to identify whether health promotion in the cancer setting is actually occurring (Miles et al., 2010).

4.5 Conflicting Advice

Despite research findings that advice from a HP may be extremely effective in altering a person's PA behaviour it would seem that many older individuals do not receive this guidance. Of those who do, the advice may often seem very confusing especially if the promoter in question provides mixed messages and conflicting guidance regarding their situation. Inconsistent advice can lead to greater levels of anxiety and frustration among all groups of

people (Stermer et al., 2004) especially the elderly who, if given warnings about PA participation, may interpret these as an instruction to be inactive or rest; resulting in this age group acting particularly cautiously for fear of injury (Hirvensalo et al., 2005)

In a study conducted by Hirvensalo et al (2005), 34% of respondents recalled both recommendations for, and warnings against, PA by HPs, with sedentary individuals having a decreased probability of recalling either advice to engage or not to engage in PA (OR 0.25, 95% CI: 0.09-0.71). This was echoed in an earlier study (Damush et al., 1999), that concluded sedentary individuals were three times less likely to recall being counselled by HPs than their active counterparts. The majority of older participants (77%) recalled negative, no or contradictory advice about exercise, and those who were married with children, were three times more likely to recall receiving only negative advice to participate in PA. This may imply that there is reinforcement from spouses or younger family members supporting these negative messages too. Although these findings may suggest a form of self-serving bias, where individuals only recall hearing what they wish to hear and with HPs usually perceived to be 'credible informants' (Godin and Shephard, 1990), the need to closely monitor wording choice when deciding whether to encourage or discourage PA participation is extremely important. This is particularly important with regard to this thesis as it has been suggested that barriers associated with initiating PA in older individuals were more pronounced if HPs provided these negative influences (Choghara, 1999).

4.6 Who Should Provide the Advice?

Much of the research to date has focused on the role of the primary care physician, such as a GP (Hinrichs et al., 2011). This is hardly surprising as GPs are able to reach a large proportion of the population, as well as providing the first point of contact for any individual with a problem.

GPs also have the benefit knowing about a person's health status and potential contraindications to exercise prior to providing them with PA advice (Britt et al., 2009, Hinrichs and Brach, 2012).

In a survey asking cancer specific HPs their opinions about who was best suited to provide PA advice, clinicians (including medical oncologists, clinical oncologists and surgeons) felt nurses (50% of respondents) and physiotherapists (33.3%) should fulfil this role. 11.8% indicated that 'other health professionals', usually fitness instructors would be best suited, and only 1.9% believed oncologists to be the right professional to give PA guidance. Of the respondents none believed surgeons to be suitable to deliver lifestyle advice (Daley et al., 2008)

Integrating other professionals in the counselling process for PA may also help overcome many of the barriers associated with providing this advice (as discussed in section 4.7 below). Investigations have evaluated the delivery of advice by practice nurses (Dubbert et al., 2008) with positive results, and another potential source of support could come from exercise specialists with the tools and knowledge to develop safe, tailored exercise programmes (Hinrichs and Brach, 2012). A trial by Elley et al. (2003) assessed the effects of a combined GP or nurse counselling session with ongoing support from exercise specialists with successful changes to PA and quality of life over a 12 month period. Patients on a cardiac rehabilitation programme also recalled confidence gained from attending PA sessions supervised by professionals with specific and expert knowledge in the area of exercise prescription (Cole et al., 2013).

4.7 Barriers to Providing Advice

Johansson et al. (2009) suggested that within the health setting three types of professional exist, all with differing views on the power and use of health promotion in the context of

disease prevention; 'the demarcater', 'the integrater' and 'the promoter'. 'The Demarcater' although willing to talk about disease prevention and take clinical tests such as blood pressure, would not want to delve into the complex role of lifestyle change due to the fact they feel under qualified for a position whereby a person's entire well-being is their responsibility. 'The Integrater' is a professional who takes a multi-disciplinary approach to disease prevention, whereby medical remedies for health improvement exist alongside the more self-managed behavioural determinants of ill health, and therefore would seek to use both in their consultations. 'The Promoter' views health promotion as a distinct component of primary prevention strategies, and fully advocates the use of lifestyle advice in individuals *before* illhealth appears. The promoter is highly focused not only on the individuals taking control over their own health but also on the importance of collaboration between other health actors, such as fitness instructors, within the community.

Although the personality traits of HPs may have a large part to play in their promotion of healthy lifestyle behaviours, low rates of PA counselling in primary and secondary care are often attributed to the huge amount of barriers promoters are faced with in the medical setting. A recent review by Hujig *et al. (2014)* looked at 59 studies on health promotion in primary health over the past 20 years. The promoting behaviours of health professionals may be influenced by a multitude of factors, organised into prominent themes including; socio-political – such as a lack of education or resources, support – from local PA facilities and personnel, and personal and patient characteristics – such as a fear of offending, or low motivation levels in the part of the individual adopting the behaviour. One of the most frequently cited barriers mentioned by GPs was the *time constraints* faced within consultations, and therefore the need to prioritise other health issues over discussions on lifestyle behaviours (Calderón et al., 2011). Professionals have also voiced concern that despite their efforts, lifestyle investigations and discussions may do very little to change behaviour

patterns in the most vulnerable patients, and therefore question its need and/or effectiveness (Jacobsen et al., 2005).

4.7.1 Negative Perceptions

Although mentioned in a study some time ago (Dupen et al., 1998), PA may still be an underrecognised risk factor for chronic disease in the medical setting (unlike the better known risk factors such as hypertension) – especially by professionals of an older generation. Therefore HPs may need greater awareness of the recent literature, and encouragement to incorporate this advice into their daily practice.

HPs also expressed the opinion that attempting to change one unhealthy behaviour in individuals with multiple poor habits would be 'swimming against the tide' in light of personal experience and patients variable motivation to change (Calderón et al., 2011). Holding personal biases around which individuals may or may not adhere to advice may also cause those who are most vulnerable due to poor lifestyles, to miss out on vital information about modifiable risk behaviours.

4.7.2 Credibility

Patient perception of their personal HP's attitude towards leading an active lifestyle also has a huge impact on a person's choice to comply with recommendations (McKenna et al., 1998). Of 411 patients questioned, 70% suggested that they would be encouraged to change their PA behaviour if they believed their practitioner to 'walk their talk' too (McKenna et al., 1998). The same study also showed that HPs who were at the higher stages of behaviour change; contemplating changing PA behaviour or currently in active maintenance of PA behaviour (as proposed by the Transtheoretical Model (Prochaska and DiClemente, 1983)) were three times more likely to regularly promote exercise behaviour to patients. Brawley et al (2003a) further supports this evidence with cancer patients, suggesting practitioners with a view of cancer as a mainly genetic disorder and not one amenable to the effects of exercise are far less likely to provide meaningful and honest lifestyle advice to their patients.

As well as the potential for lifestyle behaviours to be transferred from practitioner to patient via 'believable endorsement', this study also concludes that professionals who are the most active, cite the least amount of barriers to providing advice (McKenna et al., 1998) and thus promote healthy lifestyle behaviours more frequently than other, more sedentary members of staff. (Ribera et al., 2005).

4.7.3 Confidence

Many studies have suggested that older people are less likely to receive PA advice than their younger counterparts (Hinrichs et al., 2011, Schonberg et al., 2006). Dauenhauer et al (2006) suggests that despite practitioners positive attitudes towards exercise, awareness around optimal mode, frequency and intensity of PA for older adults is still low requiring specific skill training and confidence in administering this specific type of advice.

A barrier to health promotion specifically mentioned in primary care was that often people present to their GP with a specific health problem. GPs often expressed discomfort, therefore giving PA advice to a person who had come in complaining of an ailment which is unrelated to, or may be exacerbated by increased PA, e.g. leg pain, for fear of upsetting or annoying the patient (Holmberg et al., 2014).

These fears by professionals are somewhat justified, as patients with type 2 diabetes and obesity have expressed frustration about feeling judged by their clinician when questioned about their lifestyle choices (Nicklas et al., 2011). Regardless of this though, it has been shown that if people are provided with adequate information about healthy lifestyles, often changes are made (Baert et al., 2011) (see above section, 4.2 – 'the effectiveness of health professional advice'). Therefore, it is possible that a more collaborative approach to health promotion could be incorporated, such as *patient centred* counselling or motivational interviewing, focussing on personal goals and needs, which may be more widely accepted (Rosal et al., 2001)

4.8 What needs to Change?

The tailoring of advice in an empathetic and supportive way, as well as having a genuine interest in the happiness and well being of a patient can improve the patient-practitioner relationship and encourage a trustworthy environment, whereby lifestyle recommendations are more widely accepted (Bahrami, 2011, Posma et al., 2009). Older people have more difficulties processing and recalling complex information (Kessels, 2003), and therefore the structuring of advice must include repetition and frequent summaries when delivering personally relevant information to enhance recall and encourage initiation.

As mentioned previously, physiological symptoms such as shortness of breath and aching muscles may encourage termination of PA in an older population, despite these being a normal physiological response. Therefore physicians may be encouraged to better guide their patients to interpret these cues as positive, not negative, outcomes (Crombie et al., 2004a).

Within the secondary care setting, nurses working on wards with individuals over the age of 65 have expressed their support for an integrated approach to health promotion within their daily responsibilities (Kelley and Abraham, 2005). However, due to the hierarchical nature and protocol driven procedures of a hospital environment, it seems that health promotion also

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needs to be awarded far greater importance with enhanced training opportunities for all staff members to improve confidence.

This chapter illustrates the positive influence HP endorsement has on lifestyle behaviours, including PA. Whether delivered in primary care with supplementary materials, or as part of a multi-disciplinary team alongside exercise specialists, there seems to be a unique opportunity to promote healthy living within the medical setting, which is currently being missed. This type of counselling is not without barriers though, highlighting a distinct need for improved training, greater prioritisation and better support from a managerial level for health professionals who wish to provide a more tailored behaviour change counselling service (Levy et al., 2014).

Chapter Five

The final chapter of this literature review explores the most frequently discussed personal, psychological and social barriers to PA participation within older individuals, cancer patients and 'elevated risk' populations. The second half of this chapter describes the cultural influences an older population may have encountered throughout their lifetime, starting with the change in lifestyle advice over the past sixty years and concluding with how simply 'being older' may be a barrier itself, to engaging in PA.

5. Psychological, Social and Cultural Factors to Consider

Following the principles outlined within the HBM (Rosenstock et al., 1988) – see section 3.3, the initiation of a behaviour, such as PA, is largely determined by a combination of the perceived benefit of engaging in the behaviour versus the perceived barriers which may form a unique deterrent to engagement. Over 80% of older people acknowledge at least one barrier for participating in PA (Schutzer and Graves, 2004), however in the majority of cases the barriers are numerous and unique to each person (Deforche et al., 2006). According to the literature search undertaken, the only review investigating PA levels among older people was conducted by Sun *et al. (2013)*. Across 53 papers the percentage of adults over the age of 60 meeting the recommended guidelines of 150 minutes of moderate to vigorous intensity PA per week ranges from 2.5% (Troiano et al., 2008) to 83% (Bird et al., 2009). However, results by Tucker *et al.* (2011) reflect the likelihood of recall bias and social desirability in subjectively measured PA levels. Findings suggest only 7.25% of participants achieved adequate levels (when measured objectively by accelerometers), rising to 54.2% when the information was self reported (by questionnaire). This is supported by the Health Survey for England (Craig et al.,

2009) who reported adequate PA levels as low as 6% and 4% of adult men and women respectively via objective measurement.

The positive relationship between PA and cancer risk has been discussed in Chapter 2. However there are many other reasons to promote PA in an older population aside from cancer risk reduction, such as improved psychological health, better motor functions and a greater sense of wellbeing (Grant, 2008b); but encouraging this behaviour is not free from difficulties. As well as the numerous barriers associated with initiating a PA regime, there are many psycho-social and cultural factors which have a role to play in behaviour change in an older population. The disparities which arise when looking at self reported PA levels (Sun et al., 2013) highlight the variety of different meanings associated with the term *physical activity* not only from a lay perspective but also from a medical and scientific perspective often resulting in more questions than answers (Grant, 2002); Do all PA guidelines apply to an older population?; How much PA should an older person engage in to elicit a positive health response?; and Do older people believe their body is capable of such levels?

Following on from this, it is also important to understand that individuals born in the first half of the 20th century have been subject to many definitions of *good health* (Grant, 2008b) where emphasis was placed upon rest and passivity in old age, and the idea of exercising for the sake of it was deemed 'unnatural' (Grant, 2008b) – see section 5.1.5.2; 'Changing Times'.

Although an 'age resistant' culture is now beginning to emerge with focus on terms such as 'active ageing' (Gilleard and Higgs, 2000), for much of the 20th century perceptions and prejudices around the ageing person as a frail entity with entitlement to slow down, placed older people on the margins of society. This gave rise to often negative stereotypes around gym culture and a clear expectation around how an older person should behave – see 'Ageing and Physical Activity', section 5.1.6 (Grant, 2008b).

Although raising awareness on the benefits of being physically active certainly has merit, there is real concern that the motivation for necessary PA adherence may still provide a challenge (Brawley et al., 2003c), with attrition from structured PA programmes proving key limitations in PA interventions involving older people (Dishman et al., 1990) and adherence to home based or self directed exercise also an issue (Thomas et al., 2002).

When one attempts to objectify or quantify the reasons for PA participation - or lack thereof, it is often easy to lose sight of the person providing these statistics; giving only a limited glimpse into the way a person thinks about their health and lifestyle choices (Grant, 2008a). This chapter, and the subsequent findings from my research, aims to outline some of the lesser studied areas of PA participation in adults by taking a combined view into the common barriers, societal expectations and cultural backgrounds, which occur simultaneously (Grant, 2002) within an individual prior to engaging in PA behaviour change.

5.1 Commonly Cited Barriers to Physical Activity

5.1.1 Personal Factors

5.1.1.1 Lack of Time

The most commonly cited barriers to PA participation across all age groups are related to personal circumstance. Whether described as a lack of time or an individual's health status and perceived lack of wellbeing, these variables impact greatly on a person's choice to be physically active.

The main barrier identified for a lack of PA participation in previous studies is lack of time and the inability to fit exercise into one's daily routine. Buman *et al.* (2010) split this identified 'lack
of time' into two further categories; those who *perceive* their life to be too busy, and those who regard PA as a low priority within their lives. In an earlier study on an ageing population Finch *et al.* (1997) found a lack of time was a commonly cited barrier but the author proposed that this was more likely to be an 'excuse' as an easier way to disguise disinterest in PA or deeper routed psychological barriers such as embarrassment – see section 5.1.3 – 'Psychological factors'. Buman et al (2010) further supported this finding, with 76% of older participants (aged 50-75) expressed time management as the greatest hindrance to PA participation.

5.1.1.2 Health Concerns versus Illness Prevention

When considering the uptake of PA, a person's health status can either be a barrier or a motivation to engagement. The older population especially, hold many concerns around injury and over-exertion, feeling that PA may be too strenuous, especially at their age (Baert et al., 2011). There were also concerns about whether exercise was 'worth the effort' (Finch, 1997) due to the potential for only small health improvements but coupled with increased stress if exercise sessions were to be attended.

Crombie *et al.* (2004a) interviewed 409 elderly people with 27% reporting pain in their joints on a daily basis which made performing everyday tasks more difficult, let alone PA. Despite these figures, Buman et al (2010) found that although 29.4% within their study reported a fear of injury by initiating a PA regime, this was compared to 64.7% of participants who used health concerns as a motivator for PA to prevent further comorbidities such as heart disease and osteoporosis from occurring. It would seem that Buman *et al.* (2010) was not alone in these findings with similar results in studies by Baert *et al.* (2011) and Finch (1997). Finch's respondents reported that exercise helps one to feel a greater sense of well being whilst improving agility, flexibility and diminishing frequent sleep disturbances. As well as this, PA was thought to be essential in improving current health concerns and preventing the likelihood of further problems, resulting in a longer and happier life.

While an older person's fear of injury through engaging in PA may seem understandable, perhaps more concerning are the figures around obese people. Thomas *et al.* (2008) discovered that 83% of overweight individuals in her study state their weight as a barrier in their choice to be physically active. Differences were also found when comparing the barriers for PA reported in normal weight and overweight individuals (Ball et al., 2000, Deforche et al., 2006). Pleasure, an inherently intrinsic emotion, was the overriding reason for taking part in normal weight participants, compared to reasons such as 'looking better' and 'losing weight' – which are both extrinsic and aesthetic motivations, in those classified as overweight (Deforche et al., 2006). Performing an activity for enjoyment as described earlier is intrinsic, and has been proven to be a far more potent predictor of long-term adherence in the psychological model 'Self Determination Theory' (Deci and Ryan, 1985). If we compare this to external rewards such as weight loss given by those who were overweight, the activity becomes far less about fun and more about targets which often prove too difficult to attain, and therefore interest in PA can be quickly lost.

5.1.2 Environmental Factors

The environment in which we live is something which is often beyond our control; however the wide variety of factors which are encompassed within this category provide other deterrents for PA in the general population (Nicklas et al., 2011).

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5.1.2.1 Facilities

Despite a clear awareness in an older population of the possibilities of doing PA outside of a structured exercise setting (for example walking groups), a clear barrier for participation was the low prevalence of older age group specific exercise classes (Finch, 1997). Although these types of classes are now becoming far more prevalent, there is increasingly high demand, resulting in over subscription and often a fear of embarrassment by the majority of participants.

With regard to facilities however, the most commonly cited barrier across all age groups was the proximity of facilities (Stevinson and Fox, 2006, Baert et al., 2011, Penn et al., 2008, Korkiakangas et al., 2011) with 69.7% of interviewees in Cohen-Mansfield's study (2004) stating a 'nearby location' as either an important or very important factor in their choice to initiate PA. In an older population, the likelihood of driving is minimised, and where possible is dictated often by weather conditions and time of day (Finch, 1997). Unfortunately, this barrier is one of the most difficult to manage especially within rural locations, and even though providing subsidies for travel expenses may be effective, it reduces the feasibility of nationwide health promotion ventures (Stevinson and Fox, 2006).

5.1.2.2 Cost

Kruger et al (2007) reported that the most commonly stated barrier for participating in PA was the subscription fee, a result which is supported by Cohen-Mansfield (2004) who found that 59.9% of their participants said having a free or low cost session was 'important' or 'very important'. As mentioned in the previous paragraph, it is clear that people are aware of the alternative, free options, such as walking in parks or cycling to work, and generally individuals are very averse to paying for exercise; *"I hate paying money for a gym. I hate paying money to play a sport"* (Buman et al., 2010). Yet despite this, a controlled and structured gym environment appears to appeal most to those who need increased levels of motivation to participate (see section 5.1.3.1 on Motivation).

This factor was also mentioned frequently within an older population, who often rely on a pension as their only source of income and therefore would require subsidised or even free exercise classes to be able to afford attendance (Finch, 1997). Alongside this concern, the classes are often not the only thing which needs to be paid for, with appropriate clothing and equipment forming another expense as illustrated by the following quotation; "*I get a pension off it…not very much mind – can't buy a new pair of shoes with it, that's for sure*" (Penn et al., 2008).

More recently however, an initiative has been introduced that allows individuals over the age of 60 to apply for a free bus pass, making them eligible for travel throughout England (Penn et al., 2008). Schemes like this could potentially encourage participation in those who would have once used their locality or the cost of transport as a barrier to PA.

5.1.2.3 Weather/Seasons

A factor completely beyond our control is the seasons and the poor weather or seasonal darkness at certain times of the year. Various studies listed this as a reason for not partaking in the most popular free form of exercise, i.e. walking (Thomas et al., 2008, Casey et al., 2010, Korkiakangas et al., 2011, Penn et al., 2008). As might be expected, this barrier to PA again seems to be cited far more frequently within the elderly who regularly express their concerns about their fear of falling due to icy paths (Korkiakangas et al., 2011).

5.1.2.4 Neighbourhood Safety

The first study to find a clear link between neighbourhood safety and PA participation was conducted in 1996 by the Center for Disease Control and Prevention (1999), the findings of which were echoed by Finch (1997). It was clearly stated by many participants that feeling safe in one's neighbourhood was important for PA participation. The needs for increased traffic calming measures, sidewalks and well lit recreation centres were also highlighted in a more recent study by Schutzer *et al.* (2004).

The fear of attack was stated far more frequently among the older generation, potentially due to their increased sense of vulnerability and a greater likelihood of being alone or without transport (Finch, 1997). The neighbourhood was also mentioned in Penn *et al's.* study (2008), whereby the impact of another event, such as a mugging in an underpass many years previously, may trigger heightened fear and a barrier for participation in the years to come.

5.1.3 Psychological Factors

As well as needing adequate levels of motivation to successfully initiate a lifestyle change, an individual also needs to *believe* they have the ability and capacity to partake in a new behaviour. Much of this belief can be attributed to their confidence, which has the power to positively influence will power and determination to succeed.

5.1.3.1 Motivation

Motivation has been defined as "the embodiment of energy and direction of a particular behaviour" (Frederick-Recascino and Morris, 2004). Attempting to understand the choices

people face when considering initiation of PA is essential to better deliver appropriate and successful behaviour change interventions.

Socio-demographic factors such as one's gender and socio-economic status are difficult, if not impossible to readily change, therefore, the focus needs to be upon socio-cognitive variables which may explain the differences between individuals in motivation for PA behaviour change (Armitage and Conner, 2000).

Motivation for PA initiation or lack thereof, is something any individual can feel from time to time. One's motivation levels can change depending on various factors, some of which are beyond our control e.g. the weather, but others *are* wholly adaptable. The difficulties with regard to increasing motivation arise in convincing an individual of how the benefits of behaviour change could have the potential to far outweigh the disadvantages.

5.1.3.1.1 Regaining Normality

Often when given a negative diagnosis such as cancer, behaviours once enjoyed may need to be restricted to accommodate the illness. Cancer patients may express *increased* motivation for PA so that their lives can regain a sense of 'normality' (Blaney et al., 2010). Doing PA provided an opportunity to forget about their illness or stigmatism associated with being a cancer sufferer; *"I loved walking, I mean that was always my . . . one escape from everything . . . I suppose it was 'being normal' you know, like you want to be normal again." (CS5) (Blaney et al., 2010).* This suggestion was further supported by Emslie et al (2007) who felt exercise was a welcome break from the regularity of counselling sessions, which were often perceived as depressing, with all participants dwelling on their illness and not looking to the future with positivity.

Within the older generation generally, a greater level of motivation was often described as they believed others would respond with admiration, impressed by their ability to rebel against ageing stereotypes (Van Stralen et al., 2010). This may suggest that as one ages, although one's body may become less able to participate in vigorous PA, one's mind continues to feel young, despite acknowledging the socially expected norms regarding the 'correct way to behave'; see section 5.1.6.3; 'Acting One's Age'.

5.1.3.1.2 Prioritisation

In a survey consisting of cancer patients, Rogers et al. (2006) found that 52-57% of all respondents listed 'low self discipline', 'exercise is not a priority' and 'procrastination' as reasons for not participating in some form of exercise, making these three variables in the list of 'most cited barriers'.

Unfortunately, to reap the numerous benefits of exercise, an increased level of physical effort is needed. This is something which can form a barrier within the elderly (Finch, 1997) who describe that the effort of merely getting up, or finding their bicycle is enough to put them off PA completely; *"Up here (points to head) I'm 18. When I see that chap with the grey hair and double chin (in the mirror), that isn't me, that's somebody else…But…a bit of exercise you think, 'Oh, I just can't be bothered'."* (Man, 58) (Finch, 1997).

5.1.3.1.3 Negative Perceptions

Other than perceiving PA as too much effort, both the elderly population (Finch, 1997, Crombie et al., 2004a) and sedentary individuals (Buman et al., 2010) often possessed strong negative opinions towards PA. Active people were often thought to be of a certain temperament according to their inactive counterparts, which further discouraged participation due to a perception that they would not fit in; '*I don't like exercise...I find it bizarre that anybody would want to do that' (Man, 53) (Finch, 1997).* Korkiakangas et al. (2011) identified previous bad experiences as a potent deterrent for PA in those suffering from type II diabetes, and it has also been suggested in elderly participants in studies undertaken by Crombie et al.

(2004a) and Buman et al. (2010). A multitude of negative memories can encompass bad PA experiences, such as being the slowest at the school sports day or being selected last for the school football team, to near death experiences as a young adult, such as almost drowning in a lake (Buman et al., 2010). These psychological events can have a huge impact on PA throughout an individual's life.

5.1.3.1.4 Responsibility

If it is possible to convince oneself that there is no need to be physically active motivation is no longer needed, allowing for one to continue sedentary living without a guilty conscience. It would appear that in some individuals examined – especially those classified as obese (Thomas et al., 2008) or diagnosed at increased risk of diabetes (Korkiakangas et al., 2011, Penn et al., 2008), this denial and a refusal to take responsibility was a contributing factor in their choice not to exercise.

Temptation was cited as a major detrimental factor to health in those at increased risk of diabetes (Penn et al., 2008), as poor lifestyle habits, such as snacking, were forbidden by HP in an attempt to reduce risk. The promotion of these health behaviours became especially tested when an individual felt like the diagnosis has been unjustly given and despite their efforts to maintain positive lifestyle choices their health was burdened with problems. Nevertheless, the responsibility needed to alter risk status is essential and should never be underestimated (with new lifestyle choices needing to become habitual in nature) (Korkiakangas et al., 2011).

In Thomas' study (2008) it became apparent that overweight participants believed their success in weight loss and PA was the responsibility of a significant other such as a personal trainer; "*Give me a personal trainer that gets me out of bed every morning and makes me exercise, and yeah, I'd lose weight*", or GP. This avoidance of responsibility seems to be a defence mechanism to account for their individual lack of drive, low levels of motivation to

succeed and minimal 'self-efficacy' (see section 5.1.3.2 below) and therefore should be identified early and self confidence restored for success to be maintained in a PA programme.

5.1.3.2 Confidence and Self-Efficacy

The best known model of human behaviour is known at the *Social Cognitive Theory* (SCT) (Bandura, 1986) (See Figure 5.1). This proposes that SCT offers 'predictors and principles on how to inform, enable, guide and motivate people to adapt habits that promote health and reduce those that impair it'. As explained in an earlier section on rationality (section 3.6), this theory also suggests that while knowledge of the risks of a certain behaviour are well-known, there are many other 'self influences' which are necessary for behaviour change to occur (Munro et al., 2007). The *cognitive* determinants, such as 'outcome expectations' (one's anticipation of the outcome of certain behaviour), 'self-regulation' (one's perceived ability to manage or control their behaviour), and 'self-efficacy' (a central determinant described in more detail later within this section) are essential regulators of successful behaviour change (Redding, 2000). Of the potentially malleable variables within the model, 'self regulation' has been shown to have the strongest effect on PA behaviour (Anderson et al., 2006), with greater levels of self regulation shown in people who had planned for probable relapses in activity and maintained a strong support network, subsequently resulting in higher 'self efficacy' levels.



Figure 5.1: 'Social Cognitive Theory' (Munro et al., 2007)

Self-Efficacy as defined by its' originator Bandura, is 'belief in one's abilities to organise and execute courses of action required to produce given levels of attainment' (Bandura, 2000). Self-efficacy is distinctive in two areas. Firstly it concerns one's *beliefs* about capability of performing a task – not necessarily one's *actual* ability to perform, and secondly it refers to performance on *specific* tasks, and *not* therefore general areas of expertise. Researchers suggest that one's level of self-efficacy is changeable, and formed through a complex interaction between the person, the specific behaviour in question, and the environment or context in which the behaviour is performed.

Alongside the environmental influences on behaviour, there are four distinct mechanisms which act as informants to one's efficacy level; *performance accomplishments* (an individual's history of previous success or failure), *vicarious experience* (modelling the successful behaviour in a similar individual), *physiological arousal* (the interpretation of somatic symptoms, e.g. elevated heart rate during PA) and *verbal persuasion* (encouragement from a significant and credible informant e.g. HPs) (Bandura, 1986).

As mentioned previously in the section on SCT, a large part of the model, and self-efficacy as a whole, is acknowledging the consequences of one's actions. These consequences are known as outcome expectancies and can provide important incentives or disincentives to behaviour, depending on whether positive or negative expectations are foreseen (Courneya, 2004). Resnick (2002) was a pioneer in identifying that these outcome expectancies strongly influence self-efficacy in the older generation, and therefore their likelihood of PA initiation. In a later publication Bandura (1997) further categorised 'outcome expectancies' into three groups; physical, social, and self-evaluative. Perhaps the most important with regard to this thesis is physical outcome expectancies, where increased motivation could be associated with knowledge of disease risk reduction. Conforming to socially expected 'norms' is often related to social outcome expectancies. For example, if a person was to hear negative comments about the elderly using the gym, they may feel less inclined to visit again through fear of embarrassment or negative judgement (see section 5.1.6; 'Ageing and Physical Activity'). 'Self Evaluative' outcome expectancies, much like those mentioned previously could also have a positive or negative effect on behaviour initiation. For example, appearance when exercising can play a large role in participation: if someone bought a new pair of trainers they would feel confident in the gym and therefore more inclined to attend. On the other hand, less experienced gym-goers may feel embarrassed by their lack of appropriate clothing and because of this, choose not to engage in PA.

With a lack of confidence and low 'self efficacy' for exercise common among non-exercisers, it is hardly surprising that many sedentary individuals report discomfiture when thinking of initiating PA. Embarrassment is an extremely powerful and complex emotion which can be felt for various reasons. The effect that embarrassment plays on an individual's decision to participate in PA can be highly detrimental, especially if one has no desire to change how they feel or improve confidence levels, which, for many, is the main motivator to become more active (Baert et al., 2011)

The elderly and those classified as obese seemed to also hold concerns about feeling out of place in a specialist exercise setting (Finch, 1997, Van Stralen et al., 2010, Chang et al., 2008, Thomas et al., 2008). Gyms were stereotypically very intimidating for individuals who did not fit the 'thin' stereotype (Thomas et al., 2008), and shyness was expressed regarding showing their bodies, or indeed being judged disapprovingly by other members (Finch, 1997). This lack of confidence may result in individuals feeling increasingly isolated and disempowered in exercise situations, eventually resulting in further bad experiences becoming powerful barrier to PA maintenance, or initiation in the future (Chang et al., 2008).

5.1.4 Social Factors

One would assume that to maintain adherence to PA behaviour change, support from others is a necessary aspect. Previous studies suggest that gender and also our age strongly determine how important this support is and the most effective sources to obtain it from. The influence of HPs as a source of information and a promoter of PA has a clear impact (both positively and negatively) on one's choice to lead an active lifestyle, as discussed in detail within chapter four. This section will cover another social influence of PA - support systems, both from a spouse or family member, and social support in the form of an exercise partner or group exercise classes.

5.1.4.1 Support Systems

5.1.4.1.1 Spousal and Familial Support

The choice to increase one's activity level is not one often made independently. Many other people, whether friends or family members can effect or be affected by a behaviour change, and therefore, provide a key influence in one's decision making.

A study by Gallagher and Updegraff (2012) found that individuals with a lower body weight who were taking part in an intervention were significantly more likely to perceive their spouse as supportive towards healthy behaviour change. To further investigate the influence of a spouse in PA uptake, Gellert et al. (2011) recruited participants to a randomised controlled PA trial. Three partner status groups were established; participants in the intervention and in a relationship, participants not in the intervention and in a relationship, and those who were single. Results at the four week follow up suggest that spouses of those who participated in the intervention were far more likely to have increased their PA when compared to the other two groups. This highlights the positive influence an individual can have over their spouse if PA behaviour is initiated.

Beverly and Wray (2010) studied the influence of spousal support in type II diabetes patients with an average age of 65 years via focus groups, and found that support from a significant other was of the greatest importance when looking to either increase or sustain exercise participation. It has also been suggested that the spouses of those suffering from an illness such as type II diabetes may be at increased risk of developing the condition due to their shared environment, emphasising the importance of mutual responsibility in admitting behaviour change is necessary (Khan et al., 2003).

On the contrary however, the duty of care a spouse may often feel over their partner may sometimes negatively influence behaviour choices. In a study involving cancer patients one women expressed her husband's disapproval at the level of activity she was partaking in as he thought she was over exerting herself and it would be of no benefit (Emslie et al., 2007). These findings may also be applied to an over 50s population, whereby support from significant others was extremely relevant in the maintenance phase of PA. If this support was predominantly negative, the PA behaviour was unlikely to be continued (Van Stralen et al., 2010).

5.1.4.1.2 Social Support

Having the motivation to do regular PA is a daunting prospect, however, exercising with a 'buddy' (Nicklas et al., 2011) or within a small group of like-minded people (Emslie et al., 2007) may trigger the necessary psychological drivers which encourage initiation, and also maintenance of PA.

The importance of social interaction through exercise is mentioned in all age groups, however it became apparent that this contact was far more significant in females than males, something thought to be associated with increased exercise self-efficacy through empathetic contact (Schutzer and Graves, 2004) (See section 5.1.5.3.1; 'Gender and Physical Activity'). In a study by Ferrand et al. (2008) both females and males outlined the positive contribution social support had on their levels of motivation, and on the way individuals manage their diabetes. Women however mentioned the need for same sex exercise companions to receive emotional support, or warmth and encouragement, whereas their male counterparts used these social interactions to seek feedback and advice from more experienced individuals whom they may admire and look up to.

As well as agreeing on the benefits of exercising as part of a group, the general consensus was that group size was also important (Stevinson and Fox, 2006). Individuals who suffered from cancer, identified the need for small groups due to their less intimidating nature and ability to be comfortable around each person; *"When we started off we had 10. It doesn't sound many, but it's small enough to be personal. You feel you can actually talk to the people, as I say, establish a rapport with them" (Stevinson and Fox, 2006).* Being around others with a similar condition was also mentioned in another study (Blaney et al., 2010) but it was extremely important that it did not feel like a 'counselling session' as many valued the positive nature of exercise sessions as an escape from their *identity* as a cancer sufferer (Stevinson and Fox, 2006).

The elderly were another group where social interaction formed one of the greatest incentives for uptake of PA (Baert et al., 2011). Over half (53.4%) of the participants investigated by Baert et al. (2011) thought that having people their own age to exercise with was either 'important' or 'very important' for exercise maintenance, and over a quarter (28.1%) thought the potential to socialise *after* exercise was an 'important' or 'very important factor' (Cohen-Mansfield et al., 2004). Findings from a study by Finch (1997) suggest that exercise was a way to 'help counter loneliness and isolation' and having a social and supportive atmosphere was often stated as the best way to make exercise classes enjoyable. The positive effect of camaraderie should not be underestimated. Many individuals said that exercising as part of a group was a huge motivator to maintaining their behaviour, and believed it would have been impossible without this support, highlighting the belief they were working as a team and did not want to disappoint or let others down (Emslie et al., 2007).

5.1.5 Cultural Factors

In the previous literature on barriers to lifestyle change, far more attention is placed on the vertical divisions in societal groups, such as class and gender, and, with the exception of gerontology, considerably less emphasis is placed on divisions such as age group and generational change, which may have a profound impact on how an individual views PA (Gilleard and Higgs, 2008).

This section looks at the potential significance of being born into post-war Britain on an individual's lifestyle behaviour, as well as examining the negative stereotypes associated with PA participation in older adults. The changes which have arisen in the past six decades include increased affluence and an expansion of communication and consumption. As well as this, a shift in occupational and leisure time PA, have all impacted the health and PA levels of those who were in their youth in the late 1950's - who were undoubtedly most affected by this era of liberation, and are now in the 'third age' or later life (Gilleard and Higgs, 2008).

5.1.5.1 The Baby Boomer Generation

Although the period described as the Baby boom era stretched from 1946 up to 1965 (Buckley, 2008), for the purpose of this thesis focus will be on the older ('first wave') baby boomer (BB) cohort born towards the end of the second world war, and near approaching, or already residing in retirement.

Throughout their lives BBs have been on the leading edge of many of the profound social changes which have occurred during the last half century. These changes have often resulted in the need to adapt to and meet the needs of a differing environment, and one in which it is becoming increasingly easier to lead a sedentary existence. However, often their solutions

have not been optimal, reflected in the high levels of obesity and greater prevalence of chronic disease in this population when compared to other generational cohorts (Buckley, 2008).

Due to the improvements in living conditions, alongside advanced medical care, life expectancy has dramatically increased over the past century (King et al., 2013). This modernisation process, may lead one to speculate that BBs should be the healthiest generation yet, however the subsequent impact of affluence and changing lifestyles have resulted in this generation residing at the forefront of the obesity and chronic disease epidemic (Buckley, 2008).

These first wave BBs are known as a 'transitional generation' (Buckley, 2008) who straddled two worlds. The world of their parents' generation, and of early modernity – symbolised by strict routines, security and predictability, and the era of late modernity (generally referred to as the mid-20th century onwards) as they approached their adult lives; which encompassed flexibility, huge technological and medical advances, as well as affluence and the rise of consumer culture (Offer, 2007). This increase in individualisation and personal responsibility for one's health (Giddens, 1990) resulted in more volatile life paths, greater choice about what to eat, and how much activity to engage in -a luxury which was unheard of in their parent's era (Buckley, 2008), and therefore embraced in this new generation of young people. As described by Edmunds and Turner (2002), "The post-war baby-boomers were the first generation to live through a time when a mass consumer revolution transformed popular taste and lifestyles", and although access to better nutrition has improved over time, conversely the consumption of high-fat, convenience foods has also increased (Leveille et al., 2005). When comparing the health status of BBs compared to their parent's generation in the Health Survey for England 1994-2007 (Rice et al., 2010), the BB generation were heavier than the preceding cohort (3.02kg; 95% CI: 2.42-3.63), and reported more diagnoses of hypertension (OR = 1.48,

95% CI: 1.27-1.72) and diabetes (OR = 1.71; 95% CI: 1.37-2.12). So what changed, and why are the BB generation most affected?

5.1.5.2 Changing Times

The proportion of the population in England classified as obese has risen by 400% in the previous 25 years (House of Commons Health Committee, 2004). Interestingly however, research suggests that the British population at large are consuming around 750 kilocalories less through their diet than those in the 1970's, even after adjusting for the increase in alcohol consumption and the increased availability of confectionary and soft drinks (James, 1995). This data would suggest that it is not only dietary *content* which we must look at to try and answer the problems we face with increasing obesity related illness, but also the ways in which we expend energy through daily activity. Unfortunately, there are very few baseline data studies which give us an indication of the PA levels of the UK population in post-war Britain, due to the only recent interest in the health risk of inactivity. Nevertheless, James (1995) estimated that 50 years ago we were expending up to 800 more kcal of energy per day than we do today; the reasons for which this chapter will go onto explain.

The idea of increased affluence and choice in post-war Britain, coupled with the replacement of predictable routines is thought to have had a detrimental effect on the development of 'prudential strategies' – schemes once naturally put into place to ensure safeguarding the future (Buckley, 2008). Alongside this, the arrival of choice in almost every aspect of our modern lives; from the food we eat to the ways in which we travel from place to place, as well as the lack of an authoritative figure in which to guide our positive choices has left this generation in particular, in a state of 'frozen autonomy' (Giddens, 1990). A position where

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addictive, and often unhealthy behaviour choices, such as eating too much fast food, have become the norm.

While well known in the younger generation of today, thoughts on what behaviours constitute a healthy lifestyle have been mixed and often confusing during the past 60 years, especially regarding leading an active lifestyle well into ones retirement years (Grant and Kluge, 2007). The arrival of the 'health and fitness movement' during the 1970's (Stern, 2008), where purpose built exercise facilities were made available to the public, may also have come a little too late for the first wave BBs who, by their 20's, were often settled into a demanding job, with an ever expanding young family to provide for (Grant and Kluge, 2007).

Historical and cross-cultural observations suggest that the human body has evolved under conditions of high PA (Cordain et al., 1998). However, this rise in affluence is associated with declines in energy expenditure through activity, and a preference for sedentary lifestyles, where advances in motorised transport, mechanised equipment and leisure appliances are now regarded as the norm, and in many cases taken for granted (Prentice and Jebb, 1995). It is hard to deny then, that the twentieth century can be largely characterised as a 'century of change' in many aspects of society, including but not limited to areas such as the workplace, the home, and also outside the home with regard to transportation systems (Brownson and Boehmer, 2004). Therefore, those entering later life today have had to endure the changes and adapt accordingly, whilst considering the societal and cultural expectations placed upon them resulting, more often than not, in a shift towards more sedentary lifestyles.

5.1.5.2.1 Change within the Workplace

The transition from full time work, to retirement is often considered as a key factor in PA behaviour in later life (Barnett et al., 2012). A study by Barnett et al. (2012) suggested that the concept of leading an active lifestyle changes throughout the life course, from childhood PA

being regulated by organised activity at school and recreational play with friends, to adult PA being dominated by occupation and activities such as housework. Changes over the past 60 years have marked a large shift from manual labour jobs to administrative and service occupations, requiring little or no PA at all (Buckley, 2008). Within North America, agricultural employment, often associated with high activity levels, decreased from 12.2% of the total population in the 1950s to 2% in the year 2000, whereas those within low activity occupations increased between 1950 and 1970 from 23.3% to 41%, respectively (Brownson et al., 2005). This is further supported by Church et al. (2011) who found a decrease in the number of 'moderate activity level' occupations between 1960 and 2008 (48% to 20% respectively). These changes across westernised countries may be partially explained by the huge technological advances made within agricultural and industrial machinery, helping not only to reduce the burden of labour and decrease energy expenditure in many occupations, but also replace many manual workers in the process (Roberts, 2012). In modern day society, many more women (who would traditionally have spent their day's home-keeping) now also have full time occupations. Therefore the demand for convenience with regard to ease of food preparation and time-saving devices for cleaning the home has never been greater (Ulijaszek, 2007), also providing a potentially contributory factor in the rise of obesity.

5.1.5.2.2 Change to Home Life and Leisure Time

By understanding how individuals spend their money and fill their free time, clues may be provided for the cause of obesity across all generations (Sturm, 2004). A study on Swiss nationals (Lalive d'Epinay et al., 2001) identified large shifts in spending between 1950 and 2001. While two thirds of spending in 1950 was predominantly afforded to basic needs, such as food, housing and clothing, today this only accounts for around one third of spending. However, it is leisure time spending (including the use of transportation and travel) where the statistics are most revealing, with only 8% of spending in post—war Britain afforded to these determinants, as opposed to one quarter of all spending in modern times. This may suggest an enhanced reliance on motorised transport to get from place to place, alongside increased expenditure on sedentary leisure time pursuits such as attending the cinema.

Alongside this there has been a rise in weekly free time of 4.9 hours for women, and 4.7 hours for men (to 39 and 40 hours respectively) since 1965, which would perhaps lead one to speculate elevated levels of PA whether purposeful (household chores) or recreational (Sturm, 2004). This, however is not the case, with time spent on household chores decreasing from 13 to 6 hours per week (Sweeney, 2002), and time spent watching television increasing from 13 to 30 hours per week in the last 50 years (Telescope, 2013). When we consider that during the 1950s only 10% of households owned a television, compared to 2.3 televisions *per household* in 2012 (Telescope, 2013), these figures are perhaps not surprising. Furthermore, a study objectively monitoring the behaviour of 6329 adults suggested that participants spent, on average, 54.9% (or 7.7 hours) of their day in a sedentary activity, which further increased to 8.4 and 9.3 hours per day in 60-69, and 70-85 year olds respectively (Matthews et al., 2008).

5.1.5.2.3 Changes in Transportation

Muller (1995) describe the period between 1945 and the present day as 'the freeway era' due to a huge explosion in the number of cars on the roads, and the increased need for motorised transport to go about one's daily tasks to combat the decentralisation of urban activities, such as large shopping centres in hard to access locations. For daily travel to the work place, the proportion of trips by car increased from 67% in 1960, to 88% in the year 2000, while trips incorporating walking or cycling declined in an inverse relationship with increasing numbers of cars per household (Brownson et al., 2005).

A review conducted by the UK Transport Research Centre (UKTRC) (Mackett and Brown, 2011) showed that the number of trips taken by car each year rose from 429 in 1975 to 618 in 2010

(an increase of 44%). Conversely, in 1975, 325 walking trips (equating to 408 kilometres) were taken by the average person per year, compared to 210 trips (or 286 kilometres) in 2010. A link between time spent in a car, or distance walked, and obesity levels was discovered by Frank et al. (2004). With each additional hour in a car per day, a 6% increase in the likelihood of obesity was described, as opposed to a 4.8% reduction in obesity with each additional kilometre walked per day. Car use, although convenient, has become an 'embedded habit', creating large levels of inertia and reliance (Gärling et al., 2000), and more negative perceptions on walking behaviour in individuals who drove more in their daily lives (Loukopoulos and Gärling, 2005).

5.1.5.2.4 Physical Activity for Health

As well as the notable changes already mentioned in this chapter, the benefits of leading an active lifestyle for health is also a relatively recent discovery (Morris and Heady, 1953), and therefore only became common knowledge to the general public in the later part of the 20th century. Strong scientific debate regarding the effects of leading a physically active lifestyle during the late 19th century split medical professionals into two distinct camps; one in which PA could induce 'faintness, vomiting, and considerable exhaustion' and therefore should not be considered (Bendelack Hewetson, 1873) and the other, rather opposite viewpoint, that exercise 'could act as a means for increasing efficiency and power of the will, which in turn, would enable disease to be prevented' (Tibbits, 1878). It wasn't until 20 years later, in 1898, that this second opinion, positively advising exercise uptake, was reinforced by a study conclusively showing that PA 'was not harmful' (Sansom, 1898). Despite this, it was another 55 years until a paper examining the link between leading a physically active lifestyle, and subsequent disease risk came to light. Morris (1953) examined mortality from 'coronary thrombosis' in bus conductors and bus drivers alike, establishing that the men with the least active profession, were more likely to die from this type of cardiovascular event.

The steady increase in knowledge around the importance of PA may have somewhat influenced the arrival of 'the fitness movement' in the 1970's, during which the number of public gyms and fitness facilities increased dramatically (Stern, 2008). However, as previously mentioned, in the lifespan of those born in post-war Britain, these purposely built centres may have come a little too late (Grant and Kluge, 2007). Data indicated that in post-war Britain, a woman's role as 'in the home' was set between the ages of 19 and 23. By this point many had already married and begun a family, and care-giving roles often took priority over any personal interests, including recreational PA (Kluge, 2002). For many, both male and female, the idea of a gymnasium where people pay money to expend energy in their later years would seem ludicrous, given the view that being 'busy' in their everyday activities is thought by many to meet, and sometimes exceed, government recommendations for PA (Grant, 2008a). This is illustrated in the study by Crombie et al. (2004a) which found that 79% of adults over the age of 65 believed themselves to be doing enough activity to keep healthy, where in fact 36% did no PA at all, and a further 17% did less than two hours per week.

5.1.5.3 Gender in Physical Activity and Health Behaviour

Gender, rather than being a static demographic, is *lived*, and dependent on socially constructed beliefs, norms and attitudes (West and Zimmerman, 1987), forming a dynamic social structure (Courtenay, 2000). Past research suggests that men experience far greater social pressures to appear to conform to the masculine stereotype of strong, self reliant and tough (Courtenay, 2000). Although this may indicate a greater level of PA while the body is youthful and more capable, physical declines associated with ageing may lower self-efficacy, and motivation to adhere to this strict stereotype. Alongside this, men often also pertain to an ideology that they are invincible (O'brien et al., 2005) and therefore, often have less

motivation for health protective behaviours and reduced levels of help-seeking if and when symptoms of illness occur (Galdas et al., 2005).

5.1.5.3.1 Gender and Physical Activity

As well at the arrival of fitness centres forming a novel concept in the 1970s, the stereotypes of exercise facilities being dominated by young, fit and generally male members may have also formed a barrier to participation, especially among women of an older age group (Cozijnsen et al., 2013). This may explain why men are generally more active than their female counterparts (Sun et al., 2013) and also why women express more barriers towards PA initiation (Chipperfield et al., 2008). In the past it has been argued that, aside from gymnastics, sport was a male domain, with women having to gain their levels of activity through household chores and child rearing responsibilities (Lalive d'Epinay et al., 2001). Although this opinion has wholly changed now, older generations of both men and women do belong to a particular social group and may look to their retirement as a time for 'well earned rest' (O'Brien Cousins, 1995). As well as societal changes to the attitudes around PA, the shift in gender roles has been profound over the past 50 years (Buckley, 2008). Growing numbers of women have professional careers (Kite, 2001), which also adds to the complexity of the decision making process around behaviour change due to a more time pressured existence, and additional priorities.

In a study by Chipperfield et al. (2008) gender specific analysis allowed for certain characteristics such as income, living arrangements and health status to be examined separately. Interestingly, whilst poor perceived health status predicted significantly lower PA levels in men than in women, living alone negatively affected a woman's PA engagement and had no significant effect on the male participants within the study. Proposed explanations for the differences attributable to poor health status were that women, due to their experiences

with menstruation and pregnancy, as well as subsequent child birth and child rearing, may learn to persist with activity and exercise, even in the face of discomfort or illness (Chipperfield et al., 2008). In terms of living arrangements, women may also be positively motivated to do PA in the presence of another individual, whether that be a spouse, or housemate, consistent with the findings by Ferrand et al. (2008) mentioned in the previous section 5.1.4 -'Social Factors'. This suggests females look more to exercise companions for emotional support and encouragement, whereas their male counterparts do not.

Previous studies also suggest that previous experiences of PA have a greater impact on female PA levels in later life, compared to a man's (Kluge, 2002). It would seem that the personal background and, especially negative memories in women, are more deeply rooted, and therefore impact more greatly on choice to lead an active lifestyle throughout their lives and into their older years (Lee, 2005).

5.1.5.3.2 Gender and Health Behaviour

Within the UK men are not only more likely to experience cancer and heart disease, but are also more likely to die younger within all age groups than women of the same age (Galdas et al., 2005). Evidence from the past 10 years has supported the theory that men are less likely to use the health service, and also to seek guidance from HPs for any ailments they may have (Scott, 2010). A survey by the NHS (Airey et al., 1999) suggested that 69% of males questioned had visited their GP in the past 12 months compared to 90% of women, a factor that may be attributed to pregnancy or greater screening checks in females. However, the same survey showed that only 58% of men in self reported excellent health attended their local surgery compared to 74% of healthy women – a finding which may also indicate man's lower propensity for preventive medicine. Alternatively, another study has concluded that women may *over-report* symptoms resulting in more visits to HPs such as GPs, psychiatrists and

physiotherapists, whereas men are more likely to utilise the accident and emergency service (Corney, 1990). O'brien et al. (2005) conducted a qualitative investigation into these statistics and discovered that this reluctance in men to not only admit weakness, but also to seek help, was due to an attempt to conform to a model representation of masculinity as previously proposed.

A recent study conducted by Ritvo et al. (2013) examined this gender relationship in specific relation to CRC screening. Whilst acceptance of the FOBT procedure was high and similar across genders, females held far more reservations about the screening procedure due to stress and fear of a painful procedure, whereas men ambiguously procrastinated about the importance and need to undergo screening without any notable symptoms whilst opting for a more fatalistic attitude towards cancer risk.

In the process of 'living' gender, men and women undoubtedly have different experiences and attitudes, not only towards health behaviours and risk taking actions, but also views on illness and help seeking (Courtenay, 2000). This gender gap does, however, seem to narrow as one ages, or encounters greater illness or disease, as suggested by O'brien et al. (2005), whose findings suggest that where men had survived a life threatening situation, acceptance of the priority of their health over the preservation of masculine ideals seemed to take heed.

5.1.6 Ageing and Physical Activity

As previously discussed, adopting a sedentary lifestyle, especially in one's later years, is extremely common and the reasons for this may be a complex interplay of personal, psychological, and/or socio-cultural factors (Grant, 2008b). This chapter will now go on to explore why many older people have enthusiasm for participating in activities or voluntary programmes within their community, but struggle when asked to adhere to a long term PA programme (Dishman et al., 2004). Often in studies examining PA and ageing, much emphasis is placed upon the participants leading 'busy' lives, juggling multiple responsibilities including, but not limited to, grand-parenting duties, caring for older parents and maintaining a sense of self with regard to hobbies and socialising (Grant, 2002). The physical and cognitive declines associated with ageing are well known to older people, as they, have witnessed their parents grow older (Paulson, 2005). However, the greatest concern came not from the awareness of decline and their body not always functioning how it should, but instead, the stigma associated with an ageing person in the 21st century (Grant, 2008a).

In a study by Jancey et al. (2009) participants were said to have felt 'written off' by society, especially when negative comments seemed to be directed towards them when participating in PA. This is hardly surprising when we examine some of the social tags still commonly used when referring to an older person such as 'over the hill' or 'a financial burden' (Grant and Kluge, 2007). The result of these stereotypes of ageist marginalisation creates a class whereby the older population feel they must conform to these stereotypes of fragility and dependence and therefore, lead a much slower, and less active retirement (Grant and Kluge, 2007).

Later life in the 21st century is wholly different in character from that experienced by previous generations (Higgs et al., 2009). Where once diseases such as cancer would consistently result in a poor prognosis, they can now be not only treated, but 'cured', with life expectancy continuing to improve (Kirkwood, 2005). It can however, be increasingly difficult, as mentioned in the section on conflicting health messages, to apply the recommendations for PA in older individuals, especially when organised PA is not something they have had to consider before (Grant and Kluge, 2007).

With health now increasingly being considered to be a person's responsibility, there is now more attention given to how a person perceives their own health and well-being (Shilling, 2012). The need to not only envisage ageing as a time for change, but also a chance to negate the ageist stereotypes and become physically active is now more important than ever (Grant and O'Brien Cousins, 2001).

5.1.6.1 Embodiment and Stereotyping Ageing

In attempting to understand ageing and its impact upon PA participation we must first appreciate that 'oldness can never be understood merely by looking at its features from the outside; oldness is a quality that can only ever be encountered existentially' (Wright-St Clair et al., 2014) and therefore one must try to understand the *embodied* nature of what it means to be old.

The premise of health and well-being is another element which is thought to be *embodied* (internalised based upon societal expectations) (Halliwell and Dittmar, 2003), exemplified by a heightened sense of self-responsibility as one wishes to *age successfully* (Rowe and Kahn, 1997). The notion of health as a given commodity lessens as one enters their older years and the impression that good health needs to be actively worked at and achieved, is becoming increasingly well understood (Katz, 2000). However, the aforementioned embodied nature of wellbeing may also pose a distinct barrier to achieving goals of successful ageing (Katz, 2000), as current lifestyles (such as a sedentary existence) are often habitual, and therefore interwoven into a persons, already complex, life.

Similarly perceptions of these risk reducing behaviours, as well as health and health promotion have changed throughout the past 60 years. What was once regarded as a risk free, or even healthy behaviour such as smoking, is now commonly regarded as quite the opposite, and something which may result in detrimental consequences for one's health. In a society where messages about the ideal way to behave are ever changing, a heightened anxiety and great confusion regarding what is best suited to an ageing body is frequently expressed (Lupton and Tulloch, 2002).

It is common to hear an older person speak of their (ageing) body and (perceptively youthful) mind as separate entities. The use of these 'cartesian dualisms', whereby the body and self become separated in a person's story of ageing, act as a way of managing meaning around their changing health status (Leder, 1990). Until disrupted, the 'lived body' is a taken for granted aspect of everyday life. Growing older, and noticing decline both in functionality and appearance (in the separate discourses of ageing within men and women respectively), emphasise not only the multi-factorial experiences of ageing, but also how gender plays an important role in attitudes towards the ageing process (Calasanti and Slevin, 2001). In an early study by Charmaz (1995) the physical losses associated with chronic illness were examined, and it was argued that the individual often experiences a change in self perception triggered by the negotiated struggles of recovery and newly acquired, and unwanted disability. Although we cannot assume all individuals of an older age group have a chronic illness, this process of self re-evaluation may be likened to a person seeing something very different in the mirror to what they may expect (Clarke and Griffin, 2008).

Not only functionally, but aesthetically the impact of ageing cannot be overlooked. Body image is constructed based upon an interpretation of the social and cultural norms and expectations of a population (Clarke and Griffin, 2008). Chrisler and Ghiz (1993) suggested that body image forms an integral part of our identity and therefore, when declines occur, may form a distinct motivator for PA in an attempt to reverse the ageing process. Attempting to 'mask' this decline associated with ageing (functionally or aesthetically) by for example, maintaining busy lifestyles and learning new skills, further highlights the disparities between an inner youthful

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self, and an outer ageing body, and how each individual puts in place procedures to convince both themselves, and others, of their continuing purpose in society (Katz, 2000).

For all people 'selfhood' or identity is often determined by interactions with others, as well as perceptions about how others view them (Fealy et al., 2012). It is hardly surprising therefore that often when discussing ageing, people do not naturally draw upon conclusions about themselves personally as aged. Instead they compare themselves to others, whether real – often discussed as older family members, friends or their younger self, or imagined, by purporting themselves to be 'better than the average 60 year old' (Jones and Higgs, 2010).

The stereotypes of others also become embodied in an individual, whether they occur 'over time', from childhood and throughout the lifespan or within consumer culture and the media (by bringing views from society to the individual, also known as a 'top-down' approach) (Levy, 2009). Regardless of their manifestation, these stereotypes held in early life have the potential to predict poor health in the coming years (Levy et al., 2009). Later life is so often viewed with focus upon frailty and decreased independence (Grant, 2008b), where those who are of a older age are thought of as undervalued and unproductive within larger society (Grant, 2008a). It is thought that these stereotypes (whether negative or positive) can exert their influence across three differing pathways in each person; psychologically, physiologically and behaviourally (Levy, 2009). Within the psychological domain it has been concluded that stereotypes may act as 'self-fulfilling prophecies', guiding individuals down the path they believe to be most suited to the stereotypes they hold for an ageing person (Levy and Leifheit-Limson, 2009). For example, if one thinks back to childhood books of older characters, often appearing haggard, whilst knitting in their armchairs, research suggests holding these stereotypes will in turn encourage these characteristics to present themselves in later life.

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The physiological pathway indicates the impact of stereotypes on the autonomic nervous system, with individuals exposed to negative age stereotypes demonstrating a much higher cardiovascular response to stress compared to matched controls with positive stereotype exposure (Levy et al., 2000). Finally, and most relevant to this thesis, the behavioural pathway looks at healthy practices, whether that be in taking prescribed medication, or engaging in healthy lifestyles, individuals with a more positive self-perception and the ageing process at large, are more likely to engage in these practices in the next *18 years* (Levy and Myers, 2004).

Stereotyping aside, it has been known for many years that interest in PA disappears and adherence diminishes when enjoyment is lost (Randall and McKim, 2008). The reason for this, as suggested by Whitehead (2010), is that PA in itself is an embodied activity, and therefore a person's motivation for engaging must be derived from a personal desire, rather than just its focus on improving health or wellbeing (Grant, 2012). It is for this reason that negative stereotypes associated with the gym culture and the 'fitness movement' (Stern, 2008) have the potential to be wholly damaging in older adult's PA behaviours (Brawley et al., 2003c).

5.1.6.2 Stereotypes of Gym Culture

For those born in post-war Britain, exercising 'for the sake of it' was a behaviour considered unnatural (Grant, 2008a), with old age implying a period of rest, and advice to 'take it easy' from medical professionals common in the lives of their parents' generation (Grant, 2002)

Although many know the benefits of leading an active lifestyle (Stenner et al., 2011), as mentioned in the earlier section 2.4.1, there are many misconceptions about the intensity of PA, with some believing that it must be strenuous to give any benefit to health (Lee, 1993) with very few knowing the appropriate frequency of PA to elicit positive change (Brawley et al., 2003c). The thought of changing one's behaviour therefore can be daunting prospect for most, especially when considering entering a public fitness environment which holds its own negative stereotypes for an older population (Brawley et al., 2003c).

The exercise gymnasiums of the past were only frequented by highly masculine and working class individuals and although this stereotype has changed dramatically over the past 40 years (Stern, 2008), these perceptions still discourage endless amounts of older people from engaging in these highly sociable and supportive environments (Tulle and Dorrer, 2011). For many sedentary adults over the age of 60, joining an already established exercise group evoked apprehension for fear they would be outcast for slowing the group down (Costello et al., 2011). Even outside of the gym setting, one participant spoke of her fears about joining the local walking group, stating that she; *'won't go as fast as they go'* (Costello et al., 2011). The feeling of intimidation was rife among many of the participants interviewed, with many claiming that a new programme should be initiated so that beginners do not feel so self-conscious, or slow the other people (who were already members of the programme) down – see section 5.1.3.2, entitled 'Confidence and Self Efficacy' for more detail.

Maguire (2007) highlights that there are many views of fitness as a paradigm, all of which surround the ideals of PA as a medium for self empowerment and self actualisation, an ideology perceived by many only to be achieved by the most skilled: younger men and women with extensive exercise experience. In Evan and Sleap's study (2012) attending the local pool, although accessible and cheap, was not accepted by all, due to the affirmation that their bodies were not the 'ideal', aesthetically speaking, which further supports the notion of Vertinsky (1995) that the ageing body is becoming increasingly stigmatised, regardless of whether the person is in clinically good health. Therefore, with so many negative connotations of a gym environment in existence, it may be possible for future interventions to tap into encouraging exercise for older people in a form which is likely to be more attractive and amenable to them from a social perspective.

5.1.6.3 Acting One's Age

This idea of an older body becoming stigmatised *regardless* of health (Vertinsky, 1995) may mean that engaging in an active lifestyle is not as easy as one might assume, despite the positive health benefits to be gained (Grant and Kluge, 2007). Alongside the numerous other barriers touched upon within this chapter, today's older population are not socialised into, or even socially expected, to engage in regular PA, and therefore the need to 'act one's age' is a common barrier to leading an active lifestyle (Grant, 2012).

Competing constructs of what an ageing body is (dependent-independent, frail-healthy, sedentary-active) demonstrate that modern society's lack awareness about *how* an older person should behave. In turn, this may encourage self-oppression and confusion in older people (Fealy et al., 2012, O'Brien Cousins and Gillis, 2005, Buman et al., 2010).

In a study by Grant (2012) retired men discussed their concerns about joining an already establish PA programme because *'it's not the most common thing for men of my age to do'*. Alongside this, many questioned the point of being active into their 7th and 8th decade of life because it was 'probably too late to be of any real value' (Wright-St Clair et al., 2014), with reinforcement of these concerns by their friends and family who frequently commented; *'you're getting too old to do that sort of thing (PA)*' (Grant, 2012).

A sedentary lifestyle is also thought to *lower* expectations of ageing, whereas a more active lifestyle encourages positive experiences and heightened expectations of ageing (Sarkisian et al., 2005). This may, in part, offer a suggestion as to why sedentary older adults believe that older people should not be active.

In the future, in light of the changes in knowledge, and the increased technology in which to access information on PA and healthy living, it is anticipated that the next generation of older

people will be more active (Grant, 2012). Currently however, fear bought on by personal attitudes and even the advice of HPs, results in many older people believing that their heart 'couldn't take' exercise and irreparable damage may be sustained through engaging in PA which is too intense and unsupervised (O'Brien Cousins, 2003). Similarly, if an older person was to enrol into a gym today, the suggestion of a medical examination or need for a doctor's approval is often raised (Shephard, 2004) which may inadvertently deter motivated members. Undeniably, it is not uncommon in later life to have a few health concerns. For the majority of individuals with minor ailments this should not, but often does, act as a cause for concern (Grant, 2008b). Taking all of this into account, it becomes obvious that purely 'being old' is cited regularly as a barrier for initiation PA behaviour change (Horton et al., 2007, Jancey et al., 2009).

5.1.7 Conclusion

Chapter Five highlights the numerous personal, psychological and social barriers given to PA behaviour change in older populations, and the complex interplay of factors one must consider prior to encouraging PA initiation across different groups; including cancer sufferers, those at elevated risk of illness and apparently healthy older people. The final section of chapter five specifically considers our ageing population and the impact of social and cultural influences over a life time of changing attitudes, opinions and beliefs about PA and health behaviour generally.

Whilst environmental factors (however important), such as the weather, or neighbourhood safety may be more difficult, if not impossible to alter (Nicklas et al., 2011), understanding the more personal, and psychological concerns a person has prior to engaging in a new behaviour may provide a clearer insight into how to more effectively encourage a greater interest in PA,

especially in those of older age and 'at-risk' populations (Armitage and Conner, 2000). Alongside this, the impact of support cannot be underestimated, whether having a positive influence in encouraging PA initiation and maintenance (Nicklas et al., 2011, Emslie et al., 2007) or the opposite effect (Van Stralen et al., 2010), by exacerbating the potential dangers of PA. This chapter highlights the unique influence *other people* have on one's behaviour choices.

In summary, this chapter examined a large body of gerontological literature placing the older person, and especially their life experiences, at the centre of the debate around behaviour change (Grant, 2008a). The qualitative research in this area, and particularly the narrative accounts of older people themselves (Westerhof, 2010, Buman et al., 2010, Wright-St Clair et al., 2014), offer an insight into the *real story* around the complexities of PA behaviour change. Paradoxically, these qualitative papers, although hugely revealing, also have a tendency to leave more questions than answers, and it is on this premise that this research project was developed.

5.2 Summary of Literature and Rationale for Research

This aim of this section is to provide a brief summary of the literature discussed in the past three chapters as well as identify the areas in which the current thesis is positioned by identifying gaps and areas for further research.

5.2.1 Chapter Three

This literature has shown that a person's motive for engaging in behaviour change can be multidimensional and complex. However, one's perception of their disease risk may be a highly influential motivator for change if individuals are to believe the behaviour in question could lower their risk of developing a particular condition – as explained by the 'HBM' (Rosenstock, 1966). Despite age being one of the greatest risk factors for CC (Hewitson et al., 2008a), a study by Robb et al. (2007) suggested only 9% of adults (with an average age of 55) perceived their risk to be higher than other adults from all age groups. Although the majority of the findings within this field arise from quantitative research, and survey data, Robb et al. (2007) did interview a number of the older participants within the study in an attempt to delve deeper into how personal risk estimates are calculated. Findings suggest that those with the lowest risk estimates were more fatalistic in their approach to disease diagnosis and believed heredity to play a large role in the likelihood of a CC diagnosis. However, studies of twins suggest that on average 65% of CC cases are not attributed to hereditary factors (Lichtenstein et al., 2000), and in fact, by reducing one's exposure to poor lifestyle habits; such as smoking, excessive drinking and low PA levels, an estimated 33% of female, and 53% of European CCs could be avoided (de Vries et al., 2010). Questions around fatality beliefs in cancer diagnosis still require greater attention; especially as they may provide insight into the reasons why health promotion messages, targeting the most vulnerable adults fail to encourage behaviour change. A large qualitative review into cancer risk perception including 87 studies (Lipworth et
al., 2010) also established that individuals with the *highest* risk perception tended to have past (often negative experiences) with cancer, whether that be personally, or with a friend or family member. However, what is unclear is whether people with these cancer backgrounds are more likely to engage in healthy lifestyles in an attempt to lower their risks, and equally little research has examined whether participation in a risk reduction trial of this kind is greater among those with a family history.

The largest section of the chapter covered the 'Teachable Moment' (McBride et al., 2008) and 'Health Certificate Effect (Tymstra and Bieleman, 1987) which both postulate that a health event whether that be a significant health scare, or a clear screening check , have the potential to influence behaviours in quite opposing ways; positively in the case of the TM and negatively in situations evoking a HCE. While one might assume attending a cancer screening check could be the trigger a person needs for behaviour change, research shows quite the opposite with studies such as Larsen et al. (2007) concluding a person attends a screening fearing the worst, therefore any outcome which does result in cancer is positive; and in fact may even affirm their current (and sometimes poor) lifestyle choices. Alternatively the TM suggests that health promotion should attempt to target individuals at a time when their future health may be high on their list of priorities for greatest effect (Lawson and Flocke, 2009). Previous studies in this field have examined preference for lifestyle advice among both cancer patients (Fisher, 2007) and individuals at elevated risk of cancer, with both groups responding favourably (Stead, 2012). According to the literature search undertaken, no other study has compared the TM concept in CC survivors as well as screening patients with an elevated risk result. Therefore this area is certainly one which warrants greater exploration, so that we may better understand, not only the impact of a diagnosis, but also who to provide lifestyle advice to, and at what stage. Alongside this, although studies discussing health promotion with HPs are not uncommon (Miles et al., 2010, Hirvensalo et al., 2005), it seems that there are no studies which specifically relay patient preferences and opinions on health promotion during screening, directly to the HPs, who have the potential to change, and subsequently deliver the lifestyle advice.

Key Issues:

- There is a need to better understand risk awareness in individuals who may be at elevated risk of developing cancer in the future
- Current beliefs around the likelihood of a cancer diagnosis must be better understood in the context of fatalism, as a way to explain why current health promotion initiatives may fail to encourage adherence to PA.
- To identify the impact of a cancer diagnosis on behaviour change motivation, the phenomenon of the 'teachable moment' and the 'health certificate effect' need closer exploration.

5.2.2 Chapter Four

Chapter Four outlines the key role HPs could have in influencing the behaviours of their patients, especially in older age groups, who describe their age cohort as 'belonging to a generation who easily accept the authority of a doctor' (Bastiaens et al., 2007). Therefore, any information given within the healthcare setting must be carefully thought out so that conflicting messages and confusing recommendations are not provided; (Stermer et al., 2004) especially within a population who regularly cite a paradoxical relationship between knowing the benefits of PA, but perceiving the risks too high for engagement (Hirvensalo et al., 2005). Studies examining the success of HP advice have provided key examples of its success both in PA (Kerse et al., 2005, Elley et al., 2003, Smith et al., 2000, Josyula and Lyle, 2013) and smoking cessation (Stead et al., 2008), especially when in a more intensive (versus minimal)

personal and tailored environment (Stead et al., 2008). Therefore, taking this into account, it appears to be extremely important to determine whether HPs understand the extent of their influence over patients, and if so, why more advice on lifestyle is not currently being provided. In an attempt to answer this question a number of studies have identified possible barriers for this lack of health promotion including, but not limited to; negative perceptions about recommending PA (especially with regards to an older population) (Calderón et al., 2011), a lack of credibility in their advice (Ribera et al., 2005) and a lack of confidence in providing the specific advice; relating to a lack of knowledge (Dauenhauer et al., 2006) or a fear of offending (Nicklas et al., 2011). When considering who should provide the health advice, it seems quite common for clinicians to believe other professionals such as nurses, physiotherapists and fitness instructors were better suited to the role of promotion than themselves (Daley et al., 2008). This 'passing of the buck' could form a barrier to health promotion, and is an area which warrants greater exploration to identify whether other professionals would *indeed* be better suited to the promotional role, or whether clinicians just feel they have less of an obligation to provide this advice.

Much of the research to date has focused upon health promotion and advice giving within the primary care setting, mainly within GP Practices (Bowes et al., 2012, Calderón et al., 2011, Eakin et al., 2007). Although understandable as primary care practices have the potential to access a large proportion of the population, there is a disadvantage to this in that often individuals present to their GP with a specific health concern; and therefore health promotion may not often fit within the natural flow of conversation (Holmberg et al., 2014). With this in mind, more research into health promotion within a *secondary* setting where patients may believe their future health may be in jeopardy (such as in a screening examination) is warranted. Alongside this, exploring the interaction between HP advice and the TM concept as explored in chapter three is justified. Finally, examining whether the barriers experienced in

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the hospital setting are similar or opposing to those felt within GP practices, is necessary to better inform future health promotion strategies.

Key Issues:

- Although many studies have suggested that health professionals are successful at encouraging lifestyle change in a number of settings, many professionals still do not administer this type of advice.
- Unravelling the complexities of the barriers towards providing increased advice on healthy lifestyles is essential in an attempt to answer why these promotion practices are not yet widespread and why professionals perceive it is another person's role to provide guidance.
- The majority of the literature exploring lifestyle promotion by health professionals is centred on primary care facilities. There is a need for better understanding of the barriers towards health promotion in a secondary care setting, such as cancer screening.

5.2.3 Chapter Five

Statistics show that PA decreases as one ages, with those over 60 years belonging to the least active adult age group (Chaudhury and Shelton, 2010). However, despite this, many studies have failed to reflect the actual views and lay understanding of PA in those who are currently sedentary (Prior et al., 2014). It is therefore of paramount importance that one of the aims of this study is to contribute more fully to the understanding of socio-cultural influences in PA participation in a population of older adults, as well as discovering attitudes towards and recommendations for PA in this study population. Previous studies have also suggested that intrinsic motivation for PA (such as enjoyment) is felt greatest in individuals who are currently active and of a normal body weight (Deforche et al., 2006). What is lesser known is whether types of motivation for PA differs among certain patient groups, for example those who have been told they are at risk of cancer, compared to individuals recovering from cancer.

Finally, previous research has suggested unique differences in both the experience of ageing, and the attitudes towards diagnosis and illness prevention when comparing men and women. Although this study will not seek to specifically sample to compare across genders, interview responses will be analysed with this in mind to (qualitatively) begin to assess whether gender differences may play a role in the influences on PA in an older, elevated risk, population.

Key Issues:

 Many studies have explored the common shared barriers for PA participation in an older generation; however few have looked deeper into the socio-cultural barriers to participation which may become embodied throughout a person's life.

5.3 Research Aims and Objectives

Whilst it is not possible for this thesis to fully address all of the gaps in the research literature, a brief discussion of the major gaps above has contributed to the formulation of the following research aims;

Principle Research Aims

• To contribute more fully to the understanding of socio-cultural influences in PA participation in a population of older adults

- To identify the impact of an 'elevated risk' cancer diagnosis on attitudes towards future health and health promotion behaviours with emphasis on PA
- To compare and contrast the motivations and barriers for PA between elevated cancer risk patients and CC survivors
- To examine the issue of providing health promotion within the cancer screening setting from the perspectives of patients and health professionals

5.3.1 Themes for Exploration

- The understanding of an elevated CC risk status (and polyp removal) in patients attending the NHS Bowel Screening Programme
- The impact of attitudes towards, and experiences of PA throughout the life course and its subsequent effect on behaviour in later life
- The 'teachable moment' and 'health certificate effect' hypotheses in elevated CC risk, and colon cancer survivors
- Identify current barriers towards the provision of health promotion in the CC screening setting and possible ways to overcome these.

Chapter 6

6. Methodology

6.1 Introduction

Whilst research around the benefits of PA in reducing CC risk and recurrence appears to be consistently positive (see chapter one and two), the last three chapters have outlined the importance of this thesis in i) understanding the lesser researched and understood sociocultural barriers towards PA participation in people at elevated risk of CC, and ii) the potential health promotion opportunities within the CC screening setting.

This study aims to increase research understanding of PA participation in a group of older adults at elevated risk of developing CC following an NHS bowel screening colonoscopy, as well as compare these findings to those of similar aged individuals who are currently recovering from CC (and are thus also at elevated risk of CC returning), to determine the impact of such a diagnosis on attitudes towards health and motivation for future health behaviour change. Furthermore, it was envisaged early in data collection that the research may also add to current knowledge regarding patient perceptions on health promotion during screening procedures, and present novel findings from an unstudied population of health professionals in relation to lifestyle advice within the screening setting.

6.2 Epistemology

When formulating the research design, the questions which needed to be answered and the approach I would use to face these challenges; I was first faced with questions regarding my

epistemological stance. How is it that we come to know and does life experience count towards 'knowing'?

I was aware that, above all, I wanted to contribute to the current (although small) amount of knowledge within this field of study, and I was enthusiastic to research a topic, about which very little was known. Guiding myself through a complex literature review had taken its toll and I became frustrated with the lack of research surrounding the subjective experience of living at increased risk of cancer, let alone how an individual's diagnosis may influence their choice to lead a healthy lifestyle. It was then that I realised this was wholly due to many of these large scale exercise interventions taking a positivist epistemological approach, and concentrating solely on quantitative methods. I established, more often than not, partaking in any form of exercise lent itself directly towards interactional activity, where influences are somewhat impossible to quantify or chart, and are likely to differ markedly from person to person dependent on varying psychological, cultural and social contributors.

I fully recognise the importance of positivism in the biological, and in some cases, social sciences – due to the pressure and requirements of scientifically sound and statistically significant results. However, in my opinion, the primary interest for social scientists has been to find and define causal relationships in human behaviour. Despite appreciating that quantitative methodology would offer the quickest and, many would argue, most robust means for categorising these causal links, I propose a different view.

To fully understand an individual's experience and rationalisation in chosing to do certain behaviours, I believe you must take time to listen to their experiences and appreciate their opinions and values. This is something I felt quantitative methods did not allow, and thus by taking that approach I would have been doing each participant an injustice. Questionnaire type research would not have been sufficient to gain the rich descriptive data necessary for my analysis and through my personal experience a design of that nature can even leave you with more unanswered questions due to omitted or ambiguous responses.

It was clear then that qualitative methods were most suited to my research focus, due to my need for rich and detailed personal accounts describing experiences of living at increased risk of CC. However, views regarding my epistemological stance were still very hazy, and questions surrounding how patients would present their views of reality came to light. Personally, I think the idea that reality is 'pre-existing' is opposed to my viewpoint. I take a stance in a changeable reality, a reality in which truth is enacted, and knowledge *constructed* through interpretations of historical accounts and shared experiences (Charmaz, 2006, Strauss et al., 1994)

After extensive amounts of reading around this topic I came to realise that to gain the best insight into an individual's experiences I must conduct my research in a naturalistic way, which seemed most easily reached by adopting a constructivist paradigm (Lincoln and Guba, 2001). Constructivists suggest that reality is something that we can never truly know; instead, we use our personal views and experiences to determine our thoughts and ideas; as Schwandt (2007) explains;

'Knowing is not passive...mind does something with these impressions, at the very least forms abstractions of concepts...Constructivism means that human beings do not find or discover knowledge, so much as construct or make it' The constructivist perspective, like many other qualitative paradigms, has recognised criticisms relating to the authenticity of personal accounts, and therefore the credibility of the research in question. I agree on many levels that the subjective accounts presented within research are just tiny fragments of the bigger picture, and that bigger picture - whilst not forming a generalisation for a whole population, *can* provide a unique and original insight into how one person constructs their reality. I cannot expect, nor expect others to understand the responses presented for my questions to be the 'ultimate truth'. It is natural for interviewees to have biased or distorted memories, especially when asked to recall events some 60 years ago. It is also perfectly right to assume within their narrative, key events may not be spoken about, in many cases these may be forgotten or presented as a version of *constructed* reality to the listener (either purposefully or subconsciously). It is this, however, which I find most fascinating; the ways in which the 'story' of their illness is constructed, and the path it leads me on as a researcher.

The next challenge for me was to decide which of the many available methods would be most appropriate to address my research questions, specifically; what are the socio-cultural influences in PA participation in older individuals at elevated risk of developing CC, and how (if at all) have these factors affected their choice to participate? Parahoo (2014) argues that there are three main branches of qualitative research; ethnography, phenomenology and grounded theory and the advice given by my supervisors was to again think about my aims for this piece of research and then find a method which best fits these ideals.

It may be worth mentioning that, at this point, I became somewhat overwhelmed by my lack of knowledge about any sort of qualitative research, and indeed the level of importance this stage of the preparatory process held. That said, I enrolled myself onto an intensive masters module which covered further qualitative methods, including a brief overview of the various types of method which may have been suitable for my research. I remember clearly thinking after each four hour session, that each methodology would have its advantages and disadvantages, and I soon established that turning to the original texts for each method was the only way I could make a clear and informed decision.

I knew that I wanted the subjective views of people to inform the bulk of my analysis, and I was certain that the use of personal quotations would form the basis of my findings. Wherever possible I wanted to also strive for a combination of both an objective and unbiased approach to data collection, whilst remaining constantly reflexive of how my own experiences may guide interpretations.

Traditionally ethnography is seen as an interactional and observational approach, whereby the researcher spends an extended period of time with the participants so that they may better understand the lives, and most importantly the culture in which the phenomenon under study occurs (Hammersley and Atkinson, 2007). Although attractive to me due to the intimate nature of the researcher-participant relationship, this method was soon discounted as it did not match the sampling boundaries of a randomised controlled trial (explained in more detail during sampling sub-section 6.4.1) or my underlying research question around past experiences of PA.

The phenomenological approach was the approach which seemed to hold the greatest appeal to me, initially as it focuses on understanding human behaviour and lived experience of the participants under study; an element which would certainly be useful in this context. However, in phenomenology, it is essential that researchers enter the field with a specific phenomenon to be discovered – something which does not exist when so little is known about the subjective experience of the population studied in this research.

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Therefore through a combination of advice from my supervisors, and knowledge gained through reading varying texts (both old and new), grounded theory emerged as the most suitable research method for this particular strain of research, as its emphasis lies upon building theory to provide tentative explanations to less understood research areas (Glaser and Strauss, 1967).

The History of Grounded Theory

Grounded theory's underlying traditions are rooted in the work of two sociologists, Anselm Strauss; initially from the University of Chicago, and Barney Glaser from Columbia University. Their first work collectively focused on the experiences of those dying in hospital, which aimed to approach patients from a sociological rather than medical perspective, including more abstract concepts – and therefore more powerful accounts. Their method of generating theory combined the depth and richness of qualitative interpretive traditions, whilst preserving the logic, rigor and systematic analysis apparent in quantitative survey research, (Charmaz, 2000, Glaser and Strauss, 1967, Dey, 1999) which was first presented within their book *The Discovery of Grounded Theory* (Glaser and Strauss, 1967). At that time Grounded theory challenged a dominant emphasis on theorising in a logical and deductive way, and instead encouraged researchers to systematically develop a theory derived *directly* from the data upon *emergence* of key abstract concepts (Dey, 1999).

The popularity of using grounded theory has substantially increased over the past 40 years, with Bryant and Charmaz (2007) stating it is 'now the most widely cited qualitative research method within the social sciences tradition' (p.1). However, despite this popularity, confusion remains surrounding the correct procedures within the approach, and there is also much

debate to be had regarding one's methodological school of thought (Greckhamer and Koro-Ljungberg, 2005, Suddaby, 2006)

After the first book it was quite clear that many were having difficulty applying the grounded theory method to their own research due to its lack of clear instruction. Consequently Glaser wrote a second book entitled *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory (1978)* which he hoped 'would give a sense of what theory is, how it may be constructed when generating it' (pg. 1). Strauss later made an attempt to address these confusions also with two further books; the first titled *Qualitative Analysis for Social Scientists (1987)* and the second a publication alongside Juliet Corbin called *Basics of Qualitative Research (1990)*. These publications were far more detailed outlining rules of practice and giving researchers much greater procedural direction. In response to this Glaser was quite opposed, stating that *Basics of Qualitative Research '*distorts and misconceives grounded theory, while engaging in gross neglect of 90% of its important ideas' concluding that Strauss' adapted method is 'preconceived, forced conceptual description' (Glaser, 1992).

The argument continues to this day, however many underlying principles of Grounded Theory still remain clear and are agreed by proponents of the method (as discussed within section 'Essential elements to a Grounded Theory study'). Grounded Theory is a set of procedures to develop an inductive theory about a phenomenon, in which the theory *emerges* from the data through the use of constant comparison, theoretical sampling and a keen eye for creativity and sensitivity towards the data (Charmaz, 2006) . Considering the diversity in how the method is now described, developed, and practised within research, it has been suggested a 'family of methods' exist, all contained under the grounded theory mantle (Bryant and Charmaz, 2007). The methods within this 'spiral' (Mills et al., 2008) all bear extreme similarities in order to theorise the ways in which humans act in their own social environment.

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Strauss and Corbin never directly address the paradigm which highlights their evolved method in full, however they do position themselves as relativist pragmatists within a chapter outlining the relationship of theory to reality and truth in *Grounded Theory Methodology: An Overview* (1994) (Mills et al., 2008). Alongside this appreciation that 'theories are embedded in history' (p.280) (Strauss et al., 1994) the authors display a mixture of language which positions themselves between post-positivism and constructivism (within an ontological and epistemological continuum) (Guba and Lincoln, 1994). They understand the importance of *recognising bias* and *maintaining objectivity* within the research, but also couple these principles with the belief 'it is not possible to be completely free of bias' therefore enabling the foundations of participant experiences to form richer data reflective of each individual. These beliefs fall inherently in line with my ontological and epistemological stance and incidentally so do those of Kathy Charmaz the leading proponent of Constructivist Grounded Theory (Charmaz, 2000)

6.3. My Position on the Methodological Spiral

Constructivist Grounded Theory (CGT) appeals to me both on a personal and methodological level through its innate focus on participant experiences but also its need for the highest levels of objectivity. There is much emphasis placed upon the interactive nature of qualitative interviewing between the researcher and participants, and I was instantly gripped by how CGT research brings this relationship to the direct forefront of its analysis recognising the importance of myself, the researcher as the author (Mills et al., 2008). The desirability of a constructivist model for grounded theory has been apparent since the mid- 1990's due to the fact 'data do not provide a window on reality. Rather, the 'discovered' reality 'arises from the interactive process and it's temporal, cultural and structural contexts' (p.524) (Charmaz, 2000). Charmaz was heavily influenced by the pragmatist views of Strauss and Corbin when developing her methodology, and although similarities lie in the recognition that truth is a provisional entity and heavily influenced by past experience and interpretation, pragmatism's principle aim is to solve problems (often through explanation) whereas constructivists take the context of the situation into account whether that be in the case of a PA programme, or a research interview.

In order to seek meaning from the data I obtained it was absolutely necessary to go beyond the surface of explanation, especially with a topic where little satisfactory theory has been established. I hoped to not only build on my previous experiences to search for meaning but also, whilst doing so, question each individual's beliefs and values so that my work is evocative of the experiences of the participants in the most faithful way possible (Munhall, 2012).

6.3.1 Methodology or Methods?

A common misunderstanding of Grounded Theory is that it is either exclusively a methodology with defined steps and rules to adhere to in order to achieve one's theoretical goals, or alternatively purely a philosophical way of thinking which inform our methodological preferences (Schwandt, 2007). Neither, in my opinion, illustrate the full extent of a grounded theory study; whereby a combination of both of these elements come together to construct theory. I am instinctively aware that my personal ontological and epistemological stances have unquestionably informed my final theory, however grounded theory was without doubt attractive to me due to its level of direction also. I was inherently aware, through my lack of experience, of my need for boundaries, clear but flexible rules and, regardless of my school of thought, the distinct similarities in method which are essential for any study claiming to follow the Grounded Theory name.

6.3.2 Essential Elements of a Grounded Theory Study

As previously mentioned there are elements which every grounded theory study should consider or follow regardless of one's school of thought including; *theoretical sensitivity, constant comparison, theoretical sampling* and *theoretical saturation*.

Theoretical Sensitivity outlines what a researcher brings to the piece of research, elements such as pre-existing knowledge, professional and personal background and relevant skills, all of which are attended to when conducting the data collection and subsequent analysis. The differing schools of thought all agree that sensitivity to one's data and personal experience are essential elements of grounding a theory within data; to varying extents. The use of a literature review in Grounded Theory is one of contention, with Glaser believing they should be minimised as to avoid 'forcing' pre-conceived ideas, therefore inflicting unnecessary bias upon the data. Charmaz (2006) on the other hand suggests that a literature review can prove essential in helping the researcher 'find meaning' within the data, confirm one's emerging findings and also raise questions therein, providing the literature review is not fully comprehensive and therefore not likely to constrain the novel themes emerging from the participant transcript (Corbin and Strauss, 2008). Charmaz also believes that a researcher must be explicit around their involvement in the research process, and sensitivity is thus tied to the need for constant reflexivity (2006). Reflexivity and the thinking associated with it occur at two different levels – with regards to process or methods, such as how decisions about sampling or analysis were made – these were predominantly recorded in my research diary throughout my PhD, and secondly with regards to self-awareness – detailing my thoughts and feelings about

the data and my emergent findings – often noted in the form of a memo, attached to a certain code or theme (Neill, 2006). This continual scrutiny of my research experience definitely brought me closer to the research process, and I hope, in part, it will allow the reader to interpret the extent to which my background, interests, and initial assumptions (see initial assumptions, section 6.5) influenced the investigation.

Constant Comparison is an integral part of any grounded theory study, with some considering it the absolute cornerstone (Hood, 2007). It involves inductively analysing data, comparing data to other data, and subsequently cross-comparing it to further categories. The categories should then be compared and examined alongside other existing categories and similarly concepts with concepts to finally result in substantive theory (Charmaz, 2006). This process occurs from the very first interview and continues throughout the entire process until theoretical saturation is reached.

Theoretical Sampling suggests that the researcher must seek pertinent data to develop, elaborate on and refine the categories and therefore the emerging theory. As opposed to sampling specific participants, as a researcher does at the start of the data collection process, the aim is to instead sample *concepts* which may be better illustrated through talking to specific persons or populations (Corbin and Strauss, 2008). I saw myself likened to a detective when commencing the research process, starting with the participants (like witnesses) who were accessible and available at the time, ultimately being led by concepts with much uncertainty but openness about what they may uncover. As the research progressed it was up to me to make a decision about which situation's or indeed persons to probe additionally with the ultimate aim of learning more about my emerging concepts.

Theoretical 'Saturation' is deemed as the point in the research process where theoretical sampling is no longer needed as gathering fresh data neither 'sparks new theoretical insight,

nor reveals new properties of core categories' (Charmaz, 2006). Dey (1999) suggests within the constraints of a time-measured PhD it is however 'misleading' to claim complete theoretical saturation, and instead theoretical *sufficiency* is achieved, whilst also maintaining the relevance of the theory within the context in question to avoid over generalisations (Charmaz, 2006).

6.4 The Research

Upon starting my PhD I was aware that my sample would be selected from participants previously recruited to take part in a randomised controlled trial taking place at the University of East Anglia (known as PARC – Physical Activity and Risk of Cancer). This trial was to identify both the physiological (through the collection of blood samples and buccal smears) and psychological impacts of taking part in a 12 month exercise intervention. Research participants were individuals identified as being at elevated risk of developing further colon polyps after their screening colonoscopy at the Norfolk and Norwich University Hospital (see appendix 2 for full study protocol and participant information sheet).

After consenting (see appendix 3) to take part in the trial and all baseline measures had been taken (including objective accelerometry data excluding anyone achieving over the recommended PA levels per week), the individuals were randomly assigned to either the intervention (exercise) group or the usual care (control) group. Those in the intervention group were invited to attend the private exercise gym twice a week in the first three months (whilst encouraged to do at least three additional days of PA unsupervised at home), and once a week during the next three months (with four home-based sessions advised) – this was to try and encourage participants to achieve, and in many cases surpass, the recommended guidelines of thirty minutes of moderate to vigorous intensity PA on five or more days of the week

(O'Donovan et al., 2010). In the following 6 months, individuals assigned to the intervention group would hopefully have gained the necessary tools to do PA without supervision and maintain levels in the first 6 months alongside receiving fortnightly supportive telephone calls. Those in the usual care group would be advised to maintain their current activity levels – which was considered sedentary by the guidelines set, and attend further testing at 3, 6, 9 and 12 months (see figure 6.1).

All participants were aware at trial consent (appendix 3) that they may be approached for an interview during their time on the study.



Figure 6.1: Outline of Participant Involvement within RCT

6.4.1 Sampling and Obtaining the Sample

Upon starting my PhD my inexperience was inherently visible with the aim for my original sample to be 20 adults (ten from the exercise and ten from the control group after randomisation) identified at elevated risk of developing further colon polyps after their initial screening colonoscopy. This would therefore have resulted in 40 in depth qualitative interviews - as I proposed each participant was to be interviewed twice, once during month one, and again after the exercise intervention. However, when I presented this proposal to the members of my transfer panel I was immediately told this may be too ambitious (as the larger trial was recruiting poorly). I was then asked to think in depth about where the missing data in this field was, and most importantly what did *I* want to learn from these participants? and what were my main research objectives?

When I established that I wanted extremely detailed accounts of participant experience with regard to their perceptions of PA and their choice to lead an active lifestyle, it became clear that I needed a much smaller sample (a new target of 15). However, with fewer interviews my awareness was heightened for the need for them to contain a huge wealth of information. The criteria for my sample was rather more simple – I had to recruit from the randomised controlled trial participants, and go for balance in my choice...to represent all the divisions within the arena of study (Warren, 2002). I was also aware that adopting a methodology under the grounded theory mantra meant that it was important to introduce as much variation as possible into the sample through a technique known as 'theoretical sampling' (Glaser and Strauss, 1967). With the knowledge that I would be purposefully selecting from a group of participants taking part in a randomised controlled trial, it was clear that this need for variability in characteristics and demographics (see table 7.1) had to be balanced alongside the need to recruit a sufficiently comparable sample to develop a theory pertaining to a certain population.

All participants within this research trial were patients who had previously attended the NHS BCSP and were diagnosed at elevated (low, intermediate or high) risk of developing further colorectal polyps. It was mandatory that all individuals within this trial took part in a baseline fitness test, and also filled out a detailed health questionnaire outlining information regarding body composition, as well as previous lifestyle behaviours such as smoking and alcohol intake (see appendix 4). This information proved vital for me in initially utilising my purposeful sampling technique as I could select potential interviewees based on the largest variation in data for physical demographics (See chapter seven - 'Grounded Theory in Practice and Introduction to Findings' for tables of patient demographics). Soon after each participant had been randomised I emailed (or personally handed) the specific participant information sheet for the interview to each person (see appendix 5) which included more specific details about the content of the interview and the length of time it was expected to last. After approximately one week I would make contact with each participant and ask if they were happy to take part. If the participant agreed, I arranged a date for the meeting - ideally coinciding the interview with an exercise session day (in the case of the intervention group participants), so they did not have to make an additional trip to the University.

Recruitment to the main study was slow, which therefore had a knock on effect on the subsequent recruitment to my interviews; however I was constantly aware of my preference for a purposeful and varied sample, not a convenience sample based on who was in the study at the time. Despite this, the first 4 interviews were the first four people recruited onto the trial (3 randomised into the intervention group – two males and one female, and 1 usual care group participant, who was female). This first interview 'subsection' allowed me a great insight into my participant group and directed me to the areas I needed to sample from in future segments (i.e. the need for more usual care group participants to level out my sample).

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usual care group in the next round of interviews, I could not help but feel that the intervention group interviews were giving me much better insight into each participant, with individuals speaking more openly and in greater depth – possibly because I had seen them more frequently in the exercise laboratory and they were more confident in my presence. I also could not help but feel torn ethically when asking the usual care group participants about their PA levels after they had been specifically encouraged to maintain, their previously sedentary, lifestyles prior to engaging in the study. Therefore, I made the decision to interview intervention group participants for the most part due to the focus of my primary research question being 'experiences of PA throughout life', and not 'thoughts regarding trial participation'.

As more and more interviews were arranged and the initial phase of analysis completed I began to notice that a number of participants were unaware of their risk status (illustrated by their lack of knowledge about the nature of the polyp-cancer pathway) and also were taking part in the study for mainly altruistic reasons (not, as I had initially anticipated, to reduce their risk of cancer in the future). It was clear to me that to open up these categories and delve deeper into the meaning associated with an elevated risk diagnosis, I must theoretically sample additional populations and aim to seek pertinent data to develop my emergent theory. By recruiting CC survivors from another randomised trial at the University (known as MOVE – <u>Motivation for Exercise</u>), I was able to more specifically ask about their diagnosis, the impact the news had both physically and mentally on each participant, and most importantly (to help understand the current findings from my elevated risk participants and enhance rigour), whether the diagnosis impacted on their choice to take part in the trial and/or lead a healthier lifestyle in general (see 'themes for exploration', section 5.3.1). The non-compatibility between elevated risk and cancer survivor groups was not a problem during analysis as Glaser (1992) suggests comparisons are in fact made based upon similar properties held by both groups,

such as their participation in a PA intervention or the elevated risk of future cancer both groups possessed. Sampling these participants was relatively simple as my colleague was running the trial and could therefore forward the relevant information sheet (see appendix 6) onto each participant to consider taking part.

Following the responses from the CC survivors and the elevated risk participants in particular, it soon became obvious to me that to give a full picture of my participants' story I needed to interview HPs working within the gastroenterology unit at the Norfolk and Norwich University Hospital to examine health promotion in the screening setting from the perspectives of those working in the unit. This I hoped would provide an insight not only into the specific information provided pre and post screening examinations and whether this could, or indeed should be altered, but also the HPs perceptions of the findings I had encountered throughout my patient interviews. The recruitment process for these participants was approached slightly differently due to the busy schedules of the staff members; therefore I was assisted a great deal by one of my supervisory team (Mr James Hernon) who had personal contact with many of the professionals I would have liked to interview. This additional contact proved extremely helpful as the staff were familiar with the person approaching them and happy to take part once the interviews had been informally explained. Following this initial step their contact details (usually in the form of a work email address) were forwarded to me, and I could then email each person with the more formal information sheet (see appendix 7) and possible dates and times to meet. I was aware of the need to try and approach a varied sample of professionals within the unit, from staff nurses (SNs), to specialist screening practitioners (SSPs) and endoscopists to colorectal surgeons. This awareness of the need for a rigorous approach to theoretical sampling undoubtedly enabled me to get an overarching picture of how the unit functioned as an entity, whilst also hearing the views of individuals with differing but equally integral role. It soon became clear to me that the interviews with these professionals would be

quite different from those previously undertaken, often squeezed into a lunchtime (in the case of the nurse focus groups) or a 30 minute slot when the surgeon/endoscopist had a period of free time. This often meant the questions were far more structured and directed (see appendix 8 for HP Interview design), and therefore theoretical sufficiency (as described in section 6.3.2) was seemingly reached rather much more quickly than with the elevated risk sample (after 8 interviews and 2 focus groups).

As the research design is purely qualitative, the need of pursuing a larger sample by which generalisations could be made was not felt necessary. Despite struggling initially with recruitment into the larger randomised trial and the subsequent impact this had on sampling for my interviews, I feel the sample was not only reflective of the participant group as a whole (see demographics tables, 7.1, 7.2 & 7.3 in chapter seven), but also extremely diverse; providing richness and insights from a number of backgrounds. Therefore although the research design does not allow for the results to be generalisable the findings may be *transferable,* and clearly follows the evaluative criteria proposed by Charmaz (2006) providing credibility, originality, usefulness and above all resonance in portraying the fullness of the experience from the eyes of others.

6.4.2 Choice to use Interviews and Interview Design

Interviews are a common methodological choice when undertaking qualitative research due to their versatile and flexible nature (Roberts et al., 2001). When conducting my interviews I was certain that I needed each participant to feel comfortable in their surroundings, yet also aware of the purpose of the conversation. Therefore, I decided the best way to utilise this would be to combine an interview guide approach with an informal conversational style where possible (Patton, 1987). A loose interview guide was used in all of the interviews (see appendix 9) – drawn carefully from the literature review, which enabled me as the interviewer the ability to pick out any themes (especially during the first few interviews) if they were not covered within the natural course of the interview (Strauss, 1987). These interview guides tended to naturally transform throughout the interview process whereby questions were adapted to tease out novel topics mentioned in previous interviews, and occasionally test hypotheses emerging from the ongoing data analysis so that the emergent theory would be as close to the original transcripts and conversations as possible.

Within the elevated risk participant interviews the open question concerning their experiences of PA at the start of each interview was used to guide the participants into telling their own 'story' similar to that of a narrative approach (Gubrium, 2001). This narrative approach had been used by Buman et al. (2010) to discuss life experiences relating to PA and provided a useful tool to disentangle the complexity of choices we make and the reasons for those decisions such as barriers and facilitators to PA; a main component of my interviews. This initial narrative element allowed individuals to take an active role in meaning making, and developing their own take an historical account of the world and their position in it (Berger et al., 2002).

Another reason I liked both the narrative approach in the opening stages of each interview, and the flexibility of an interview guide throughout the remainder, was that it also allowed the participant the chance to withhold information without having to refuse to answer any questions which bode well ethically. It was hoped that this style of qualitative interviewing would provide some structure to the interviews giving guidance for those that did not take naturally to the process, but also allowed those who spoke more openly the opportunity to express their ideas, culminating ideally in the sort of rich descriptive data that was necessary to answer the research question. The cancer survivor interviews tended to take a similar format initially with a slightly more focused opening question regarding how each person believed perceptions of health generally had changed over their lifetime, but culminated in greater structure detailing the impact of their cancer diagnosis personally and how this may or may not have had an effect upon both their perceptions of health and also their choice to take part in a physically active lifestyle.

As previously described the HP data collection differed slightly in that most of the surgeons/endoscopists were on an extremely tight schedule which left little room for open questions. I believe this worked particularly well with the professionals due to their familiarity with having to talk concisely including all of the relevant and necessary elements when discussing a patient's diagnosis. There were two groups of nurses I was particularly keen to talk to as well; the SSPs – solely responsible for looking after all people enrolled onto the NHS BCSP, and the SNs who admitted and discharged patients pre and post screening respectively. Working within teams where communication and cooperation are integral to the successful running of the unit, I believed the dynamics of a focus group where I would be able to see the subtleties of interaction would be the best fit method for this data collection.

I suggested four nurses for each focus group, and conducted them at the hospital over lunchtime with refreshments provided so that the session was mutually convenient for all involved. The interview design (see appendix 10) was slightly less structured than what was necessary in the shorter, HP interview slots, however they still included the necessary questions regarding personal roles, their thoughts on the advice given to elevated risk participants and whether they believed this could or should be changed. The choice to use focus groups for these members of staff I felt worked well and I believe allowed not only a unique insight into the dynamics of working to NHS protocol, but also sparked debate allowing for differences of opinion to emerge between smaller sub-teams working within the screening setting. The interview designs throughout every interview conducted within this research study assisted me a great deal in being able to structure my interview, especially at the beginning if the participant veered slightly off track or indeed when, at times, I lost my way with the questioning. Despite growing in confidence, and adapting the questioning towards the latter stages to confirm or deny emergent themes, the guide was always there as a personal safety blanket, making sure I covered all of the necessary aspects but allowing for novel and unique themes to emerge.

6.4.3 Conducting the Interviews

Identifying my sample and conducting the subsequent interviews took place over 15 months, starting in December 2012 and concluding in March 2014. This period of data collection was essential due to the difficulties faced in gaining ethical approval for the larger randomised controlled trial and the need for additional substantial amendments to interview cancer survivors and HPs as my research progressed. Despite the lengthy recruitment process the nature of Grounded Theory requires continual analysis of data from the initial interview, therefore data collection and data analysis occurred as an iterative process as opposed to analysis forming a distinct stage after the interviews had been completed (Glaser and Strauss, 1967). This was one of the key aspects of my research design, and proved crucial in the final levels of theorising with emerging ideas in the initial stages forming further areas to explore more rigorously in the interviews which followed.

After each participant agreed to be interviewed I strove to arrange a convenient date and time for each person immediately either via email, or over the phone (depending on their communication preference). The interviews with the elevated risk and cancer survivor participants always took place within the University of East Anglia in a private room, close to the exercise and testing laboratory, although a more mutually convenient location were offered such as their homes for those in the usual care group (an option which was declined by all). I tried, where possible, to arrange each interview for a time when the participant was at the University (either for a pre-arranged exercise class, or repeat testing) to avoid the need to make an additional, unnecessary journey. I also arranged to meet each person at the exercise laboratory (a location which all were familiar with) and walk them to the interview room – which was always located on the first floor of the same building. The HP interviews were all conducted within the hospital, and in varying locations – depending on whether the interviewee was needing to remain within the unit (for example if they are in scrubs) or if they had a private office which could be utilised. Although initially daunted by the prospect of this less 'organised' framework, I found it worked relatively well and taught me a great lesson in positivity, recognising that things do not always have to be meticulously planned to achieve positive results.

Much to my surprise I was astounded by the level of agreement for being interviewed by all participants approached, with no one declining participation. I base this upon the nature of the interviews covering a fairly neutral topic, and the fact that many participants (within the trials) feeling that the interview was a required part of the larger study – for which they had previously consented in full for. I did get the impression from many of the elevated risk participants that when discussing the information provided during screening (or lack thereof) regarding the impact of a healthy lifestyle on polyp reoccurrence and cancer risk, interviewees often became passionate of the need for a change to the advice given. This could have formed an 'ulterior motive' for their interview participation and potentially impacted upon the final analysis of results, however instead, this encouraged my inclusion of HPs in my interview population.

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Due to my lack of experience prior to undertaking this research project my thoughts prior to the first few interviews was predominantly of nervous apprehension as illustrated by this quote from my research diary;

"I worry I have not prepared enough, and therefore they will not respond to my questions in depth, what if they hate my interviewing style, and what will I do if they go off track...or worse...not talk at all" (5th February 2013)

Despite the expected variability within interview subjects I feel all of the interviews went remarkably well and I responded with understanding and professionalism during a number of cases where my emotional guard could have been broken (for example when discussing the loss of family members, or the devastating impact of a cancer diagnosis). I was also concerned how participants would react to my relative youth, especially when discussing their childhood and how perceptions of healthy living and especially PA have changed during their lifetime. Although these concerns did not seem to impact upon participant responses, I did notice that many individuals spoke of their memories, especially of childhood with great fondness, something which may have been portrayed differently had I been an older person myself.

A constructivist approach requires the researcher among other things to establish a relationship with all interview participants in order to 'explicate power imbalances and attempts to modify these imbalances' (Mills et al., 2006). Traditionally the researcher participant relationship is represented hierarchically with the participant being subordinate to the researcher (Denzin and Lincoln, 2000), however in some cases, as described below this is not the case.

It has been suggested by Seibold (2000) that one can minimise any potential power differentials during interview by asking a series of consciousness-raising questions, things such as, how is this person like me? And how are they not like me? In all cases throughout this

research process I endeavoured to ask these questions, however I was always mindful to refrain from adopting a judgemental stance to any interviewees. This however was tested with one interviewee – a health professional who was highly regarded within the department. In this circumstance specifically I was inherently aware of my position as a researcher, and my need to be reflective in all situations that arose, potentially viewing each encounter as a learning experience, both for myself and also the interviewee;

"I felt like the interviewee, for the first time since I began interviewing a year ago now, I felt inferior...I think his shorter responses impacted upon those feelings of a power imbalance greatly...I'm sure he did not intend to upset, however its good I am now able to reflect on the situation and learn from it in order to better my interviewing style in the future." (10th February, 2014)

Despite the interviewee's personality, willingness to talk about issues, or professional position I strived to pursue a friendly relationship from initial contact through to the interview termination and above all someone they could trust to not only maintain confidentiality but represent their stories in the most authentic way possible.

6.5 My Initial Assumptions

In keeping with the importance of reflexivity in a constructivist grounded theory (CGT) study I feel it would be a good time to voice my initial assumptions entering this piece of research prior to detailing my data analysis procedures.

Despite striving to remain conscientious throughout the research process in concealing my own personal biases, prior to starting data collection I found it hard to believe that people, when faced with the news that they are at elevated risk of developing cancer, would simply do nothing about it. Instead it was my assumption that this would form a 'light-bulb moment', a health scare which would encourage them to think about their health and how their lifestyle choices may be having an impact.

My second assumption was that participants who were eligible for the study and later consented to taking part would be aware that their current activity levels were regarded as sedentary (according to national guidelines). With this in mind I expected that their narrative accounts at the start of each interview would mention reasons for their sedentary behaviour or indeed factors contributing to having to decrease activity levels.

It soon became clear through detailed data analysis that these primary assumptions were actually incorrect, something I was initially confused but also intrigued by. These assumptions I can only assume arose due to my previous background in Sports Science and therefore increased knowledge of the benefits of PA on cancer risk, as well as my personal desire to engage in more than the recommended guidelines for PA per week. However, this discrepancy between my own initial assumptions and the findings from my participant interviews I believe encouraged me to deconstruct the transcripts even further and more readily ask questions of the data; processes described in greater detail in the section below.

6.6 Data Analysis

Starting data analysis was a daunting prospect to me, after the first interview I was aware of the need to transcribe the interview as quickly as possible and then begin coding (with the N-Vivo software as an organisational tool for my codes). Transcription itself was a lengthy process but one which I regarded as essential as it enabled me to feel a connection with my data and more closeness to the structure of the participant responses before having to put my own interpretation on it, an aspect I hoped would be a reflection of the care taken to ensure the emergent themes would be as close as possible to the data. I was extremely slow at first – taking approximately 7-8 hours to transcribe a one hour long interview, it was tedious, but I kept to my original aim of getting transcriptions completed before the next interview took place – a method which undoubtedly helped me to keep on top of my data collection when, at times, it became overwhelming.

Remaining true to the data was essential from the very beginnings of the grounded theory approach (Glaser and Strauss, 1967) and was of paramount importance to me throughout the analysis process. However, taking into account the more recently suggested necessities such as heightened awareness, constant reflexivity and the need for documenting the whole research process, I believe has allowed for greater transparency when discussing the development of my entire analysis (Charmaz, 2006).

I began my analysis rather tentatively with initial coding. Here my data, initially line by line, was examined and I tried to code each segment generating a huge amount of ideas. The use of gerunds (verbs ending in 'ing') in my codes emphasised action and process which helped me to avoid engaging too heavily in 'conceptual description' (Glaser, 1992) – something I was inherently aware of avoiding after reading earlier Grounded Theory texts. For example, where one participant spoke fondly of riding his bike to the beach with friends many times within his childhood, this was coded under the term 'Remembering Childhood Activity' as opposed to a more descriptive code such as 'Childhood Bike Riding'.

Remaining open to as many emerging theoretical possibilities as I could, allowed for me to move towards defining some core conceptual categories at this stage (e.g. 'Changing times') and gave me many opportunities to question and tease out my thoughts and feelings early on in the process. Despite my increased awareness of avoiding description where possible, and the need to keep the codes as close as possible to the data I did find myself often going from

one end of the spectrum to the other, with codes occasionally being far too basic and descriptive, and at other times getting slightly ahead of myself and using abstract and interpretive concepts. Although I originally worried that this would be a problem my supervisors assured me that eventually, as analysis progressed, the categories would begin to take shape and the earlier codes would fit in to place naturally.

As previously described I began by approaching four interview participants – which meant this allowed me to transcribe and initially code these four interviews prior to approaching my next participants. This helped a great deal by giving me insight into areas I could improve on with regards to my interviewing style, but additionally highlighted interesting and novel concepts I would need to explore in more detail in the up and coming interviews. These ideas and initial thoughts about the data were stored in the shape of memos on the N-Vivo programme which meant I could re-open and add to whenever I needed (see paragraph on Memoing).

After I had completed, and initially coded another four interviews (giving me 8 in total) the sheer extent of the task ahead of me was beginning to show with hundreds of basic codes and seemingly no structure in which to organise them. It was at this stage the secondary stage of coding begun whereby far more focus was applied to the original codes and I took a step back from the raw data, selecting the concepts which best fit together and generating more generalised over-arching categories which encompassed a number of lower order categories and therefore the quotes which would eventually illustrate them. Being an individual who prefers getting hands on with the task in hand to sort this data I printed off the codes and manually played with them to identify commonalities and differences. Constant comparison, used to enhance conceptual understanding of the data, (Charmaz, 2006) is one of the most important aspects of a grounded theory study and by printing off the various codes I was able to simultaneously compare existing codes and collect more data to add to the coding structure. Once happy with the loose structure I had begun to formulate manually, the N-Vivo

package was an excellent tool to be able to organise and arrange these codes into hierarchies (see 'Use of N-Vivo', section 6.6.1). It was also at this stage that other more general codes – as described earlier in my fear of them being 'too descriptive', could be transformed into more abstract concepts. As expected, when coding line by line, there were certain codes which did not seem to fit the structure - usually relating to personal facts about their family members which were unrelated to their own experiences of PA. I was aware that 'all is data' and that 'a good theory needs to be able to adequately account for a variety of individual experiences with every piece of data needing to be accounted for' (Silverman, 2010) therefore I decided to combine these codes into a 'miscellaneous' category so they would not be lost but instead continually re-checked and opened to see if new insights had emerged, another aspect of the analysis process where rigour was enhanced. Alongside these 'miscellaneous' codes, responses from some participants often did not appear to fit the norm. These opposing views on topics such as 'perceptions of cancer risk' or the 'impact of technology' I believe highlight the changeable nature of this complex population, emphasising the need for a tailored approach to PA promotion in an environment where one size certainly *does not* fit all.

The analytical inductively derived decisions occurring throughout this process remained close to the data and therefore grounded within the concepts - much to my own surprise I found this came quite naturally and the use of memos (in the form of hunches and continual questioning) certainly helped to tease out the more theoretical underpinnings of behaviour.

Memo writing was ongoing in my research and recorded on N-Vivo, prompting analysis of the data and identifying areas I wished to explore further. At the start of my research the memos mainly took the form of questions, I asked why people were responding in a certain way and what may have been the cause of their attitudes and impressions. This is illustrated by the following excerpt where the concept of conscious vs. sub-conscious PA was something I considered to be important;

"What is the difference between sub-conscious and conscious PA? Is subconscious PA inbuilt e.g. from childhood or occupationally and therefore 'natural'? How do you develop PA into a 'subconscious' behaviour? Is conscious PA harder to encourage? Are more uncontrollable factors associated with conscious PA participations e.g. location of house/ facilities, cost of gym?" (Memo on Conscious vs Sub-Conscious PA)

Many of the memoed ideas were of little direct use to subsequent analysis although certainly helped to adapt the interview schedule to encompass all of these unanswered questions. As analysis progressed it was also possible to assign memos to certain quotes or participants and reference relevant studies within a similar field. All of these qualities helped support my findings and develop basic theory.

As data collection progressed towards the latter stages these steps were repeated so that constant comparison could be utilised and I could be sure all of the avenues and associations had been explored in an iterative way. Testing out ideas I had throughout the analysis process was an invaluable task which supported both the inductive, and then deductive nature of Grounded Theory, and subsequently when I started to notice similarities in participants' reasons for participation in the trial, this questioning encouraged me to look into the cancer survivor group for possible answers.

The analysis of cancer interviews took a very similar format as the elevated risk participant interviews, with both sets stored on the same N-Vivo folder so that comparisons between the data could be made. The one exception where comparisons could not be made was with regards to the 'impact of cancer diagnoses', so therefore a new higher category was constructed and a hierarchy of lower categories were formed. Overlaps and subtle differences did occur between certain themes within the data sets as I had originally hoped, such as 'reasons for trial participation' between the two groups. This helped to illuminate further the notion that being 'at risk' was not enough to elicit a health scare and therefore a 'light bulb moment' for health behaviour change, but also provided some insight into why the
recruitment had been so slow for the elevated risk trial, but extremely successful for the cancer survivor trial.

The HP interviews were approached with a similar tact whereby data collection and analysis occurred simultaneously, and early interviews informed subsequent interview designs to probe novel ideas and themes. However, due to the more structured nature of the interviews, especially with regards to the short and often factual answers given by the surgeons and endoscopists, the analysis was completed slightly differently. Instead of coding line by line I was far more flexible with the sections of data, often including a number of sentences, or indeed a whole response (providing it was detailing the same concept), into a more thematic coding approach. I found that this worked well as my aim for the HP interviews was not to formulate an abstract theory, but instead triangulate the patient findings on health promotion with the impressions, attitudes on and barriers towards health promotion from the perspectives of professionals working within the unit.

Once all interview analysis was completed to a focused coding level where key categories and theoretical concepts were emergent, I began to design a model to try and illustrate the overarching categories throughout the populations, as well as attempting to discover links between the categories in a process known as 'initial axial coding' (Charmaz, 2003). A representation of a thematic map (figure 7.3) where I attempted to include all of the relevant categories and sub-categories is illustrated in the following 'Grounded Theory in Practice' chapter. I concluded that I failed to achieve the level of complexity required to illustrate all of the main categories which would go on to form my theoretical perspective so I went on to expand into another thematic map (figure 7.4).

By looking at the thematic maps a clearer picture around the thesis structure began to come to light, although I still struggled to identify a cohesive way in which to present my findings within

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the thesis. I knew I wanted to explore the influence of life experiences with regards to PA participation, as well as incorporate the other two populations (namely cancer survivors, and HPs) to illustrate the potential impact of a diagnosis on health behaviour, and whether more could and should be done to encourage PA participation at an earlier stage. Initially I thought that structuring the thesis by three 'participant characteristics' for example; 'The Older Exerciser', 'The At-Risk Exerciser' and 'The Motivated Exerciser' (ascertained through their choice to take part in a PA intervention), would be a suitable reflection of my findings; however upon further thought, and numerous cross comparisons between current findings and the participant groups, this structure did not fit. Firstly, it did not take into account that the focus of my research (the elevated risk participants) possessed all three 'characteristics' concurrently, and therefore with regards to these sub-categories it was virtually impossible to assign barriers or motivators to PA participation without confusion and overlap. Secondly, within this structure the findings of the HPs did not naturally fit within one of the three characteristics to make for a coherent thesis. It wasn't until I went back to my findings on another occasion, and thought about presenting my findings not only in the same order as the conversation naturally progressed within each of the interviews, but also the pathway through the screening programme, that a chronological order in terms of the findings would seem highly reflective of participant experiences, and able to incorporate the participant groups successfully. When the chronology (as explained within the 'Grounded Theory in Practice and Introduction to Findings', chapter seven) was set, the final stages of coding really fell into place with many of the analytical groups forming the backbone of my three findings chapters. It was also at this stage that theoretical saturation (the point in category development at which no new properties, dimensions or relationships emerge during analysis (Strauss and Corbin, 1990)) was reached, as examining the distinct time points from childhood to diagnosis, developed no new insights.

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6.6.1 Use of N-Vivo

Within Grounded Theory there is often a tendency to construct 'conceptual analysis' instead of formulating the required substantive theory due to failure in demonstrating the interrelations between concepts and categories as they emerge (Charmaz, 2003). By providing a transparent account of the entire research process it is possible to not only create theories from which hypotheses can be generated, but also to maintain a level of quality assurance for the entire project (Bringer et al., 2004). Johnston (2006) suggest that the use of qualitative data analysis software (QDAS) such as N-Vivo, can provide a complete record of the decision making process throughout the entirety of data collection and analysis, highlighting the evolving theory and therefore providing assurances that the study has progressed within the lines of the grounded theory approach.

N-Vivo has the capacity to record concepts previously linked and matched by the researcher, as well as increasing the efficiency of the analysis process if harnessed in the correct ways (Bazeley and Jackson, 2013). Richards (2002) explains that making the software work for each project is of paramount importance, as opposed to fitting the data to the programme. It is also essential to remember that computers are not intended to replace the ways in which people learn from data, and, especially when considering CGT, the way in which a researcher influences the interpretation of such findings.

Being an inexperienced qualitative researcher, N-Vivo helped facilitate the iterative process essential for a grounded theory study. Whilst becoming overwhelmed initially by the huge amount of codes produced by the first few interviews, various functions of N-Vivo helped me to organise these basic findings into a manageable library. Also N-Vivo greatly assisted when beginning to develop theoretical ideas as I was able to visualise the coding structure and hierarchies developing within my coding structure. N-Vivo allows for the creation of nodes (or codes) by simply highlighting the text, right clicking and either assigning a new name to the quotation, or indeed fitting it into a code which already exists. This style of concept identification allows for the data to be opened up and broken apart (Corbin and Strauss, 2008) and subsequently stored so that they may be easily accessed for future reference. Tree-nodes were also used to link groups and delve further into the developing categories in order to identify commonalities and multi-dimensional properties by forming coding structures and hierarchies. By being able to create additional nodes as and when new concepts emerged allowed me as the researcher to remain open, oscillating between both levels of coding (basic and focused) without finding myself forcing concepts upon the categories, which both the earlier texts of Glaser and Strauss (1967) and Charmaz (2006) actively discourage for the research to be a *true* Grounded Theory. These hierarchical structures also formed much of the backbone for the theoretical maps (See chapter 7; Figures 7.3 & 7.4) constructed so that I may more easily notice linkages between data and begin to develop a thesis structure which includes all of the necessary elements of my theory presented in a logical format.

From the first interview N-Vivo has helped me to store multiple memos around the ongoing theoretical development within my findings. These memos were an excellent way to ask questions of my data in order to confirm or deny some of my aforementioned preassumptions, as well as document any analytical decisions I was planning to undertake in future interviews to help guide my theory. When approaching the final few interviews my memos also served as an excellent way to identify areas which needed further exploration and therefore helped to contribute to my decision of theoretical 'sufficiency' as no new theoretical insights seemed to emerge from additional participants.

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6.7 Ensuring Research Quality

Within all qualitative research it is essential that research quality is assessed where possible, and measures are taken to ensure research rigor and transparency. Within this piece of research, as is similar for many qualitative studies, one must rely on truthful accounts, recognise limits within the reliability of memory and also be aware of one's own interpretations and biases throughout data collection and analysis to achieve research of good quality (Charmaz, 2006). To ensure that these findings are trustworthy; four elements of CGT were monitored and maintained throughout; credibility, originality, resonance and usefulness (Lincoln, 1995).

6.7.1 Credibility

The use of multiple data sources as well as purposive sampling within the elevated risk sample is thought to 'enrich' gathered data by providing a number of viewpoints and perspectives in which to propose emergent theories and ideas (Bryant and Charmaz 2007). The analysis process, as outlined in detail throughout this chapter and chapter seven highlight the approaches and steps taken to ensure memos, and codes were sorted thoroughly as well as matched appropriately to the categories, which form my overarching findings chapters. The reader may further assess the credibility of the analysis procedures by judging the fit of participant quotations, as well as the flow of chapters throughout my findings and discussion chapters. The ability to be continually reflexive throughout the research process, by completing an ongoing reflexive research diary, allowed for certain assumptions and the potential impact these may have on participant responses to be made clear; such as my position as a person who adheres to current PA guidelines and the participants possible attempts to justify their sedentary behaviour during interviews. Being transparent with my initial assumptions prior to beginning the research during chapter six I hope also illustrates my position, and lack of bias as a researcher within this study by ensuring the reader understands how my interpretations differed significantly throughout the research process.

6.7.2 Originality

The assessment of a quality piece of qualitative research is also determined by the originality of the information provided with respect to the previous literature (Charmaz 2006). Clear gaps within the literature, especially surrounding research of any kind within an elevated risk cancer population have allowed this study to be valued within the field of PA participation in a clinical population. Health promotion during screening examinations outlines the focus of two findings chapters as well as the majority of the discussion and, alone, is an incredible worthy and novel area in which to focus research with very few previous studies conducted in the bowel screening setting. Finally, to my knowledge, this is the first study of its kind to compare the responses of elevated risk and cancer survivor patients with regards to motivations for PA, and is also the only study to use these particular findings to inform discussion with relevant HPs in the screening setting.

6.7.3 Resonance

Within 'Constructing Grounded Theory', Charmaz (2006) states that a good research study fully portrays the fullness of the experience under exploration. Throughout this study's analysis, procedures were undertaken to ensure that the findings chapters reflected the sheer variety of responses given within the participant interviews. During analysis all codes were accounted for, and those which did not appear to fit into my original coding structure were placed into a 'miscellaneous' coding category to be reconsidered at a later date. Alongside this, contrasting view points were used in the findings chapters where possible, to illustrate the variety of responses provided by participants when discussing a topic and, at times, provided a rationale for interpretation due to their exception to the general rule. Finally, my finalised coding structure and a number of my more detailed interpretations were emailed to interview participants to determine their relevance and concurrence within the sample. Of the participants who responded, all showed strong agreement with my interpretations thus hopefully showcasing particular resonance with the patient population at large.

6.7.4 Usefulness

To subscribe to the concept of 'usefulness', the analysis must offer clear interpretations of practical importance, as well as spark additional research within this, and other related areas; ultimately resulting in the contribution to a 'better world' (Charmaz 2006). Above all other elements listed, I feel this research has particularly highlighted its usefulness by informing future health promoters on PA initiation and maintenance within an older, and at risk population. This research has also highlighted the sheer complexity of health promotion, not only within the screening setting, but also across all health professions with regards to a lack of time, knowledge and resources.

Research quality, especially within a qualitative study, is also heavily dependent on the individual skills of the researcher particularly in relation to the personal biases and idiosyncrasies which may have informed my interpretation. Although trying to leave the majority of the literature unexplored until after I had completed a number of interviews, my own personal views and experiences may have impacted upon the questions asked, especially within the first few interviews. With this in mind I have paid close attention to the 'aesthetics' (Holloway, 2005) of writing, and attempted to bring to life the experiences of the participants under study, despite using my own interpretations to theorise around their PA influences, by maintaining the integrity of their powerful narratives and life long memories of healthy living.

6.8 Ethical Considerations

My previous background in quantitative studies had introduced me to the importance of ethical guidelines and I was continually aware of my obligation to ensure research participants would not suffer any 'harm' as a result of my research.

As far as possible with my qualitative aspect of the research project I wanted to establish a good rapport so that each individual came out of the experience with positive memories. It was also important to me that I tried, in part, to make sure each participant gained something from the discussion, just as I would be gaining, in a research capacity.

The power imbalance was something which I was also fully aware of prior to the interviews. I was concerned that my position as researcher would put me in a position of considerable power and it was my duty to respect any wishes they may have to provide as comfortable an environment as possible. However, on the contrary, I was just as concerned that my much younger age when compared to the participants could have been seen to be indicative of a lack of experience and professionalism. These issues I felt had to be addressed early on in the research process although I was fully aware that I would not truly become aware of each individual's reactions until the time of the interview, whereby I had to adjust my demeanour accordingly.

The realisation I must even out the power imbalance as much as possible was extremely influential in my choice of an open, free flowing, narrative style of interviewing to hopefully provide an excellent insight into the subjective experiences of living at increased risk of CC. And finally my choice to dress in smart casual attire was one which I thought would elicit the correct response when asking the participants talk freely of their experiences, whilst maintaining the essential air of professionalism and integrity. The research was approved and conducted in accordance to the guidelines and code of conduct outlined within the Norfolk Research Ethics Committee and the Economic and Social Research Council (ESRC) research ethics framework for qualitative research (Economic and Social Research Council, 2012)

6.8.1 Confidentiality & Anonymity

Despite the fact I believed the topic under discussion was not particularly sensitive, I was aware that, as with any conversation, details which are specific and extremely personal in nature were likely to be conversed, and therefore it was of the utmost importance that I should be able to guarantee complete anonymity.

It was essential that the maintenance of confidentiality and processes surrounding anonymity were carefully planned so that upon execution all participants, from the first to the very last were aware of my commitment in ensuring I was both a respectable researcher, and also a trustworthy ally whom they felt comfortable communicating with.

From the first contact with each participant (whether that was during an exercise session in the case of those randomised to the intervention group, over the telephone with individuals who were randomised to the usual care group, or indeed over email communication with the HPs), confidentiality was again stressed and I made sure participants were aware no personal information regarding their name or contact details would be traceable after study completion. Upon meeting each participant prior to the interview I had a more informal script (see appendix 11) that I would run through reiterating that confidentiality was of paramount importance within the research study, and if I was to use quotations to illustrate points both in my thesis, or subsequently any published papers, pseudonyms would be used to ensure their anonymity. Conducting only one interview per person removed the need to keep personal records of any kind, and the transcripts were stored on a password protected computer system that only I had access to. After each interview, and post transcription completion, all raw audio data was destroyed as promised, and any identifiable information pertaining to the participants name, address or date of interview was either removed or changed (in the case of participant pseudonyms) accordingly on each transcript.

6.8.2 Informed Consent

All participants within the randomised controlled trial who were approached to take part in the interview element had previously acknowledged that they may be asked to take part in an interview during their participation within the trial timeline within the original consent form (see appendix 3). Alongside this I made sure that if selected to take part in an interview, the relevant participant information sheet (See Appendix 5 for Elevated Risk Info Sheet & Appendix 6 for Cancer survivor info sheet) was either personally given (if taking part in an organised exercise class at the University) or emailed following a short phone call (generally to those in the control group so they did not have to make an additional trip to the University) so that each person could read in detail about the qualitative aspect of the study, and make then an informed decision as to whether or not to take part. The HPs were initially approached by their colleague (and one of my supervisory team) within the gastroenterology unit at the Norfolk and Norwich Hospital to gauge interest, and providing they agreed, the relevant 'Health Professional information sheet' (Appendix 7) was then handed to them to read through before I contacted them on their NHS work email to arrange the meeting. Upon every participant's arrival I made clear the purpose of each interview (or focus group) and allowed opportunity for the interviewees to ask any questions they may have had. Following this I received written informed consent (see appendix 12) agreeing to audio recording for analysis purposes and the use of their direct quotations (with pseudonyms) in my final thesis as well as publications I write as a result of the research. Once the tape recorder was turned on, I then followed a rough script (See Appendix 11) which repeated many of the aforementioned details, as well as their personal right to withdraw at any time, maintenance of confidentiality and also reassurance regarding participant responses.

6.8.3 Debriefing

The debriefing procedure which occurred after the interview had ended was largely very informal, and initially I followed a rough script (See Appendix 13) to ensure I covered all aspects I believed to be important. I made a point of emphasising my gratitude for their participation firstly, but reassured them that the audio files on the dictaphone would be destroyed as soon as transcription had been completed so no one, other that myself, could listen to the recording. I also stressed that they had the right, and indeed were very welcome to contact me at any time with questions they may have about the study, or indeed any developing findings. Finally I mentioned that any papers I have successfully published could be forwarded onto them if they would like and that my PhD thesis would be public property, so therefore they would have every right to obtain and read a copy.

6.9 Conclusions and Lessons Learnt

A rollercoaster of emotion is the first thing which springs to mind when reflecting on the research process in its entirety.

Looking back, obtaining the sample was much harder than I had originally anticipated, not because of the difficult nature of the interviews or indeed the willingness of people to take part, but instead because I often found myself reliant on the success of a bigger and unfortunately less successful trial than my team had envisaged. Working within a randomised controlled trial (and therefore as part of a larger team) had its positives and negatives methodologically too. Whilst I had other PhD students for help and moral support, I often felt my study was seen as the smallest element of a much bigger body of research. In turn this did mean I often had to help with the ongoing running and recruitment of the trial (such as conducting informed consent meetings and 3 and 9 month follow up examinations) despite a number of these participants never having participated in one of my own research interviews; a frustrating time constraint but necessary element in order to maintain the workings of a united and balanced team.

My fears approaching the interviews were predominantly centred on how each participant would respond within the interview setting. I was concerned that my lack of experience would show, and most importantly if a person was uncomfortable in the situation they would not talk in depth about their past leaving me struggling to think of questions thus disrupting the natural flow. Despite some individuals being happier in the situation than others it was in fact the opposite situation that I found most difficult, where certain people would talk in length about, highly interesting, yet entirely irrelevant topics to my research question. I soon learnt therefore to try and guide the interviews in a (gently) directive manner after having to transcribe a number of unrelated lengthy excerpts. There was one occasion in my interviews where I had to adapt and use my initiative in order to achieve the best results from my participant; this was in the case of a gentleman with rather severe dyslexia towards the end of my elevated risk interviews. Although quite happy to take part in the interview he made it quite clear to me that he was unable to read, and subsequently understand lengthy questions. While I realised that this wouldn't be a problem, I did have concerns about the open narrative element at the beginning of each interview and decided instead of asking for complete recall I would split the questioning into; memories of childhood and school, secondary school and teenage years, adulthood and occupational PA and finally retirement. This worked incredibly well, and in hindsight may have been a slightly better way to approach the interviews from the start so that I may have had a more complete 'PA story' from each individual.

Through interviewing three differing populations I was fortunate to be able to see how the dynamic of interviews change depending on whether they are structured or unstructured, short or lengthy, and as an individual or a group. The importance of anonymity throughout the process was paramount, especially with regards to the HPs where I often got the sense of a professional hierarchy and the worry that those in a position of lower seniority within the unit could not always speak their mind for fear of their opinions causing conflict.

Even with the seemingly never-ending task of data analysis I did find this the most satisfying element of the research process, especially towards the latter stages when I could see my concepts getting richer and the theory (and thesis outline) as a whole coming together (see thematic maps in chapter 7). At times I felt overwhelmed but I believe by remaining organised, and using a methodology which fitted the research question well, it allowed for me to build in confidence and successfully generate a theory about PA behaviour in a population where very little is currently known.

Chapter Seven

7. Grounded Theory in Practice and Introduction to Findings

Despite providing a comprehensive methodology chapter, the complexity of Grounded Theory I believe naturally lends itself to an additional 'linking' chapter to clarify, in the context of my own research design, many of the necessary components required within this design, and how they have been used to inform the decisions made throughout the process. As well as this I believed that the three findings chapters which follow on from this section needed an introduction so that the decision making process around structuring could be made clearer through thematic maps and the nuances of my formatting strategies.

As previously described, despite desiring a purposefully selected sample at the start of my research the slow recruitment onto the trial as a whole warranted the use of a convenience sampling method for the first four participants interviewed. Figure 7.1 below illustrates the sampling framework, beginning with elevated risk individuals, whose preliminary findings subsequently informed the recruitment of two groups of cancer survivor patients. Shortly after recruiting the initial group of cancer survivors and almost three quarters of the way through my elevated risk patient interviews the HP interviews took place within the hospital with questions informed and formulated by the findings of both clinical populations.



Figure 7.1: Sampling Framework for the Study

Figure 7.1 illustrates the sampling timeline, however this does not illustrate why decisions were made to interview the two additional populations during my research project. Figure 7.2, I hope provides a greater insight into these choices. Within the flowchart quotations and their relevant coding category above (notice the use of gerunds – '-ing words', within the dashed boxes) are viewed alongside extracts from relevant memos which encapsulated my initial thoughts, and also additional questions arising from the data which I intended to ask of participants in the interviews which followed.

The direction of arrows shows the path that my thoughts, and therefore decisions took, with the left hand flowchart signifying the sampling and amendment pathway, the speech bubble symbol including the types of quotations which caused me to consider approaching additional populations, and the mind bubble symbol encompassing the memos and subsequent questions asked of the findings.

This figure illustrates just a small number of examples where the use of questioning has promoted the need to examine in more detail the research topic through theoretical sampling of different populations, namely the cancer survivors and HPs. Although this flowchart by no means encapsulates the entire thought making process, which was indeed extremely complex and multi-dimensional, I do believe it represents my understanding of the need to view the research question from a number of angles and use many of the core principles of Grounded Theory to arrive at a comprehensive theory about the health behaviours of elevated risk cancer patients.



Figure 7.2: Thought process flowchart for additional populations'

7.1 Descriptive Characteristics of the Sample

The summary table outlining the demographic attributes of the elevated risk patient population (see table 7.1) shows the diversity in risk status, fitness level and additional comorbidities between the interview participants on this research project. The average age of the qualitative sample was 67.6 years, with a male to female ratio of 62.5%: 37.5%, which was comparable to the trial sample (with an average age of 68.7 and a male to female ratio of 65.6%: 34.4%). The similarity in age between the elevated risk interviewees and the cancer survivor interviewees (with a mean age of 66.8 years) (see table 7.2) also demonstrates how the differences between the two patient populations regarding the impact of a risk diagnosis may not be attributable to age differences. All patient population interviewees were Caucasian in fact every participant who consented to be part of the trial were of the same ethnic group, a limitation I will go on to discuss in chapter 11. The characteristics of the HP interviewees (table 7.3) show the variety of ages within the sample (22 to 63 years) as well as the variation in years of experience within the CRC and screening setting (from 1 year to 26 years). The 'professional' demographic table also identifies the self reported PA behaviours of those interviewed, which highlights how varied the PA experiences and attitudes may be within this population.

These figures are purely illustrative of the research sample, and, due to the sampling methods utilised cannot in any way said to be representative of *all* adults at elevated risk of developing CC, who have survived CC, or indeed practice within the cancer screening setting. However I do believe these tables show the diversity within and across these populations, allowing the findings to be based on a varied sample.

Pseudonym	D.O.B	Age	Group	Risk Status	Smoking	VO2 Max	History of CC	Other Co
			Allocation		Status	Baseline		morbidities
PARC Susan	27/02/1953	60	Control	High	No	23.3	No	Joint Problems
PARC James	24/03/1945	68	Exercise	High	No	25.8	No	HBP, Joint
								Problems
PARC Bob	07/09/1942	71	Exercise	High	No	17.7	No	HBP, Stroke,
								Joint Problems
PARC Diane	20/03/1938	76	Exercise	Intermediate	No	16.6	No	TIA
PARC Margaret	16/08/1953	60	Exercise	Low	No	11.2	N/K	Heart &
								Pulmonary
								Disease, Spinal
								Injury
PARC Ryan	10/01/1950	64	Exercise	Intermediate	No	24.5	No	HBP, Joint
								Problems
PARC David	12/08/1948	68	Exercise	Intermediate	No	30	No	Joint Problems
PARC Tom	12/03/1942	72	Control	Intermediate	No	30.8	No	НВР
PARC Terry	23/02/1946	67	Exercise	High	No	27.7	No	Asthma
PARC Priscilla	30/03/1945	69	Exercise	Intermediate	No	19	No	None
PARC Simon	23/08/1941	72	Exercise	Low	No	31.5	No	None
PARC Ray	25/04/1950	64	Control	Intermediate	No	24	No	T2D, Back Pain
PARC Michael	31/08/1944	68	Control	Intermediate	No	19.8	No	T2D
PARC Grace	02/01/1948	71	Control	Intermediate	No	24.7	N/K	None
PARC Lucy	25/02/1948	66	Exercise	Intermediate	Yes (10 pd)	16.9	No	Asthma, Joint
								Problems
PARC Geoff	20/01/1947	67	Exercise	Intermediate	No	17.9	N/K	HBP, Joint
								Problems

Table 7.1: Elevated Risk Participant Demographic Table (HBP = High Blood Pressure, T2D = Type II Diabetes, TIA = Transient Ischemic Attack)

<u>Pseudonym</u>	<u>D.O.B.</u>	<u>Age</u>	Group Allocation	Date of CC Diagnosis	Treatment
MOVE John	22/03/1940	74	Control	February 2012	No Chemo
MOVE Howard	13/10/1950	64	Control	'Summer' 2009	No Chemo
MOVE Mandy	03/02/1951	63	Control	August 2012	Chemo
MOVE Jane	19/02/1953	61	Control	November 2012	No Chemo
MOVE Joseph	06/04/1942	72	Exercise	April 2013	Chemo
MOVE James	17/02/1944	70	Exercise	July 2012	Chemo
MOVE Barry	04/09/1948	66	Exercise	October 2011	Chemo
MOVE Richard	18/08/1943	70	Exercise	December 2012	No Chemo

Table 7.2: Cancer Survivor Participant Demographic Table

Table 7.3: Health Professional Participant Demographic Table	le
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<u>Pseudonym</u>	<u>Gender</u>	Age	<u>Role</u>	<u>Years Experience with</u> <u>Screening</u>	<u>Active (yes/no)</u>
Endoscopist 1	Male	47	Consultant Gastroenterologist	7	Yes
Endoscopist 2	Female	58	Nurse Endoscopist	6	Yes
Endoscopist 3	Male	44	Consultant Gastroenterologist	6	No
Endoscopist 4	Male	48	Consultant Gastroenterologist	8	Yes
Surgeon 1	Male	51	Consultant Colorectal Surgeon	18	Yes
Surgeon 2	Male	54	Consultant Colorectal Surgeon	26	Yes
Surgeon 3	Male	63	Consultant Colorectal Surgeon	8	No
Surgeon 4	Male	46	Consultant Colorectal Surgeon	20	Yes
SSP 1	Female	57	SSP	9	No
SPP 2	Male	36	SSP	3	Yes
SSP 3	Female	56	SSP	1.5	No
SSP 4	Female	30	SSP	1	Yes
SN 1	Female	22	Staff Nurse	1	Yes
SN 2	Female	51	Staff Nurse	1	No
SN 3	Female	22	Staff Nurse	1	No
SN 4	Female	50	Deputy Sister	11	No

7.2 Translating Codes into Chapters

The greatest personal challenge entering into this research project was giving each participant a voice and respectfully representing the nuances of their individual stories in a coherent and comprehensive format (see appendix 14 for brief biographies of each elevated risk participant). The elevated risk and cancer survivor interviews produced around 2500 individual codes which all needed to examined, and analysed time and time again to ensure the category structure that was in place encompassed each of the components discussed within the interview. The need to go from lengthy in depth codes to more abstract concepts was something which came naturally, however, trying to find over-arching themes for these codes was, at times, incredibly challenging (See appendix 15 for an example of how one participant interview was used to develop the coding structure alongside memos and reflective accounts). In an attempt to clarify some of the thought processes, it was suggested that a thematic map – highlighting all of the key themes with their main coding structures attached, may help to identify linkages between concepts, as well as emphasise the themes which stood out as potential chapter headings (see figure 7.3). Within this map the key theme of 'changing times' highlighted in purple (alongside the 'sub-themes' in green and linked by arrows), highlights the key areas discussed within the first findings chapter; 'Perceptions of PA throughout Life'. Also within this map, primary categories from the second findings chapter, 'The Diagnosis' can be located in blue, along with links to the relevant psychological models of behaviour change (highlighted in red) which, for the most part, have been introduced within the literature review, and will go on to be examined in greater detail in the discussion section. Figure 7.3 formed the initial pictoral interpretation of my vast coding structure, and although it was constructed manually, it did follow the N-Vivo coding hierarchy extremely closely. By starting with my primary code and the emergent theme (changing times) which seemed to underpin much of my participant's lives and reasoning for their current lifestyle choices, it became

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possible to see linkages within the data set. This encouraged me to ask many more questions with regard to why certain themes were appearing more frequently than others, and eventually greatly helped to develop my overall thesis structure. Within figure 7.3 it is clear to see some themes from my other two findings chapters emerging, codes such as 'HCP influence' and 'attitudes to cancer', however this diagram was neither focussed nor large enough to include the findings from my other two participant populations in adequate detail and this Figure 7.4 was envisioned. Elevated risk participants continually spoke of the influence of a HP in their choice to be active and both cancer survivors and elevated risk participants gave a mutual reason of 'finding a cure' but very different, and I believe key, personal reasons for taking part in the study as a whole. Figure 7.4 was constructed under the same principles as the former; however my aim was to somehow include all three of the participant groups within its structure.





Although extremely helpful in confirming my key findings, both of the thematic (mind) maps did not reduce my initial apprehensions regarding finding a thesis structure. As described in chapter 6, many meetings were spent going through ideas about how to present my findings in a way that would make sense to the reader, and ultimately take them on a personal journey whilst incorporating the key findings of three extremely different, yet equally significant populations. I was aware throughout these discussions that the focus of my research was on those who were classified as 'elevated risk' following their screening colonoscopy due to their relatively unstudied nature in previous literature. Alongside this I had taken a life story approach from the outset whilst interviewing these participants, and knew that somehow all efforts must be made to identify how experiences - in childhood and right through into retirement, may have a profound impact on one's choice to be active. Despite being classified as 'sedentary' (set by the current PA guidelines (O'Donovan et al., 2010)) it was made quite clear by all participants that 'activity' (albeit in many formats, and rarely structured or planned) had played a large part throughout every stage of their lives, and therefore must be the start point in presenting my findings. The next task was then to decide how the other two participant populations would present themselves within the elevated risk 'story'. The course of conversation within each elevated risk interview naturally progressed through life in a chronological order, as one might expect, usually concluding with their screening examination. Alongside this, the order at which I decided to approach my three patient populations was informed by the emergent findings from the patient population which preceded it (see figure 7.2). Therefore it seemed sensible to begin considering the presentation of my findings with this in mind, starting, as previously mentioned, with life up to the point of diagnosis, continuing with the potential impact of a diagnosis (first in relation to polyp removal, and next with regard to CC survival – illustrated in chapter 9), and finishing with the a look towards the future of the screening setting and health promotion in general – see chapter 10. As a visual

learner, and with a knowledge of how the original thematic maps had aided my thought processes, bubble maps were constructed (figure 7.5 & 7.6), outlining the key structure, as well as links not only across themes but also between chapters.

Within this figure the bubbles represent coding hierarchies within the data set – with the larger bubbles symbolising the larger codes, and the smaller bubbles (without a fill colour) depicting the sub-themes within the area. The bubbles which overlap the horizontal lines (indicating the three findings chapters) signify codes which may apply, and therefore are presented within two of the findings chapters (or in the case of the chapter 10, both elevated risk and HP participant populations).

These bubble maps illustrate my grounded theory; an attempt to understand and explain the PA behaviours within this unique and understudied population. Figure 7.5 is a summary of the codes associated with 'a lifetime of physical activity', all of the aspects of the interviewee's lives which were thought to have had an impact upon their now increasingly sedentary lifestyle choices. When looked at collectively, these codes paint an incredibly complex picture of the numerous differing reasons why PA may not necessarily be considered essential or even relevant at their current life stage or health status. Unlike much of the previous research which has outlined barriers commonly cited across all age groups for PA participation e.g. a lack of time, or access to facilities, this theory highlights the more deep rooted socio-cultural influences which are just as important (or potentially even more so due to their engrained nature) and far less recognised in the field of health promotion in older individuals.

Similarly figure 7.6 links the hierarchical structures of the patient and professional codes in relation to the impact of a change in health status on motivations for behaviour change, the subsequent impact of how this diagnosis may impact on one's choice to be active, and how we

may more effectively utilise this potential teachable moment to encourage healthier living with the hope of reducing cancer onset and recurrence.

I will go on to describe within chapter eleven and my discussion how best to make use of these new theoretical insights by combining the key findings from this study into new health promotion strategies for an ageing and at risk population.

7.3 Reading the Findings

The context of each findings section will be provided in the form of a short introduction to each chapter, and, I hope through reading the findings (and by using the bubble map provided within this chapter (figure 7.5)) the ordering of key thoughts and ideas will not only engage the reader in the complexity of the story around behaviour change in an ageing, and elevated risk population, but also leave many areas where further research could be proposed.

Throughout the findings chapters the overarching categories are highlighted through the use of <u>underlining</u> and *italicised* lettering. Within these headings often words or phrases will also be italicised, and this signifies both subthemes within the over-arching categories, or at times in-vivo coding, such as; *'nothing to do'*. Lastly the use of underlined words or phrases *within* participant quotations highlights emphasis in one of two ways. Either, a participant placing emphasis on a certain term throughout their interview e.g. "when I went for screening in the past, nothing was said, and it's bad really, I think we have a <u>right to know</u> if the research is out there that it might help..." (MOVE Barry, Interview) – Chapter 10". Or alternatively, emphasis from a researcher perspective, with a term which will go on to be discussed in greater detail within the context of the findings; "Often when referring to gyms participants would use the word '<u>them</u>' e.g. "The gym stereotypes exist, especially for people of my generation as we never really used <u>them</u>" (PARC Susan, Interview) – Chapter 8".

Finally, throughout the three findings chapters the direct participant quotations are indented, and following each is the pseudonym of each interviewee. Within the elevated risk participants the pseudonym is also preceded by either PARC or MOVE to signify which randomised trial each person belonged to; either the elevated risk following screening study (PARC) or the cancer survivor study (MOVE).

Now the research rationale, and previous literature has been discussed and the methods have been outlined and explained in reference to practice; the following three chapters will present the findings from the interviews conducted with individuals at elevated risk of developing CC (chapters 8, 9 & 10), CC survivors (chapter 9) and HPs within the screening setting (chapter 10).



Figure 7.5: Bubble Overview of the Grounded Theory – A Lifetime of Physical Activity



Figure 7.6: Bubble Overview of the Grounded Theory – Combining key patient and professional codes

Chapter Eight

8. Findings One: 'Perceptions of Physical Activity throughout Life'

As previously discussed in the literature review there are many well known prerequisites of an active lifestyle; close proximity to facilities, a perceived safe and friendly environment in which to exercise, as well as adequate free time in which to carry out a fitness regime, and these are certainly influential to name but a few. However, less well known and researched are the socio-cultural influences on PA initiation and maintenance. This chapter looks to explore how influences around cultural beliefs or social expectation throughout each participant's lives may have shaped intentions to lead a healthy lifestyle into their older years.

The narratives used at the start of each interview demonstrated that until my participants received their diagnosis of CC or an elevated risk of developing the disease, their lifetime experiences of PA from childhood, into adult life, and finally retirement followed an extremely similar pattern. This initial findings chapter explores 'Perceptions of Physical Activity throughout life' from the eyes of each of my participants. The analysis explores how ageing during an era of change in post-war Britain may have impacted upon their own reasons for leading an active lifestyle at each stage of their lives.

Being born in the 1950s and living their childhood through this decade was a common consideration which ran through many of my participants' recollections of childhood when asked to reflect on their younger years. It appeared in many cases as a time of forward thinking, but was somewhat tinged with the memory of the war and uncertainty (especially from their parents' perspective) with regards to the coming years. With the country suffering economically and many families struggling to make ends meet with continued rationing, this was very much a time of 'making do' and 'pulling together'. Despite this, my participants all talked very fondly about memories of how their childhood was full of creative and active play, a type of activity that was not forced, but instead came naturally to them as part of their everyday lives. It is this essence of 'natural' PA which appears to have had a profound impact on their changing activity levels throughout life, and their subsequent sedentary lifestyles in their older years (mentioned in Chapter 2).

Despite officially falling below the current PA guidelines of 150 minutes of moderate to vigorous PA per week (part of the eligibility criteria for being part of the research study) it would appear that our patients all believe that their memories of an active childhood have positively influenced their choice to lead an active (although not *sufficiently* so) lifestyle, well into their 60's:

"I think that's important when you are growing up as it sort of...sets the basis of how you are, how you live your life...I do think you build it up when you're a child, that's *so* important" (PARC Terry, Interview).

8.1 The Meaning of Physical Activity

This discrepancy between actual PA levels and meeting the current PA guidelines may be explained by their perceptions of leading an active lifestyle and their potential lack of knowledge with regards to what constitutes 'meaningful' PA. Many of the individuals interviewed were either approaching or currently in their retirement years, and with that for many comes the need to fill their lives with other tasks and interests to keep 'busy'. This serves several purposes; predominantly it provides a transition from working life into retirement which often stereotypically may be associated with 'slowing down'. But also being 'busy' defends retired people against judgements of obsolescence and allows them a chance to prove that despite losing the structure of a working day, they are able to adapt and still be regarded as a contributory member of society; "when working on the buildings I am working every evening and weekend on my own property, extending it, moving it...I've always been very very busy even if I haven't done any 'exercise" (PARC Michael, Interview)

This theory could also be applied when the participants often discussed regular hobbies as a way to keep themselves active. Certainly worth mentioning here is that all of these tasks could indeed be classified as PA, however what is key, and what may be missing from the knowledge of an individual within this generation, is the *intensity* at which these are carried out in order to elicit a positive health response. Gardening, for example, was an activity many people spoke about doing at length;

"have nearly an acre of garden which I do myself, my husband only gets involved in the constructional things, I do pretty well all that myself, I've always been very keen on gardening" (PARC Grace, Interview)

"I'm always active (in the garden), picking things up, putting them down, twisting around, all these exercises I'm doing in the classes here, all relate to things I have to do, like picking up trays of seeds you know..." (PARC Lucy, Interview)

It was often clear to see that individuals within this age group enjoyed keeping active 'naturally' by doing activities that they did not ordinarily consider to be exercise *per se* and therefore what exercise they did achieve seemed somewhat 'subconscious'. Whether this activity was at the recommended 'moderate to vigorous intensity' was a parameter none had actively considered and instead, doing the activity for intrinsic reward such as enjoyment was something regarded as far more important;

"It's (walking) more pleasurable, than thinking, oh I must go to that class, or I have to do that this evening, putting lots of pressure on yourself to do something. I think it has to be enjoyable...and you have to want to do it for you...not for anyone else, or to make others happy" (PARC Priscilla, Interview). These excerpts, particularly the quotation above spoken by Priscilla highlight an incredibly important message which needs to be understood by individuals designing PA interventions or promotional messages for people in an older age group.

What seemed to emerge after talking to many participants was that being physically active as a child was a *natural* part of growing up. For many it was their only source of entertainment in an era when modern electrical appliances were virtually non-existent; whether using their imagination to create games to occupy their evenings, or having to cycle to and from school each day, being physically active was integrated from a very early age and became part of *childhood identity*.

8.2 During Childhood

8.2.1 Childhood Identity

Two sites of PA were mentioned by participants when discussing childhood PA; the casual recreational outdoor type, which mostly occurred on the empty streets of their village, and the more structured Physical Education classes at school.

"In weekends and evenings after school, I'd go out as soon as I got home to play with my friends, if it was the weekend I'd be out 10-12 hours at a time, just roaming around the streets...that was my exercise I suppose, well, other than sports at school" (PARC Ryan, Interview)

It is this emphasis on not having had to force PA, which might lead one to speculate that this may be one of many reasons why doing an organised, pre-planned PA regime may not only be seen as 'too much effort' in later life, but also an unnecessary addition to their already 'busy'

lives.

This is further supported by the notion that during the participants' childhoods there were far more chores to be completed which required naturally occurring PA, and far fewer distractions inside the home to ensure sedentary leisure time. Often participants found reasoning for their continual outside play because they felt there was *'nothing else to do'*;

"I think all through my youth I was out all the time doing something or other, because that's all there was...I was lucky enough to be in an era when there wasn't anything to do but a bit of exercise..." (PARC Terry, Interview)

"...life was full of activity; there was no televisions, nothing to keep us indoors nothing to distract us from our friends or having fun." (PARC Tom, Interview)

Another factor which inevitably elevated natural PA levels was the distinct lack of motorised transport during the 1950's and even 1960's for many families, and therefore if the participants as children needed or wanted to get somewhere it would be necessary to walk or cycle;

"We didn't have cars, my parents didn't have a car until very much later in life, I'd have been 13 or 14 by the time Dad had the car. If you wanted to go anywhere you went on the bike, or walked, If I needed to get somewhere I'd get on my bike, if I wanted something I'd have to get there myself...it was then up to you to do it." (PARC Michael, Interview)

Ryan describes an era where the roads were bustling with activity; memories of children playing and neighbours keeping watch were retold by a number of individuals, all providing assurances that their outdoor play was safe due to the lack of cars;
"...we lived quite a distance from the city without a car so we walked places, the roads were quiet back then, well bustling with activity, but not with cars" (PARC Ryan, Interview)

The unstructured activity during childhood, was often mentioned alongside the more organised, and often far stricter nature of school in Physical Education classes. When discussing PA during school hours there tended to be mixed memories, with often the less academic children excelling in sporting pursuits and those who disliked activity frequently falling to the bottom of the school pupil hierarchy. Some participants commented on how sport allowed them to excel in one aspect of academia due to weaker results in the more traditional, academic subjects;

"I wasn't that bright at school, so I had to go out and play, it was kind of the only thing I was really good at to be honest" (PARC Bob, Interview)

Whilst others members spoke of how being unable to do sport at school, whether that be in the case of Susan who perceived herself to be un-skilled during physical education lessons (and exemplified by her memories of being picked last for the team), or Margaret who actually suffered a medical condition which prevented sports participation, this had subsequently resulted in negative perceptions of PA into later life and had inadvertently impacted on their choice to do planned activity for fear of failure or embarrassment;

"I was always the last picked for the team sports you know, which hurts. It makes you think 'oh I'm no good at this' and it always leaves a bad impression in my mind, and even to this day I hate team activities because it brings back those terrible memories." (PARC Susan, Interview)

"In school, exercise wise, that was non-existent, I wasn't allowed because of my heart thing, and I used to get really teased for it, children couldn't understand why I couldn't do P.E. they used to make fun of me a lot..." (PARC Margaret, Interview) For those who enjoyed the compulsory physical education lessons, many were chosen to represent their school team, which in turn elevated their status and popularity within their peer group. Despite this, many stopped participating in recreational activity when they left school and began working full time.

Interestingly a number of individuals, who mentioned disliking the compulsory physical education in school, actually spoke of fond memories doing unplanned PA outside of their homes. Although the physiological health benefits were rarely, if at all mentioned, by any participant, the *'learning of life skills'* at an early age was one of the main outcomes discussed which many believed stood them in much greater stead when applying for work as they got to employment age;

"I think games, playing outside, used to be where children found their feet, they started to learn life skills and become the person they were naturally meant to be, whether they were a leader in life, or worked best in a team..." (PARC Geoff, Interview)

8.2.2 Physical Activity and Safety

8.2.2.1 Safety on the Roads

This shift in the perceptions of safety from childhood to the present day seems to be a huge deterrent for doing exercise outside on the street in modern society. Whether it was preventing participants from cycling or walking for fear of being knocked down, or forcing individuals to adapt their cycling route (by using paths) for fear of the consequences, many spoke of both the *volume* of cars and the *speed* in which they travel as a significant barrier to them doing more PA;

"I like cycling, although it's much more dangerous now mind with all the traffic, I often cycle on the path if I can, I just know that I would worry for my safety on a road, the cars are so fast and frequent" (PARC Tom, Interview)

"Oh yes, they (cars) certainly put me off, the traffic, I just feel so vulnerable, I'd have no hope against a car at all, it definitely does put you off doing any exercise on the roads" (PARC Susan, Interview)

8.2.2.2 Safety within the Community

The sheer volume of outside play was regarded as commonplace in 1950s Britain, and was seemingly made possible or even encouraged, not only due to the lack of motorised transport, but also because of a heightened sense of '*community spirit*'. The children would not fear for their safety because they were in a familiar environment and played with the children on the street on a daily basis. The parents of the village would therefore often act like a self-styled neighbourhood watch scheme, keeping an eye out, not only for their own children, but others too;

"We were part of a community of villages, and were known by a network of families and farmers. Everyone knew everyone, so it felt like home you know, it was safe, like a bit of a community bubble." (PARC David, Interview)

"We would be doing exercise all the time...your parents didn't know where you were half the time, but no one really cared – people weren't afraid in those days, everyone looked out for each other in the community, and the parents of all the kids would keep an eye, it felt safe..." (PARC Tom, Interview)

The sense of *'life moving slower'* in post war Britain was one which appeared as a common theme throughout many of the participant narratives when the changes in times between then

and now were discussed;

"It's just how it was then, lives moved much slower, you could sit back and enjoy it, rather than be wrapped up in a whirlwind like today." (PARC Tom, Interview)

Whether talking literally, with regards to a lack of motorised transport and therefore the need to walk or cycle to get from place to place, or more metaphorically with regards to the sense that everyone in 21st century Britain seems to be so entrenched with their own busy lives to pay attention to the community around them, the thought of life existing at a much quicker pace now might provide an explanation for 'a lack of time' being a commonly cited barrier PA, but might also exemplify the changing perceptions of safety caused by many aspects of modern life.

8.3 Into Adult Life

8.3.1 The Impact of Technology

8.3.1.1 Impact of Technology on Community Spirit

Following on from the conclusion of my last sub-topic of, 'safety within the community', communication, or a lack thereof, was certainly mentioned as a change which has occurred in the past fifty or so years and negatively influenced choices to not only participate in PA but also feel valued as a part of the local community;

"There was more openness then, everyone knew each other, and actually talked to each other not like now, I don't even know my neighbour, let alone the entire street." (PARC Ryan, Interview) Despite acknowledging that technology has allowed for more ways than ever to communicate with one another, many people have suggested that because the need to communicate face to face has become a distant memory. This has heightened people's fears about who may be living in the neighbourhood, and resigned individuals to staying indoors and avoiding social interaction or outdoor PA pursuits;

"Communication is becoming a forgotten art! The art of conversation is totally lost on people now because of technology, and that has resulted in fear about what might be lurking on your street or the other end of the internet feed" (PARC Michael, Interview)

It could also be argued that individuals residing in this older age group may have heightened concerns about neighbourhood safety nowadays, resulting in an elevated perceived vulnerability. This is illustrated by the views of my oldest participant Diane, aged 76, who suggests that she now does not walk on a regular basis for fears she may get attacked;

"...there's another walk I could do, but it's through trees, and muddy footpaths, quite secluded, and unless I have one of the children with me, I definitely wouldn't do it on my own, because of the safety aspect...if I was attacked nobody would hear, and now, at my age, it definitely is that safety aspect, there are limits" (PARC Diane, Interview)

Although these types of comments were quite uncommon during my interviews, many other interviewees touched on the influence of the media and how much more *exposed* they felt in 21st century Britain. With the ability to access the news through various devices in today's society, crime seemed to appear much closer to home;

"...I think you are more exposed, or at least we think we are more exposed as things are more in the newspapers, cause there's more communication out there, we know what's going on out there more..." (PARC Terry, Interview) "...people hear so much more about it *(crime)* nowadays don't they? The news is very accessible, on the IPhones, or tablets, the newspapers, television, you can't escape the headlines, and most of the time the headlines aren't about happy things!" (PARC Ryan, Interview)

It could be proposed that the impact of 'stranger danger' within villages has a profoundly negative impact upon active lifestyles. If participants hold strong memories around feeling safe as a child due to an untold 'neighbourhood watch' system, it is hardly surprising that many do not feel comfortable leaving their homes and integrating with the rest of their close community to do PA.

8.3.1.2 The Impact of Technology on Increased Choice

Despite change occurring in every time period throughout history, the considerable changes that occurred within the second part of the twentieth century especially with regard to technological advances were astounding. The people within this study have all lived through, and in many cases, had to 'adapt' to these advances in order to move with the times;

"I'm of a generation where I needed to catch up all the time...I still feel like I'm always a few steps behind, things just move so fast nowadays, you master one thing, and then something else comes out, it's distracting!" (PARC Susan, Interview)

Whether these changes have been in terms of communication, technology, motorised transport as previously mentioned, or healthy living their arrival has meant that people have been offered the element of *choice* in their daily lives. It could be argued it is the arrival of these new and often 'time saving' options which have been the biggest detriment to an older

populations PA levels.

The rapid increase in reliance on technology, and the expectation that leisure time is moreoften than not, filled with distraction, was the most frequently mentioned cause of decreased PA levels population-wide, within the participant group;

"...there's too much choice nowadays, with every aspect of life, food, technology, exercise, it would make so much more sense to not give people the choice and I think people would be far healthier" (PARC Geoff, Interview)

Despite an awareness of the detrimental effects this additional 'choice' has placed upon their activity levels; it was extremely common that the participants talked about the negative impact on the *children* of today rather than themselves in older age. This may be because many held strong, positive memories, of their active childhoods whereas they look to their grandchildren now and do not see the same level of enjoyment;

"I think it (technology) has decreased physical activity for the kids, most definitely. Most of the kids I come into contact with now are all about their mobile phones and their computer games. Their idea of exercise is staring at a screen and moving their thumbs around. Which is a real shame; there is a whole world out there that the majority of them are missing out on." (PARC Geoff, Interview)

The thought that many of these technological advances were now 'taken for granted' was one which was mentioned a number of times. This may suggest that the integration of things like television and motorised transport was smooth and importantly, felt *necessary*, to sustain reportedly busier lives. The next quotation from a gentleman demonstrates a reflection of just how much the arrival of 'time-consuming' goods (such as television or computers) and the entertainment industry has influenced sedentary living in a negative way;

"it was a completely different way of life, from the way things have developed subsequently where lots of things have been taken for granted now...you hear people comment a lack of activity, umm, and they choose entertainment now, and I look back to those days, people have said in war time people were healthier as there weren't as many choices for food, or distractions from playing outside, I can understand that, I choose to be inside watching TV now too." (PARC David, Interviews)

Alongside the arrival of 'time-consuming goods', 'time-saving goods' (devices that reduce the time required to perform a household task; such as a washing machine, or dishwasher) became increasingly popular – and were welcomed by masses of families where domestic chores took up a huge proportion of their potential leisure time.

One female participant spoke of how she speculates technology may eradicate movement altogether, and while this may seem a farfetched argument, if we were to look at the changes which have occurred during her lifetime and the past 60 years it doesn't seem quite so fantastical;

"...eventually one day people will be able to just sit in one of those wonderful electric chairs pressing buttons and wouldn't need to even move. Technology is amazing, it has saved me lots of time doing chores, but it is making it easier for people to lead a sedentary life. I think when remote controls, first came about I thought, my goodness me, if people can't get off their bottoms to change the channel over that's so ridiculous...but now we reach and wonder where's the remote control, instead of just standing up and changing the channel on the television. You don't need to even move..." (PARC Priscilla, Interview)

While the general consensus from participants was that the arrival of more technological appliances reduced a person's PA levels there was a sense that because they grew up within a time without these distractions, the need, and the knowledge surrounding the benefits of PA was 'built in' to their lives already:

"It (technology) is terrible. It's impacted dramatically, too much, far too much. I didn't have a television until I was 13, and by then I was already enjoying being outside it was already built into my lifestyle. If children have a TV regularly from a very young age they don't understand the benefits of outdoor activities..." (PARC Michael, Interview)

While the previous quote would suggest that this participant believed he had avoided becoming completely distracted by technology even into his later years, for the majority the realisation that they have become increasingly sedentary throughout their lives and are now having to live with the physiological consequences (in the following case with regards to his 'large tummy') was a prominent theme:

> "...there has been less activity throughout my daily life, less and less, as more and more things are developed that actually stop you doing the simple things, like a mobile phone, remote controls on television sets, all those sorts of things, are just one aspect of the lifestyle where little bits of natural exercise have been eradicated simply by technology moving on, we (humans) haven't been developed to sit on a couch pressing buttons, so, umm, I think part of my large tummy, and the fact I'm not particularly fit, is partly to do with the introduction of this technology in ordinary life and how it's just taken over without me realising really..." (PARC James, Interview).

Conversely, whilst the majority of thoughts around the arrival of these advances in technology were negative in relation to activity behaviours, some were conscious about mentioning the positive impact of technology in terms of raising awareness of healthy living and the importance of exercise:

"You watch television today and you see so many news reports or programmes telling you how important it is to keep active, and slim, how important it is not to smoke, and you kind of have to take notice and pay attention (*to the advice*) don't you, or you're a fool..." (PARC Tom, Interview) Although this is correct, and the information about the benefits of leading an active lifestyle is far more readily accessible with the arrival of marketing campaigns and the internet, it does beg the question about who these programmes and adverts are targeting due to their exposure on predominantly sedentary mediums. This also highlights the real need for balance; equilibrium between embracing the technology and using it to our advantage, but also being aware of other, less sedentary activities, which could also fill leisure time and make us healthier:

"...technology advances have to happen to make life easier, but whether it's moved on too far; there could definitely be a happier balance" (PARC Tom, Interview)

8.3.1.3 Technology and Choosing the Easy Option

If the key to encouraging physically active lifestyles is purely down to a matter of balance, choosing to be disciplined and dedicated at least in some aspects of our daily lives would seem like a reasonable recommendation. However, as suggested in the following quote and as described in the literature surrounding the rationality of behaviour, often as human beings, we decide to choose the easier option instead;

"...humans, if given the choice, would rather be lazy and not make the effort, and by having all these various distractions indoors it's a no brainer which we choose really..." (PARC Ryan, Interview)

The concept of situated rationality explained within section 3.6, suggests that behaviour is directed due to 'rational' alternative viewpoint e.g. people may know that getting out to take part in PA would benefit their health, however other influences, such as a sedentary partner, may make the decision to engage in a behaviour less desirable. The use of the word 'we' within

the previous quote could be claiming a sense of responsibility on this gentleman's part, that despite acknowledging that the more sedentary lifestyle choices we make involve less effort and may even be regarded as 'lazy', *we* decide to take them anyway.

An excellent example of choosing convenience over necessity would be the arrival of central heating in the late 1960's early 1970's. Many of the interviewees remember a time when playing outside was warmer than sitting inside – especially during the winter months, however, in a time of central heating now no energy needs to be expended to make oneself warm;

"It was also a time of no central heating, so it was actually far warmer outside playing, than sitting inside, we often had frost on the insides of the windows it was so cold." (Roy, Interview)

This dependency in more recent times on these, now common, luxuries, and quite possibly the older generations' memories of a time when life was far tougher, may encourage more sedentary, home-based leisure activities, especially during the colder months.

8.3.1.4 Technology and Increasingly Sedentary Jobs

Perhaps common knowledge in today's society is that occupations are, in general, becoming increasingly sedentary. The arrival of technology and machinery in order to assist people working within previously labour-heavy professions, coupled with the stricter rules around health and safety in the workplace, has resulted in a number of people unwittingly reducing their daily levels of PA and leading increasingly sedentary lives;

"I used to work hard in my job, doing something energetic but then I didn't need to fit extra exercise in really, as it's gone on I've gotten more lazy and the job got easier because of machinery and health and safety regulations I guess but It's the ones in the offices, which sit down all day which are the real worry I suppose" (PARC Tom, Interview)

Due to the lack of awareness from individuals both regarding how much their PA levels had changed within the workplace *and* what this may be doing to impact on their health negatively, many individuals did not seek other, more purposeful, ways to expend energy. In the following quote this is illustrated, alongside how stereotypes of gyms still exist in older people;

"The gym stereotypes exist, especially for people of my generation as we never really used them. I mean I'm sure they existed, but mostly people got exercise in other ways, from doing an active job, or just doing more walking from place to place..." (PARC Susan, Interview)

As described previously, in post-war Britain – during my interviewees' childhoods, being physically active was a part of life. The incentives for being active were intrinsically dominated; they enjoyed the creativity and feeling part of a community, which in turn meant the exercise, came effortlessly to them and was not a conscious decision. When asked during the interview about knowing the positive health outcomes of PA in those times, the suggestion was practically laughed at;

"I've always ridden bicycle, I like riding a bike, umm, so, I suppose in a way that helped me, but it was never, it was never, err, from my point of view, taken as exercise, it was incidental that it was exercise rather than I set out to exercise for me own good..." (PARC James, Interview)

This idea of having PA as a '*natural*' part of their lives at an early age, may in part have lead them to believe that joining a gym was unnecessary throughout their adult lives and instead possess a distorted image that generally being busy and active through other social ventures or within their profession served enough of a health benefit.

8.3.2 The Arrival of Health Advice

The 'Arrival of Health Advice' and subsequent popularity of gyms was also quite a recent change in the memories of my participants when questioned about their choice not to engage in recreational PA throughout their adult lives. Doing PA for health benefits was never considered; possibly because government messages about the importance of leading an active lifestyle did not reach the general public quite so readily as it does nowadays;

"It's quite a new thing though, I never remember thinking it was good for me when I was younger, it was just something we did – and into my adult life really, I think it was only the past 20 years really that fitness has become so...umm, much a necessary part of life I suppose." (PARC Tom, Interview)

"You didn't go to gyms in those days as such, and err, there wasn't so much of an exercise ethos around, there wasn't government statements telling you that things are good or bad for you, you know, because it wasn't on the agenda like it is now with the obesity epidemic" (MOVE Joseph, Interview)

Another theory as to why people in the older generation rarely attend organised exercise facilities and illustrated by the following quote, is exactly *when* the arrival of health advice really came to be common knowledge. With the majority of participants being born in the late 1940's and early 1950's by the time the 'fitness movement' really elevated in popularity most of my participants would have had young families to support resulting in less money for luxuries of this kind, and full-time jobs meaning shortages in their personal leisure time;

"we are talking about sort of 1970's perhaps even late 70's when exercise really took off...so you're talking of me in my early 30's really, and although I was surprisingly active for my age due to the job, I think many of my generation, the advice maybe came a little too late, they were already into their routines which didn't involve organised physical activity, they had families and other priorities." (MOVE James, Interview) This unfamiliarity with organised PA and thus the types of facilities in which exercise can be undertaken resulted in a number of stereotypes of gyms and the culture of people who frequent these types of exercise facilities being suggested.

8.4.1 Stereotyping Gym Culture

Although the gym in modern day society is no longer entirely an environment dominated by males and filled with complex and specialised equipment (which was little understood, as was much the case towards the start of the fitness movement), the impressions of a gym as described by many of my participants, still seem to convey these old fashioned stereotypes in many ways.

Generalised negative perceptions of 'gym culture' were held by many individuals within this age group too. Often when referring to gyms participants would use the word '<u>them</u>' e.g. "The gym stereotypes exist, especially for people of my generation as we never really used <u>them</u>" (PARC Susan, Interview). This appears to exemplify the disconnect felt between their happiness with 'natural' PA levels and the additional effort required to attend regular 'organised' exercise classes. Many comparisons have been made between attaining the adequate PA now, and comparing those to the levels people used to get when they lead a more active role within their occupation;

"...the fact that now there are places you can go to err, umm, to exercise and to take up those things which normally would have been part of your employment or so on, so that you are actually getting some exercise and 'working out', it (exercise) is what humans have been developed to do..." (PARC James, Interview)

The sense that the gym was becoming more like a 'fashion statement' (possibly due to the

marketing strategies and types of people expected to attend the fitness centres) was also mentioned by both male and female interviewees. Participants spoke of an increased knowledge and raised awareness around the negative impact of having a sedentary job, suggesting that allowances should be made to do more exercise in their free or leisure time; a view which has now become the norm in modern day society;

"It's become more fashionable for people, ordinary people to have a regime of exercise, where they have to do exercise classes to 'fit the mould'" (PARC James, Interview)

"There is a new era of planned activity now and it became very trendy didn't it?" (PARC Grace, Interview)

This notion of 'fitting the mould' may be one which those of an older age group do not see themselves abiding by, and therefore has further exaggerated the stereotype already associated with gym-goers.

The 'thin' stereotype which is so often associated with those who frequent the gym, was typically a reason for not attending these types of exercise establishments later in life for fear of embarrassment, or intimidation that they would not fit in;

"I knew I should do it (exercise), but I was mostly worried about the gym part, I had an image of all these fit 18 year olds strutting around, and also you'd have to wear a certain type of clothes you know? I would feel selfconscious." (PARC Susan, Interview)

"I was always worried, I might be a lot older than all of the other people going, and I do worry that I won't be able to manage and then not want to go again" (PARC Priscilla, Interview)

The sense that the 'stereotypical gym user' was not someone the participants would traditionally warm to or identify with was also expressed by a number of interviewees. This may suggest that individuals within an older age group need to not only enjoy the exercise they are partaking in but also be within the company of others who they feel are of a similar mind-set to themselves;

"...if I'd joined a gym I'd absolutely hate it, I could not join a gym. Because...umm, I'd be in the company of unknown body fascists, I'm afraid, and I wouldn't want to be associated with that." (PARC David, Interview).

This may relate in part to the impression of isolation within the gym setting which was also a common perception mentioned throughout the interviews by both men and women within the older population. In a number of instances interviewees discussed how they felt the typical gym goer was a secluded individual;

"...in a little cocoon, no one notices what they do, it's too isolated, doesn't appeal to me..." (PARC Diane, Interview)

It was clear that these individuals regarded the gym regulars as choosing to disengage with the rest of the outside world, purposely attending the fitness centres as a means to escape the hustle and bustle of their lives and have time to themselves. This impression, although not expressed by all interviewed, seemed to discourage many participants from even considering attending the gym as it 'wasn't for them';

"...sitting in a gym, with headphones on, it's almost like you're isolating yourself, you don't want that interaction, that's my impression of gyms anyway, and it's not me..." (PARC Geoff, Interview)

Finally there was a real sense that many interviewees viewed the gym environment as boring, monotonous and plain. The generalised responses exemplified the repetitive nature of walking on a treadmill machine and being unable to connect with nature. This may be why we tend to associate the older population with leisurely country walks as opposed to being a gym obsessive;

"I think going on the treadmill is absolutely mind blowingly boring, so I won't do it...You can see things outside when you go for a walk, but I can't when I walk on a treadmill!" (Norman, Interview).

Despite this, there were certainly individuals who recalled positive experiences of attending the gym. John discovered that the fitness classes (where groups of people exercise together) provided an opportunity to interact with others, give support and join together to do something pro-active to improve one's health;

"I actually like the companionship I've found in my gym classes, a lot of the people there have the same outlook as I do, they might not all be older, or struggling like we are, but they are all trying to better themselves in some way, I didn't expect I'd get support in a gym, but how wrong I was" (MOVE John, Interview)

Alongside this, another individual admitted that the study had certainly changed his impression of fitness centres, and also the types of people who would attend, vowing that he would be going to the free gym on his next cruise and would not feel shy to ask for help or advice from the instructors;

"We would laugh and joke about seeing people in the gym, but we would never consider trying it. But now I have tried it (gym), I wouldn't be so judgemental I don't think. I'd go one step further...if I was put back on that cruise I'd definitely be going in there and getting on a bike for a bit, or asking advice about the weights." (MOVE Barry, Interview)

Whilst a number of the barriers listed may be valid interpretations of an older person's aversion to gym attendance, it is also possible that these barriers are merely good excuses

used to disguise a far deeper rooted concern – a fear of over exertion, a lack of knowledge surrounding how, and at what level to exercise, and more broadly the *social expectations of older people*.

8.4 Into Later Life

8.4.1 Ageing, Physical Activity and Social Change

Despite living in a time where it is widely accepted that muscles, however old, are meant to be moved, socially constructed beliefs provide a great influence on the ways in which an individual behaves. If we look at PA from an historical perspective, and towards the era of my participants parents; 'the silent-generation', we see a group of people who were more often than not born into a poverty stricken country, recovering from World War I, and subsequently had to live and work through World War II prior to raising their own children. The life expectancy of people born within the first half of the 20th century, such as the participants parents (for males 58 years and females 60 years), differed dramatically to the life expectancy at birth for the participant cohort who were born around 1950 (with a life expectancy of 66 and 71 years for males and females respectively) (Kinsella, 1992). This undoubtedly will have altered views on what it meant to be old, and the ways in which an ageing person should live.

Retirement for the 'silent generation' signified a period of slowing down – often recommended by the medical profession, and a time where they could afford to rest their well worked bodies in preparation for decreases in mobility and functionality. For many of my participants' born at a later date these recommendations still resonate, and through observing their parent's retirement years they see later life as a time to allow their bodies to recuperate; "With all this research now, people are living longer, and you want to live as long as you possibly can...when I was 16 it used to be 3 score plus 10, would be how long you're expected to live for, so I'm technically on borrowed time now aren't I? So I suppose even though things have changed I look to my parent's, and lead by their example as to what I should be doing." (PARC Tom, Interview).

There was also a perception within the sample that others held ageist stereotypes, people within that age group have an obligation to act and behave a certain way, live how others expect them to live, and 'let go' as this participant describes when referring to seeing older people within the gym setting;

"And I'm inclined to think, you're all old phonies like me, isn't it time to let go already" (PARC David, Interview)

Alongside the personal views of an individual about their bodies' capabilities, the advice a person receives from their family and friends also appeared to be incredibly influential when it comes to making a decision to be active or not. Whether it be from family members who just fear for their loved ones health and safety, or a friend who separates the older generation from typical gym-goers by making fun of the idea of a controlled exercise programme, all play a huge part in influencing a person's behaviour;

"I had to keep telling myself, 'you know you're now 70, you can't keep doing these kinds of things, you'll burn out'. I look to others for guidance, and my family tends to think I should be slowing down too, I think people just think exercise is for the young guns..." (MOVE James, Interview)

"I don't think you'll ever change the minds of my generation when it comes to exercising, as a whole. I mean I was having a chat with this one chap...I've told him about the study, and you get poo-pooed you know, it's as if he thinks there should be a big red cross over going to the gym, golf fine, bowls fine, not the gym!" (MOVE Barry, Interview) This awareness of a need to start slowing down is further exemplified when we look at how one participant compares his ageing body to that of a motor car with only 'so many miles in the tank';

> "I have a theory in life, it might be crazy, my body is a bit like a motor car, I've got so many miles in the tank, on the engine, I've given them a fair hammering, the joints, and they are beginning to rattle a bit! So I think now, fine, ok, my brother wants to go and run marathons, and I say 'look, you're getting too bloody old for that! Do enough, but don't push it' and that's where I am now! I do enough to keep myself reasonably fit, without trying to wear everything I've got left, out, I think people can go, it can become obsessive." (PARC Michael, Interview)

This metaphor could also go some way in attempting to explain why many people of a certain age group fear injury and over exertion when they engage in strenuous forms of physical activity. Many spoke of the need not only to understand how *much* PA they needed to be doing to elicit health benefits, but also needing better knowledge around using the *'correct techniques'* to avoid causing unnecessary strain and also motivate them to continue making improvements in the future;

"I don't really know that I'm doing things, *correctly*... it's no good me, putting myself in hospital by breaking something or doing something a bit too much." (PARC James, Interview)

"I have trouble with technique, I can't swim quite properly and it definitely helps having someone show you the way, no, it's true I suppose if you learn to do something properly that can help you know, give you confidence, encourage you and motivate you to do it..." (PARC Terry, Interview)

The importance of an experienced instructor, especially within this population due, more often than not, to their additional comorbidities appeared to be important to participants within this study. Within this group, participants looked to knowledgeable advisors for support, motivation and above all guidance when it came, not only to technique, but also the frequency and intensity of their PA sessions.

8.4.2 Awareness of Health and Ageing

There seemed to be an innate awareness in each of the participants interviewed about their current health status and the thought that as time passed inevitable deteriorations would occur; preventing them from doing tasks they once took for granted;

"I do worry as I get older I can't do as much, and my body won't go for as long as it used to, and I might run out of gas, but while I can do something I know how important it is so I'm gonna do it!" (MOVE Howard, Interview)

A number of interviewees were already beginning to see that their body struggled to do menial tasks that they once took for granted. '*Noticing declines*' in health by comparing their current health to their younger self was looked at in a variety of ways; from matter-of-fact conclusions drawn out of the perception that an older body naturally becomes frail, to more concerned outlooks about the years to come. One individual, James, spoke at length about his passion for travelling long distances on his motorbike, and the difficultly he now occasionally faces when trying to start it;

"If you wake up and you can't start your motorbike – which I've begin to notice I struggle with now, it plays on your mind, and you feel a slight sort of unease. Not to the point of worrying too much about it, but it's just not great that what you know you used to be able to do with ease isn't so easy anymore" (MOVE James, Interview)

Noticing this decline did act, for many, as a source of motivation to increase their PA levels and begin to live a more healthy life. Participants, like John, spoke about an increased awareness that it may be very difficult to suddenly begin PA especially in light of their recent health scare which may have suggested their bodies had already suffered enough. Nevertheless, for the majority attending the exercise sessions, it was seen as a positive opportunity where improvements may be realised;

"The problem is at our age it is maybe a little too late, the damage is somewhat already done, and it's hard to repair, so what I'm trying to do is salvage a bit about what's left by starting to up my exercise, with any luck it'll make my body work for a little bit longer" (MOVE John, Interview)

Similarly, the view by both elevated risk and cancer survivor participants was that as they aged their days were becoming increasingly numbered, and however fatalistic, this awareness, seemed to drive a number of participants to be pro-active in beginning to slow this deterioration down;

"you kind of are aware that your days are numbered and that life will inevitably start slowing down so you need to try and do something about it before it is too late..." (MOVE Jane, Interview)

8.5 Summary

This chapter considers the significant changes which have taken place over the past 60 years in Britain and how these may have had an impact upon the study populations' PA habits throughout their lives. By looking at the entire life course of an older individual, it becomes clear just how different times are now to how they were in post-war Britain. Socially, culturally and economically, these continual changes, and the need to adapt or alter their occupational and leisure time activities, may have had an impact on their lifestyle choices.

The next chapter will go on to discuss the impact of a significant health event, and how, if at all, the arrival of an elevated cancer risk diagnosis or survival from CC, may have impacted

upon their attitudes towards their personal health, and subsequently their intentions to engage in healthier lifestyle behaviours.

Chapter Nine

9. Findings Two: 'The Diagnosis'

The previous chapter considered the lives of each participant interviewed and discussed experiences and attitudes towards PA. Within the childhood memories of frequent outdoor play, and reflections of working life, to the changes in technology and transport and how their retirement years signified a very different time period from that of their parents' generation.

Taking these factors into account the participant group, consisting of elevated risk patients and cancer survivors, were homogenous in many respects with similar cultural influences up until the point of their respective diagnoses (see tables 7.1 & 7.2 of participant demographics; chapter 7). This chapter analyses the impact of a diagnosis, and how a change in health status (namely discovering an elevated risk status, or alternatively CC) may have differing effects on the way an individual perceives their own health and well-being.

9.1 Attending Screening

To be eligible to take part in the study all of the elevated risk participants would have needed to have had a screening colonoscopy under the NHS BCSP. All people over the age of 60 in the UK are sent a faecal occult blood test (FOBT) through the post, and if the result of this test appears to be abnormal, each individual is invited to have a full colonoscopy within a local hospital. Although Norfolk has one of the highest bowel screening uptakes in the UK (at around 65% in 2013) that still results in approximately 35% of people not returning the test kits. Finding out what encouraged the participants on this trial to return their FOBTs may give indication as to the type of individuals on the study, as well as what types of people who have failed to be approached for this study, and therefore may benefit from improved recruitment strategies in future interventions. Whilst all elevated risk participants interviewed for this study were sedentary prior to engaging in the trial, their increased motivation to attend to screening, and their desire to 'catch something early'; may be a factor worth considering in light of the findings in this sub-set of individuals.

9.1.1 Catching something early

The most common reason for attending screening was awareness that they would have a better chance at curative treatment of any potential cancers if a cancer was discovered at an earlier stage;

"...worst case scenario at screening is they might find something and I'll catch it early, so it means I'll have a fighting chance then doesn't it? But I'd never refuse it, why would you, I'd do anything if it means it might help me!" (PARC Michael, Interview)

The success in treating CC was relatively well known amongst the participants, which also encouraged individuals to attend screening, as it seem the logical thing to do. This may suggest a greater level of education, or indeed past experiences with the illness and/or screening itself;

"you can prevent it (colon cancer) it's one of the one's they seem to know how to treat well, and that's better isn't it -1 don't want to have cancer at all and by going to screening it will check me out, give me peace of mind, so it's for the best" (PARC Bob, Interview)

Later on in Bob's interview he mentioned that this was his third colonoscopy as he had attended each time he was called for surveillance since the age of 60. He, like many others, used the regular screening check to give himself 'peace of mind'. It allowed him an opportunity to accept help from experts, and although acknowledging the procedure was somewhat uncomfortable he suggested that it was worthwhile to put his mind at rest;

"...it's their job to give us peace of mind, and if I'm a little uncomfortable for half an hour then so be it! There's no real pain, they knock you out a little bit, which is nice! I think if somebody is good enough to try and help you, then you're a fool to turn it down, I really do. I'm thick in other aspects of life, but not with my health." (PARC Bob, Interview)

9.1.2 Encouraging Others

Another gentleman known here as Ryan, also suggested the importance of screening and the examination giving 'peace of mind'. He even suggested that he often encourages his friends and other family members to break 'barriers' towards screening and attend because of his heightened awareness that cancer was everywhere;

"I personally tell people about my situation and what's happened, I think we have to break this barrier...because cancer is happening all the time...and as a result of going through the whole screening process it's given me peace of mind, that's the most positive thing, so I would encourage anyone to do it" (PARC Ryan, Interview)

9.1.3 Risk

Screening programmes are often put in place to target individuals who do not yet have any symptoms, however thoughts often turned to risk awareness and whether or not the individuals had worries about their personal risk status which may have impacted upon their choice to attend;

"I didn't think before I went for screening about being at 'risk' of cancer as you put it...I didn't feel like I was ill, and I didn't have symptoms, so I figured I would be pretty safe down there, I just thought if the opportunity to check was there, I should take it. I didn't label myself at all." (PARC Ray, Interview)

Many individuals felt surprised when their FOBT results were returned as 'abnormal' due to a lack of symptoms or previous family history of CC. The majority of interviewees then turned towards putting the examination to the back of their minds and trying to remain positive without expecting the worst – which in this case would have been a CC diagnosis in the case of Diane;

"I suppose it did surprise me when the result from the post-test came back abnormal, and they asked if I'd come and have a proper check but you try and put that to the back of your mind and think positive, and I was A-OK thankfully." (PARC Diane, Interview)

It was clear through talking to the participants that despite acknowledging that screening was an uncomfortable experience the alternative (the likelihood of CC) was not worth thinking, and therefore it was irresponsible to not attend screening, especially after receiving an abnormal FOBT;

"It's no good saying, 'yes I might have bowel cancer as this thing (FOBT) has flagged something up, but I'm not gonna do anything about it' I don't think that's a sensible way to go about it at all, it seems logical to go, regardless of how uncomfortable I am" (PARC James, Interview)

The previous quotations also illustrate the aforementioned point regarding this study's participants being of a more motivated and informed sub-set at a later stage of change (as described by the Transtheoretical model (Prochaska and Marcus, 1994)) with regard to health choices.

Above Diane referenced her polyp result and therefore heightened risk status as being 'A-OK'. Although having polyps is a positive outcome in reference to fearing cancer prior to the examination, the need to discover the level of understanding around what patients believed a polyp to be was extremely important in trying to determine current views on their personal health status.

9.2 Polyp Awareness and Understanding

When questioned many of the elevated risk participants within this trial appeared unaware of what a polyp is, the polyp-cancer pathway and what polyp removal means for their future cancer risk status. The use of the word 'polyp-things' within the next quotation highlights this level of uncertainty within patients and the 'weight' that HP advice and assurances may have on patients' risk interpretation;

"According to the one's in the know, I'm perfectly healthy down there (*points to bowel*)...well apart from a couple of these polyp things, I think they are called, but I was assured they were nothing to worry much about so I won't be worrying myself about them!" (PARC Simon, Interview)

"I think they found a few polyps in there, but thankfully they were all benign, everything else was clear, and they said I was absolutely fine, no cancers, and nothing to worry about, I only needed to come back three years later" (PARC Tom, Interview)

The second quote further exemplifies this point and clearly illustrates the *'health certificate effect'* as mentioned in the literature review. The reassurances from HPs coupled with their relief of not having cancer and the fact that they remain under surveillance for further polyps in the years to come, appears to be a powerful indication to patients that they have 'nothing

to worry about' and that they can continue on with their lives without consideration of their screening outcome.

It was even suggested that polyps were not fully explained in one participant interview, with the gentleman having no recollection of being informed about the differing polyp grades and how they could potentially develop into cancer;

"I didn't realise there was anything worse than intermediate risk to be honest. I'm not sure the different grades of polyps were ever explained to me until the study, I just thought I had cancer or I didn't" (PARC Ray, Interview)

It is hard to say in this case whether the gentleman simply could not remember the information being provided during the HP meetings, or whether the HP actually failed to describe the basic details around polyp formation, however, it does emphasise the need for increased clarity and repetition during these patient contacts without causing unnecessary concern or distress to the patient.

A number of individuals only realised that polyps may be a cause for concern after they agreed to participate in the study and the polyp-cancer pathway was described more clearly. Whilst the relief of having an 'all clear' for cancer during their colonoscopy was the immediate feeling post-screening, a few of the more health conscious participants reflected upon their initial positive emotions with a little concern for what having polyps actually means in terms of their future health;

"Immediately I felt relief that I presumably don't have bowel cancer and they didn't need to see me again for another three years but also there's the fact they did find polyps - and that kind of dawned on me after, well since doing this programme really, I think it (finding polyps) was played down obviously, as it's a positive outcome, but I guess it's not that great is it?" (PARC David, Interview) It became apparent that there appears to be a lack of understanding about the heightened future cancer risk of further polyps after polyp removal from a patient perspective, but whether patients actually want this type of information to be provided during their screening examination was another area which warranted exploration. Participants undoubtedly expressed a need for renewed clarity in the way that results are given to elevated risk patients; this however would need to be delivered tentatively as to avoid scaring people or raising unnecessary alarm;

"I wouldn't want them (health professionals) to scare me, but it can't hurt being warned a bit, told 'polyps do actually increase your risk of getting cancer in the future even if you have had them removed'. It might make you step back and think, 'oh, well maybe I should be a bit more careful, or keep attending these screening checks'." (PARC Priscilla, Interview)

In reference to the impact of the *diagnosis* on choice to engage in PA, this apparent lack of understanding and subsequent '*health certificate effect*' may be a real factor into why so few individuals within this 'at risk' population feel the need to lead a healthier lifestyle;

"I can't remember receiving any kind of advice, especially not on exercise, so no; I wouldn't have thought 'oh I need to be concerned about this'. I was told I was fine, go home and 'be happy'!" (PARC Ray, Interview)

By making comparisons with the cancer survivor group on the impact of their diagnosis and also their reasoning for taking part in a PA intervention such as this, it became clear that a cancer diagnosis had a greater impact on current perceived health behaviours, something which was important to explore. Whilst each cancer survivor came to terms with their illness with varying degrees of apprehension, all agreed that living through cancer was certainly a life event which triggered a TM and encouraged them to think toward their future health.

9.3 Impact of the Cancer Diagnosis

Despite cancer treatment and the chances of survival continually improving, a cancer diagnosis is, for many, still an incredibly upsetting time. When asked to reflect back to the point of diagnosis the cancer survivors who were interviewed expressed very varied responses on how they felt. These emotions included fear, with Mandy describing feeling *'cold inside'* when she failed to get the *'all clear'* from the FOBT, ambivalence with Barry explaining he was *'not shocked'* but just hearing the word cancer still *'chilled (him) to the core'*; and at times suspicion in the case of Joseph, who had suspected something was amiss due to some *'pretty bad symptoms'*.

Whilst the reactions to diagnosis were varied and sometimes opposing, the general consensus from all interviewees was that they would try to do everything in their power to stop the cancer from returning if possible. One female interviewee was not alone in worrying that she could have done more to reduce her chances of getting cancer in the first place, and to combat recurrence she was more determined than ever to become a healthier person in her recovery;

"I also thought a lot about stopping it from coming back. I did think to myself a lot, 'why me', not a case of what had I done, but more what had I not done, could I have done more..." (MOVE Jane, Interview)

The feeling of 'why me' was a common theme. Cross-comparisons were made with friends or members of their family who had smoked, drank or were obese their entire life and had no health scares, whilst they remained conscientious with their well-being and 'unfairly' had developed cancer. In the following quote, James appears to externalise the problem of developing cancer by appearing helpless and powerless when it 'found him'; this alone may provide personal justification for a lack of PA initiation. Although this diagnosis was clearly shocking and frustrating it was surprising just how many of my interviewees developed the ability to adapt, look forward and try to 'get over' the illness with as much positivity as possible.

"...psychologically it was a bit of a mine field, I was thinking, it's far too early for me, it's not fair – I am quite well behaved, I eat well, I keep fairly active, I just didn't understand why it had found me and it's something I guess you just have to adapt to, and get over." (MOVE James, Interview)

This positivity resonated within all of my cancer survivor interviewees with all describing the need to maintain a strong mental attitude and in order to pull them through the illness. It is difficult to determine whether this common personality trait was due to the fact we approached the participants post-recovery, or indeed whether studies of this kind just appeal more to a more optimistic individual, however it was certainly a factor all cancer survivors cited in helping them get through the disease.

9.3.1 Looking forward

For many, the need to look forward and accept any help which was offered was of paramount importance. Barry compared himself to a car which needed a new engine with regard to his decision making around treatment. He saw no other alternative but to listen to the HP's advice and go through with whatever treatment they deemed necessary. The sheer determination to recover, and continue improving under all circumstances was obvious and could be a real reason for their interest in an intervention study aimed at improving health;

"If you take your car for a service and they say it needs a new engine you make that decision don't you, if you take yourself to the hospital and they

tell me at that time, if you do some exercise, or change this or have this, I would have definitely done it, you have to look forward, the alternative isn't worth considering" (MOVE Barry, Interview)

Wanting the life that they used to have back was a common theme expressed throughout the data collection, and this seemed to drive a number of people to be proactive in their recovery. Two gentlemen mentioned that being able to do something active as soon as possible post-surgery was the thing that regained a sense of normality in their lives, whether that be something as simple as walking or slightly more challenging such as playing a full game of table tennis in the cases of James and Barry respectively;

"I was up and walking as soon as I possibly could after my chemo to be honest – I made sure I was up and about, I needed to regain a sense of normality in my life, and it's the little things which do that." (MOVE James, Interview)

"Once I knew I could play a game of table tennis I felt like myself again, it made me feel a bit more human again, not just a pin cushion recovering from this terrible illness and this study certainly helped with that." (MOVE Barry, Interview)

Howard was another man who spoke about wanting his *old life back*, but owed thanks to his stubborn yet positive persona which he believed was the reason why he was so focused on achieving his goal;

"So all in all, I didn't find it as tough as some people might expect, all I wanted was my old life back and that was all I really cared about, nothing else crossed my mind so I was quite proactive with my recovery...I think a lot of how you react to an illness is about the person, and what kind of personality you have, and I'm positive but stubborn so I knew I would try my damnedest to get through it." (MOVE Howard, Interview)

As illustrated by the above quotations many of the cancer survivors wanted to be proactive and move forward, with the hope that the cancer would not return. However, they often remarked about wanting to get back to their old selves who were actually sedentary prior to receiving the diagnosis. In the quotation by John below, although similarly speaking and moving on; there was certainly a sense of looking forward to a new self;

"It (cancer) made me step back and think. Without any doubt at all. Yes. It made me realise that, I needed to be healthy, I need to change, if I'm going to be able to carry on. You know, you're diagnosed with a cancerous condition, and I was lucky enough to fight one lot off, so your immediate thought is, right, I need to try and stave off any horrible things that may try and come back in the future, not just cancer, but everything, and I won't do that by just sitting around" (MOVE John, Interview)

It was however, this level of proactivity and forward thinking which really set the two patient populations apart. Whilst the cancer survivors wanted to do everything they could to prevent the cancer from returning, the elevated risk participants seemed rather more static with many leaving their screening unaware of their renewed risk status post-polyp removal and not considering change;

"I have wanted to lose weight for ages...but that's not because I thought I particularly needed to, and it certainly isn't because I knew that it would have any impact on my polyps, I didn't really think they were a big issue really!" (PARC Lucy, Interview)

This distinct difference might help to explain the disparities when examining the recruitment rates for each of the randomised interventions in question. Whilst the elevated risk intervention recruited slowly over a long period of time, the cancer survivor intervention was extremely successful, encouraging a similar amount of participants who maintained participation, over a much shorter recruitment window.

9.4 The Teachable Moment

9.4.1 Cancer Survivors

When asked about their reasons for participation within the study, cancer survivors were far more recovery focused, whether that was in relation to learning from the illness as an important health scare or lessening their chances of recurrence.

Discovering cancer was certainly a life changing experience for the majority of the participants within the cancer survivor study. For many it was the 'light bulb moment' that encouraged so many to pursue a healthier way of living, and despite a number of participants speaking about how they had previously lived an active life, the scare seemed to make them reassess their previous life choices and encouraged them to really engage in new lifestyle behaviours;

"I'd say the cancer has massively heightened my attitude to the importance of doing exercise, and living healthily. I wouldn't say our attitudes have changed, we have always like being active, but I have most definitely had the screw turned a little tighter, which has given me that kick up the backside and told me not to flaff around with getting back on the road to living healthier" (MOVE John, Interview)

"something that gives you that much of a health scare, I think it has to make you think for sure, it certainly did for me...and I am doing small things to change my health, small but hopefully significant things" (MOVE Jane, Interview)

One gentleman, Richard, did not fit the mould when he spoke about the impact of his cancer diagnosis. A number of years previously, Richard explained he had become very unwell with a brain tumour; it was as if this illness was perceived as a far greater concern than the subsequent CC diagnosis;

"I was still surprised by the cancer, yes, but then again having this brain tumour in 1992 taught me to take these things as they come, that (the brain tumour) was certainly more life-changing than the cancer for me, but from my understanding it (brain tumour) was also more life-threatening, so that probably made a difference" (MOVE Richard, Interview)

Despite this anomaly, the common views regarding pursuing a healthier lifestyle post-diagnosis were often expressed when asked about their reasons for participation within the exercise intervention. These reasons for study participation (and therefore the opportunity to be placed within a behaviour change intervention) showcased a unique difference between the two patient groups – a factor which may explain why we recruited so poorly to the elevated risk interventions in comparison to the cancer survivor trial.

9.4.1.1 Second Chances

A number of the more spiritually minded individuals on the study spoke of how they felt that they had been offered a second chance through surviving cancer, and that as a result of this it was essential to take every opportunity for help that arises whether that was medically or more proactively by doing more PA. In the case of John and his wife Alice, they saw the PA within the study as a clear sign to begin paying attention to their health and make the most of their second chance;

"... we think that you do get second chances in life, like I have had with my cancer, but it doesn't come along easy, and you can't just go and knock on its door, you need to prove yourself worthy in this life first, make the most of it, take every opportunity that arises to help yourself really." (MOVE John (& Alice), Interview)
9.4.1.2 Sense of Duty

Duty was another frequently mentioned theme, both in relation to being offered a second chance as mentioned previously, but also in feeling like without research they would not have survived cancer and therefore it is an obligation to try and help future cancer sufferers through volunteering in studies such as this;

"I just think it's my duty to help seen as without research I probably wouldn't have survived cancer, and it's kind of my second chance isn't it, to make a change to myself and do something positive." (MOVE James, Interview)

"I just think someone must have had to go through a similar thing in the past to have helped me survive cancer, and if I can help find a cure, or get better treatment then I feel I absolutely had help in some way, it was my duty to help in some way" (MOVE Barry, Interview)

Similarly, the feeling that by participating in a trial they were contributing towards a greater good and need to *find a cure* was repeated by quite a few of the interviewees. The importance of research and the need to have willing volunteers 'pushing together' was well understood and resonated as a popular reason for not hesitating in trial participation when the invitation letters were received;

"Then obviously I thought it would be great to help out with the research, and maybe help people in the future in some way – the more people doing research the better our chances are of curing this thing so we all need to push together really" (MOVE Joseph, Interview)

Following on from the themes of *duty* and *finding a cure*, the quality of care received whilst in the hospital, and post-surgery was also a large part of why individuals felt they had a

responsibility to do all that they could to help the cancer fight even if it did mean a little bit of spare time was utilised;

"I mean I've had wonderful care from the team at the hospital, sooner or later they have got to find a cure surely, and I'm in the mind-set that every little helps, and if it takes a little bit of my time that's nothing really, finding this cure is so important." (MOVE Mandy, Interview)

9.4.1.3 Personal Gain

Prior to starting the study I assumed that the chance to be part of a personalised exercise programme (despite there being an equal chance of selection for the usual care arm of the trial) would have been a strong incentive for prospective participants to volunteer. The idea of personal gain from the study was, in fact, one of the least mentioned contributors, and only ever mentioned when talking to the cancer survivors, not the elevated risk individuals. In the case of Joseph, he hoped that being part of an intervention focussing specifically on motivation for exercise would get him 'back into the habit' of being physically active;

"...really my first thought was extremely selfish, I thought to myself it (*the study*) would be a really great way to improve my fitness and get me back into the habit of exercising, you know, after the cancer." (MOVE Joseph, Interview)

Richard specifically spoke about feeling lucky that he was put into the intervention arm of the trial as it not only allowed him to feel he was contributing to society, but also that he was also feeling improved health outcomes as a result;

"I was very lucky at being put in the half where you get worked hard, I really enjoy that and it's helping me out no end with aches and pains...having actual benefits for my health is really helping me out too I wouldn't say it's the only reason I'm taking part but it's certainly a great perk." (MOVE Richard, Interviews)

The randomisation and group allocation did raise important ethical questions; especially within the cancer survivor study as doing exercise may have had some beneficial psychological and physiological outcomes for all survivors;

"I'd like to get back to the gym again. But I am very aware I am on this study, and I'm in the control group, and I have been told in a roundabout sort of way, try to keep to what you've been doing the last three months...so I'm conscious of that, but certainly it is a bit disappointing not getting the exercise" (MOVE Mandy, Interview)

Despite encouraging the maintenance of previous exercise behaviour in individuals in the usual care group to get a clearer picture about the effects of PA during the study, we did offer them exercise sessions after the final follow-up assessment as a gesture of good will, however only 3 out of 13 participants within the control group decided to agree to this.

9.4.2 Elevated risk patients

Looking at the findings around motivation for trial participation and PA generally from the elevated risk participants, again really demonstrates the difference between the two groups. By looking at each person's reasons for participation within the study, it may be possible to apply this to daily life and their willingness to change their lifestyle with the hope of improving future health.

9.4.2.1 Altruism

Altruistic tendencies really seemed exaggerated within the elevated risk participant group, with all interviewees claiming they were participating in the research study to 'be useful' or to 'help others'. Whilst Diane focused on making use of her extra time during retirement in a positive way, Ryan made it clear than his participation was purely a selfless venture to help people in the future;

"...if I can be of any use in helping people in the future, I try to be, I think people like to feel useful, especially during retirement when you tend to have more time on your hands" (PARC Diane, Interview)

"...my reason for doing this wasn't for my own personal benefit, I didn't know which group I'd be in, it was because I thought I could help someone else recovering from cancer, or prevent someone from getting cancer in the first place, make the research in this area a little clearer for people." (PARC Ryan, Interview)

Cancer still seemed to be thought of as a disease which happened to *other* people and, despite acknowledging that volunteers are needed for this type of research the reasoning for participating was certainly for the benefit of others, rather than to reduce their risk of developing the disease in the years to come;

"Someone needs to volunteer don't they, someone needs to give a little back into research, and if I can do that, then so be it. It's only a couple of hours, it's not the end of the world is it, if I can help maybe save someone in the future, or give someone a better way of life, or better advice on how to prevent a bad situation then I want to do it really" (PARC Michael, Interview) Occasionally the driving force for participation was when the individual had been exposed to cancer in the past either through a friend or family member, or indeed had known someone who had been positively affected by research;

"I have had a history of cancer in my family, and close friends, over the years who have both won and lost battle with cancer, so that was a real driving force to be honest, I wanted to help as much as I could because I really know how studies like this can help." (PARC Geoff, Interview)

9.4.2.2 Wanting to help the science

The main similarity between the elevated risk and cancer survivor participant interviews was the awareness by all of the interviewees around the importance and need for good quality research studies. As well as looking to the future, individuals often mentioned how far we had come with medical advances and life expectancy in the past few decades, and how this would simply not be possible without the help of research, and research volunteers;

"I can really see the importance of research in helping make life better for people in the future. You need volunteers to come forward; nothing would ever get done if we didn't." (PARC Geoff, Interview)

"I mean think where we were 100 years ago with any kind of disease and you'll see huge advances, both in knowledge and also the bits and pieces they use to detect things and cure people. Without tests and trials none of those things would have been found out" (PARC Susan, Interview)

The distinct differences between these population groups demonstrated in this chapter through exploration of reasons for study participation emphasise the sheer impact of a cancer diagnosis on a person, and conversely the lack of stress placed upon the significance of an elevated risk screening outcome. If we want to heighten the awareness within the elevated risk patients in the future to encourage healthier lifestyle choices, HP's in the screening setting are likely to have a central role in this transition. This issue was explored within participants, as explained in the following section, and HPs, whose main findings are reported in the final findings chapter.

9.5 Influence of Health Professionals

When questioned none of the participants could recall receiving any lifestyle advice aside from the 5-a-day fruit and vegetable leaflet offered during their pre-screening interview with the SSP. There appeared to be a real respect for the advice given by a HP and many suggested that if a professional was to give any guidance on PA specifically, it would be something that would stand out and be remembered;

"no, they never gave any advice about that type of healthy living stuff, I reckon I'd probably have remembered if they had said something I'd have thought...if a doctor told me to do it (exercise), it would stick in my mind a bit more" (PARC Diane, Interview)

These findings were also echoed by the HPs who confirmed that no lifestyle advice is currently given to patients who are identified as being at elevated risk of developing CC after their screening colonoscopy – something I will cover in great detail within the final findings chapter, 'An Opportunity Missed?'

9.5.1 Trust

Trust is of paramount importance when it comes to a patient-practitioner relationship. Whether that be in relation to a declaration of confidentiality within a hospital, giving medical advice on treatment and prevention, or with regard to taking part in a research study purely because a HP has endorsed participation. Whilst we were very lucky to have the support of the HPs within the gastroenterology unit and all interviewees agreed that having the approval of a team of experts certainly aided their decision to take part, it did seem that the professionals who encouraged the study more, received the most positive response and the greatest uptake;

"I think having a nurse to tell you about the study is great. I think it really encourages people, and patients need to be got at that stage whilst in the hospital, whilst they might be swayed more easily ...but also because you are more likely to listen to someone in uniform!" (PARC Grace, Interview)

Susan in the quote below concluded that if greater time was taken and more information about the nature of the study was provided (including that it would take place in a private gym and not in front of other people) recruitment levels would have been much greater. This example is just another aspect where HPs have a huge influence over a patient's behaviour and contact time should not be overlooked;

"...more people would be interested in taking part in this study if the doctors and nurses really emphasise that it's not in the main gym with the public. They (*HP*'s) kind of mentioned the study, but didn't exactly tell me much about what it involved and having that extra few minutes with them really backing it up would sway a lot more people I'd imagine" (PARC Susan, Interview)

Interestingly one interviewee, Barry, suggested that people within 'his generation' especially, were far more likely to pay attention to the advice of a HP, especially if that advice was targeted, tailored and directed towards them;

"...especially with my generation, having them (*HP*) say something would definitely scare you more. If it was in a magazine or on TV it doesn't apply directly to you does it? You feel like the message is for you if they direct it to you personally...and I defy anyone who wouldn't at least stop and take a

bit of notice at what a doctor or surgeon said to them." (MOVE Barry, Interview)

"...if a doctor asks me to go and do anything have a check for this or that, it's not worth turning it down, they are the ones we can trust, they are in the know." (PARC Tom, Interview)

Taking into account the findings throughout this chapter; namely the lack of patient knowledge regarding risk status, the *'health certificate effect'* experienced by polyp patients in contrast to the *'teachable moment'* elicited after surviving a cancer diagnosis, and the potential influence HPs have over patient choices, it seems than an important opportunity for health promotion amongst polyp patients is being missed within the screening setting. The following chapter will go on to explore this potential 'opportunity' as well as outline the complexities of delivering this type of advice within the screening programme.

Chapter Ten

10. Findings Three: 'An Opportunity Missed?'

By looking into the perceptions around what an 'elevated risk' of developing cancer diagnosis means to individuals within this qualitative sample after their screening procedure, it could be concluded that the level of understanding around future risk status and the preventive behaviours which may lower this risk seemed to be relatively low. This chapter seeks to explore in greater detail from the perspectives of both the patients attending screening within the randomised controlled trial and also HPs working in the screening setting, the views on health promotion within the screening setting at present, and whether this specialist environment may provide a unique opportunity for health promotion.

10.1 Polyp Awareness and Understanding

As mentioned in the previous chapter, it was suggested by the participants interviewed that HPs tended to play down the significance of having polyps removed during screening. For the majority this signified an 'all clear' message, however, for the more health conscious individuals it did give them time to think about what a polyp could signify, and whether the implications of having polyps in the first place should be explained in greater detail;

"...they found these polyps after my colonoscopy, benign or not, they still found something, and although that technically means I'm all clear for cancer, I guess it does definitely make you think, but the nurses don't really make you believe they are a cause for concern, I think it's only because I am very health conscious it worried me, it's definitely not emphasised" (PARC David, Interview).

Alongside this, there were a small number of individuals who wondered whether they may be to blame for their polyps, and also whether there was anything they could change in order to prevent additional polyps forming in the future. These thoughts alone suggest that there is no mention of the influence of lifestyle on cancer risk and also polyp formation throughout the screening process, something backed up by many of the interviewees;

"I can't remember receiving any kind of advice, especially not on exercise, so no; I wouldn't have thought 'oh I need to be concerned about this'. I was told I was fine, go home and 'be happy'!" (PARC Ray, Interview)

"I may be mistaken (about receiving no advice) to be honest, I was concentrating more on how the procedure would be, I was always up for that, because as I said earlier, if you go to a doctor and you have a complaint, and they say you need to do this, then you *do it*, or there's no point in going. There was no emphasis, so far as I recall, there was no emphasis on the exercise side of things..." (PARC James, Interview)

10.2 Patient Opinions about Receiving Health Promotion at Screening

The opinions of patients when asked how they would feel about receiving health promotion during their screening procedure were generally quite mixed. The majority believed that hearing this advice would not be detrimental, and therefore thought there would be no harm in providing it, whilst others mentioned that to encourage elevated risk individuals to do more PA there should be more solid evidence and greater research to warrant providing the information;

Necessary Component

"And if exercise is the big thing, like you think it might be, I don't know why it's not sold more, I don't know how you sell it, but it should be, especially after the headlines making top story today. I think most people would take up exercise, they would be a fool not to if they thought it could really help." (MOVE Barry, Interview)

"I think any kind of exercise advice maybe needs to be on a one to one basis, if they feel the person is leading an extremely unhealthy lifestyle then they really do need the advice, it would be wrong to not encourage it really" (PARC Ryan, Interview)

Many participants expressed the view that all patients have a *right* to be given details about certain risk reducing behaviours if it may benefit their future health status. The following quote is by a cancer survivor taking part in the programme, who appears to feel a little cheated that he did not receive this type of information in screening checks prior to finding out about his cancer diagnosis;

"I wish they had said something about exercise after my operation, or even before, when I went for screening in the past, nothing was said, and it's bad really, I think we have a <u>right to know</u> if the research is out there that it might help, we should know about it. It didn't come out until I started this programme." (MOVE Barry, Interview)

Need for more Research

As briefly touched upon a large amount of the participants made comment that to justify giving solid advice on the benefits of doing more PA to each and every patient during screening, there would need to be a greater number of studies confirming the assumptions that risk is significantly reduced;

"I think that is one of the main reasons you lovely ladies are doing all that you're doing, to find out whether exercising actually makes any difference or not... from the things that I have been told, or the things I've learnt from other sources, basically, not as much is known about various types of cancers, not enough is known for people to say yes should or no you shouldn't" (PARC James, Interview) Despite this, and the 'right' to get guidance that individuals occasionally mentioned, a large proportion spoke of the positive outcomes of PA, not only in reducing disease risk, but also in terms of mental health and well-being. This suggested that regardless of whether the specific research determined a key link between the health behaviour and polyp risk or recurrence, individuals should be encouraged by HPs to increase their activity levels regardless, due to the additional physical and psychological benefits which may come as a result;

"That's the biggest thing I've learnt from this, and even if it (*PA*) doesn't work for everyone, why not just give the advice anyway – it won't do us any harm, most of us could do with losing weight!" (MOVE Barry, Interview)

"It (*PA*) is a natural thing though, for someone to say you should take more exercise, for lots of reasons, everybody should take more exercise" (PARC Terry, Interview)

Conflicting Advice

Another feeling, expressed by one of my participants, is that often so many messages about cancer prevention are suggested; the advice can often feel contrived and become confusing for the general public. This sense that 'everything causes cancer' seems to give each piece of preventative advice less weight, and encourages many people to adopt a fatalistic attitude that nothing they can do will prevent them from getting cancer, regardless of their choice to be healthy or not;

"...you don't want to put the fear of god into people by saying; 'you'll get cancer if you don't take exercise', they won't take any notice of that, cause there's so many conflicting reports, about this stuff...healthy lifestyle, what you eat, how much exercise you do, and then someone comes up and says 'oh it doesn't make any difference', a glass of red wine a day is good, it's not good, you know, people don't take any notice of that anymore" (PARC Terry, Interview)

Unnecessary

Only one individual stated that he felt lifestyle advice during the screening setting was unnecessary, however he did not mention that he would not welcome the advice if it was provided, just that it would not be an effective way to encourage him to participate personally. He favoured HPs to have a somewhat more traditional role when it came to information giving, and preferred simply 'hearing the facts' of the procedure and the diagnosis;

"I think on that basis the information I was given was enough they could safely give me without umm, having me running around like a chicken with his head cut off because I might get cancer, there was no emphasis one way or the other, it was just the facts, and that's what I like" (PARC James, Interview)

10.3 Expected Barriers for Promotion from a Patient Perspective

Whilst the majority of participants supported the inclusion of lifestyle advice within their screening procedure, a few individuals provided their thoughts as to why it isn't already being implemented, taking into account elements such as the complexity of behaviour change, the lack of time within the HP discussions before and after the procedure and an anticipated lack of success.

10.3.1 Complexity of Behaviour Change

Many acknowledged that changing one's behaviour is not something which happens overnight, and for this reason, suggested that the current advice given does not include lifestyle guidance which would need to be tailored, and in many cases, continually monitored for the best results; "If I've learnt one thing through doing this programme it's that getting lazy people like me to do exercise is a pretty complex process and to promote the value of exercise in hospitals, especially to those in the 'at-risk' category would require quite a bit of time and a specialist team of people. All with different expertise, things like psychologists and physiotherapists are necessary, as well as knowledgeable instructors and medics who are allocated the time and physical resources to empathise with and most importantly motivate individual patients" (PARC David, Interview)

The idea that a team of specialists would also be required to successfully implement a lifestyle change was also an element a great number of participants within the intervention arm of the study suggested – possibly because they have seen the multi-disciplinary nature of lifestyle change first hand through participating;

"it's very complex this exercise thing, I've noticed that with this study, Liane tries to do the exercise but also talk about how we are finding it, and that is so important, so any doubts or problems are knocked on the head before they become a problem, and health professionals just don't have that constant contact unfortunately" (PARC Ryan, Interview)

10.3.2 Feeling Rushed

Another element linked loosely to the previous point is the feeling that within the discussion before, during and after the screening procedure only necessary information is discussed. Therefore, the strict regulation around the timing of each of these encounters would allow very little time to discuss lifestyle. Participants were concerned about rushing these essential talks to try and squeeze a lifestyle discussion into the protocol, something which would need a great level of care and time, and may in turn, take away from the other, compulsory elements important to each patient at each stage of their screening;

"But also, isn't it the 8 minute rule or something, they only have 8 minutes per patient and that isn't enough time to assess someone's motivation to exercise or quit smoking, and to change behaviour like that it takes so much time" (PARC Ryan, Interview)

10.3.3 Hypocrisy

A small proportion of the participants interviewed spoke about how they would find it more difficult to take advice from a HP if they themselves did not appear to be 'practising what they were preaching'. The need for professionals to act as a role model and encourage patients to lead by their example is an interesting finding in relation to advice giving within the medical setting;

"I have never really been spoken to about my exercise levels by a GP or anything. But they aren't the healthiest bunch are they, makes you think 'why should I listen to you'." (PARC Ryan, Interview)

10.3.4 Fear Factor

Concerns about scaring patients by giving them additional lifestyle advice was only mentioned by one individual, a lady within the elevated risk intervention, who had also undergone a number of hospital treatments for various health problems throughout her life. She spoke about how receiving an 'abnormal' result on the FOBT was worrying enough, and giving additional information about lifestyle at this stage may leave patients feeling they are to blame for their elevated risk status;

"I imagine they don't want to scare people. I was already a bit freaked out by my abnormal test anyway, so telling people information that might make them feel they are to blame, I guess that could be a reason why they don't say anything" (PARC Margaret, Interview)

10.3.5 Lack of Success

The final barrier spoken of when discussing the potential for lifestyle advice in the screening setting was that patients would not listen to or remember the advice, and therefore was there any point in wasting time providing the guidance if only a very small portion of patients would follow the recommendations;

"It's whether anyone would actually listen to the advice too, I mean it's all well and good saying it, but if people don't listen then it's wasting time isn't it" (PARC Ryan, Interview)

10.4 Preferred Method of Receiving Advice

The general view from most of the participants interviewed was that if lifestyle advice was to be incorporated into the procedure it would need to be repeated and made 'more obvious' by giving the information in multiple formats.

The need for the advice to be given face to face was often discussed, stating that it would provide a more personalised message which may encourage those least likely to listen to adverts or television programmes, to actually pay attention as it was aimed at them;

"I would assume people will listen to a nurse or a doctor, especially in something one to one, if they show a more personalised interest in your well-being. If it's just a general message it's aimed at the public generally, whereas this is just you" (PARC Grace, Interview)

This was also coupled with the need of a 'supporting' document, like a leaflet in order to allow each person to reread the facts given during the discussion, as well as reminding them of the benefits of increasing their PA levels, which would then allow them make an informed decision about whether to change their lifestyle; "I need to have the risks, the benefits, and the general things explained to me, if that's in the form of a document then that's good, then I can make my decision, I'm not pressured into it, I like to make an informed decision so I can take on board everything." (PARC Michael, Interview)

Speaking to individuals working within the gastroenterology unit was then decided upon, with the hope of illuminating possible disparities between patient and professional stories around health promotion, and identify potential areas for improvement.

10.5 Health Professional opinions about providing Health Promotion at Screening

There are differing professions within the unit at the hospital, with all individuals performing their own roles much like an individual cog in a clock. It is only through entering the ward that the importance of each of these cogs really becomes clear with everyone working together like a well oiled machine on the surface, this multi-dimensional team and typical patient pathway through the screening setting is illustrated in figure 1.1.



Figure 1.1: Patient pathway through Screening.

To get a clear picture of the screening setting, it was essential for me to talk to as many professionals as possible to identify whether their impressions of the lifestyle advice given could be improved, but also how this might be achieved and what barriers are preventing these changes from being implemented.

Four professionals were interviewed; the colorectal surgeons, endoscopists, SSPs and finally SNs. Learning the different roles of each of these professional groups was an essential element of the preparation needed before each interview as, although the questions asked of each interviewee were similar, the wording would need to be slightly changed to be relevant to each interviewee. By looking at the pathway in figure 1.1 it is clear to see that health promotion and specifically the promotion of PA behaviour could be given by any number of these professionals, and also during varying stages of the screening process.

10.5.1 What Advice is Given?

This part of the study set out to explore from the perceptions of HPs, whether any health promotion or PA advice is given, by whom, at what point and in what format that advice was given. However, the general response from the professionals was that advice is currently not given. The SSPs and SNs stated within their focus groups that the only information given to patients regarding lifestyle choices was a sheet pertaining to the recommended intake of five fruits and vegetables;

"We have the information and we give that out as a matter of routine in the umm paperwork they take away they get a symptom awareness leaflet, and a 5 a day leaflet, but that's about it" (SSP 1, SSP Focus Group)

With regards to the endoscopist and colorectal surgeon the majority of responses suggested that there was a lack of awareness not only in relation to the lifestyle advice provided by the nursing teams pre and post screening, but also generally the information discussed with patients during their introductory and admittance interviews; "I'm not aware of what they (nurses) discuss really; I don't think they (patients) get any stuff about lifestyle though, not as far as I'm aware..." (Endoscopist 1, Interview)

10.5.2 Current Protocol

In terms of what is actually discussed with the patients during the pre-screening interview, and admittance meeting, it became clear that there was a written protocol which needed to be followed, and a certain *prioritisation* of the information both given (e.g. details about the procedure) and taken (such as questions around the patients' health status). Therefore in the limited time allowed for these meetings in an extremely busy unit, certain aspects took priority such as the importance of attending screening itself, discussing potential family history of CC, the pathophysiology of a polyp, and the polyp cancer pathway in an attempt to clarify the results which may follow if the patient was to be diagnosed at 'elevated risk';

"Our interviews are quite formulated and structured; we follow a pattern, A, B and C. But we do ask them, have you understood this, do you have any questions...we always try to cover everything important from the procedure itself to the important health questions we need to know before taking anyone into a procedure like this" (SSP 2, SSP Focus Group)

Despite the successful tried and tested current protocol, the response by HPs around including more detailed advice around the importance of lifestyle was, in the majority of cases, extremely positively received. Many interviewees spoke of the importance of giving this advice to elevated risk participants due to their higher risk of developing more polyps, or even cancer in the future;

"Well they certainly should give (elevated risk patients) more advice because umm, having had polyps they are actually at a higher risk of getting more polyps or cancer so they are the ones who are most likely to benefit from lifestyle advice in the long term" (Surgeon 1, Interview)

10.5.3 Positives of Utilising the Screening Setting

As well as this the HPs from a variety of roles within the unit could identify that by providing the advice during their screening exam, naturally a time when the patient was more focused upon their current health status and future wellbeing, could be a positive step to encouraging PA in a predominantly sedentary older population;

"...screening patients are usually more worried about their health, at the end of the day that is probably why they attended screening in the first place, so yes, they may listen more to that kind of prevention advice, especially in the hospital, I can see that..." (Endoscopist 4, Interview)

"Maybe just the screening people should be approached for promotion, because they are fit, or asymptomatic, but they must be more motivated to investigate their well-being, so I suppose you could suggest they are more likely to take on advice of any kind, and know what's good for them." (Endoscopist 2, Interview)

Other HPs suggested that maybe those patients identified at 'low risk' of developing further polyps and therefore cancer, should be the focus of health promotion efforts due to the fact their bowel is pre-disposed to polyps and therefore cancer following screening, but these individuals are not followed up. Due to the removal of only a very small polyp, any individual identified as 'low risk' for developing further polyps, would not automatically be enrolled onto the 1 or 3 year surveillance register (as is the case in intermediate or high risk patients respectively). This therefore means that the next chance they would have their colon examined would be if they again had an abnormal reading from a subsequent postal FOBT test – a procedure which is known to not be particularly accurate or sensitive;

"we would have to sit down and really look at those people who are going to get surveillance, the patients who may in fact actually be at higher future risk of cancer are those with lower risk polyps in their colonoscopy as they aren't really followed up at all." (Endoscopist 1, Interview)

"I suppose actually if you've got someone who has say got 2 adenomas less than a cm, so they do have some predisposition to polyps, *that* group is possibly the group that may benefit from lifestyle advice more as they are an at risk population in theory, but they don't get followed up..." (Endoscopist 3, Interview)

10.5.4 The Need for Health Promotion

Of course there were a number of opposing views regarding the necessity of health promotion advice within this population, and most often this was relating to the above quotations and the fact that intermediate and high risk patients are put onto a surveillance list. As briefly described above this means the patients are monitored during follow-up colonoscopies and any polyps which may be found during their early stage of formation within this time can again be removed, a fact which appeared to negate the need for lifestyle advice in some health professionals;

"If we are purely thinking of those people who have had polyps removed and are at higher risk so under surveillance, the sensitivity of a colonoscopy is very high...in the high 90%s, occasionally somebody gets missed, and they will develop a subsequent cancer a few years down the road, but those numbers are incredibly small, much less than 1%..." (Surgeon 3, Interview)

"...a patients risk is actually reduced by being on the surveillance list, and coming for follow up colonoscopies. Providing they do that, they should not find a cancer as it usually takes 10 years or so to develop from a polyp to a cancerous tumour so giving advice <u>purely</u> with cancer reduction in mind is probably not necessary..." (Surgeon 1, Interview).

This quote could be viewed in one of two ways; firstly Surgeon 1 could be suggesting that

there is no need to change our lifestyle behaviour if we remain under a surveillance programme (a somewhat paternalistic approach and something which would not be cost-effective for the health service), or he could, instead, be emphasising that there are multiple benefits to doing PA – not just the fact it reduces one's risk of develop further polyps or indeed cancer; 'giving advice *purely* with cancer in mind'.

The multiple additional benefits of doing PA was another incentive for giving increased lifestyle guidance within the screening setting for many HPs and could be something which is emphasised to patients when providing the health promotion;

"I think the key to giving lifestyle advice is to keep the message simple. I mean exercise is good for a number of reasons, cardiac disease, stroke and also reducing your risks of certain cancers, it is something which applies to everyone and we need to focus on that." (Surgeon 2, Interview)

Despite Norfolk having one of the greatest uptakes for their screening service when compared to the rest of the UK – with around 65% of individuals over 60 years returning the postal FOBT, screening itself only targets a small minority of the entire population as illustrated by an endoscopist within the unit;

"For the screening FOBTs they are between the age of 60 and 75, and only 2% of people have a positive test, so 98% of people who send back their test do not come for a full screening, of those around 30% fall into the higher risk groups...of the 2%, so we are talking about 0.6% of the entire population, in that group you're mentioning. So umm, we could give them advice, but is it really going to make a difference to the population as a whole?" (Endoscopist 4, Interview)

The question raised here is, of course, a valid one which warrants further exploration. How do we target those who are quite possibly least healthy (due to their choice not to return the FOBT in the first place) and therefore the most vulnerable, and what about the 98% of people

who are not called for screening because the result of their test comes back as 'normal', a result which may result in false reassurance of good health?

Many HPs asked suggested earlier promotion at a national level suggesting that habits are engrained from an early age, so through encouraging healthy living and active lifestyles and specifically the reasons why these are important, the behaviours will come as second nature and continue into late adulthood;

"...in your 20's and 30's you might get into some lazy habits if those good behaviours aren't engrained in your younger years, at school age for example, and really at that point you need to have the guidance to change, and the habits already in place in order to prevent the things that may occur when you reach your 50s and 60s" (SSP 1, SSP Focus Group).

Others suggested that GPs could do more to target a wider audience within their practices by taking an interest in those who may need a little guidance and support with regards to any type of lifestyle modification and provide continued monitoring, due to their accessibility;

"I believe any lifestyle advice needs to be given population wide, not just to certain people otherwise it is not fair, which would suggest the GP would be best to give this as they are likely to see the person much more often, they can maintain contact and keep monitoring progress?" (Endoscopist 4, Interview)

Although relevant, both of these solutions to the ongoing problem of obesity and unhealthy lifestyles have their own difficulties with barriers to health promotion varied and numerous. The need for increased advice was well understood and appreciated with many concurring that regardless of who provides the advice, or at what life stage it is given, it should still be provided if the opportunity arises, and even if it only impacts a small amount of people, that still remains a positive change;

"The benefits of PA needs to be indoctrinated, especially at an early age, but who are we to dictate who receives the advice young or old, healthy or unhealthy, I still think we need to give these older people the knowledge then they can make an informed choice, you never know some might surprise us, even if it changes one person that's all that matters really." (SN 1, SN Focus Group)

As well as the barriers for health promotion that one would predict when approaching HPs about making big changes to the system already in place; such as a lack of time within the role and a waning NHS budget, there were surprising additional deterrents which arose through personal prejudices when discussing the promotion of PA with an ageing population.

10.6 Ageing Stereotypes

10.6.1 'Too little, Too late'.

Ageing stereotypes in varying formats were quite frequently shared between the members of the HP sample. These were expressed during these interviews and focus groups providing a key deterrent for many professionals when the idea of giving lifestyle and especially PA advice to individuals of screening age (60-75 years) was proposed. The first and most common perception was that this type of advice specifically would be 'falling on deaf ears' and that if patients were not currently leading an active lifestyle, would changes to behaviour really be made?;

"I just think maybe for people who are in the screening programme it may be a little too late, they are in many cases stuck in their own ways, and if they wanted to be active they would be doing it already regardless of whether we advocate it or not." (Endoscopist 1, Interview)

"This will now sound terribly controversial, but I wonder when you get to your mid-60's you have a polyp removed, and you're not doing exercise anyway...that it's a bit like closing the door after the horse is bolted" (SSP 1, SSP Focus group).

There was also a feeling that changing behaviour habits in individuals of that age group may be far too difficult (with the need for additional guidance) and reap little to no benefit in terms of alleviating current health problems or preventing illness in the future;

"We don't tend to go on about lifestyle so much, as most are in their 70's or 80's and I find in terms of things like diet or exercise the damage is already done, changing something small like that will not create a field change and rid them of all their problems..." (Surgeon 4, Interview.)

"...when you're dealing with people in their older years, they are often quite stuck in their ways, and feel a change would be too difficult and unnecessary – especially a big change like telling them to use a gym or something the guidance would need to be incredibly high or you won't have any success at all I'd imagine." (Endoscopist 3, Interview)

10.6.2 'Live and Let Die'

There was also a view that individuals within an older age group deserve to decide how to spend the later years of their lives, and if that did not include doing PA, then who were the HPs to push that decision onto them?

"I would imagine even more they feel they deserve a rest and to grow old gracefully, why should we try to stop that from happening" (Endoscopist 4, Interview)

Similarly, there seemed to be a general consensus during the SSP focus group that people attending screening were often very aware of their increasing age, and that they would feel PA unnecessary due to the belief they were approaching the end of their lives and that changing their current lifestyles would be a burden more than a benefit; "It's a very difficult call, you may get people who turn around and say, I've got to this age, I'm at the end of my life anyway, I just want to live exactly how I am, what's the point of changing now..." (SSP 2, SSP Focus group)

When asked to imagine patients completing the recommended levels of PA as suggested by current guidelines the HPs struggled to see it as a feasible target for the majority. These estimates were often made based upon comparisons of the HPs own PA levels, or lack thereof, and their relative good health status they possessed when judged alongside the majority of screening attendees;

"Trying to get an hour seems far too ambitious for some of our screening people I would imagine; it's an ambitious target for me, let alone someone in their 70s..." (SSP 1, SSP Focus group)

Finally a small number of the HPs did express the belief that older patients would not exercise at intensities necessary to elicit a positive effect due to personal experience or fears regarding overexertion; this I will go on to discuss in greater detail during section 10.9.1 - 'need for tailoring advice';

"I can't imagine any 60 year olds taking enough exercise, my parents used to walk now and again, and cut the grass but they wouldn't go for a jog, I doubt getting breathless would appeal to many, it's not a pleasant feeling" (Endoscopist 4, Interview)

10.7 Changing Times

The HPs often reflected upon their awareness of how times have changed during the typical screening attendees' lifetime, both with regards to the changing advice around lifestyle and within the healthcare setting as a whole. This reiteration showed many parallels to the dominant theme of 'changing times' which emerged through the analysis of the elevated risk

and cancer survivor interviews, thus verifying the importance of this overarching theme with regards to encouraging PA participation in this population.

The awareness of these changes over time appeared to act as a further disincentive for providing the necessary lifestyle advice to patients in HPs, who many believed did not exercise because it had never been something they thought was necessary;

"they didn't go to a gym, they probably didn't even exist really, they would just stay slim, maintaining weight wasn't really an issue up until now, you walked places, there wasn't this temptation, or an obesity epidemic to worry about so it's hard to explain that to people if they feel they are behaving in the same way as they used to..." (SN 4, SN Focus group)

Despite acknowledging that PA was a necessary and natural part of growing up in the 1950's the discussion between two SSP's below illustrates that clearly the behaviour which was a normal part of their childhood has not translated into their older years. Therefore, it was proposed that the reasons for exercise given to these individuals during promotion needs to be less focused on health and more on the social or psychological benefits;

"SSP2: I'd bring in the childhood aspect...you know, 50 years ago, children were out playing more than they did now.

SSP1: But that (playing outside) hasn't helped them has it, or all these older people would all be active now, they would have it ingrained as part of their lives...

SSP2: Well no, but I was going to say, but people just did exercise as part of their lives didn't they? They didn't have to go to a gym; they did exercise to have fun – not because it was good for you particularly, so the way we promote it must be different." (SSP Focus group)

The advances in the technological equipment we now take for granted were also mentioned as an element which makes health promotion far more difficult due to the constant distractions and therefore formation of bad habits which have escalated unwittingly over the past 40 or 50 years;

"It's far easier to not live an active lifestyle nowadays; they didn't have the distractions from TV or the car...that makes encouraging it so much more difficult, people have now got into bad habits" (SN 1, SN Focus group)

Despite the recentness of the evidence suggesting the negative impact (especially on cancer risk) of being overweight and engaging in low levels of activity, professionals believed that many of the patients were well aware of the research, and therefore often attended screening feeling that they, in part, were to blame for their abnormal FOBT (regardless of the fact they were yet to find out about the outcome of the procedure itself);

"I think in most cases in screening, a lot of them are aware that they are overweight, and that hasn't helped their cancer risk at all, there is a lot documented about it now isn't there, so do we really need to emphasise it more? I'm not so sure" (Surgeon 4, Interview)

"a lot of our patients do seem to present themselves with a lot of guilt at screening, talking about medication for diabetes, cholesterol, it's scary how many take meds for purely for lifestyle factors, and they know that hasn't done anything positive risk wise" (SSP3, SSP Focus group)

Therefore many HPs acknowledged, especially in a scenario where the individual may have felt partly responsible for their risk status, that health promotion and increasing knowledge around the importance of leading a healthy lifestyle, could be a potentially beneficial addition to the protocol.

10.7.1 The Changing face of Health care

When discussing the role a HP plays in health promotion in 21st century Britain a large amount of the professional interviewees reminisced about a time when medical teams and particularly GPs knew each patient and their families personally. This close relationship was thought to have more or less diminished now; resulting in HPs feeling uncomfortable offering such delicate advice to individuals they have very little knowledge of;

"They used to have the family doctor, and I doubt many GP's know their patients now, so who are they to start telling them about living a good lifestyle if they don't know the first thing about their situation or family" (SN2, SN Focus group)

A number of these interviewees also spoke of their personal experiences of attending GP surgeries and how they felt no longer treated with familiarity and compassion, but instead *processed* as if thrust onto a conveyor belt of numbers, only seen when a small and insignificant slot became available;

"I'm not sure I'd recognise my GP in the street, mainly because I don't attend, but also because the person I would see is always changing. And I don't feel the same trust either. I feel I am being processed, even when you ring up for an appointment you get spoken to like a number, and when can they squeeze you into a little slot" (Endoscopist 2, Interview)

10.7.1.1 Perceptions on Health Professional Preference

When questioned about who, within the gastroenterology unit, would be best suited to providing this type of lifestyle advice, it became clear that there were unique discrepancies between the perceptions of the endoscopists or surgeons, and the nursing teams with regards to their views on patient preference for who should provide lifestyle guidance. Those within the surgical team tended to take the view that due to the traditional view that nurses are more caring, patients would be far more inclined to listen and respond to advice given by a member of the nursing team; "I usually find umm, patients are, they listen much more to nurses than to doctors, they are less intimidated by a nurse than a doctor. That's the traditional role, nurses are seen to be caring, and more in contact with the patients whereas doctors tend to stand away a little bit, pontificating" (Surgeon 1, Interview)

Alternatively, the nurses had a wholly opposing view suggesting that a doctor's advice carried far more weight in the eyes of a patient due to the hierarchy which seems to exist within a hospital environment, and the perception of increased expertise in professionals who have trained for a longer period of time i.e. doctors and surgeons;

"If we (nurses) were to say something exactly the same as what the doctor would say it, they would still believe the doctor over you, their advice seems to have more weight, as it's this hierarchy in a hospital, especially with the older patients". (SN3, SN Focus group)

These conflicting views by various HPs around patient preference showcase an interesting dynamic to be considered when encouraging health promotion not only in the screening procedure but also within the medical setting as a whole. Whilst the patients interviewed as part of this study did not mention *specifically* trusting, or preferring to hear guidance from either a nurse or a doctor, upon closer inspection when questioned about whether they would follow the advice given by a HP, the majority of participant responses suggested if a *doctor* or *surgeon* provided the advice it would certainly carry more weight (see *Influence of Health Care Professionals,* 2nd Findings Chapter). Although this does not necessarily mean that patients tend to prefer the advice of professionals with *higher* qualifications, it does highlight an area in which more research is warranted.

10.8 Barriers to Health Promotion

10.8.1 Accepting and Retaining the Advice

Another common barrier to providing additional advice was the belief that the patients would not accept it and therefore would there be any additional advantage of spending time explaining PA recommendations and current guidelines? As previously mentioned many HPs were of the opinion that patients knew very well the benefits of exercising regularly, but for a variety of reasons, make a choice to not engage in enough to meet the current PA guidelines;

"But we also cannot assume that people do not already know, I think people do know, very well, if you exercise, overall health will be better, it's naive of us to think they have no idea...it's whether they accept that or not." (SN 4, SN Focus group)

The decision by much of the general public, to not engage in risk lowering behaviours, may in part be due to the assumption by HPs that there are so many conflicting messages around health and things one can do to prevent cancer, that the communication can often become confusing and seem contradictory; a factor also expressed within the views of patients interviewed at the start of this chapter;

"...there's so much stuff the public get about lifestyle, its one week avoid this, and another week...I'm always slightly nervous about giving too much advice about anything lifestyle related because of that confusion." (Surgeon 2, Interview)

In a related area, interviewees at the hospital stated that we already have a number of adverts, posters and television or radio features which encourage and support healthy lifestyle choices; adding additional promotion attempts would be unnecessary and pointless;

"we already do all sorts of things though don't we, we have TV programmes coming out of our ears telling us what to do or not do don't we, I'm not sure what else we can do, if people aren't taking notice of those, they probably won't take notice to anything in my opinion." (Surgeon 4, Interview)

There were a smaller proportion of individuals who took the opposite view however, believing that patients, especially within the older age group, would be the ideal targets for this type of advice due to their increased receptivity towards HP advice, and their increasing free time approaching or currently residing within, retirement;

> "It's the older patients which seem more responsive to advice, they listen more, and they are going into retirement so may have more time on their hands." (Endoscopist 1, Interview)

10.8.2 Blame

One of many emotional deterrents from providing elevated levels of lifestyle advice was the fear that patients would feel blamed for their potential risk status by the health care professionals adding unnecessary and additional stress in, what is for many, an already relatively worrying procedure;

"Their fear is obviously heightened because they think immediately they have got cancer when the test comes back as 'abnormal', and then you put that it might be their fault, I just think it would be too difficult to do, and unnecessarily scary for them..."(SSP 2, SSP Focus group)

Often HPs looked back at encounters with patients when small amounts of lifestyle advice regarding eating fruit and vegetables, or quitting smoking had been given. They spoke about how an automatic change in body language would occur, and on occasion the patient would respond somewhat defensively suggesting they were uncomfortable with the topic of conversation;

"Yes, you almost always see a change in them, when you ask them about behaviours, I often say 'I'm not here to judge you' I feel like I have to be overly sensitive, but they do start getting quite defensive about their behaviours, as if we are blaming them..."(SSP3, SSP Focus group)

'Finding a balance' between the support needed in patient interaction especially within the screening setting and the need for honest and helpful answers was something frequently mentioned. It appeared as though the HPs knew more detailed information around healthy living and this should be provided especially to those who appeared the most vulnerable, but whether this would come at a cost to patient welfare and mental stability was recurrently disputed;

"I mean it's difficult to gauge, we don't want to blame them, but in many cases, for example in endometrial cancer, the patients, whether you call that blame or not, I don't know, but being overweight has more than likely caused their poor health so really they should know that – whether we upset them or not" (Surgeon 4, Interview)

10.8.3 Causing Offence

Similarly offending patients was a major concern throughout all of the professionals within the unit. The screening procedure itself is purely to discount any current cancers, and possibly eliminate future cancers through the removal of polyps. Alongside this knowledge there was a distinct view amongst HPs that, above everything else, they had a duty of care to uphold;

"we have to be a little bit careful about being, upsetting patients, because we are trying, we are that patients doctor, and we are looking after them, we don't really want to get them offside, it's no good them coming through the door with a cancerous polyp, and us telling them that they are fat...we have to be euphemistic and careful, and maybe scatter around the issue a bit" (Surgeon 4, Interview)

The complexity of delivering behaviour change interventions as suggested by the patients, was also expressed within the views of HPs who believed it to be a time consuming and lengthy process, which, if breached with the necessary level of sensitivity, would take too long in the limited consultation time allowed with each patient during screening discussions;

"You might upset some patients, if they look overweight and you start talking about exercise they might feel you're having a go at them, and in a busy clinic you don't want to start doing that at the end of a consultation because then it's likely to run on too long, so yer, the concern about upsetting people" (Surgeon 2, Interview)

10.8.4 Reassurance

This need for balance as briefly mentioned above also supports the need to reassure patients of their results. Having polyps, in the boundaries of a screening examination for CC is, in clinical terms, a good result; due to the fact the patient does not have cancer. However often, as suggested by the elevated risk participant findings, the outcome of polyp removal may not be adequate to elicit consideration as to why the polyp was there in the first place;

"you have to be sensitive, the procedure is a pretty intimidating thing to go to, so you have to be reasonably positive with them, reassure them and be upbeat that we got it, and it's all out" (Surgeon 2, Interview)

"It's a very difficult line to tread though, you can't have people thinking oh my god, I've got polyps in 10 years' time I'll have cancer, because that's just not true in most cases. It's finding the balance between saying enough to make them think, but reassuring them too..." (SN1, SN Focus group) This apparent HCE as explained within the literature and supported by many of the elevated risk participants during interview didn't come as a surprise to the nursing staff within the unit with many reflecting on their personal conversations with patients post-procedure. The realisation that the wording often used to reassure patients of the positive news about their lack of cancer may indeed be interpreted as a completely upbeat diagnosis with no negative connotations;

"I'm sure all of us have said that 'we have removed the polyps, it's nothing to worry about, they are all gone'. We are so keen on reassuring them that there isn't a cancer, perhaps the message is getting a little confused..." (SSP 1, SSP Focus group)

"We as nurses want to make people feel at ease, but maybe we use the wrong wording sometimes, and people can misinterpret what we are saying..." (SN 4, SN Focus group)

Alternatively a lead endoscopist on the unit expressed his belief that the screening patients 'have a right to be reassured' with the feeling that if it is transposed that their colon has no cancer, and all polyps if present have been removed, then they are correct to feel that their colon is completely healthy;

"Well I suspect they are right in believing they are 'all clear'. They come forward on a cancer screening programme and they do not have cancer, so I think they are perfectly right to be reassured." (Endoscopist 4, Interview)

10.8.5 Retention

As a health promotion technique, giving patients lifestyle guidance during their screening procedure may only work, providing they retain that information after leaving the hospital. Although this may sound obvious, this fact alone raises concerns about whether this strategy would ever be successful and if so, at *what stage* the advice should be given to achieve the greatest results.

10.8.5.1 Pre-Screening

During the pre-procedure interview and admittance discussion, as well as having to work through a set protocol of essential questions, the HPs are often faced with extreme apprehension and often confusion about the procedure about to take place on behalf of the patient. Professionals from all areas of the gastroenterology unit were fully aware that the predominant focus for each person when arriving in the unit was the thought that they may have cancer, and were simply looking for 'peace of mind';

"...personally, my sole concentration, a bit like going for a mammogram, is have I got cancer or not, and if not, I'm not really too bothered about what you have to tell me about anything else." (Endoscopist 2, Interview)

"it's amazing how much information a person will forget about even when they are told in clinic umm you know, once you put the word cancer into a conversation everything else goes blurred they don't focus on much else at all really" (Surgeon 2, Interview)

"they (patients) are worried about cancer, they don't come to you, to coax them into stop smoking, or stop drinking or lose a bit of weight, they come in asking 'have I got cancer, yes or no' and that's the big question they all want answering, for peace of mind" (SSP 3, SSP Focus group)

It was this awareness which prevented many HPs even considering giving lifestyle advice because they knew that it would not be remembered and therefore acted upon after leaving the unit regardless of their level of endorsement. Whether or not the advice could be given or structured in a way to encourage patients to actively listen is something I will go on to discuss.
A further disincentive of giving lifestyle prior to a screening examination on the basis of elevated risk status was purely that the results were not yet established. Therefore encouraging PA on the basis of their increased risk status may cause unnecessary worry or confusion pre-procedure highlighting the sheer complexity of this issue;

"I'm not sure it would be too sensible to do promotional things preprocedure, I think they are not going to listen...plus we don't know what we will find until after, they may have a completely healthy bowel with no polyps." (Surgeon 2, Interview)

10.8.5.2 Post Screening

The alternative then to giving health promotion prior to screening, would be to offer it after the procedure had been completed; however this suggestion was not completely free from concerns within the HP team either.

Prior to each screening examination the patient is offered the option of slight sedation to alleviate any potential discomfort during the process. Whilst many HPs acknowledged that the levels of sedation are, in the majority of cases, relatively small and would wear off fairly quickly afterwards, it was still something which would need to be considered in order to ensure recollection of the information was maximised as much as possible;

"Obviously the patient has been sedated in the majority of cases so any kind of information given on our part would have to be after the effects of that sedation had worn off, just so that the patient can actually recall the information" (Endoscopist 3, Interview)

Echoing the perception that patients only attend screening to give them 'peace of mind', many professionals also recalled the lack of interest in anything other than their cancer 'status' when

delivering the screening outcome post-screening. Therefore it was suggested that promotion

efforts need to be offered in multiple settings with repetition being the key focus;

"...even if you explain it's a really large polyp which needs to go for histology as there's a high chance it may be cancerous, they still only hear they haven't got cancer, completed blindsided by it really." (Endoscopist 2, Interview)

"health promotion has got to be given in multiple settings, rather than just the one session, because, particularly if that is the session where they are being given their diagnosis, because they are concentrating only on whether they have cancer or not and not really listening to anything else" (Surgeon 1, Interview)

10.9 Complexity of Behaviour Change

Although welcomed by a large proportion of the HPs within the screening setting, the complexity of implementing behaviour change strategies was not overlooked and echoed the concerns raised by the elevated risk participants towards the start of this chapter when asked to discuss potential barriers to health promotion. The sheer amount time and continued support required in order to encourage behaviour initiation and subsequent maintenance was something appreciated by a number of HPs. Therefore it was often suggested as something which simply would not fit into their already incredibly busy schedules;

"...we don't really have the time to implement any lifestyle changes because that is an incredibly lengthy process and could take months" (Surgeon 1, Interview)

The lack of knowledge about the specifics around PA behaviour and techniques associated with implementing these changes was also made quite clear with the proposition that having a behaviour change specialist on the team would be well received and possibly hugely beneficial;

"You almost need a 3rd person there, a person that specialises in behaviour change, and has a background in nutrition or exercise training to give each person a programme and their support, I think that would be a very positive thing." (Endoscopist 3, Interview)

"I'll be honest, I wouldn't know, personally, how to deal with someone wanting to lose weight, wanting to stop smoking. I don't really know the first thing about it, so it would be good to have a specialist..." (SSP3, SSP Focus group)

10.9.1 Need for Tailoring Advice

The need for sensitivity when considering an individual's background, whether that be their socio-economic status or personal situation was of paramount importance when considering providing adequately structured and tailored lifestyle advice;

"I think with bowel screening we cover such a large population, and the Norfolk population is extremely varied in its lifestyles, backgrounds. We see all sorts, very wealthy, to fairly impoverished, we would need to bear that in mind and tailor any advice accordingly..." (SSP3, SSP Focus group)

HPs were often also mindful of the unique need for tailoring PA advice towards the older

population, many of whom may have unique requirements and/or specialist concerns when it

comes to becoming increasingly physically active;

"The advice in terms of what sort of exercise would be helpful may need to be different depending on who you speak to as well, because in their 60s and 70s they may not be able to be as active as someone younger" (Surgeon 2, Interview)

Similarly the way in which lifestyle advice should be presented to a person within the older generation was generally thought to have to be slightly different to the type of advice you may

give a younger individual in order to make it seem more achievable and wholly enjoyable in order to encourage initiation;

"In terms of exercise, it's a word which people probably think of sport, especially in that age group. So, it might be worth looking at ways of explaining it to them that exercise can come in a variety of ways, housework to walking..." (Surgeon 3, Interview)

"It's the way of offering exercise to them as well, I honestly don't think in many cases you'd catch them at the gym, I think it would need to be a social event, walking group, to get them to do it, without realising they are doing it..." (SN4, SN Focus group)

There was also a view that PA was a far more difficult behaviour to implement in individuals

than encouraging something like smoking cessation, where the unhealthy habit was having to

be omitted rather than added to one's life;

"Behaviour change particularly in relation to weight gain or loss is especially tough, alcohol can be stopped, smoking can be stopped, you can even tell someone to stop eating a certain thing, but targeting obesity is tougher" (Surgeon 1, Interview)

This proposition was supported by the belief that individuals may find it easier to take something out of their lives (and understand the significance of stopping a poor habit), but finding the time to add a behaviour (in the case of PA) seemed a step too far in their already demanding lives;

"I think exercise has the potential to get far more widely accepted as a preventative mechanism, but it's tougher to convince people to actually change their lives, especially when people are already so busy". (Endoscopist 1, Interview)

Many HPs also reflected upon the level of public awareness into the importance of PA in

relation to health and more importantly within this context, disease risk reduction. Comparisons were made between the frequent hard-hitting smoking campaigns as well as the more recent smoking ban, alongside the 'five a day' slogan which has become a well-known phrase over recent years, and concluded that the knowledge around PA simply wasn't as strong and therefore, why would people be going out of their way to incorporate it into their daily lives;

"The smoking campaigns have been going on for years, and they are pretty hard hitting, and more recently diet has been pushed reasonably hard in the media, but exercise has definitely taken a back seat at the moment" (Endoscopist 1, Interview)

"Obviously people know the risks of drinking and smoking, and the links with smoking and health, I think that's obvious now, but I don't think people think that doing more activity would help them much, they are probably aware, but not enough to actively do something about it." (SN4, SN Focus group).

10.10 Ideas for Improvement.

10.10.1 Incorporation into Protocol

What became clear through discussions on health promotion with HPs working in the screening setting was their focus on impeccable care alongside standardised procedures built within a structured protocol. This standardisation not only allowed each patient to receive the same level of exacting attention, but also ensured each professional asked the necessary questions of each patient prior to undergoing the procedure. Because of this element, for health promotion to exist within this setting, it would have to be fully integrated and incorporated into the medical protocol so it became a natural part of each patient encounter;

"It would have to be built into the protocols, the one thing we do very well is standardised care, so if we did set it up and say, particularly in sub-groups or everyone, if we say these certain people, whether that be nurses or surgeons will need some focused information about lifestyle, and exercise then it will be done." (Endoscopist 1, Interview)

"I'd be happy to say it to everyone regardless. Especially if it was part of protocol and it became part of our routine it would be easy to tell everyone who it would apply to, so long as it became habit." (Surgeon 2, Interview)

10.10.1.1 Need for Training

When HPs were questioned during each interview about their knowledge on the current PA guidelines and their thoughts on whether these adequate enough to reduce one's risk of developing future polyps and subsequently CC, there was a distinct lack of awareness;

"In terms of giving specific advice I have to admit I am really not sure to what levels they need to be doing exercise, or for how long." (Endoscopist 3, Interview)

"I am just going to put my hand up and say no, I'll be honest, I don't know the guidelines really. I know they are relevant, but how many hours a week...I'd guess at 2, maybe...I am probably wrong though, no idea!" (SSP1, SSP Focus Group)

This lack of knowledge was however, more often than not quickly accompanied by their interest in engaging in additional training to enhance their level of understanding. The belief that they would not need to have 'all of the answers' but just enough to at least plant a seed in someone's mind of the importance of leading an active lifestyle and the most recent evidence to support this, was an element which many requested in the form of a regular teaching seminars or lecture based training; "It doesn't really matter if we don't have all the answers yet, but just knowing that the knowledge is out there is a positive thing for everyone involved." (Endoscopist, 2, Interview)

"Oh definitely, I mean personally, I'd like to know more, how strong is the data you know, err, sort of a teaching day on the recent studies and exercise and cancer would be well received and very interesting, I think a lot would turn up." (Surgeon 2, Interview)

10.10.1.2 Piloting Programme

If incorporating additional lifestyle advice into the screening protocol is something which may be seriously considered in the future, the content would ultimately have to be piloted to identify its success before being rolled out nationwide;

"It would have to be sort of trialled and then become a nationwide thing. The literature they get if they attend screening is quite good, if you could get into that national literature somehow then that would be excellent, although, I imagine that is extremely difficult to do." (Surgeon 3, Interview)

10.10.1.3 Method of Promotion

The way in which this advice would be presented was also discussed and debated with the majority of HPs using their previous experience to identify the format they believed would achieve the best recall and adherence rates in patients. Interestingly, in complete parallel to the views of the patients, the general consensus was that giving advice in multiple formats would achieve the best results. Professionals commented on the fact that verbal communication from a trusted person within health care may appear most effective initially, but literature in the form of a leaflet could be used to reinforce the core messages and provide a 'take home message' which the patient could explore further. The need for the information to feel personally tailored and specific to each individual was also an element mentioned to

encourage greater engagement in the behaviour which further supported the need for not only a leaflet but also some form of personal contact;

"I think you need leaflets to reinforce whatever advice you give, but verbal recommendations are always helpful because it comes from someone they trust and seems personal." (SSP1, SSP Focus group)

"The literature, in a sort of leaflet may help as well...a lot will just chuck leaflets in a waste-paper bin, but if someone talks to them, and then asks if they have understood what we have spoken to them about, then mention that you will send some more detailed information...then I think people will actually take time to look through it and read it." (Surgeon 3, Interview)

10.10.2 Gauging Interest

There was also much support around the idea that it may be possible to ask those with an elevated risk diagnosis whether they may be interested in receiving lifestyle advice prior to sending out additional information during their follow up telephone call as shown in the patient pathway in figure 1.1;

"Usually we do a follow-up telephone conversation just to see how our patients are, that may be a really good time to find out just if they are maybe interested to hear about more lifestyle advice?" (SSP 4, SSP Focus group)

This proposal was thought to allow freedom of choice, and have an element of 'selfadmittance' similar to that of the screening examination which would eliminate individuals who were the least motivated, and therefore those who would take little notice of the advice, but target people with a real desire to change;

"Having a sort of interest questionnaire would be potentially a good way of gauging interest though, as they are again self-electing, so the potential for success would be much higher as these people actually want to change

something about their health and we can then target them more easily." (SSP3, SSP Focus group)

"Yes, questionnaires could easily go out with the diagnosis information asking 'do you feel overweight' 'do you want to do something about it, or do more exercise', then depending on how they respond that can formalise people into specific interventions with specialist people who know about weight loss, or exercise prescription or smoking cessation." (SSP1, SSP Focus group)

10.10.3 Additional Follow Up

Although offered a follow-up phone call by the SSPs following their procedure, to explain the results and answer any questions the patient may have, individuals attending the screening programme do not have another face to face meeting with a HPs within the gastroenterology unit. Due to the power of personal contact as discussed by both professionals and the patients within their respective interviews, members of both the nursing team and the surgical team expressed a real desire to see a patient one additional time to fully reinforce the message about the impact of lifestyle on polyps;

"Patients would maybe benefit from getting advice immediately afterwards and also some sort of follow up, because again, the amount patients take in, particularly if it's been a stressful procedure, is far less than you would ever imagine they would take in. So it needs to be repeated a lot, to get any effect on patients I would expect." (Endoscopist 1, Interview)

"In an ideal world it would be great to see these patients again to say, look you have had a good result, but there were polyps, AND if you made changes in this and that it might help you in the future. But in reality, that opportunity is lost really because we don't have another follow up" (SSP1, Focus group)

10.10.4 Adapting Polyp Guidance

Illustrated within this chapter there appears to be much discrepancy between what the patients think they have been told and what the HPs believe they are telling patients about the nature of a polyp, the polyp-cancer pathway, and ultimately the things they can do in an attempt to slow this pathway down and avoid cancer in the future (although both professionals and patients agree more could be said). It appears that, despite the HPs insistence that information pertaining to polyps and their impact on future cancer risk, patients are simply 'not making the link' and therefore are not adapting their behaviours to reduce future risk accordingly;

"People just don't think the word polyp is anything to worry about. And I tell them every cancer starts as a polyp, but not all polyps turn into cancer, but you'd think that alone would send off a little alarm in your head, they don't seem to get that at all" (Endoscopist 2, Interview)

"I mean we all know it (having polyps) heightens their future risk of more polyps, but umm, so it's a shame in a way really, that people that have been found to have polyps aren't thinking well what can I do to prevent them" (Surgeon 2, Interview)

Whether this is due to the aforementioned 'focus on cancer' which seems to take precedence during the screening process rendering all other information insignificant, or indeed whether the polyp information being provided is not clear enough, is something yet to be established. Either way, it suggests that the information given to patients about the nature of a polyp should be adapted;

"They need to better understand the range of what a polyp can be, small enough to fit into a biopsy, but also large enough to have surgery, so just hearing polyp may make people feel relaxed but in some cases it could be something more worrying, I think we need to make that clearer" (SN3, SN Focus group)

"I suppose we should be adding that they have had polyps and that means they are prone to more polyps, and these are the ways they can reduce them" (Surgeon 2, Interview)

"Patients need to know if they already have had polyps they could definitely get more in the future. So although they may feel it's *just* polyps...they probably need a bit more of an explanation of the implications and how they might be able to maybe reduce these" (SN2, SN Focus group)

To conclude, many of the views around health promotion within the screening setting are echoed by both the patients attending screening with an elevated risk diagnosis and the HPs working within the screening environment. It would appear that the unique environment of a screening setting could be utilised more successfully and may provide an excellent opportunity for healthy lifestyle promotion, however, what this research really highlights is the sheer complexity and number of barriers to be overcome if these changes were to be implemented in practice nationwide.

Chapter Eleven

The findings from the previous three chapters have demonstrated the chronology of participant influences in relation to PA initiation and maintenance. They have also highlighted the key similarities and differences in motivators to being physically active between those classified at elevated risk of developing CC following their screening colonoscopy, and those who have survived CC. The final chapter further questioned the necessity of health promotion at an earlier stage in the cancer pathway by examining and comparing the responses from elevated risk participants and HPs within the screening setting and the complexities associated with delivering this advice. Although the findings have been presented across three chapters, this discussion will endeavour to link the main elements together (especially with regard to the findings from chapters nine and ten) and thus present a comprehensive discussion as a single entity.

11. The Discussion

The descriptions within the three findings chapters have also addressed the primary research aims (see chapter five) and expanded upon the previously identified themes for exploration. This includes contributing towards better understanding regarding the impact of a diagnosis on PA participation and the potential effect this increased level of understanding has had upon utilising theories such as the teachable moment (McBride and Ostroff, 2003), and health certificate effect (Tymstra and Bieleman, 1987) in practice.

This chapter will further analyse and discuss the research findings, giving an interpretation of the results in light of some of the aforementioned research aims, and current gaps within the existing literature. In summing up and drawing together the research findings, this chapter will conclude with a section outlining the limitations of this research and offer suggestions for future research.

11.1 The Meaning of Physical Activity

Throughout the first findings chapter the data analysis across the participant group, would suggest that the *meaning* of what it is to be physically active has changed overtime. This may provide an explanation as to why so few people within the older population achieve the recommended levels of PA (O'Donovan et al., 2010), yet still believe they are 'active enough' and even surpass the levels expected of someone their age (Crombie et al., 2004b).

Findings from this research confirm the results from other studies (Crombie et al., 2004b), that people are generally aware of the benefits of leading an active lifestyle both for mental and physical health, yet still do not engage in PA at the right level or intensities. Whilst this study also confirmed many of the well known barriers for PA initiation; such as fear of injury (Schutzer and Graves, 2004, Buman et al., 2010), embarrassment or isolation (Costello et al., 2011, Tulle and Dorrer, 2011) and poor neighbourhood safety (Carver et al., 2008, Buman et al., 2010), it greatly highlighted the lesser studied area around the influence of life experiences and socio-cultural factors, which are much more difficult to measure quantitatively, and often exist subconsciously, as memories, within the individual (Grant and Kluge, 2007).

Many participants spoke of how 'busy' they are from day to day, whether as an active member of their local community, a doting grandparent, or an avid participator in a hobby, such as gardening. When discussed with each person, maintaining this busy lifestyle appeared to buffer a transition from work and into retirement, not only to defend against the common stereotypes of growing older (see 'Acting ones Age', section 5.1.6.3) but also to prove to others that they remain a contributory member of society. The 'Busy Ethic' (Ekerdt, 1986) is a philosophical standpoint which suggests that many older adults themselves suggest the key to 'successful ageing' (Havighurst, 1961) is to remain busy through pursuing a full schedule of activities. Although largely discarded by gerontologists who can view the theory as too narrow minded, pertaining often to the encouragement of a particular lifestyle (Bearon, 1996), it is hard to ignore the number of participants within this particular study who frequently claimed that their activity levels were sufficient as a result of their busy lives. These results, although suggest that older adults are not averse to engaging in later life, highlight the need for increased education around the correct level and intensity of PA to elicit a positive health response (Katz, 2000). Alongside this, many participants within the intervention group expressed an interest throughout the trial in working towards targets and learning to listen to one's body in order to predict whether they were working at the correct level. These unreported findings, alongside previous research (Bandura, 1986) suggest the need to encourage awareness about common physiological responses to exercise, which may be misinterpreted as an adverse and negative reaction (as described within 'self-efficacy' as physiological arousal (Bandura, 2000)) - see section 5.1.3.2.

Negativity around PA participation, whether that be in the form of childhood memories of school physical education lessons, or negative stereotypes around the types of people attending structured gymnasiums, has been suggested as a powerful deterrent for PA initiation both within this study, and other studies in the past (Korkiakangas et al., 2011, Buman et al., 2010, Crombie et al., 2004b). Negative childhood memories, seem incredibly influential to adult PA levels, highlighting the need for activity to be re-imagined within these individuals, not as an activity surrounded by ridicule and embarrassment, but instead as a way for personal development, and above all *enjoyment* (Randall and McKim, 2008). The need to market PA as an *enjoyable* activity for older generations is essential. Many participants within this study

spoke about how enjoyment was the single greatest motivator and predictor of PA initiation and adherence, and, although undeniably important, the marketing of PA as a 'health behaviour' therefore may be deduced as a less effective form of promotion within this population. Enjoyment is an intrinsic motivator (Deci and Ryan, 1985) and, as discussed within chapter five, these factors are often felt in greater number within 'normal weight' compared to 'overweight' participants (Deforche et al., 2006). Extrinsic factors relate to elements outside of the individual in question, such as monetary reward, or weight loss, and these are shown to be higher within those who are sedentary, and perhaps more importantly, individuals who do not continue to engage in PA participation after initiation (Ball et al., 2000). Taking this into consideration, one could assume that for those who have negative memories around PA in school, the structured nature of PA in a gym setting - with a lack of support and unfamiliar equipment, may remind these people of the type of PA they disliked many years ago – and therefore provide a potent barrier for PA participation. On the other hand many of the participants spoke fondly of childhood play as an 'unplanned' form of PA, and even at times expressed the belief that their activity into adulthood and subsequent retirement, were positively influenced by these active childhoods. These associations however, result in a paradox, whereby participants are not meeting the recommended PA guidelines in order to be eligible for the research trial. Could it be possible that instead of childhood levels of activity informing PA into later life as suggested in some literature (Telama et al., 2005), it is the maintenance of a *planned* PA regime throughout adulthood which may serve the best predictor of activity levels in older individuals? Or instead, might it simply be that the participants within this study do not understand what is meant by 'sufficient PA' at a high enough intensity?

Aside from this, it would seem logical bearing these ideas in mind, that older adult PA must draw upon many of the *enjoyable* aspects of childhood play in order to maintain adherence.

This could be achieved by ensuring that the activities are less structured and more familiar than your typical gym environment, as well as being surrounded by a network of friends and high quality instructors in order to build a sense of community and support.

11.2 How have 'Changing Times' affected Physical Activity?

Prior to beginning discussion on this topic area, it is worth considering that the findings of the elevated risk and cancer survivor population in particular, heavily rely upon the biographical information provided as a narrative account at the start of each interview. This biographical approach makes possible the exploration of an individual's past life, whilst providing dynamic stories (Lalive d'Epinay et al., 2001) about childhood and adult life throughout the second half of the 20th century. However, the critical methodological weakness of this approach is the reliability of memory, and more specifically the tendency to reminisce about the past through 'rose tinted spectacles' (Harley, 2003). Many participants spoke fondly of their 'slower paced' lives growing up (despite the fact there was more natural PA), and how modern times seemed rushed and less welcoming. If we look at those times in post-war Britain however, it might be suggested from another perspective that times were far tougher, without the luxury of accessible travel, endless nutritional choice and numerous gadgets to both create, and fill ones free time (Karsten, 2005). The question still remains though, why do we often see the past through 'rose-tinted spectacles', and in a study methodology with its' roots firmly positioned in the construction of a reality in the eyes of each participant, is this actually a limitation?

A topic which was mentioned in all of my elevated risk interviews was the impact of technology in one form or another. We know from the statistics presented within chapter five of the literature review, that the arrival of sedentary leisure time pursuits, emerged with the greatest impact in the lifetimes of the interviewees (Sturm, 2004), however, perhaps

surprisingly, only one person out of sixteen interviewees described these advances as having a *positive* impact upon PA participation (in the form of increased advertising around the benefits of healthy lifestyles). Whilst this may be a direct representation of the negatives of qualitative research, and my position of influence over the interviewee responses (discussed in greater detail within 'Limitations of Research', section 11.6), one may also determine that a greater need for balance in the domain of technology usage, is warranted if we were to markedly encourage PA participation in this population. Technology is viewed from three negative angles within this thesis;

1. As a contributory component in a society with more *choice*, especially around sedentary leisure time pursuits and time-saving devices, which reduces the time spent expending energy doing household chores,

2. As the arrival of *motorised transport* which reduces the time spent walking or cycling to get from place to place

3. As a replacement reducing *occupational PA* in manual labour professions through advances in machinery

Many participants suggested that these changes to technology were just as much a natural part of living in 21st century Britain, as outdoor play was during their childhood years, and therefore notions of taking these advances for granted was often mentioned during the interviews. Interestingly, a small number of participants remarked about the *necessity* of change with regards to time saving devices and motorised transport in order to accommodate their 'busier lives'. This is particularly interesting as surveys suggest people now have around 5 hours *more* leisure time per week than in the 1960s (Sturm, 2004), television watching has increased by 130% each week (from 13 to 30 hours) (Telescope, 2013), and time spent on household chores has decreased by 53.4% (from 13 to 6 hours per week) (Sweeney, 2002).

These findings have been echoed in other literature (Robinson and Godbey, 2010, Sturm, 2004). Wajcman (2008) introduced a fascinating debate; 'is time speeding up in modern society or is television a black hole which makes time disappear'? The acceleration of time is a common theme in sociological accounts of post-modern society (Wajcman, 2008). Beck and Camiller (2000) have supported statements proposed in the literature review which suggests that the pace of social and cultural change is far more rapid than any previous era. This, in turn, may result in those who have witnessed such changes (within the older generation) perceiving that the 'rhythms of life' are occurring at a faster pace, leaving it increasingly difficult to find time for themselves. Rosa (2003) examined in detail the idea of an 'acceleration society' and identifies three distinct categories of acceleration, which neatly corresponds with the three areas of technological change within this study and identified briefly above.

- First, the most obvious form of acceleration between life in the 21st century and life six decades ago, is 'technological acceleration' the speeding up of communication and transport for example.
- The second area is that of 'social change' around the areas of gender roles, occupational demands and changing family responsibilities.
- The third and final domain is aligned with comments around the quickening 'pace of life', as identified in this and other literature examining PA participation, largely suggesting a 'lack of time' as the main barrier (Buman et al., 2010, Withall et al., 2011, Chang et al., 2008).

Although many of these advances are there to *save* time and effort – especially with regards to machinery in what once were manual labour jobs, and it could be proposed that instead individuals are more likely to multitask, leaving little time, solely for their own leisure; resulting in a perception of no free time, and thus decreasing recreational PA levels.

Finding equilibrium between the sedentary pursuits, which so frequently dominate lives in the 21st century, and a more active existence, whereby energy is expended at a moderate level for at least 30 minutes per day, is really the aim of all research which focuses on promoting PA. However, this research has also highlighted the tendency for people to, when given the opportunity, 'choose the easy option'. If this point is considered on the basis of evolutionary psychology, humans once had to hunt for their food; requiring much energy and effort. More recently, before the industrial age, only the very wealthy had surplus food, with the remainder of the community having to rear or hunt animals and tend to their land, to simply survive (Paffenbarger et al., 2001). Of course, within the majority of westernised societies today, there is an abundance of food, however the sub-conscious mind may still act with reference to tougher times (back to the early beginnings of man in the more extreme sense, or even in the case of the study participants, their childhoods as rationing was still at large) and therefore will eat more frequently, and consume more energy dense foods than is necessary to sustain daily living. Alongside this, the effort required to, for example, maintain a vegetable patch as opposed to driving to the supermarket, and buying freshly prepared vegetables is very different. Aside from the evolutionary perspective of attempting to conserve energy where possible in case of emergency, in modern times, individuals, especially within the older generation, may feel a sense of entitlement for living a sedentary lifestyle as they have spent their entire life working and supporting their families, thus believing retirement sparks a time for rest (Grant, 2008a). Again these discussions lead towards a need to find a balance: educate the older generation on the benefits of leading an active lifestyle - not purely for health benefits, but also for social interaction and psychological gain. The need to not do this through mediums which are associated with sedentary living; such as television advertisement campaigns, which can seem impersonal and wholly unwarranted for a person who believes they may be entering the final stages of their life is also essential.

The sense that childhood play was so common in post-war Britain was supported by the frequent discussions around a greater sense of community, and therefore the perception of safety which existed in many of the villages where the study participants grew up. What seemed clear from a number of interviewees was their sheer disappointment that within the community they now live; there is a distinct lack of neighbourhood spirit and support, which, in turn, results in feelings of isolation and heightened fear; especially with regards to engaging in PA outside of their homes. Previous literature has suggested that fear is only *weakly* correlated with the objective figures and statistics of crime levels (Farrall et al., 2007) and therefore this must suggest that something else is impacting upon how we perceive crime levels in society today. The *victimisation perspective* is based on the;

'...principle that fear of crime within a community is caused by the level of criminal activity or by what people *hear* about activity – either from conversations with others or from the mass media.' Bennett (1991).

Merely *hearing* about unpleasant events, within the local community and nationally, may contribute negatively to one's personal perception of risk (Jackson, 2006). The dimensions of increased vulnerability including; the exposure to said risks, the anticipated severity of consequences and the loss of control, as proposed by Killias (1990), all combine and interact to leave individuals with elevated fear levels. Alongside this, physical, social and situational aspects can have an impact upon a person's apprehensions. This study's participants are all of an older age group, and many have other comorbidities or health concerns (physical), feelings of isolation within their community were also often suggested (social factors) and a small number expressed their concern that if something was to happen whilst out walking, no one would be there to help (situational). Alongside a combination of these factors, and continuing with the reoccurring theme of change, the everyday exposure to varying types of mass media in the 21st century, allowing for 24 hour access to the biggest news stories locally and

worldwide may also have a negative effect on one's perception of crime. Prime time television news reports are saturated with stories of violent and seemingly sporadic crime, resulting in portraying a world 'more filled with menace than most of us inhabit' (Romer et al., 2003) leaving 'typically' vulnerable people with the feeling that no one is safe. These manifestations are extremely difficult to overcome, as often, perceptions such as this are deep rooted. However, to encourage PA, and a society of older adults willing to leave their homes, utilise their local parks and socialise with the rest of their neighbourhood it is essential that supportive and friendly environments are introduced to the community.

11.3 Embodiment within the Research Population

This study particularly focused upon individuals who had recently either been told that they were at elevated risk of developing cancer, or had recovered from a cancer diagnosis. Critically in the sense of embodiment though, all of these individuals were approaching their later years, and thus provided an interesting insight in what it means to be 'old' in modern day society, how this differs from times gone past, and how this may impact upon one's choice to be physically active, well into retirement age. Previous work has identified the early baby boomers (those born towards the end of the second world war and into the early 1950s) (Buckley, 2008) as a 'transitional generation'. A group of people who have been influenced by the attitudes, behaviours and values of two distinct cohorts – their parents generation – the silent generation (who lived their lives bound by routine but with much more safety and security), and the second wave of baby boomers – born 1955-1964, whose lives were dominated by huge advances in technology and medicine, as well as affluence (Leach et al., 2013). This study has gone further in highlighting that this population is certainly a bridging generation in more ways than one; both with the arrival of change and the real need to adapt

to 'move with the times', but also with regard to the societal expectations placed upon them in later life – should retirement signify a period of rest and respite, as it was in their parents' generation, or indeed should they be using retirement to regain a sense of purpose by taking advantage of the increased life expectancy, and enjoying their well earned pensions?

11.3.1 'Live and Let Go'

The overwhelming response from participants within this study was that they wanted to 'live', and not just in the literal sense, but also psychologically. This is achieved by making use of their relatively good health and attempting to defy any negative stereotypes of ageing (many of which are discussed in the findings of HPs who voiced their belief that those within the older generation have a right to make their own decisions about PA rather than be coerced). With the knowledge of the benefits of PA being at an all time high (Crombie et al., 2004b), there is certainly a desire within this participant population to be more active, however, even within this (particularly motivated) sample, there was complex interplay of factors which could affect ones choice to continue with PA. Growing old gracefully can mean very different things to different people; the fear of becoming a burden to society by getting sick (Penedo and Dahn, 2005) could be a motivator to do PA in many people, however there were certainly apprehensions within this population whether a) they would be a nuisance in large PA groups and slow others down, or b) they should just 'let go' and 'act their age' by conforming to ageing stereotypes.

Using metaphors, and likening a body to that of a machine is something that is reported within the previous literature (MacCormac, 1986) and likened to the 'medical model of health' proposed in the late 19th and 20th century; around the time the study participants were born (Scriven, 2010). Then the focus of health was predominantly centred on the *treatment* of disease, as opposed to the *prevention* of it. Within these comparisons and medical models, the body is seen as a complex machine – designed for durability, however subject to 'wear and tear' and ultimately irreversible breakdown as it ages (Bellamy, 1995). One elevated risk study participant and one cancer survivor likened their bodies to that of cars which resulted in very different attitudes towards engagement in PA. The cancer survivor suggested that for him, receiving advice on PA from a HP would certainly encourage participation, just like if one was to take a car for a service and the mechanic suggested certain components need to be fixed or could be improved. Conversely, a similar comparison between body and machine in an elevated risk participant, forged a distinct barrier to PA, emphasising that his body only had 'so many miles in the tank' and therefore there were worries centred on strenuous activity and overexertion for fear of irreparable damage. These findings particularly illustrate the importance of a proficient and knowledgeable instructor to guide individuals, especially within an older age group, and indeed suffering other co morbidities and concerns, to correctly tailor and provide PA advice to a complex population. These findings support results from other studies with similar populations, indicating that a lack of knowledge around the correct technique, level and intensity for PA, was a key barrier for participation within both older participants (Lucas et al., 2000) and cancer survivors (Ottenbacher et al., 2011). Alongside the capabilities of instructors, their personality (centred particularly on a non-judgemental attitude and caring environment), seemed to play a large role in the initiation and maintenance of a PA programme both within this study and the studies which have preceded it (Van Stralen et al., 2010) emphasising the need for both physical *and* emotional support.

Becoming aware of declines in one's body was a theme which seemed to resonate with many of the participants within this study, and was often discussed with reference to what their body used to be able to do. This is a concept introduced in a study by Jones and Higgs (2010) examining the differences between 'natural, normal and normative' ageing. Whilst previous generations may have been attuned to the *natural* decline of an older body as part and parcel

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of the ageing process, individuals born into a time of medical advancements and change have become more aware of a *normal* decline; and thus, often draw their own conclusions about their capabilities by comparing oneself to other people of a similar age. If we take life satisfaction as an example, Mroczek and Spiro III (2005) have suggested that, although the rates of change differ from person to person, generally satisfaction increases up to age 65 and then decreases thereafter. This is potentially an indicator now, that *normal* ageing differs subjectively from person to person, and ageing perceptions may therefore be more judged normatively, on personal goals, rather than one's health status, offering a possible explanation for the 'unease' faced by one participant when he could no longer start his motorbike.

Cartesian Dualism, as proposed by Descartes is the belief that the immaterial mind and the material body exist separately, something that was exemplified in a number of participant's accounts of their ageing self. Although not *specifically* talking of a separation between their body and soul, many individuals spoke about how their 'body would not go for as long as it used to' or that PA may make their 'body work for a little longer'. In my opinion this suggests they felt their body was deteriorating, but their *mind* was separate, remaining youthful and above all capable of being active. Worth considering, is that this dualism was expressed more clearly in the accounts by cancer survivors compared to the elevated risk participants. Perhaps again, drawing on the TM phenomenon which suggests the cancer diagnosis may have caused these individuals to take a more concerned outlook on their life and future health. These individuals are assessing the differences in how they feel mentally and physically, and how these perceptions may impact on their motivations to be physically active.

Dualism is a common theme expressed within the literature around embodiment and ageing as a general concept (Leder, 1990, Mendes, 2010), however this study emphasises the role that this separation, or dualism, may play when considering PA participation. Although, one might perceive themselves as 'young at heart' and initiate PA with a highly enthused and motivated attitude, the body, and its decreased capabilities also have the potential to diminish this confidence and lower a person's self-efficacy if the outcome or experience is not as positive as one might have envisaged.

Ageing was once viewed as a time for slowing down (Grant, 2012), and although these views are beginning to shift to recognising the need for a more active older population, later life is still commonly viewed with negative connotations, and a time for frailty and dependence upon society (Grant, 2008a). Previous research, as identified within the literature review has also suggested these negative stereotypes, may ultimately form 'self-fulfilling prophecies' (Levy et al., 2009). As illustrated within the findings of this research individuals questioned the point of PA initiation, as it may be 'a little too late' for any measurable benefits to occur in older individuals. One might believe that these fatalistic attitudes displayed across both populations, may provide a distinct barrier to participation, however it did seem to impact on the elevated risk and cancer survivor populations differently. While elevated risk participants tended to conform to the idea that there would be little point in changing the behaviours they had done throughout their lives, cancer survivors seemed more encouraged by the fact that some exercise, must be more beneficial than none at all, and this, once fatalistic attitude to ageing and societal expectations, seemed instead to form a motivator for PA participation.

Gender (as opposed to one's sex which is a static demographic) is *lived*, and therefore one may argue that, like age, gender can become embodied and determine the choices we make throughout our lives, based upon socially constructed norms (West and Zimmerman, 1987). Much literature on the impact of gender and PA places its focus on the role of masculinity, particularly within youth culture, and how this variable may have a positive (Courtenay, 2000, Mahalik et al., 2007) or negative (O'brien et al., 2005, Gough, 2006) effect on health and helpseeking behaviours. While stereotypes of a male body being strong, self-reliant and tough (Courtenay, 2000) may encourage PA participation, and especially weight training to conform

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to these ideals, these 'labels' may also result in a deterioration of health. This is due to the view that only *weak* or more feminine men will report to their doctor with health concerns, (O'brien et al., 2005) or begin a programme of dieting and exercise classes (Gough, 2006). What this study has highlighted are the *differences* in memories of PA across genders and also experiences of activity in later life; novel topics yet to be widely covered within the literature. Within the narrative style component of each interview, it was certainly the male interviewees who spoke more frequently about childhood play, climbing trees, cycling miles each weekend and using their creativity to design games for the village. Memories of PA in school, was a topic frequently discussed by both male and female interviewees, however the women were the only participants to speak about PA within schools in a negative light both due to a personal dislike of PA, or a childhood illness which prevented them from engaging in P.E. lessons thus further singling them out to other pupils. Some of the reasons women mentioned for disliking PA at school was being picked last for the sports teams, not enjoying being outside or being cold, having to change into different clothes, and disliking being sweaty. Many of these reasons, such as feeling too cold, and disliking being sweaty can also be associated with prejudices placed upon women being weaker, and being picked last for the team could be due to the impression that girls are the less capable sex. Women were also viewed then, more as 'home makers' (Lalive d'Epinay et al., 2001), and thus potentially held the view that they should not enjoy vigorous, and more masculine activities before they had even started in school. Interestingly, upon closer observation of transcripts, these attitudes appeared to impact upon later life as well, and perhaps more than was originally anticipated; with women mentioning the impact of advances in *time saving* appliances (such as remote controls for televisions, or washing machines) and men speaking more readily of the impact of time using devices, for example televisions and computers on lowered PA levels (see page 158, Chapter *Eight*). These assumptions may, in part, also explain, why we recruited far less women onto the

intervention (66% men and 34% women) not only because men are more likely, in general, to participate in research trials (Murthy et al., 2004), but also that women are more apprehensive, and therefore less likely, to engage in a controlled programme of PA due to preconceived attitudes and potential negative memories about PA in school and beyond.

Embodiment, defined as the internalisation of societal expectations with regards to factors such as ageing or gender (Halliwell and Dittmar, 2003), is an interesting concept, and despite being difficult to measure objectively, there is no denying that it exists and can alter our perception of who we are; whether that be at 8 or 80 years, or the ways we, as men and women, choose to live (Laz, 2003). However what is clear from the findings from this research is that the body, although 'embodied', is perceived as being merely a vessel and does not shape our identity; the way a person responds to an ageing stereotype, or recovers from illness. Although certainly a key factor in determining PA participation, what both health promoters and PA facilities need to be aware of in order to increase participation in this population, is that it is not simply a 'one size fits all' approach, with each person having a different experience of what it means to be them.

11.4 Teachable Moment versus Health Certificate Effect

By comparing the age demographics and characteristics across the elevated risk interview population and the cancer survivor interview population, it is possible to conclude that the interviewees are all of a similar age (on average 67.8 years and 66.8 years respectively) and had all agreed to participate in a trial focusing on PA and lifestyle change. Although this does not reveal the socio-economic status across the two participant populations, the other factors alone, do allow us the opportunity to cross compare any differences between groups, and conclude with greater confidence, that any responses in relation to PA initiation, *may* be attributed to the different impact associated with their diagnoses.

Within the cancer survivor interviewees there were great differences across the participant group with regard to the immediate impact of a cancer diagnosis, with some, understandably experiencing fear and apprehension, and others feeling wholly relaxed and positive about their recovery. Whilst it is impossible to know (as this information was not obtained), whether this was because their cancers were of differing grades, or indeed whether the time since diagnosis was greater for those who were more positive, this demonstrates the need to treat each case individually, especially with regard to lifestyle advice and thinking about future health, as well as tailoring the advice provided to suit their psychological state. What remained a consistent theme across all participants and throughout these interviews post-recovery was each person's determination to prevent the cancer from returning (Lyons et al., 2002, Cimprich et al., 2005). This resolve certainly provided a clear motive for many to initiate, and at times, reengage with healthy lifestyles, resulting in the cancer diagnosis forming a 'light bulb' or TM for behaviour change and also possible subsequent consent for study participation. Many participants, across both groups, and especially the cancer survivors, felt they were already leading relatively healthy lifestyles up to the point of diagnosis and therefore often asked the question 'why me?' Despite these feelings of victimisation, it is reassuring that the study participants in particular were seemingly not deterred from healthy living, and instead appeared even more motivated to make positive changes.

In previous research too, there seems to be selective uptake in health promotion messages following cancer diagnosis with awareness of lifestyle risk factors being no higher in cancer survivors than those who have never had cancer (Lykins et al., 2008). In a study by Demark-Wahnefried et al. (2005) only 25% of cancer survivors consume adequate amounts of fruits and vegetables, and approximately 70% of breast and prostate cancer survivors are overweight or obese. In a further study by Harrison et al. (2009) although 80% of breast cancer patients reported doing PA at all time points between baseline and 18 months following diagnosis, 50% were not achieving the recommended amounts, and these levels of PA did not increase as time progressed following diagnosis. What's more results of a multi-cancer site survey (Blanchard et al., 2003) of almost 400 survivors suggests that 46% of smokers quit smoking and 47% of respondents improved their dietary habits, but 84% of participants either decreased or did not change their PA habits.

If we compare these results to the findings from the elevated risk interviewees, who, like the cancer survivors, frequently remarked about their 'active lives' before their heightened risk diagnoses, they rarely stated personal reasons (such as 'improving lifestyle' or 'increasing PA') for agreeing to participate in the intervention. This could be due to two reasons outlined throughout 'the diagnosis' findings chapter. Firstly, and as supported by the interview responses of elevated risk, HP interviewees and previous studies (Stead et al., 2012), very little information on general lifestyle behaviour, and no information on PA specifically, is provided to patients at heightened risk of developing further polyps following screening. Secondly, many elevated risk participants expressed their lack of understanding around what a polyp actually is, and the subsequent role they play within the polyp-cancer pathway (Fearon and Vogelstein, 1990). However, unlike the previous reason (pertaining to a lack of lifestyle advice provided at screening), the clarity of guidance on risk status is much disputed between patients and professionals, with the latter participant group claiming clear and correct information on polyps is provided to every screening attendee at numerous time points. With both groups of participants agreeing on the shortcomings with regards to lifestyle advice, and clear differences in the opinions of the provision of adequate polyp information, it may not come as a surprise that the elevated risk patients in this study saw no need to change their lifestyles. The greater question therefore is whether the information should be altered to encourage greater awareness (discussed in more detail in section 11.5; 'An Opportunity Missed?').

In line with the previous literature on cancer patients (Blaney et al., 2010, Emslie et al., 2007) this research supported the idea that being able to participate in some sort of PA programme was a way to 'regain normality', after what was for many, a frightening and uncertain time. A similar concept explored by Kennedy et al. (2007) namely returning to work following a cancer diagnosis, has the ability to enhance a person's quality of life (Steiner et al., 2004) as it has been suggested revisiting familiar settings whilst interacting socially with friends or colleagues, increases feelings of control over the illness and perceptions of a positive recovery (Peteet, 2000). After focusing so much of their attention on fighting the disease, a participants' desire to return to a cancer free life, and a behaviour regarded as 'normal' might also be applied in the case of these interviewees and their personal goal to be more active.

Cancer survivors also differed from elevated risk interviewees as they often felt thankful for their recovery, and looked upon it as a second chance; hence it was their duty to rectify any poor lifestyle habits. Despite this focus and determination to change, this study particularly illustrates that, especially following a serious illness, although a significant predictor of intention, good motivation may not simply be enough, with the majority valuing the knowledge and experience of the instructors to guide them back into correct levels of PA in a supportive environment.

If these suppositions are correct and elevated risk participants do not choose to participate in this type of trial for personal gain, their participation may be explained by applying 'The Gift Relationship' (Titmuss et al., 1998). Since its first publication, 'the gift relationship' has argued for the role of altruism in society, by exploring the phenomenon of voluntary blood donation (Rapport and Maggs, 2002). Altruism, has many definitions, and also can refer to varying degrees of giving; from purely unconditional acts, to those which appear to benefit both the receiver (in this case individuals who may benefit from this research) and the giver (the participant) (Batson and Shaw, 1991). Acts of pure or unconditional altruism are extremely rare – occurring within family groups in the majority of cases, however acts of altruism in general are thought to increase if one feels empathy, or a personal connection to the receiver. For example, if an individual has benefitted from research in the past, or associates with a future cancer sufferer because they or a close acquaintance have suffered cancer (Rapport and Maggs, 2002). Similar to responses given when asked why one should give blood, study participants frequently suggested that helping others, made them feel good, and therefore, although not necessarily participating for positive outcomes (especially with regards to individuals in the control group), there may be psychological benefits which can be ascertained through trial participation.

Although the previous literature suggests a mixed response to behaviour change following cancer, especially in reference to PA, it does suggest that more could be done to utilise the teachable moment as documented in this study and previous research (McBride and Ostroff, 2003), as well as taking better advantage of health promotion opportunities either during screening for those at risk, or following cancer treatment.

11.5 An Opportunity Missed?

Although both the patients and HPs confirmed other literature findings (Stead et al., 2012) suggesting that no lifestyle advice is currently being provided within the screening setting, there were certainly discrepancies around what the HPs understood they had discussed with each patient about polyp formation and risk, and what the actual patient remembered from their consultation. Although an opportunity to sit in consultations to determine the exact content of the information provided, as well as the speed at which this information was delivered was not possible, the findings do suggest the current guidance is limited (especially around PA), as well as regimented and prescribed, due to the need to follow strict protocol. The elevated risk participants are a relatively atypical 'clinical' population often due to their lack of symptoms prior to attending the screening procedure. This often meant that the need for a screening examination following an abnormal FOBT came as a shock to many, with a number of people making clear their fears around the potential of a cancer diagnosis. Although knowledge around the importance of catching cancer in the early stages was high among the interviewees, it is highly possible that the apprehension around the worst case scenario may have inadvertently impaired their ability to process additional information within the health profession pre-interview or follow up conversations (Diethelm and Jones, 1947). This study highlights the need in practice, for professionals to be aware that any information provided to patients may not be absorbed fully in these high anxiety situations. Therefore, the need to ensure clarity regarding polyps and the heightened risk a polyp poses for further polyps and future cancers (even when removed), as well as how this elevated risk may be reduced by changing lifestyle behaviours, is paramount.

11.5.1 Balancing Understanding with Reassurance

Data from many of the HPs interviewed identify their primary role as providing care to patients, and therefore their interest in encouraging screening attendees to 'feel at ease' throughout their screening procedure is arguably warranted. However, what has also become more apparent through conducting this research is that the information around the pathology of CC and a patient's risk awareness is lower than one might expect. Many professionals claim this is due to their need to focus on reassurance around a good screening outcome (where any polyps are removed), and a misinterpretation of the significance of polyps by the patients in attendance.

Despite HPs frequently agreeing that the screening setting may provide a perfect opportunity for offering lifestyle advice to patients due to perceptions that attendees may be more motivated than the average person to monitor their health and wellbeing, many professionals justified their position on reassuring patients due to their initial fears of a cancer diagnosis prior to the examination.

In line with the HP comments on the necessity of reassurance especially within this population, one endoscopist interviewee described how he believed patients deserve the right to reassurance and positivity around the screening outcome – after all, these patients are being screened for cancer, so effectively anything other than cancer *is* a positive outcome. This begs the question; as a society, are we making relatively 'healthy' individuals into patients and therefore giving them a potential cause for concern, earlier than is essential? Aronowitz (2009) examines the converging relationship between risk and disease in his study. In support of this study's findings, Aronowitz suggests patients once considered 'healthy' (who are at risk of developing a condition), are subjected to increased surveillance and guidelines akin to those patients actually *suffering* the disease, despite there being no certainty that the illness in

question will go on to manifest (Barsky, 1988). Screening examinations are largely 'successful' as they allow patients to feel they have control over their fears of getting cancer (Aronowitz, 2001). Therefore, it may become a problem if emphasis is placed upon future risk and lifestyle choice as opposed to the positive outcome where no cancer was detected during screening. It may leave the patient unduly fearful of the consequences of their actions and result in them feeling they are to be blamed for having polyps in the first place (which, in fact, are relatively common in older individuals (Levine and Ahnen, 2006)). There is therefore a requirement to actively *balance* the need for more information and patient awareness, not only around lifestyle choices but also on risk status, with the overarching expectation for HPs to care and reassure patients, especially in light of a positive health outcome following cancer screening.

11.5.2 The complexity of making this change

One of the research aims that this study set out to explore was health promotion within the screening setting, what information is currently being provided to screening attendees and whether, at this time, an opportunity to encourage healthy lifestyles is being missed. Whilst all of these areas have been explored, and the findings have suggested clear examples of positivity towards giving, and receiving health promotion from HPs and elevated risk patients respectively, this research has identified the sheer complexity of this task.

To attempt to unravel these complexities, it is essential to look at four different questions raised by the findings presented in chapters nine and ten;

- *Why* should we do health promotion?
- When should health promotion be provided?

- Who should be providing this lifestyle advice?
- How should this guidance be delivered?

11.5.2.1 The 'Why'

Firstly, HPs questioned the need for health promotion within elevated risk patients attending screening due to the nature of the surveillance list following screening. Any individual who is identified at 'intermediate' risk following their procedure, will receive another full colonoscopy after 3 years, and for those identified as 'high' risk, it is suggested a further surveillance examination takes place after only one year (Dennis et al., 2011). Although the surveillance scheme is excellent for reducing cancer risk due to the fact any polyps which may develop into cancer in the future are removed before it is too late, this may be projecting a paternalistic image that patients need no longer worry about their health, because, regardless of their lifestyle, the NHS will 'keep them safe'. As well as being highly inefficient in terms of cost, this view is not aligned with the changing face of health care which now places a lot more emphasis on personal responsibility (Schmidt, 2009). There is much controversy around the potential to ration health care practice and treatment, around those individuals who appear to have little respect for their bodies and limited motivation to engage in a healthy lifestyle. Many perceive an altered system would seem unjust and lack compassion, whilst a large number feel it is their right to choose what path they take with regard to lifestyle behaviours (Buyx, 2008). Regardless of these perceptions it is known that almost half of the NHS budget per year (46%) is spent on treating conditions (e.g. high blood pressure and type II diabetes) (Scarborough et al., 2011), which for the most part, are linked to poor lifestyle behaviours. Within this study several professionals expressed another opinion forgoing the necessity of health promotion: due to the belief that most people are fully aware of the benefits of healthy

lifestyle behaviours and the consequences of, for example, smoking, heavy drinking and a poor diet, but still choose to ignore these health messages. Exposure to health messages on the television frequently has to compete with the complex psychology of behaviour change and habit formation, and therefore, although these television campaigns may be a successful tool for the minority, are wholly unsuccessful for the most vulnerable populations nationwide (Wakefield et al., 2010). The problem with these passive campaigns is their distinct lack of personalisation. This tailored element would be able to be delivered in a one to one consultation with a HP who can convey appropriate and well tailored advice, as well as guidance around the local programmes and access to specialists which may be able to facilitate these changes. Specifically in relation to PA, HPs within this study also spoke about their concern that of all health behaviours, PA was possibly the hardest to change. Reasons for this was the need to find time to add PA behaviour to peoples already busy lives, as opposed to taking smoking, drinking or poor eating habits away. Alongside this, and as previously covered in this discussion, the meaning of PA is never "black and white" unlike smoking for example where people either do, or do not smoke. There are varying types of PA, as well as intensities at which to engage, and for the most part, every person will engage in some form of activity in their daily lives, it just may not be enough to result in positive health outcomes. Both of these points highlight the need for something to be done to decrease the influence of a 'toxic environment' - where unhealthy habits are now the norm (Schwartz and Brownell, 2007), and increase the provision of positive, personalised (arising within HP consultations) health promotion strategies, especially around PA, to enable the general public to engage in personal responsibility for their own health.

When discussing whether or not health promotion would be a feasible option for elevated risk attendees to the screening programme, many professionals voiced their concerns that information retention of information within the meetings between patient and practitioner in
that setting was surprisingly low – emphasised by the discrepancy between what information pertaining to polyps is retained by patients and what is actually provided by professionals during consultations. This presents a clear barrier to engage in lifestyle change conversation due to the already tight schedules having to be managed within these interactions. This does beg the question whether there are more effective consultation strategies which could be taught to encourage active listening. Currently health promotion education follows the Yale-Hovland Model of communication (McGuire, 1996) whereby the message must be constructed and distributed in a sensitive way which inherently appeals to the patient, however this is difficult to achieve in the often rushed nature of patient-practitioner meetings both pre and post screening procedure. The model also suggests that for the communication to be effective, the patient should be receptive and have a readiness to accept this guidance, often resulting in attempts to change. This secondary point emphasises another concern of HPs, whereby, even if information was provided, and the patient was at the most amenable 'stage of change' (Fallon et al., 2005), the actual behaviour might never be actually initiated; known as the 'Intention-Behaviour Gap' (Sniehotta et al., 2005). A possible way to limit this disparity between intention and behaviour was suggested by a small number of HPs, whereby gauging a patients interest around receiving lifestyle advice may be utilised. This could be done within the screening consultations, or indeed by a questionnaire sent out to patients following their procedure with a more detailed account of their results alongside a lay explanation of what this means for their future risk. If, following the receipt of this letter, a patient decides they might like additional help with one or multiple types of health behaviour, their details may then be passed on to a relevant team or health trainer local to them, and a tailored programme can be implemented. As well as the elevated risk and cancer survivor interviewees perceiving that lifestyle change (and especially PA) may be 'a little too late' at their age, HPs also frequently mirrored this claim with some outwardly believing older people tend to be 'stuck in their ways'. Therefore it was suggested these elevated risk individuals would not change even if supported, and others suggested that changing lifestyle behaviours in later life, may result in little or no long term health benefit anyway. Seedhouse (2004) suggests that health promotion on any level must 'propose a theory about itself' therefore becoming part and parcel of everyday health practice (a philosophical tradition). There are two important reasons for this, firstly patients are then expectant of receiving advice during each professional interaction thus reducing a negative emotional response and feelings of blame, and secondly professionals in turn reduce their own prejudices and concerns, by treating every person as an individual case, and not a static group, where advice would be unnecessary.

11.5.2.2 The 'When'

The findings from this research really highlight the time constraints faced by HPs during screening consultations and therefore the virtually impossible task they face if they wish to even consider discussing a complex topic such as lifestyle change within this limited time frame. There were a number of problems associated with giving lifestyle advice at both meetings with patients, either side of their procedure. Pre-screening promotion was faced with concerns due to the need for prioritisation of other health questions and information, as well as the fact each patient is yet to know their screening outcome. Conversely post-screening, suffered barriers whereby the effect of a sedative may impair memory, and many feel the patient is solely focused on hearing they may have cancer that all other information becomes lost anyway.

As mentioned within the previous section, gauging patient interest might be a useful strategy to access the most motivated and willing patients for behaviour change, as well as saving time by only focusing on those who really wish to hear this type of information. The SSPs spoke about their desire to have a third meeting with patients to cover the information usually sent in a letter such as the results of the screening examination and the implications this may have on future health (see section 10.10.5), whilst also making risk reducing strategies such as PA guidelines the focal point of the discussion. What was also suggested was that GPs may be better suited to this additional 'follow up' role. This is because their knowledge around more local services for patients, additional time for health promotion, and their maintenance of a more personal relationship with each patient, may enable regular follow ups to discuss any concerns or problems. Research around the area of health promotion in primary care is far more common than secondary care (Ribera et al., 2005, Dubbert et al., 2008, Hinrichs et al., 2011, Walseth et al., 2011) with varying degrees of success. However, what was surprising in this study's findings, was the somewhat unstable relationship between GPs and secondary care professionals, with many of the interviewees on the gastroenterology ward believing GPs often did the 'minimum' in terms of offering advice to patients about screening, and relied too heavily on screening staff for care both prior to, and following the procedure.

11.5.2.3 The 'Who'

Following on from the previous discussion point about unstable relationships *within* the health professions, it might seem implausible to propose that a multi-disciplinary team of specialists (fitness instructors, nutritionists etc), coupled with primary *and* secondary health care teams would be best suited to the delivery of community health promotion schemes. However, with previous literature suggesting that patients have no particular preference about which professional delivers health promotion (Elley et al., 2003), it does seem sensible to not only utilise multiple points of contact in order to reiterate the importance of healthy living, but to also spread the huge task of delivering promotion at a time when the most commonly

mentioned barrier for health promotion both within this study, and the previous literature (Neidrick et al., 2012) is a lack of time. Within health promotion, two broad approaches can be utilised – the 'high risk' approach, or the 'whole population' approach (Scriven, 2010). Generally both approaches need to be taken so that the greatest number of people can be targeted (as it is unlikely the same health promoters will have access to the same members of the public) – therefore again, this is why building upon developing a successful working partnership across HPs is essential. With this proposal, comes great responsibility on the part of each HP to be aware of their individual roles and responsibilities (Kelley and Abraham, 2007) as well as recognising limitations within their own expertise. If this was to occur, the referral of patients onto community 'health trainers' (who are specifically employed to promote healthy lifestyles and use specialist behaviour change techniques designed to increase self-efficacy and empowerment (Thirlaway and Upton, 2009)) should be better utilised. The need for health promotion to become an integrated and multi-disciplinary pathway (for example from a colorectal screening through to a local walking group) could not only provide a clear system in which health promotion becomes integrated throughout health care practice, but also leave the patient feeling as though sufficient, personalised and credible support was being provided, thus encouraging initiation and maintenance of the behaviour in question (Brawley et al., 2003b).

11.5.2.4 The 'How'

As previously mentioned many professionals wished they had greater knowledge around lifestyle behaviours and their impact upon health, however even given this knowledge, incorporating the information within consultations and practice, may prove more difficult due to the need to follow widely tested protocols. Working to a routine/protocol is predominantly how medical professionals are trained (Seedhouse, 2004). This encourages using specific outlines for patient consultations, such as asking medical questions in a specific order prior to a screening examination, to ensure that patient safety is prioritised. Although these procedures maintain consistency (and wellbeing), these conversations unfortunately lack the flexibility and a patient centred approach which a health promotion conversation would ultimately require. Professional interviewees on this study suggested therefore, that if health promotion was to become common part of practice there would need to be a 'unifying rationale' (Seedhouse, 2004), whereby the same care and same advice was given by all members of staff – regardless of personal values or concerns.

The complexity of health promotion was not underestimated by the majority of HP either, with many admitting their lack of knowledge around the current guidelines for PA and their need to have increased training to be able to deliver this type of advice. Health promotion is a relatively new concept, only becoming a term in the 1970s (Lalonde, 1974) and encompassing a huge quantity of techniques and strategies from a wide number of educational disciplines. Epidemiological research provides the answers from countless surveys detailing the general public's general health status; psychology tends to provide the techniques most associated with behaviour change, whilst sociology often focuses upon expected norms with regards to health and health behaviour. Alongside a good general knowledge of the physiological benefits of leading a healthy lifestyle, all HPs have the ability to teach patients empowerment and increase self-efficacy levels *if* the provision for these new skills were made available (Seedhouse, 2004).

It also cannot be assumed that all individuals have the capacity, or indeed freedom to choose the healthiest lifestyle options, especially if socio-economic status is a limiting factor (Contoyannis and Jones, 2004). The 'fear of causing offence' was commonly regarded as one of the biggest barriers for providing lifestyle advice, and HPs mentioned that to avoid feeling like they were blaming the patient for their health condition 'scattering around the issue' of lifestyle choices was a common conversational style. These techniques, although understandable, may result in the confusion faced by many patients, especially of an older generation (Hirvensalo et al., 2005) with regard to PA. Combined, the factors highlight the need for advanced training, so that lifestyle advice may be presented in a way which increases awareness whilst reducing the likelihood of a negative emotional reaction.

11.5.3 Is Change Possible?

To answer the question of whether the suggestions listed in this discussion to incorporate lifestyle advice into the screening setting are feasible, it is essential that we consider previous research in this area (Anderson et al., 2013). The largest health promotion intervention delivered in conjunction with cancer screening is the American 'Well-Integrated Screening and Evaluation for Women Across the Nation' (WISEWOMAN) programme (Homan et al., 2014). This scheme attempts to target the most vulnerable, uninsured women aged 40-64 years, who are offered screening for hypertension, hypercholesterolemia and abnormal glucose levels, and, following their results are offered lifestyle interventions on diet, PA and smoking where relevant. Preliminary findings are incredibly convincing with positive changes to blood pressure, BMI and PA levels being noted, as well as around 43,000 women participating in at least one lifestyle session (Anderson et al., 2013).

With regard to CC screening, Anderson et al. (2013) outlined five studies which have focused on changing poor lifestyle behaviours in older individuals attending a screening colonoscopy, however only three of these studies (Caswell et al., 2009, Emmons et al., 2005, Smith-Warner et al., 2000) focused specifically on individuals who have an elevated risk diagnosis, following adenoma removal. Of these three studies, two (Smith-Warner et al., 2000, Emmons et al., 2005) focused on dietary intake with successful outcomes being noted for red meat intake (Emmons et al., 2005) and fruit and vegetable intake (Smith-Warner et al., 2000). Caswell et al. (2009) were the only researchers to examine PA behaviour across an intervention and control group and found no significant changes for PA between groups, despite the use of one face to face contact with a HP, as well as mailed literature on PA.

Finally and most recently the results of a similar trial to the RCT conducted within this study; encouraging healthy behaviour change in those with colorectal adenomas was implemented in Scotland with positive results (Anderson et al., 2014). Like this trial, all participants were approached following a screening examination and offered the opportunity to consent to be part of a randomly assigned trial, whereby one arm would receive lifestyle change advice and guidance and the other would continue on with their usual care. Of those randomised to the intervention group, three, one hour long, individual face to face visits with a counsellor took place during the first three months, where lifestyle change was discussed and motivational interviewing strategies (such as goal setting) were used in an attempt to encourage healthier living. Following on from this, during the remaining nine months, nine fifteen minute phone calls were administered to continue supporting and advising throughout the process. The usual care group received no guidance, and just attended for baseline and final testing measures. Despite there being no significant differences between the two groups at baseline, those within the intervention group lost on average 2.7kg more over the 12 months than the usual care group and also reported a significant 694 more steps per day when compared to the control group. Although a full cost-benefit analysis was not conducted, this study does show how a relatively *minimal contact* intervention with continual support, has the potential to improve future health outcomes in 'at risk' individuals within the screening setting.

The qualitative findings from this study can be directly applied to the more quantitative results obtained from the BeWEL study as the participants in both are of a similar age group and have also been identified at elevated risk of developing CC following a bowel cancer screening procedure. Perhaps the most convincing finding of the BeWEL study is that even though the contact is minimal compared to the trial within this thesis, there were still positive in terms of weight loss and step count. The qualitative findings from the PARC study suggests that to further enhance PA adherence within this population, a greater appreciation of an individual's life experience is necessary. The need for trusted and respected HPs to highlight the positive qualities of PA engagement such as enjoyment (aside from the widely known health benefits of engagement) is essential to increase intrinsic motivation for behaviour initiation.

Therefore, through careful consideration, if a programme like this is to be truly successful it would seem that a more *supportive* (and not necessarily intensive) approach to weight loss and PA adherence is needed, including *multiple* contacts with various HPs and a continued guidance throughout the process.

11.5.4 Reengaging with Activity: using these insights in practice

When considering these findings in the wider world and their potential for policy change it is essential to focus on the entirety of the grounded theory proposed within this study (see figures 7.5 & 7.6). The results from this study are novel due to their explicit reference to the socio-cultural influences an older individual may have to overcome in order to change their health behaviours. Whilst previous research has offered much focus on the more generic and widely accepted personal, psychological, social and environmental barriers which may impact on an adult's choice to be physically active, this study specifically highlights the influence of life experience, upbringing and most specifically *change* as a new area which should be considered when providing health promotion to an ageing population.

If this theory stands true for the majority of the ageing population then health promotion in older adults may need to be offered with a new set of guidelines in mind. Whilst older participants spoke of an incredibly active childhood (often a predictor of adult PA in more recent studies) these childhood behaviours have not always been translated effectively into their later years. Thus it is possible that more could be done to encourage a more positive association between the fond memories of childhood play as referenced within their narratives and the often mentioned negative stereotypes a foreign gym environment in their later years. For example, if health professionals tried to highlight the similar qualities (such as enjoyment and social engagement) between activities such as walking groups now and the childhood play they remember with fondness, the incentive to engage in PA may be increased as intrinsically beneficial.

These findings of course stand alongside the equally pivotal findings suggesting far too little information about lifestyle is currently being provided during the screening setting anyway. Thus, not only do we first need to encourage *more* health promotion in the general sense, but also we must ensure there is a unified understanding that for many people of all different age groups, simply giving lifestyle advice for health benefits alone may not elicit a positive response.

11.6 Quality Control and Limitations of the Research

11.6.1 Qualitative Research

Qualitative research seeks to improve understanding of a specific phenomenon (in the case of this study, the PA influences in those at elevated risk of developing CC), by exploring the perspectives of individuals who *are* at elevated risk, as well as other, potentially relevant

people who may help to enhance understanding of the specific population under study. The difficulty with this type of research is that most qualitative researchers (myself included) strive to present more than merely descriptions within their analysis, and instead must both rely on the truthful accounts, and reliability of memory. Within this research the requirement for participants to recall memories (for some almost eight decades ago), as well the interviewee's knowledge of my position as a researcher with clear knowledge of PA recommendations and practice, may have reduced the credibility of their constructed stories. However, to ensure quality, four elements of CGT were monitored and maintained throughout; credibility, originality, resonance and usefulness (Charmaz, 2006), the approaches taken to ensure that these elements were maintained are explained the greater detail during section 6.7.

11.6.2 Study Participants

As explained within the methodology chapter, this qualitative research study formed a relatively small part in a large randomised controlled trial making the implications for application across an entire population of 'elevated risk' individuals extremely difficult to claim. All participants on the initial study were approached due to their heightened risk status following a bowel cancer screening procedure at the local hospital. Not only does attendance to this type of procedure alone limit the applicability of the findings, but the findings are even further limited because consenting to be part of a study of this kind (asking for a 6 month commitment to a lifestyle change programme) requires a certain type of person. All of the participants on this study (including cancer survivors), could be assumed to possess a greater level of motivation for change and were therefore more willing to consider initiating PA behaviour; all were Caucasian, living in close proximity to the university, and very often had a good understanding of the benefits of leading an active lifestyle. Although this is to be expected in studies of this kind, it does highlight the need to attempt to target the more

vulnerable members of the public with low levels of PA and poor lifestyle habits, who certainly would not consent to a behaviour change trial, and who also may never consider attending a screening examination.

11.7 Thoughts for Future Research

Although this study has provided a comprehensive exploration of PA behaviours within an elevated risk population as well as identifying the possible impact of a diagnosis on motivations to be active, and the possibility of a screening examination as a currently underutilised space for health promotion, it has also unveiled a number of equally fascinating areas for further exploration in the area of PA participation.

This study has particularly highlighted the changeable meaning PA has for people at elevated risk in an older population. Although very revealing in terms of needing to better clarify the guidelines around what constitutes 'meaningful' PA for these individuals, more research should be conducted to establish the lay perceptions of the current recommendations for PA in an older population, as well as increase knowledge around the sources that 'baby boomers' use in the health decision making process. Alongside this, the participants on this study were particularly unique because they had all been classified as 'sedentary' however, due to their interest in engaging in a PA programme, were possibly at a different 'stage of change' (Prochaska and Marcus, 1994) to their less motivated sedentary counterparts. Comparing the knowledge and attitudes towards engaging in organised PA between individuals who are sedentary and *not* considering behaviour change, age matched individuals who are currently *maintaining* engagement with a PA programme, and this studies participants who are all

beginning their PA journey, could provide a unique insight into how engagement in PA may have an impact upon positive ageing in general and attitudes towards future health.

Many of this studies interviewees spoke quite passionately about their childhood, and how the children of today are 'missing out' on the outside world and losing the ability to learn life skills due to the arrival of technology at a key time for child development. Comparing the views of this older generation and their grandchildren would be, I believe, a unique participant group, and an excellent tool in determining how play and the knowledge of the benefits of PA may have changed between generations – not to mention those from the same family. Exploring why individuals often 'romance about the past' and see their childhoods through 'rose tinted glasses' would also be an interesting and novel research area, which may help future researchers make sense of the way in which narrative, or lifetime accounts are constructed, and even the changeable nature of memory in studies of this kind.

This study focused primarily on health promotion within the secondary care setting due to the main focus of previous research in primary care. However by conducting *focus groups*, including a number with HPs (including screening practitioners, GPs, health trainers, fitness instructors and nutritionists for example), discussions could focus upon the perceived difficulties of utilising a multiple contact approach, as well as potential for a wider acceptance of a health promotion initiative across all health care domains. Also, observing actual patient-practitioner consultations, both in the screening setting, and also generally around health promotion, would be extremely interesting to determine not only the *way* in which information is provided to patients, but also whether the content provided is remembered by patients. Lastly, more *qualitative* research is needed to determine the actual preferences of patients from all age groups regarding the type of professional they believe would be most effective and most suited when providing lifestyle advice.

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Finally, a greater investigation into the health promotion campaigns and their approaches for PA engagement, as opposed to anti-smoking or binge drinking campaigns and dietary advice is warranted. By talking to the leaders of these organisations, as well as scrutinising the marketing strategies, answers may be provided about whether more emphasis much be placed upon the future promotional efforts for PA as a risk reducing behaviour.

11.8 Conclusions

This thesis has extended the understanding around socio-cultural influences on PA participation in a group of elevated risk adults following their bowel cancer screening examination and a sub-set of CC survivors. This has been achieved by exploring life stories and PA experiences, as well as comparing the impact of a change in health status on motivations to be physically active among the study participants, and age matched cancer survivors also participating in a randomly controlled PA intervention. Alongside this, and following on from gaps identified within the previous literature, this research has also outlined the potential complexities of utilising the screening setting for a health promotion initiative. It has also outlined the need for future research in this domain if a multi-disciplinary approach to health promotion, utilising both primary and secondary health settings as well as community specialists, is to be considered in the future.

The first findings chapter, with codes pertaining to the narrative accounts at the start of the elevated risk participant interviews, highlighted the disparities around what PA *means* to an older group of individuals. The need for greater understanding and clarity around the current guidelines, recommended intensities, and the ways in which these are able to be achieved; aside from attending a structured or organised PA gymnasium or class is warranted. What these findings have also confirmed is the need to look at each person individually when providing recommendations for PA. Tailoring PA advice around age, gender and health status may indeed be a positive place to start with regard to personalising messages and encouraging initiation. However, to maintain adherence, it is essential PA is not promoted with extrinsic factors in mind. Instead, the focus must be redefined as behaviour to be enjoyed with multiple additional benefits, such as socialising with friends and increasing quality of life, suggesting a key finding of this study was that participants needed to have intrinsic enjoyment of PA.

The second findings chapter referred to data collected from the latter part of the interviews with elevated risk, and cancer survivor participants. This supported previous research, by

revealing the lack of information provided to screening patients regarding risk status, and lifestyle following polyp removal. As well as this, the inclusion of cancer survivor interviewees meant that the impact of a cancer diagnosis alongside an elevated risk screening result on motivations for PA behaviour could be compared. Whilst initial assumptions prior to starting this research project outlined the perception all elevated risk participants would view their change in health status as a TM, this research stressed the difference between the two groups. The lack of awareness and knowledge around their new risk status, as well as limited understanding of the polyp-cancer pathway resulted in a HCE in elevated risk participants, whereas the life changing diagnosis of cancer and subsequent recovery seemingly provided the extra incentive needed for a TM for behaviour change to occur in the cancer survivors.

Whilst ones initial reaction to these findings may suggest an imminent change to screening practice (and thus improved patient awareness) is essential, the third findings chapter highlighted the sheer complexity of this task from the patient, and also HP perspective. Raising awareness on the importance of lifestyle behaviours and cancer risk was favoured by all patients, and most HPs interviewed. However, logistically the numerous barriers to providing this advice would make a change to practice incredibly difficult. Working as a multi-disciplinary team of health specialists would help to overcome many of the obstacles cited within this study and the previous literature by utilising numerous points of contact between patients and HPs. This process has the potential to save valuable time during each patient contact (especially during the protocol driven screening consultations), could allow for specialists with expert knowledge around the tailoring of lifestyle advice to take over where other professionals lack specific experience, and might also provide ongoing support systems to function throughout the behaviour change process; essential if behaviour change is to maintained. The disparities mentioned by the patients around awareness of risk and knowledge of polyps (or lack thereof), contrasted with professionals adamant that this

information is provided to each person, and emphasised a critical area which needs immediate consideration. The opposing accounts of the patients and professionals cannot be proven as the exact information covered during each consultation was not observed. However, if the professionals are certain this type of information is made clear, and yet the patients are not recalling the specifics, surely it is possible to conclude that the information around polyp formation, and their impact on future health risk, is not presented in a clear and memorable enough way for patients to remain mindful of their screening outcome. If this element is addressed sensitively, those with an elevated risk status following a screening examination may indeed feel that they have been given a 'second chance' and see it as a clear opportunity for behaviour change and lifestyle improvement.

APPENDICES

APPENDIX 1

The History of Grounded Theory

Grounded theory's underlying traditions are rooted in the work of two sociologists, Anselm Strauss; initially from the University of Chicago, and Barney Glaser from Columbia University. Their first work collectively focused on the experiences of those dying in hospital, which aimed to approach patients from a sociological rather than medical perspective, including more abstract concepts – and therefore more powerful accounts. Their method of generating theory combined the depth and richness of qualitative interpretive traditions, whilst preserving the logic, rigor and systematic analysis apparent in quantitative survey research, (Charmaz, 2000, Glaser and Strauss, 1967, Dey, 1999) which was first presented within their book *The Discovery of Grounded Theory* (Glaser and Strauss, 1967). At that time Grounded theory challenged a dominant emphasis on theorising in a logical and deductive way, and instead encouraged researchers to systematically develop a theory derived *directly* from the data upon *emergence* of key abstract concepts (Dey, 1999).

The popularity of using grounded theory has substantially increased over the past 40 years, with Bryant and Charmaz (2007) stating it is 'now the most widely cited qualitative research method within the social sciences tradition' (p.1). However, despite this popularity, confusion remains surrounding the correct procedures within the approach, and there is also much debate to be had regarding one's methodological school of thought (Greckhamer and Koro-Ljungberg, 2005, Suddaby, 2006)

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After the first book it was quite clear that many were having difficulty applying the grounded theory method to their own research due to its lack of clear instruction. Consequently Glaser wrote a second book entitled *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory (1978)* which he hoped 'would give a sense of what theory is, how it may be constructed when generating it' (pg. 1). Strauss later made an attempt to address these confusions also with two further books; the first titled *Qualitative Analysis for Social Scientists (1987)* and the second a publication alongside Juliet Corbin called *Basics of Qualitative Research (1990)*. These publications were far more detailed outlining rules of practice and giving researchers much greater procedural direction. In response to this Glaser was quite opposed, stating that *Basics of Qualitative Research* 'distorts and misconceives grounded theory, while engaging in gross neglect of 90% of its important ideas' concluding that Strauss' adapted method is 'preconceived, forced conceptual description' (Glaser, 1992).

The argument continues to this day, however many underlying principles of Grounded Theory still remain clear and are agreed by proponents of the method (as discussed within section 'Essential elements to a Grounded Theory study'). Grounded Theory is a set of procedures to develop an inductive theory about a phenomenon, in which the theory *emerges* from the data through the use of constant comparison, theoretical sampling and a keen eye for creativity and sensitivity towards the data (Charmaz, 2006) . Considering the diversity in how the method is now described, developed, and practised within research, it has been suggested a 'family of methods' exist, all contained under the grounded theory mantle (Bryant and Charmaz, 2007). The methods within this 'spiral' (Mills et al., 2008) all bear extreme similarities in order to theorise the ways in which humans act in their own social environment.

Strauss and Corbin never directly address the paradigm which highlights their evolved method in full, however they do position themselves as relativist pragmatists within a chapter outlining the relationship of theory to reality and truth in *Grounded Theory Methodology: An Overview* (1994) (Mills et al., 2008). Alongside this appreciation that 'theories are embedded in history' (p.280) (Strauss et al., 1994) the authors display a mixture of language which positions themselves between post-positivism and constructivism (within an ontological and epistemological continuum) (Guba and Lincoln, 1994). They understand the importance of *recognising bias* and *maintaining objectivity* within the research, but also couple these principles with the belief 'it is not possible to be completely free of bias' therefore enabling the foundations of participant experiences to form richer data reflective of each individual. These beliefs fall inherently in line with my ontological and epistemological stance and incidentally so do those of Kathy Charmaz the leading proponent of Constructivist Grounded Theory (Charmaz, 2000)

APPENDIX 2

WHOLE STUDY PROTOCOL

1. INTRODUCTION

1.1 Background to the study

In the UK, colon cancer (CC) is the second most common type of cancer by absolute incidence in males and females combined. Malignant neoplasms of the colon were responsible for 8248 deaths in England and Wales in 2010, of which 95% were in persons aged 60 or over (Office for National Statistics, 2011). The aetiology of CC follows the adenoma-carcinoma sequence model described by Fearon & Vogelstein (1990); whereby mutations can inactivate tumour suppressor genes and concurrently activate oncogenes associated with tumour development. This can lead to the formation of benign abnormal tissue, known as an adenoma. Adenomas usually take the form of polyps (small extrusions on the lining of the large intestine) which can eventually become cancerous. Since this seminal work, the model has been updated to account for the genetic and epigenetic disparities between CC types (Harrison & Benziger, 2011).

A strong body of evidence suggests that lifestyle factors influence cancer risk, and there is now convincing evidence that a physically active lifestyle is associated with reduced risk of developing colon cancer (Wiseman, 2008), a position which is substantiated by several systematic reviews in the field (Friedenreich *et al.*, 2010; Samad *et al.*, 2005; Slattery *et al.*, 2003; Slattery *et al.*, 2004). Furthermore, a recent meta-analysis of 52 case-control and cohort studies of the relationship between physical activity and CC estimated that regular physical activity confers a 24% reduction in risk (Wolin *et al.*, 2009). In accordance with these observations, American Cancer Society (ACS) guidelines recommend a minimum of 150 min of moderate to vigorous physical activity per week to help reduce the risk of cancer, but one hour per day on at least 5 days per week is likely to bring added health benefits (Kushi *et al.*, 2006). However, according to the 2008 Health Survey for England (HSE) self-report measures of physical activity, only 39% of males and 29% of females aged 16 or over are achieving the 150 min per week minimum, and according to accelerometry data, this is as low as 6% and 4% in males and females, respectively (NHS, 2010). Therefore, there is a need for effective lifestyle interventions which are aimed at reducing the risk of CC in populations who are more susceptible to developing the disease.

Research has shown that people recently diagnosed with an illness can be highly receptive to health promotional messages, with the illness forming a 'teachable moment' or a catalyst for lifestyle change (While, 2011). To date, one study (Hoff et al., 2001) has established whether informing patients classified as at moderate risk of CC after screening has provoked a lifestyle change. Their findings suggest that after a 13 year follow up, those informed of the presence of a colon polyp had improved smoking habits and less BMI increase than those not informed.

Few studies have investigated the efficacy of behaviour change interventions in patients classified as being at elevated risk of CC after colonoscopy {Caswell, 2009 #39;Emmons, 2005 #40} or flexible sigmoidoscopy (Robb et al., 2010). These interventions aimed to decrease risk behaviours such as poor diet, alcohol consumption and inactivity, with a minimal-contact protocol. Only one study {Emmons, 2005 #40} specified which theoretical model the behaviour intervention was based on. The duration of the studies varied from 10 weeks {Caswell, 2009 #39} to 4 months {Emmons, 2005 #40} and 6 months (Robb et al., 2010). Participants received printed materials or phone calls ranging from twice per month to once per month and there was no direct contact with the participants. No study was able to show significant improvements in physical activity levels. This might be due to the short duration of the studies or minimal amount of contact time with the participants. Clearly, more effective interventions for engaging patients at elevated risk of CC in regular physical activity are needed. Additionally, further studies of the barriers and facilitators to exercise are needed to understand how these factors interact to influence behaviour change in this patient group.

1.2 Study rationale

1.2.1 Intervention design

Given the low self-reported physical activity levels in elderly populations (NHS, 2010), physical activity interventions for this patient group need to evoke meaningful and

sustained changes in physical activity behaviour to increase the potential for improvements in CC risk profile to occur. According to a recent systematic review of lifestyle interventions that targeted weight loss and higher physical activity levels, the effectiveness of an intervention increases when well-defined behaviour change techniques are used {Greaves, 2011 #43}. Increased contact time with the participant was also found to be a predictor of more positive behaviour changes. In accordance with these recommendations, a recent study {Silva, 2011 #44} investigated the effects of a 1year behavioural intervention with overweight women over three years of follow-up. Participants in the intervention group received 30 theory workshops aimed at increasing physical activity levels and energy expenditure. After one year, the intervention group achieved significantly higher levels of moderate and vigorous intensity exercise and weight loss in comparison with a control group who received general health advice only. More specifically, mean exercise levels and percentage weight loss in the intervention group were 300 min per week and -7.3%, as opposed to the control group (179min per week, -1.7%). The differences between groups were still significant after 3 years.

The intervention was based on a psychological model called the Self-Determination-Theory (SDT). According to this model, motivation can vary in level and orientation which means that the amount and type of motivation can differ amongst people {Ryan, 2000 #45}. The more intrinsically regulated a motivation the more autonomously the behaviour is performed, which means the behaviour is carried out because of enjoyment. In turn, more extrinsically regulated motivations are performed with less autonomy which means the behaviour is controlled and performed because one was told to. People are more likely to maintain regular physical activity if the behaviour is intrinsically motivated. On the other hand, when physical activity behaviour is not yet maintained but in a stage of preparation or contemplation, then motivation regulation is more extrinsic {Thogersen-Ntoumani, 2006 #46}. These findings demonstrate that the effectiveness of an intervention is dependent on the motivation to perform a specific behaviour and they highlight the need to target motivation for a specific behaviour to promote long-term changes in that behaviour.

When implementing such a behaviour change intervention, it is important to understand its efficacy in relation to underlying determinants of behaviour change. Tools have been developed to measure key constructs influencing physical activity behaviour change. In addition, qualitative techniques can be used to gain deeper insights. An intervention that uses the SDT aims to implement changes in autonomy or self-determination, where a change from low autonomy to high autonomy is desired. This is because higher levels of autonomy are associated with greater adherence to a given behaviour over time, and this increases the likelihood for long-term maintenance of the adopted behaviour. It is therefore important to monitor the progress of this change to evaluate the effectiveness of the intervention. authors Mullan et al. {Mullan, 1997 #63} developed questionnaires to measure the level of autonomy with which a certain behaviour is performed. However, although autonomy is a predictor of physical activity behaviour, other variables, such as intention and self-efficacy, mediate between the two {Hagger, 2009 #58}. Hence, in order to draw conclusions about the constructs that underlie the effects of the intervention, intention and self-efficacy need to be measured alongside measures of self-determination. Finally, as intention, self-efficacy to exercise and self determination to be physically active can be high and actual physical activity behaviour low, it is also necessary to assess the amount of physical activity that is performed over a defined period of time. Several physical activity questionnaires are available for this purpose.

Qualitative methods can also be used to gain a deeper understanding of the multidimensional factors influencing physical activity behaviour. In particular, narrative research allows light to be shed upon previous experiences and how they influence current decisions regarding physical activity behaviour (Carless and Sparkes, 2008). Buman *et al.* (2010) used a narrative interview approach to analyse barriers and facilitators to physical activity within the elderly. His findings accounted for how previous experiences can formulate intention and self- efficacy and therefore constructs which could predict initiation and maintenance (McAuley et al., 2003). O'Brien-Cousins (1997) reported similar findings which established links between early life accomplishments and past success history, in relation to current self-efficacy levels and confidence for physical activity participation.

Through the use of interviews and focus groups at the end of the 12 month intervention, more insight can be gained about personal experiences relating to the impact of the intervention not only with regards to health benefits and wellbeing but also social and psychological influences of taking part in the trial. Barbour (2000) suggested that many theories and health promotional strategies can be formed through the use of qualitative research. These gauge how personal experiences within interventions can influence health promotion messages in the future by drawing on individual accounts of most and least successful aspects. Issues surrounding the recruitment process and maintaining adherence can also be suggested, and prove invaluable when designing interventions of this kind in the future.

1.2.2 Impact of the intervention on CC risk markers

Many studies have attempted to elucidate how lifestyle factors - especially diet modulate the pathways involved with cancer progression (Lund et al., 2011). Despite the relative wealth of evidence in favour of a physically active lifestyle, the mechanisms by which it dictates any changes in CC risk are largely unknown. To date, only one randomised controlled trial has examined the effect of exercise on physiological risk markers associated with CC in sedentary individuals, the findings of which were published in three papers (Abrahamson et al., 2007; Campbell et al., 2007; McTiernan et al., 2006). Although a 12 month exercise programme resulted in favourable changes in colonic cell growth patterns, especially in males who improved their aerobic fitness by > 5% (Abrahamson *et al.*, 2007; Campbell *et al.*, 2007), the effects upon important genetic/epigenetic markers, nuclear beta-catenin status and indices of chronic inflammation were not examined. Recent work has indicated that these markers are associated with CC stage and prognosis, and might serve as predictive tools in individuals at risk. Widespread aberrant DNA methylation, including a general loss of DNA methylation from the genome (global hypomethylation) together with CpG island (CGI) hypermethylation of tumour suppressor genes is a hallmark of advanced CC (Harrison & Benziger, 2011), and there is much potential in using CGI methylation status in genes known to be associated with colon carcinogenesis (e.g. APC, WIF1, SFRP1, MGMT, p14, p16) as indicators of risk (Hughes et al., 2012; Kim et al., 2010; Walther et al., 2009). Indeed, marked differences in CGI methylation exist in such genes between normal and neoplastic colon tissue (Belshaw et al., 2008), and increased aberrant DNA methylation is associated with poorer prognosis in colorectal cancer patients (Kim et al., 2010; Mitomi et al., 2010). Furthermore, negative nuclear betacatenin/CTNNB1 status appears to be associated with improved disease-specific

survival in colorectal cancer patients who undertake ≥ 18 MET hours/wk of physical activity, but not in individuals with a positive status (Morikawa *et al.*, 2011). Similarly, disease free survival in stage III CC patients undertaking ≥ 18 MET hours/wk of physical activity was improved by 47% compared with their inactive counterparts (Meyerhardt *et al.*, 2006).

Current research has also suggested that chronic, systemic inflammation – whilst known to be a feature of the neoplastic milieu – might predispose individuals to greater CC risk (Chan *et al.*, 2011; Kim *et al.*, 2008), perhaps through aberrant cytokine-induced activation of signalling pathways associated with tumorigenesis (Terzic *et al.*, 2010). Moreover, regular exercise is known to exert a potent anti-inflammatory effect (Petersen & Pedersen, 2005), and it is therefore possible that reductions in chronic inflammation achieved by an active lifestyle might confer decreased likelihood of CC initiation in populations at risk.

2. PURPOSE OF THE STUDY

The purpose of this study is to investigate the effects of a 12-month physical activity intervention on physical activity behaviour and biological markers of CC risk in individuals classified as being at elevated risk of developing further polyps following surveillance colonoscopy. The physical activity intervention will use self-determination theory (SDT) to create an autonomy-supportive environment, an approach that was recently shown to evoke greater physical activity levels and weight loss than general health education in overweight women (Silva *et al.* 2010). Secondary outcomes will explore the impact of the intervention on aerobic fitness, health-related quality of life and the underlying determinants of behaviour change (i.e. self-efficacy, intrinsically motivated regulation, etc). In addition, interviews and focus groups will be used to obtain narrative accounts of patient experiences, their perceived health benefits from participating in the intervention and the barriers and facilitators influencing adherence.

3. STUDY HYPOTHESIS

Patients randomised to the intervention group will have higher physical activity levels and improved CC risk profile in comparison to usual care controls after 12 months.

4. METHODS

4.1 Study design

The proposed study is a randomised controlled trial, with participants stratified for risk status ('low', 'high' or 'intermediate'). Participants will be randomly allocated to either the physical activity intervention (Active Lifestyle Programme: ALP) (Fig 1) or the usual care control group (UC) (Fig 2). Participants randomised to UC will receive usual medical care but no specific lifestyle advice or exercise sessions. Outcomes will be assessed at baseline, and after 3, 6, 9 and 12 months (Table 2).









4.2 Participants

Participants will be patients attending the Norwich and Norfolk University Hospital (NNUH) Gastroenterology Unit for a screening colonoscopy. Patients will be from two different screening groups: 1. Patients undergoing a screening colonoscopy as part of the NHS Bowel Cancer Screening Programme, and 2. Patients referred to the hospital for a colonoscopy by their GP after presenting with symptoms.

Those who are deemed 'low', 'intermediate' or 'high' risk for the development of further polyps as a result of the procedure will be eligible to take part in the study. Inclusion criteria are i) diagnosis of 'low', 'intermediate' or 'high' risk as a result of the screening colonoscopy; ii) aged 60 years and above and iii) physically able to partake in regular exercise. Exclusion criteria will include i) physical activity levels that meet the most recent American Cancer Society (ACS) guidelines for maintenance of health for at least the past 6 months; ii) presence or history of other co-morbid conditions which might preclude patients from safely undertaking regular exercise, including cardiovascular or pulmonary disease or stroke; iii) presence of other colorectal conditions (e.g. inflammatory bowel disease) or known familial colorectal cancer syndrome; iv) chronic use of any treatments or alternative therapies that may affect the results of any study of colorectal tissue e.g. high corticosteroid, anticoagulant or laxative use, regular enemas, high dose vitamin or antioxidant supplements, etc.; v) previous diagnosis of cancer; vi) inability to adequately understand written and spoken English, vii) presence of drug controlled type II diabetes mellitus and viii) current involvement in other ongoing research. Current health and demographic data will be captured from consenting participants using a bespoke questionnaire designed by the researchers. Data captured will include age, gender, ethnicity, medication profile (type of medications, dosage level and frequency), family history of colon cancer, comorbidities, spouse present in the home, occupation, socioeconomic status (estimated using first half of participant's postcode), level of education, current involvement in ongoing research, alcohol consumption, smoking status and number of GP visits in the past year. The questionnaire will be administered again after 12 months to monitor any changes that occur during the trial.

4.3 Recruitment and informed consent

Recruitment differs for the two patient groups. Both groups will be first approach by the clinical staff, either with a letter or after their pre-assessment appointment. Retrospective recruitment is the same for both groups. The following paragraphs will explain the different recruitment strategies for both patient groups.

4.3.1 Recruitment via National Bowel Cancer Screening Programme

Patients attending the hospital for their pre-assessment (1-2 weeks prior to their screening colonoscopy) will be given a study invitation letter, a patient information leaflet and a consent form. The form will request their approval for the collection of five small research biopsies if they are classified as, low, intermediate or high risk during the colonoscopy (See Appendix 2). Prior to their colonoscopy one of the researchers will call the patient using the phone number provided during their colonoscopy pre-assessment in order to discuss any questions the patient may have regarding their participation and ascertain their interest in the trial. If the patient is not willing to take part in the study, a researcher will then ask a few further questions regarding their choice not to participate (See Appendix 9). This element would take no longer than five minutes, responses would remain anonymous and again patient participation would be entirely voluntary. We hope this will provide some insight into an often over-looked group of patients (the non-participators) and would go some way to inform future researchers about recruitment into similar interventions.

On the day of their screening colonoscopy, patients will return their signed consent form if they are happy for the research biopsies to be taken, and the colonoscopist will be informed of the patient's willingness to participate in the study. A letter will also be sent to their GP outlining their interest in the study and providing contact details if they have any further questions.

If the patient is identified as falling into a low high or intermediate risk polyp group, five small research biopsies will be taken from the sigmoid colon by the colonoscopist and placed in RNAlater® formalin, Carnoy's fluid or frozen in dry ice for the subsequent collection by the research team. When the patient returns to the hospital for

their results (approx 1-2 weeks later), those who consented to having research biopsies taken will be informed if this was carried out and whether they are eligible for the study. The contact details of eligible patients will be passed on to the researchers by the bowel cancer screening nurse subject to further consent (Appendix 4). Patients who consent to be contacted will be telephoned by the researchers within a week to organise an appointment at the exercise facility at The University of East Anglia. At the appointment, the researchers will explain the study and give the potential participant the opportunity to ask any questions before gaining full written informed consent (Appendix 5). During this meeting, participants will be given equipment for monitoring their baseline physical activity levels and a questionnaire booklet which includes measures of physical activity and behaviour change determinants.

After randomisation, based upon an initial agreement of contact regarding the qualitative aspects of the research and baseline demographic data, approximately 10 participants from both the ALP and UC group will be sent a further information sheet detailing the content of the interviews at 1 and 12 months. These participants will be contacted a week later to arrange a date for their initial interview. At the interview a further consent stage will be established with specific qualitative criteria. The process will be repeated after the intervention for the focus group participants. Health professionals within the gastroenterology unit at the Norfolk and Norwich University Hospital will be invited to attend a presentation introducing the study, including information about the focus group topic and what can be expected of them if they agree to participante. Here Miss K Semper will give out 'Information about the Research – Focus Group, Health Professionals' and then gain permission from interested participants will be contacted and a date for the focus group arranged.

4.3.1.1 Recruitment via Big C charity

Posters and flyers will be posted at the Big C facility in Norwich which is located near the NNUH and on the Big C website. These briefly introduce the topic of the research and what can be expected by the participant. Contact details of the researchers are printed on the posters. In the event that an interested potential participant contacts a researcher, the study will be explained fully to them via the phone and further questions will be answered. The research team will make the interested potential participant aware of the colon cancer screening programme or, if they are already enrolled in the programme, advise them to ask the specialist nurse at the NNUH when they are scheduled for their next colonoscopy appointment about the 'Active Lifestyle Programme'. Recruitment will then proceed as described above (4.3.1).

4.3.2 Recruitment of patients referred through their GP

Patients that present to their GP with a symptomatic bowel (e.g. change of bowel habit, rectal bleeding) will be referred to the NNUH to undergo a colonoscopy. The booking staff at the Gastroenterology Department at NNUH will send out a letter with an appointment for a colonoscopy to these patients. Together with the appointment letter, the patient will receive an invitation letter and a patient information sheet explaining the study, and be informed that a researcher will be present on the day of their colonoscopy to speak to them should they be interested in taking part in the study. The patient will be able to ask questions and the researcher will explain the study in more detail. If the patient is interested in taking part in the study they will sign a biopsy consent form that will allow the researchers to take 5 small pinch biopsies from the sigmoid colon during the procedure if the patient is diagnosed with an increased risk of developing further polyps.

4.3.3 Retrospective recruitment of historic patients

Eligible patients who have undergone a screening colonoscopy in the past three (3) years (either as part of the National Bowel Screening Program or referred by their GP as a result of symptoms) whose diagnosis was 'low', 'intermediate' or 'high' risk will be identified by the research team from patient records retrieved by the clinical care team at the Norfolk and Norwich University Hospital Gastroenterology Unit. The researchers have obtained honorary contracts, a Research Passport and undergone mandatory NHS Information Governance training to ensure that they are qualified to handle personally identifiable data. A modified Invitation Letter and Patient Information Sheet will be posted to them. Responders to this material by telephone or email will be invited for a consultation at the University of East Anglia where the researchers can explain the study and gain full written informed consent.

4.4 Randomisation

After baseline measures have been completed, participants will be randomised into the control or intervention group and stratified by risk status (low/intermediate/high). Randomisation will be completed using a bespoke programme based at the Institute of Food Research. Participants will be assigned a unique code which blinds the researchers as to their group allocation during analysis. A further code which details time of sampling for the repeated measures during the proposed study will also be used.

4.5 Usual Care (UC) Group

The UC group will not receive an intervention or any other form of advice in regards to lifestyle behaviours. However, they will have the opportunity to take part in a limited number of supervised exercise sessions and receive an intervention workbook at the end of the study. They will not receive any lifestyle advice or supervised exercise sessions until the end of the 12 months study period. There is the possibility for some participants in the UC group to be contacted from one of the researchers to be included in the qualitative interviews or focus groups.

Participants in the UC group will undertake the baseline measures and repeat these at the same time points as ALP. This will include fitness test, body composition, blood samples and all questionnaires at 6 and 12 months and some selected questionnaires at an additional two time points, at 3 and 9 months of the study.

4.6 Physical activity intervention (ALP)

All participants in ALP will attend a familiarisation session in the week before the trial starts. They will be introduced to the equipment available in the exercise facility (treadmill/rowing machine/cycle ergometer). The researchers will also demonstrate the various resistance/bodyweight exercises that the participants will be required to perform. These will include bicep curls, dumbbell flys, sit-ups and chest extensions (with Theraband). In the first 12 weeks of the study, participants will attend the exercise facility on 2 d/wk (time of day to be at the discretion of the researchers and participants) and complete a supervised exercise session. This will consist of a ten minute warm up,

30 minutes of aerobic exercise at 65-80% maximum heart rate (HR) as determined by the $\dot{V}O_{2 max}$ test (it is acknowledged that some participants will be unable to exercise at 80% max HR for 30 min at the onset of the trial, so intensity will be adjusted accordingly to ensure a full 30 min bout is completed) and 30 min of resistance exercise using the exercises described above. Sessions will follow the principles of progression and overload such that participants continue to improve their fitness. On \geq 3 days per week, participants will complete home-based exercise at the exercise facility will take place on 1 d/wk only, and home-based exercise will take place on \geq 4 d wk. For the remaining 24 weeks, participants will be expected to complete \geq 300 min of moderate to vigorous exercise per week, spread over \geq 5 days.

4.6.1 Physical Activity Workbook

To encourage exercise participation and maintain adherence, ALP will be provided with a bespoke physical activity workbook (the PARC workbook) designed by the researchers, which outlines suggestions for physical activity, and includes physical activity logs, progress monitors and contact details of the researchers. The participant will keep this workbook for the duration of the trial. Furthermore, ALP will be provided with pedometers, which will be used as a motivational tool to promote exercise (i.e. brisk walking) behaviour.

4.6.2 Active Lifestyle workshops

Theory-based workshops will take place at the University of East Anglia every fortnight for the first 6 months of ALP and once a month for the remaining 6 months. The workshops will be based upon the Self-Determination Theory (Ryan & Deci, 1985) and will cover a range of topics including goal-setting and exercise barriers (Table 2). The workshops will be designed and delivered by Mrs Liane Lewis. During the first 24 weeks of ALP, ALP will attend one workshop every two weeks after a supervised exercise session, which will last for approximately 30-45 min. The remaining 24 weeks, participants will receive a monthly phone call during this time, to provide support for the home-based exercise routine. An outline of the workshops is presented in Table 1.

Table 1. List of ALP workshop topics and schedule.

Week	Content
	Theory session
1	Introduction to the program
	Interactive 'getting to know each other'
	Outline of the intervention
	Identify an activity they like
	Activity targets
3	Exercise intensity
	Monitor your exercise
	SMART gaol setting
5	Health benefits of exercise
	Assess exercise readiness
	Goal re-setting
	Barriers
7	Principles of exercise training
	Overcoming barriers
	Strategies to maintain physical activity levels
9	Household activities
	Environmental barriers or cues
	Relapse prevention
	Assess value of being physically active
11	Re-assess goals
	Are you meeting your target exercise levels?
	Do you have problems meeting your targets?
13	Discussion about feelings of last few weeks exercise regime.
	How do you feel about exercising?
	Discuss barriers with others and find own strategies to overcome these (how do others deal
	with barriers)
	Compare goals achieved
15	How to involve friends and family
	Discuss exercise opportunities in neighbourhood (parks, pavements, bike paths, gyms, etc)
17	Re-evaluation of barriers and goals
19	Exercise planning and building into daily routine
	Planning strategies
xvii	
	Cues
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21	Stay active on holiday, after injuries
	Coping with environmental factors that may prevent exercise
	How to adapt exercise plan to other unplanned changes in schedule
23	Final discussion of Barriers and goals
	Future plans and strategies

4.7 Outcomes

An overview of the outcome measures can be seen in Table 2. All outcome measures will be repeated after 6 and 12 months. A sample of selected questionnaires will be repeated after 3 and 9 months in addition to this. To minimise bias due to perceived expectancy, all physiological samples collected will be coded so as to blind the researcher conducting the analysis (BS) as to the group allocation and time of sampling. The subjective nature of the self-report instruments used for evaluation of the intervention is accepted and every effort will be made to minimise potential bias due to this dynamic. In particular, patients may over or under report their health status depending on the trial arm to which they have been assigned - although randomised, it will be obvious to the participants which arm of the trial they are in. Baseline primary self-report assessments will however be completed by the participants before they are randomised. Due to the one-to-one participatory nature of the intervention, it will not be possible to blind study participants to their group allocation. However, analysis of outcome measures will be conducted by a researcher that is blind to group allocation. The Qualitative researcher, although aware of each participant's group randomisation upon interview, will have no additional contact with the purposefully selected participants throughout the 12 month intervention.

4.7.1 Primary outcomes

4.7.1.1 Physical activity

Objective free-living physical activity levels will be assessed over 7 days using accelerometry (ActiGraph®). The small unobtrusive accelerometer is worn on the hip and collects data on activity counts, step counts and total exercise energy expenditure. Self-reported physical activity will also be assessed using the International Physical Activity Questionnaire (IPAQ) (Friedenreich *et al.*, 1998) and the Godin Leisure Time

Exercise Questionnaire (Godin and Shephard, 1997). Both questionnaires are selfadministered and use a 7-day recall period. The IPAQ is designed to measure four domains of physical activity: 1) Job-related; 2) Transportation; 3) House work; and 4) Recreation, sport and leisure-time. An additional question asks for the time spent sitting. Amount of exercise in MET-minutes per week is calculated by multiplying minutes and intensity of specific activity undertaken. The validity of the IPAQ has been rated as acceptable for the different activity domains {Hagstromer, 2006 #48}. The Godin Leisure Time Exercise Questionnaire is a short four-item questionnaire that assesses the number of times that strenuous, moderate or mild exercise was performed for more than 15 min over the last 7 days.

4.7.1.2 CC risk markers

Biopsies will be collected at initial surveillance colonoscopy (baseline) and after 12 months at their follow-up visit. Five small research biopsies of the sigmoid colon will be obtained during the screening colonoscopies. Two biopsies will be placed in fixative solutions (one in 10% formalin and one in Carnoy's fluid), two in RNAlater ® and one frozen on dry ice, for collection and transfer to the Institute of Food Research. Samples will be stored at -80°C until analysis. Biopsies will be analysed for global DNA methylation status by quantifying the methylation of the repetitive elements LINE-1, Alu and Satellite repeats, previously demonstrated to be suitable surrogate indices of global methylation, using a qPCR assay adapted from Iacopetta et al. (2007). Genespecific CGI methylation status of a panel of genes previously shown to be involved in colon carcinogenesis and whose methylation status has also been demonstrated shown to be susceptible to environmental influences (Tapp et al. submitted) (e.g. APC, WIF1, SFRP1, MGMT, p14, p16) will also be determined using a quantitative methylationspecific PCR (QMSP) assay developed at the Institute of Food Research (Belshaw et al., 2008). RNA and protein expression regulated by these genes will be analysed by quantitative real-time polymerase chain reaction (PCR) and Western blotting, respectively. In addition, nuclear CTNNB1/beta-catenin status in colonic cells will be measured using immunohistochemical methods, which will detail its expression (none, weak, strong) and distribution (nucleus, cytoplasm, membrane). Markers of chronic inflammation (e.g. TNFa, IL-10) will also be investigated by multiplex ELISA. Mitotic and apoptotic figures and colonic crypt dimensions will be determined in microdissected crypts from Carnoy's fixed colon sections using the Feulgen's staining method established at the Institute of Food Research. Cross-validation of crypt cell proliferation and apoptosis rates will be obtained by immunohistochemical labelling of crypt sections for Ki67 and activated caspase 3. The phosphorylation and expression of regulatory proteins involved in signalling pathways known to be associated with colon cancer progression (e.g. ERK, AKT) will also be determined by Western blotting.

4.7.1.3 Blood and buccal cell markers of CC risk

Venous blood will be obtained by venepuncture of the left or right antecubital vein by a trained phlebotomist. 2 x 5 ml of venous blood will be transferred into a plasma collection tube containing EDTA anticoagulant and gently agitated. Once collected, whole blood samples with EDTA will be refrigerated at 4°C. A further 2 x 5 ml of venous blood will be transferred into a serum collection tube and left to clot for 30 min at ambient temperature. Buccal smears will also be obtained. All samples will be subsequently transferred to the Institute of Food Research. Here, serum will be centrifuged at 2500 g at ambient temperature for 15 min, and the supernatant aliquoted into cryovials for storage at -80°C. Remaining whole blood will also be stored at -80°C. The methylation status of DNA extracted from peripheral blood leukocytes and buccal cells will be analysed using the techniques detailed in section 4.7.1.2 above.

4.7.2 Secondary outcomes

4.7.2.1 Anthropometry and cardiopulmonary fitness

Stature, body mass, body mass index (BMI) and waist-hip ratio will be measured using standard techniques. Cardiopulmonary fitness will also be assessed at baseline and after 6 and 12 months. Before the cardiopulmonary exercise test, participants will complete the Physical Activity Readiness Questionnaire (PAR-Q) (Thomas *et al.*, 1992) (Appendix 10). This questionnaire is developed to determine the safety or risk of exercise for the participant by answering a series of health-related questions. Resting blood pressure and a 12 lead ECG will also be taken prior to the test. Participants will

then perform a test of maximal aerobic capacity ($\dot{V}O_{2 max}$) on an electronically braked cycle ergometer, which should last for approximately 8-12 min. The test starts with a 2 min freewheeling-period and intensity increases every 2 min by 25 Watts until exhaustion. During the test, a continuous ECG trace will be monitored by a medical professional, and the test will be stopped immediately should any abnormalities arise during the exercise bout. Once the participant has reached their $\dot{V}O_{2 max}$ and is unable to continue, the test will finish and the participant allowed to 'freewheel' for as long as they deem necessary. Participants will then have the opportunity to shower and change and will be allowed to leave after their resting heart rate and blood pressure has been checked. This will be completed at baseline, and 6 and 12 months thereafter (Table 1).

4.7.2.2 Dietary analysis

Participants will complete a 4 day food record specifying any foods or liquids ingested, their approximate mass, and time of consumption. Completed records will be analysed for dietary macronutrient and micronutrient composition using the CompEat 5 (Nutrition Systems) software package. This will be completed at baseline and at, 3, 6, 9 and 12 months thereafter (Table 2).

4.4.2.3 Psychological measures and health related Quality of Life (QoL)

Participants randomised to the ALP will receive a questionnaire booklet which contains all self-report questionnaires and a 4-day food diary. This will be completed at home and returned at their next visit to the research facility. A researcher will give instructions on how and when to complete the questionnaires and will check through them with each participant when they attend the research facility for other assessments. The assessment booklet will include the following questionnaires:

Behaviour Regulation for Exercise Questionnaire (BREQ)

The BREQ, designed by Markland and Tobin {Murcia, 2007 #62}, measures the continuum of motivation regulation, components of the Self-Determination Theory. It has been used widely in the sports and exercise domain. Questions are designed to measure amotivation, extrinsic, introjected, identified and intrinsic motivation for exercise. Nineteen items are rated on a scale from 1 ('not true for me') to 4 ('very true for me').

<u>Short Form-36</u>

The 36 item self-administered quality of life questionnaire was developed to be used in a generic setting with no target on a specific age group or disease. Numerous studies have used the SF-36 in a variety of clinical settings. Reliability has been tested extensively and results exceed the minimum standard of 0.70 advocated for group comparison measures. It consists of an 8-scale profile of physical and mental health scores: Physical Functioning, Bodily Pain, Role- physical, General- Health, Vitality, Social Functioning, Role Emotional, and Mental Health. Responses to each item are produced on a 5- Point- Likert Scale.

Self- Efficacy for Exercise (SEE)

The self-efficacy scale is a 9- item questionnaire assessing the participant's confidence to exercise under different situations such as pain, bad weather or being tired. On a scale from 0 (not very confident) to 10 (very confident) the participant assesses their confidence to exercise 30 minutes on most days of the week when confronted with such a situation. Items are developed specifically for an elderly population.

Intention to exercise:

This short two-item questionnaire assess participant's intention to exercise regularly for the next month and for the next 6 months. Responses are rated from 1 (Do not agree at all) to 7 (Completely agree).

4.4.2.5 Qualitative analysis

Ten participants from both ALP and UC will be purposefully sampled and invited to take part in face-to-face interviews at 1 and 12 months. The purposive sampling frame will draw on priority criteria ensuring diversity in conceptually relevant characteristics of potential participants, to include: age, sex and baseline fitness ($\dot{V}O_{2 max}$). Additionally, three focus groups will be administered at the end of the intervention with the ALP, UC and relevant health professionals (HP). For detailed Interview and Focus

group designs see Appendix 10. Separate information sheets and consent forms (see Appendix 7) will be given to the trial participants at the end of the intervention phase, which will represent a separate consent stage for the focus groups at the end of the 12 month intervention. The main information sheet provided at the start of the trial will state that after the completion of the intervention participants may be asked to participate in a structured focus group. All qualitative measures will take place within the University of East Anglia, and will be audio recorded for analysis purposes – participants will also be made aware of this in the initial patient information sheet. All interviews and focus groups will take approximately 90 minutes. Interviews will also ideally be scheduled when other outcome measures need to be taken – for example at baseline and trial termination.

Interview 1 (Start of Intervention)

Aim: Narrative accounts to gain information regarding how various life experiences and attitudes towards physical activity shape beliefs surrounding a physically active lifestyle in the present day for each individual.

Other Objectives:

- Establish level of knowledge regarding the benefits of physical activity, especially within this specific population.

- Conclude if too little information is provided to this specific population regarding the health benefits of physical activity and gauge views as how best to administer this advice, and at what stage throughout adulthood

- Identify key barriers and facilitators to physical activity in this population and establish whether the risk diagnosis has provided a 'teachable moment' in these individuals.

Analysis: *Grounded Theory Approach* - Identify key concepts formed within the narrative accounts, and group these into categories with the final aim to create novel theories in order to better explain the participant of the research.

Interview 2 (End of Intervention)

Aim: Semi-structured interviews post intervention will be defined mainly upon emergent analysis from initial interviews to establish thoughts on the 12 month intervention and how attitudes towards physical activity may have changed.

Other Objectives:

- Compare experiences from the supervised and home based exercise interventions to establish a successful framework for future intervention.

- Establish whether this length of exercise intervention is sufficient enough to elicit a long term motivation to maintain physical activity.

- Assess the importance of group randomisation, effects of being placed in the control group.

Analysis: *Grounded Theory Approach* - Identify key concepts formed within the interviews, and group these into categories with the final aim to create novel theories in order to better explain the participant of the research.

Focus Groups (End of Intervention)

Aim: To compare and contrast differing experiences within the 12 month intervention and also cross compare issues regarding the recruitment and adherence to these sorts of studies with experienced health professionals.

Other Objectives:

- Hear thoughts on the intervention as a whole from both the exercise and control group in order to gain valuable insight for future intervention design.

Analysis: Broad thematic analysis will be used to analyse focus group date and identify emerging themes.

Table 2. Measurements taken from participant, their frequency and time of sampling

Туре	Item	Baseline	3	6	9	12 months
			months	months	months	
Physiological	Colon tissue	✓	×	×	×	✓ (high risk only)
	Venous blood	\checkmark	×	\checkmark	×	\checkmark

	Buccal smear	\checkmark	×	\checkmark	×	\checkmark
Psychological	SF-36	\checkmark	×	\checkmark	×	\checkmark
	SEE	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
	BREQ	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
	Intention	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
Qualitative	Interview	\checkmark	×	×	×	\checkmark
	Focus group	×	×	×	×	\checkmark
Habitual Physical	Godin Leisure Time	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
Activity	Exercise					
	Questionnaire					
	IPAQ	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
	Accelerometer(7	\checkmark	✓	\checkmark	\checkmark	\checkmark
	days)					
Diet	Food record (4 days)	\checkmark	×	\checkmark	×	\checkmark
Fitness	Exercise capacity	\checkmark	×	\checkmark	×	\checkmark
	12 lead ECG	\checkmark	×	\checkmark	×	\checkmark
	Mass/BMI/Waist-hip	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
	ratio/body fat %					
	Heart rate/Blood	\checkmark	×	\checkmark	×	\checkmark
	pressure					

4.8 Statistical analysis

4.8.1 Sample size calculation

4.8.1.1 CGI methylation

The sample size was based upon the numbers required to demonstrate a clinically important change in aberrant CGI methylation and leisure-time physical activity as determined by the Godin Leisure-Time Exercise Questionnaire (Godin & Shephard, 1997). Previous work has demonstrated that aberrant CGI methylation in key genes is inversely related to the progression of sporadic CC (Grady & Carethers, 2008; Kim *et al.*, 2010). Indeed, aberrant activation of the Wnt signalling pathway is a common pathological feature of colon carcinogenesis. One reason for this is that the gene encoding the lipid binding protein Wnt inhibitory factor 1 (WIF1) that can inhibit this pathway is frequently methylated. Therefore, the statistical power for the present study is based on the assumption that exercise will i) significantly reduce the proportion of participants in whom the WIF1 gene is methylated in > 11% of alleles, and ii) reduce their WIF1 methylation profile by the equivalent of ten years of ageing. The 11% threshold was based upon data collected from the Biomarkers of Risk of Colorectal Cancer (BORICC; Food Standards Agency) study which indicated that 11% of participants aged between 47 – 53 have > 11% of WIF1 alleles methylated, compared

with 33% in those aged from 57 – 63. To achieve a significant reduction ($P \le 0.05$, 80% power) of WIF1 gene methylation from 33% to 11%, in participants with > 11% of WIF1 alleles methylated, it was calculated that n = 124 (i.e. 62 participants per group) is required. However, an attrition rate of 15-20% is to be anticipated based on former studies.

4.8.1.2 Leisure-time physical activity

Previous work in elderly colon cancer survivors has suggested that to demonstrate a meaningful increase in physical activity levels according to the Godin Leisure-Time Exercise Questionnaire (Godin & Shephard, 1997) after a 12 week exercise intervention (associated with significant improvements in functional fitness), at 90% power, alpha 0.05 and an effect size of 0.713, a total of 86 participants is required (43 per group). A total of 124 participants should thus be sufficient to demonstrate any changes in these outcomes.

4.8.2 Measuring effects

All quantitative data will be analysed by a researcher blinded to participant identity and group allocation (BS) using appropriate statistical tests. These will be performed on the 'R' Statistics package (R Core Development team, http://www.R-project.org) based at the Institute of Food Research. Ongoing assistance will be provided by the in-house statistics team at the Institute.

4.8.2.1. CGI methylation, inflammatory markers and protein phosphorylation /expression

Change in global CGI methylation (i.e. percentage of alleles methylated in all genes studied) and two-way analysis of variance (ANOVA) for treatment x time. Percentage change in the CGI methylation profile of specific genes will be detected by n way analysis of covariance (ANCOVA) to determine the relative effects (if any) of covariates including age, group allocation, BMI etc. N way ANCOVA will also be used to detect differences (if any) in chronic inflammation for each individual marker and differences in phosphorylation and expression of signalling proteins involved in pathways associated with CC progression.

4.8.2.2 Colonic cell proliferation/beta-catenin status

Change in distribution of colonic cell apoptosis, mitosis and beta-catenin status pre and post intervention within groups will be assessed using the χ^2 test. In addition, the tests will be performed between ALP and UC at baseline and post-intervention to detect any differences in distribution between groups.

4.8.2.3 Questionnaire responses

Responses to questionnaires will be compared using Student's t test to detect differences between ALP and UC. Where data is non-normally distributed, a Mann-Whitney test shall be employed instead.

4.9 Project timetable

The project will take place over 2.5 years (30 months) including preparation and write up/ dissemination time. Participants will be recruited on a 'rolling' basis, so that as participants go through the trial, new ones will be recruited. The estimated time from the first participants beginning the trial to the final participants ending the trial is 18 months.

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Norfolk and Norwich NHS University Hospitals NHS Foundation Trust

The Effects of a 12 month Active Lifestyle Programme on patients diagnosed as being at increased risk for developing further polyps by their screening colonoscopy.

Patient Information Sheet

We are inviting you to take part in our research study. Before you decide whether or not to take part we want you to understand why we are doing this research and what it will involve for you. This information sheet provides an overview of the study, and it should take about fifteen minutes to read. Please feel free to discuss the study with family and friends. If there is anything you are not clear about, the contact details of the researchers are provided at the end. We will happily go through the information sheet with you and answer any questions you have.

We have compiled a list of Frequently Asked Questions (FAQs) which cover the main aspects of the research:

What is the purpose of the study?

Recently, some evidence has accumulated which suggests that people who have exercised regularly throughout their life might be at reduced risk of developing certain types of cancer, in particular colon (bowel) cancer. However, at the present time, we do not know whether a physically active lifestyle can have a positive effect on biological markers associated with colon cancer risk. Also, we do not know how taking part in a programme like this affects exercise behaviour and attitudes towards exercising after colonoscopy screening.

Therefore, we are aiming to find out whether an active lifestyle programme, incorporating supervised exercise sessions and healthy living workshops over a 12-month period has a positive impact on bowel health and exercise behaviour in people diagnosed with benign polyps or adenomas as a result of their screening colonoscopy. We also want to investigate if changes in exercise habits can affect physical function and feelings of well-being.

Why have I been invited?

You have been selected as being a potentially suitable participant as you have presented to the Norfolk and Norwich University Hospital on the National Bowel Cancer Screening Programme. We are looking to recruit participants from this population subject to the outcome of your test.

Do I have to take part?

Your participation is entirely voluntary. If you decide not to take part, this will not affect the standard of care you receive from the hospital or any other health professional. You are also free to withdraw from the study at any time without giving reason. In order to answer any questions you may have about the study one of the researchers will call you prior to the screening procedure using the number provided during your colonoscopy pre-assessment. If you do not wish to take part in the study we would ideally like you to answer a few short questions during this phone call about your choices to not participate. We hope this will provide some information regarding recruitment to better inform future researchers. This will take no longer than five minutes and like the study your responses will be completely anonymous and your participation entirely voluntary.

What will happen to me if I take part/what do I have to do?

If you decide to take part and you meet our inclusion criteria (i.e. the surgeon identifies you as being as either 'low', 'intermediate' or 'high' risk for developing further polyps during the routine colonoscopy) you will have five small pinch biopsies taken from your colon, as well as any abnormal tissue that would be routinely removed. Once you have the results of your colonoscopy we will contact you to arrange a formal meeting with the research team at the University of East Anglia. If after the meeting you are still happy to take part, we will invite you to complete

baseline tests. Afterwards, you will be randomly assigned to one of two groups; namely the Active Lifestyle Programme (ALP) or Usual Care (UC). You have an equal chance of being in either group. This is known as a randomised controlled trial, and we are running the study this way because we do not know which treatment is best. You will be involved in the study for 12 months, and the total length of the research will be 2 years. The figure below outlines all of the procedures involved:



The second colonoscopy at the end of the study only applies to those individuals diagnosed as 'high' risk at the first colonoscopy, which is routine. As before, the surgeon will take five further pinch biopsies as well as any abnormal tissue. We will monitor your physical activity levels, body composition, and diet, and ask both groups to complete questionnaires every 3 months. We will take venous blood samples from you and ask you to complete a fitness test every 6 months. The principal difference will be that the ALP group will aim to achieve 300 min per week of moderate to vigorous physical activity for the duration of the study; whereas UC will maintain their normal lifestyle habits. To help achieve this goal, ALP will receive 36 personal training sessions at the University of East Anglia over 6 months. This will be complemented by 12 lifestyle workshops at the University. You *may* also be asked to participate in a face to face interview at the start of the study.

Can I expect any payment/reimbursement of costs?

Unfortunately, we cannot offer any financial reward or cover any personal expenses. However, ALP will receive free personal training and lifestyle workshops, and we will make data pertaining to health such as body composition, cardiorespiratory fitness and diet analysis available to both groups at the end of the study.

What are the treatment alternatives?

Currently, there are no treatment guidelines for individuals diagnosed as being intermediate or high risk for developing further polyps, other than further screening colonoscopies.

What are the possible disadvantages/risks of taking part?

The potential for risks to occur will be minimised. We will make sure that you can safely complete the exercise sessions before you take part, so that the likelihood of anything untoward happening during the exercise will be minimal. Exercise protocols will be tailored to your needs and your heart rate will be monitored during the exercise. In the event that something does go wrong and you are harmed during the research study, there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you might have grounds for legal action for compensation, but you could have to pay your legal costs.

Are there any side-effects of taking part?

If you haven't exercised for a while, and are part of the ALP group, physical activity might initially make you feel tired, and you could feel slightly breathless, but as you do it more regularly you will feel increasingly better.

What are the possible benefits of taking part in this study?

We cannot guarantee that you will benefit personally, but you will receive free fitness tests. The information which we will obtain might help improve medical care for patients at elevated risk like yourself.

What happens when the research study stops?

When the study finishes, we plan to publish the findings in a peer-reviewed scientific journal. We will not monitor you after your involvement in the study has finished. We will make data pertaining to health such as body composition, cardiorespiratory fitness and diet analysis available to both groups at the end of the study. If you are randomised to UC, you will be given the materials provided to ALP should you request them.

What if there is a problem?

In the event that something does go wrong and you are harmed during the research study, there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you might have grounds for legal action for compensation, but you could have to pay your legal costs.

Will my taking part in the study be kept confidential?

The confidentiality of our patients and the data which this study will generate is of utmost importance. All data from this study will be anonymised with a unique code during the study so the researcher analysing your data will be blinded as to your identity, which group you are in and to information collected during the study. This is one of the clauses, which you will sign in agreement on the official consent form. Our procedures for handling, processing and storage of and destruction of data are compliant with the Data Protection Act 1998.

What if relevant new information becomes available?

We will inform you if relevant new information becomes available which might affect the way we treat you. We will also discuss whether we need to make any amendments with the trial steering committee, which is responsible for the conduct of the research.

What will happen if I do not want to carry on with the study?

You are free to withdraw from the study at any time without giving reason, and this will not affect the standard of care you receive from the hospital or any other health professional. Should you wish, we can also destroy any identifiable data/tissue samples that we have collected from you.

What if there is a problem?

If you have any cause to complain about any aspect of the way in which you have been approached or treated during the course of this study, the Patient Advice and Liaison Service is available to you. In order to use this service you can choose one of the following options:

Phone: 01603 289036 Email: PALS@nnuh.nhs.uk Website: http://www.pals.nhs.uk/

Will my GP be notified?

With your consent, we will write and inform your family doctor that you are taking part in this study.

What will happen to any samples I give?

Any tissue samples that you provide will be transferred to the Institute of Food Research, where we will analyse them for indicators of bowel health. They will be stored there for the duration of the study. Responses to questionnaires, physical activity, diet and fitness data will be stored and analysed at the University of East Anglia for the duration of the study.

Will any genetic tests be done?

There are several genes which are known to be involved with the development of bowel cancer. These genes can be affected by ageing, which may in turn affect the risk of developing the disease. We want to understand whether exercise can reverse the gene ageing process, and we will look for signs of this in the colon biopsies we obtain. We also would like to see whether any changes are reflected in other areas of the body, which is why we would like to analyse these genes in your blood and cheek cells. We will only analyse genes that are known to be implicated in bowel cancer, and we will *not* sequence your entire genome.

What will happen to the results of the research study?

We plan to publish the results of this study in a peer-reviewed scientific journal. However, you will not be personally identifiable from these results. In addition, the results from initial fitness testing and overall conclusions of the study will be available to you. Any further information will be available upon request. With your consent, we will anonymously store any leftover blood and tissue samples we collected from you at a NHS approved tissue bank for a period of 5 years. These samples might be used for future research into bowel health. You can still take part in the study even if you do not wish to have any leftover tissue stored in this way, in which case they shall be destroyed once the study has finished. All of these procedures will be compliant with the Human Tissue Act 2004.

Who is organising and funding the research?

The research forms part of a PhD programme funded by the University of East Anglia. The research is being conducted in collaboration with the Norfolk and Norwich University Hospital and the Institute of Food Research.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Norfolk Research Ethics Committee.

Further information and contact details

If you have any specific questions about the study, we will be more than happy to answer them for you.

In the event of further questions please contact:

Mr Barnabas Shaw BSc. MSc. Email: B.Shaw@uea.ac.uk 07933090196

Miss Liane Lewis BSc. Email: Liane.Thomas@uea.ac.uk 07933090197

Miss Kelly Semper BSc. Email: K.Semper@uea.ac.uk

Thank you for taking the time to consider participating in this study

Prof John Saxton (Project co-ordinator), Tel: 01603 593098, Email: john.saxton@uea.ac.uk



PATIENT CONSENT FORM

The University of East Anglia

Norfolk and Norwich NHS University Hospitals MHS I Franks

The effects of a 12 month exercise intervention on patients diagnosed as 'intermediate' or 'high' risk for developing further polyps by their screening colonoscopy.

Patient Identification Number for this study:

Investigators: Consultant, Professor John Saxton, Students Name of patient:

- 1. I confirm that I have read and understood the Patient Information Sheet Version dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
- 3. I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals of the research team, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- I consent for tissue collected during the study (i.e. venous blood, cheek swab and colon tissue) to be transferred to the Institute of Food Research for analysis purposes
- 5. I agree to my G.P. being informed of my participation in the study.
- I agree to take part in the above study.
- 7. I am aware that I may be contacted to be interviewed.

Name of Participant	Date	Signature
-		-
Name of individual taking consent (if not researcher)	Date	Signature
		_
Researcher	Date	Signature

Please initial
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Norfolk and Norwich NHS University Hospitals

Health Questionnaire

Preventative Action against risk of Colon Cancer (PARC)

Title: Name:	Gender M□F□		DOB (dd/mm/yyyy) :
Address:		Telephone nun Mobile number	nber: r:
Postcode:		Email:	

Medical information

1. Please tick if you suffer from, or have suffered from, any of the following:

□ Heart disease (e.g. angina, palpitations) □ High blood pressure □ Vascular disease (e.g. peripheral arterial disease, hypercholesterolaemia) □ Stroke □ Type 2 Diabetes □ Pulmonary disease (e.g. asthma, COPD) □ Inflammatory bowel disease (e.g. Crohn's disease, ulcerative colitis) □ Familial adenomatous polyposis (FAP) □ Cancer □ Seizures □ Joint problems (e.g. arthritis) □ Back pain □ Other

If you have ticked any of the above, please give details, including any treatments:

2. Is there a history of colon cancer in your family □ Yes □ No

If yes, please give details:

Has your doctor advised you against taking regular exercise? □ Yes □ No
 If yes, please give any reasons why:

4. Do you take any laxatives (e.g. bulking agents, stool softeners, irritants)?
□ Yes □ No

If yes, please give details as to the type of medication, the amount, and how often it is taken:

Medication

Amount

Frequency (per week)

 Do you take any non-steroidal anti-inflammatory drugs (NSAIDS) (e.g. aspirin, ibuprofen)? □ Yes □ No

If yes, please give details as to the type of medication, the amount, and how often it is taken:

Medication

Amount

Frequency (per week)

6. Do you regularly take any other prescribed or over the counter medication? Yes Do If yes, please give details: Medication Amount Frequency (per week)

7. Do you smoke cigarettes? 🗆 Yes 🗆 No

If yes, how many per day?: _____

8. Do you drink alcoholic beverages? 🗆 Yes 🗆 No

If yes, how often per week?

 \Box Less than once \Box Once \Box Twice \Box Three to six times \Box Daily

Approximately how many units of alcohol do you drink per week (for reference, 1 pint of standard beer, lager or cider = ~ 3 units; a standard 175 ml glass of wine = ~ 2 units; and a single measure of a spirit = ~ 1 unit)?:

9. What is your marital status?

□ Single □ Partnered □ Married □ Separated □ Divorced □ Widowed

10. How many visits have you made to your GP in the past 12 months?

Please state: ____

Thank you.





Information about the Research Study <u>Interview</u>

Norfolk and Norwich NHS University Hospitals NHS Foundation Trust

"The Effects of a 12 month Active Lifestyle Programme on patients diagnosed as elevated risk of developing further polyps by their screening colonoscopy".

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 15 minutes Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study **Please ask us if there is anything that is not clear**.

Part 1

What is the purpose of this study?

The team of researchers working on this study at the University of East Anglia believe it is important to understand the incentives and barriers for participating in physical activity when diagnosed at elevated risk of developing further colon polyps after a screening colonoscopy. We are also interested to find out whether early life experiences have an effect on these reasons to participate as we go through life, and whether the knowledge of risk provides a trigger to establish a healthier lifestyle.

Why have I been invited?

You have been invited because you expressed an interest to be contacted regarding this part of the intervention in the initial consent form. You will be one of approximately 20 other people that will be interviewed for this study.

Do I have to take part?

It is up to you to decide to join the interview. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen if I decide to take part?

You will be asked to take part in one research interview at the start of the intervention

During the initial interview we will ask you about previous life experiences which may have affected your reasons for leading an active lifestyle. We will also ask you about your experiences and attitudes towards your increased risk of developing further colon polyps, and your level of knowledge regarding the benefit of leading a healthy lifestyle to reduce risk.

The interviews will be held at the University of East Anglia, in a private room and will last for approximately 90 minutes. Each interview will be conducted by a researcher within the study team and will be audio recorded for analysis purposes.

You will not be asked to talk about anything you feel uncomfortable about discussing, however, if for any reason you feel uncomfortable you are free to stop the interview without giving any reason.

What are the possible disadvantages and risks for taking part?

We do not think there are any disadvantages of taking part, beyond the time taken to be interviewed.

What are the possible benefits for taking part in the study?

All participants taking part may be helping improve treatment for those at increased risk of developing further colon polyps in the future.

What happens if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

<u>PART 2</u>

What happens if I do not want to carry on with the study?

You can withdraw from the study at any time, but please keep in contact with us to let us know your progress. Information collected from this initial interview may still be used unless you wish otherwise.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions our contact details are at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this via contacting the Patient Advice and Liaison Service (PALS) at <u>www.pals.nhs.uk</u>. Email: <u>PALS@nnuh.nhs.uk</u> or telephone: 01603 289036.

How will my taking part in this study be kept confidential?

The interview will be recorded on an audio device. This is so your thoughts and experiences are accurately recorded. Only the specific researchers involved with the study will listen to the recording, and it will be securely stored and destroyed after study completion. The interview will be transcribed so that we have a written account and all names will be coded so that those taking part will not be identified in any way in the results. Any specific information which may identify you to others will not be used when reporting findings of the research.

The only reason that confidentiality might be broken is if what you tell us shows there is a serious risk to other people or the welfare of children.

What happens with the results?

We would like the results of the study to inform other researchers of the thoughts regarding the choice to lead an active lifestyle. In the future we hope this may also inform the health service of the needs of those at increased risk of developing further colon polyps. We will also write up the results from this study for publication within an academic journal, which may lead to further research in this area. You will not be identifiable within any report however any of these publications will be made available to you upon request.

Who is involved in organising and funding the study?

All organisation and funding is provided by the University of East Anglia.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Norfolk Research Ethics Committee.

Further Information and Contact Details:

Upon attending the interview a copy of both this participant information sheet and a signed consent form will be provided for you to keep.

Kelly Semper (PhD Research Student)

Email: K.Semper@uea.ac.uk Tel: 07557796917



Information about the Research Interview



"A behavioural lifestyle intervention for colorectal cancer survivors"

We would like to invite you to take part in our **research interview** as part of the above mentioned study. Before you decide we would like you to understand why this interview is being done and what it would involve for you. We'd suggest reading this information sheet through should take about 15 minutes and you are welcome to talk to others about the study if you wish.

Part 1 tells you the purpose of this interview and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study as a whole **Please ask us if there is anything that is not clear**.

<u>Part 1</u>

What is the purpose of this study?

The team of researchers working on this study at the University of East Anglia believe it is important to understand the incentives and barriers for participating in physical activity especially after becoming a cancer survivor. As well as this we hope to elicit current knowledge about the importance of exercise and your specific attitudes and perceptions towards leading a physically active lifestyle.

Why have I been invited?

You have been invited because you are currently a participant within the study "A behavioural lifestyle intervention for colorectal cancer survivors" within the Exercise Physiology Laboratory at the University of East Anglia.

Do I have to take part?

It is up to you to decide to join the interview. We can describe the study and go through this information sheet in more detail if you wish. If you agree to take part, we will then ask you to sign a consent form prior to the interview. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen if I decide to take part?

You will be asked to take part in one research interview at the University of East Anglia at a time convenient for you (potentially on the same day as your three month follow up appointment at the University in the near future).

During the interview we will ask you about previous life experiences which may have affected your reasons for leading an active lifestyle. We will also ask you about your experiences and attitudes towards receiving a cancer diagnosis and your level of knowledge regarding the benefit of leading a healthy lifestyle now you have recovered to reduce risk your risk of cancer in the future. You will be asked to take part in one research interview at the start of the intervention

During the initial interview we will ask you about previous life experiences which may have affected your reasons for leading an active lifestyle. We will also ask you about your experiences and attitudes towards your increased risk of developing further colon polyps, and your level of knowledge regarding the benefit of leading a healthy lifestyle to reduce risk.

The interviews will be held at the University of East Anglia, in a private room and will last for approximately 90 minutes. Each interview will be conducted by a researcher within the study team and will be audio recorded for analysis purposes.

You will not be asked to talk about anything you feel uncomfortable about discussing, however, if for any reason you feel uncomfortable you are free to stop the interview without giving any reason.

What are the possible disadvantages and risks for taking part?

We do not think there are any disadvantages of taking part, beyond the time taken to be interviewed.

What are the possible benefits for taking part in the study?

All participants taking part may be helping improve treatment for those at increased risk of developing further colon polyps in the future.

What happens if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

<u>PART 2</u>

What happens if I do not want to carry on with the study?

You can withdraw from the study at any time, but please keep in contact with us to let us know your progress. Information collected from this initial interview may still be used unless you wish otherwise.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions our contact details are at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this via contacting the Patient Advice and Liaison Service (PALS) at <u>www.pals.nhs.uk</u>. Email: <u>PALS@nnuh.nhs.uk</u> or telephone: 01603 289036.

How will my taking part in this study be kept confidential?

The interview will be recorded on an audio device. This is so your thoughts and experiences are accurately recorded. Only the specific researchers involved with the study will listen to the recording, and it will be securely stored and destroyed after study completion. The interview will be transcribed so that we have a written account and all names will be coded so that those taking part will not be identified in any way in the results. Any specific information which may identify you to others will not be used when reporting findings of the research.

The only reason that confidentiality might be broken is if what you tell us shows there is a serious risk to other people or the welfare of children.

What happens with the results?

We would like the results of the study to inform other researchers of the thoughts regarding the choice to lead an active lifestyle. In the future we hope this may also inform the health service of the needs of those at increased risk of developing further colon polyps. We will also write up the results from this study for publication within an academic journal, which may lead to further research in this area. You will not be identifiable within any report however any of these publications will be made available to you upon request.

Who is involved in organising and funding the study?

All organisation and funding is provided by the University of East Anglia.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Norfolk Research Ethics Committee.

Further Information and Contact Details:

Upon attending the interview a copy of both this participant information sheet and a signed consent form will be provided for you to keep.

Kelly Semper (PhD Research Student)

Email: <u>K.Semper@uea.ac.uk</u> Tel: 07557796917



Information about the Research Study Health Professionals.

Norfolk and Norwich NHS University Hospitals

<u>"The Effects of a 12 month Active Lifestyle Programme on patients diagnosed at elevated</u> <u>risk of developing further polyps by their screening colonoscopy".</u>

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 15 minutes Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study **Please ask us if there is anything that is not clear**.

Part 1

What is the purpose of this study?

The team of researchers working on this study at the University of East Anglia believe it is important to understand the views of health professionals regarding choices to lead an active lifestyle in patients at increased risk of developing colon cancer after their screening colonoscopy.

Why have I been invited?

You have been invited because you work within the gastroenterology ward at the Norwich and Norfolk University Hospital and expressed interest in participating at the study presentation. We hope to recruit approximately 8 people to take part in this focus group.

Do I have to take part?

It is up to you to decide to join the interview or focus group. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen if I decide to take part?

You will be asked to take part in an interview or focus group.

During the interview we will ask you about your experiences, and impressions of the advice given to patients at increased risk of developing colon cancer and whether you believe any improvements could be made. We are also interested to find out your thoughts on why patients would and would not participate in physical activity, as well as barriers for participation in interventions such as this.

The interview or focus group will take place in a private room at a convenient time within the Norfolk and Norwich University Hospital.

You will not be asked to talk about anything you feel uncomfortable about discussing, however, if for any reason you feel uncomfortable you are free to leave the focus group without giving any reason.

What are the possible disadvantages and risks for taking part?

We do not think there are any disadvantages of taking part, beyond the time taken to be interviewed.

What are the possible benefits for taking part in the study?

All participants taking part may be helping improve treatment for those at increased risk of developing further colon polyps in the future.

What happens if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

What happens if I do not want to carry on with the study?

You can withdraw from the study at any time, but please keep in contact with us to let us know your progress. Due to practicalities, any information you give within the interview and focus group cannot be destroyed however we ensure anonymity is maintained throughout.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions our contact details are at the

end of this information sheet. If you remain unhappy and wish to complain formally, you can do this via contacting the Patient Advice and Liaison Service (PALS) at <u>www.pals.nhs.uk</u>. Email: <u>PALS@nnuh.nhs.uk</u> or telephone: 01603 289036.

How will my taking part in this study be kept confidential?

The interview will be recorded on an audio device. This is so your thoughts and experiences are accurately recorded. Only the specific researchers involved with the study will listen to the recording, and it will be securely stored and destroyed after study completion. The interview will then be transcribed so that we have a written account and all names will be coded so that those taking part will not be identified in any way in the results. Any specific information which may identify you to others will not be used when reporting findings of the research. We do ask all members of the focus group to ensure confidentiality is not breached.

The only reason that confidentiality might be broken is if what you tell us shows there is a serious risk to other people or the welfare of children.

What happens with the results?

We would like the results of the study to inform other researchers of the thoughts of health professionals with regards to lifestyle advice in this population of patients and how they may differ from the actual patients experiencing care. In the future we hope this may also inform the health service of the needs of those at increased risk of developing further colon polyps. We will also write up the results from this study for publication within an academic journal, which may lead to further research in this area. You will not be identifiable within any report however any of these publications will be made available to you upon request

Who is involved in organising and funding the study?

All organisation and funding is provided by the University of East Anglia.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Norfolk Research Ethics Committee.

Further Information and Contact Details:

Upon attending the interview a copy of both this participant information sheet and a signed consent form will be provided for you to keep.

Kelly Semper (PhD Research Student)

Email: K.Semper@uea.ac.uk Tel: 07557796917

Health Care Professional Interviews

Endoscopists and Colorectal Surgeons

Are you aware of the evidence suggesting the impact of physical activity on colon cancer risk?

Do you currently offer any physical activity advice to patients who are within the elevated risk category after their screening examination?

Do you believe advice should be offered?

<u>YES</u>

By Whom?

At what stage?

In what format? Leaflet, Spoken advice, Website?

<u>NO</u>

Why?

What are the barriers to providing this type of advice currently?

Do you have anything else to add?

Interview Design - Exercise and Usual Care Group Elevated Risk.

<u>"The Effects of a 12 month Active Lifestyle Programme on patients diagnosed as 'elevated'</u> risk for developing further polyps by their screening colonoscopy."

INTERVIEW 1 (Narrative)

1. Physical Activity History

In your own words could you tell me about your past experiences with physical activity including attitudes and beliefs have developed from early life to the present day? *Aim to elicit how early life experiences with exercise shape attitudes and beliefs towards physical activity in later life.*

2. <u>Knowledge – The benefits of an active lifestyle</u>

Could you explain to me the benefits of leading an active lifestyle? Aim to establish whether benefits are known and are chosen to be ignored <u>or</u> too little information is provided.

Have you been told anything in the past 12 months about physical activity (or exercise) and its role in cancer prevention?

Aim to gage knowledge regarding exposure to relevant information on cancer prevention.

Should more information of the benefits be given? By Whom? How? At what stage? Aim to gain increased understanding of whether the education available is sufficient to give a positive change.

3. <u>Barriers and Facilitators to Physical Activity.</u>

Could you describe for me the main barriers you have towards doing physical activity? *Aim to understand the common barriers surrounding an active lifestyle in this specific population.*

Could you describe for me the main incentives for doing physical activity BEFORE you were diagnosed moderate/high risk of colon cancer?

Aim to gage level of motivation before the diagnosis.

Have these incentives towards doing physical activity changed at all now you have been diagnosed? *Aim to encourage subject to expand on the effects the diagnosis could have on activity behaviour.*

4. <u>Final Thoughts</u>

Is there anything else about your own experiences or thoughts regarding physical activity that you would like to add?

<u>Control Group (questions asked following 1st and 2nd question listed above)</u>

1. <u>Control Group Placement</u>

What were your initial thoughts on being placed in the control group? Did you manage to maintain your previous physical activity levels? If not, why not?

How, if at all, did the testing procedures every 3 months affect your physical activity levels? PROBE: Was this a good or bad thing?

Aim to establish whether control group placement is disappointing. Highlight potential for patient preference trials to give more valid data.

2. Recruitment

What was the main incentive for taking part in the study?

Do you believe the recruitment process was informative and efficient?

In your opinion could this have been improved in order to get more participants? *PROBE: Show Information sheet, and consent forms to recap memory*

Would your choice to consent have changed knowing that you would be in the control group?

Aim to identify any improvements with general recruitment strategies. Also explores thoughts on control group placement.

Were you made aware of the benefits of physical activity, especially for reducing colon cancer risk PRIOR to the intervention?

3. Adherence

Did you find it easy or difficult to maintain previous levels of physical activity from before the diagnosis?

How accurate do you believe the self reported physical activity levels were throughout the 12 month intervention?

4. Final Thoughts

Do you have anything more you would like to add?
Interview Design

"A behavioural lifestyle intervention for colorectal cancer survivors"

Perceptions and Attitudes to Physical Activity

What are your thoughts on leading a physically active lifestyle?

Aim to elicit how life experiences shape attitudes and beliefs towards physical activity in later life especially in light of their cancer survivorship.

Do you think our attitudes towards 'healthy living' have changed in the past 50 or so years?

Knowledge of the benefits of leading an active lifestyle

Could you explain to me the benefits of leading an active lifestyle? Aim to establish whether benefits are known and are chosen to be ignored <u>or</u> too little information is provided.

Have you been told anything in the past about physical activity (or exercise) and its role in cancer prevention?

Aim to gage knowledge regarding exposure to relevant information on cancer prevention.

Should more information of the benefits be given? By Whom? How? At what stage? *Aim to gain increased understanding of whether the education available is sufficient to give a positive change.*

Impact of the Cancer Diagnosis on Physical activity

Did the diagnosis have impact upon any your lifestyle choices? *Explore the teachable moment concept in participants.*

Probe: What advice did the nurses give at the hospital regarding physical activity?

Barriers and Facilitators to Physical Activity.

Could you describe for me the main barriers you have towards doing physical activity? *Aim to understand the common barriers surrounding an active lifestyle in this specific population.*

Have your reasons towards doing physical activity changed now you are a cancer survivor? *Aim to encourage subject to expand on the effects the diagnosis could have on activity behaviour.*

Reasons for study participation

What were your reasons for deciding to take part in our study when you received the invitation letter?

Aim to identify if the reason for participating in the trial is personal or diagnosis related

Final Thoughts

What makes a good exercise programme for you?

Aim to identify important factors specific to this group of individuals, when compared to individuals with colon polyps.

APPENDIX 10

Health Professional Focus Group

Screening Practitioners and Staff Nurses

Are you aware of the evidence suggesting the impact of physical activity on colon cancer risk?

Do you currently offer any physical activity advice to patients who are within the elevated risk category after their screening examination?

Do you believe advice should be offered?

YES

By Whom?

At what stage?

In what format? Leaflet, Spoken advice, Website?

<u>NO</u>

Why?

What are the barriers to providing this type of advice currently?

Additional Questions if time Allows;

1. <u>Recruitment</u>

What do you believe encourages people to consent to taking part in a 12 month exercise intervention?

2. Adherence

In your opinion what are the main barriers and facilitators to maintaining adequate levels of physical activity in this population?

What do you believe is the most important qualities for an exercise intervention specific to this population?

Do you believe physical activity promotion in this population is necessary?

If so, how would you best promote physical activity levels in this population? If not, why do you believe it to be unnecessary?

Do you have anything else to add?

Pre Interview Script

The following 'script' was followed very roughly at the beginning of each interview/focus group. This script was a guide only, to ensure that all research respondents received different information.

Introduce myself and explain;

- The purpose of the research and the importance of narrative interviews
- What will happen to the information given by participants
- How the results will be disseminated

Introduce the tape recorder; explain how it will be used purely for analysis purposes.

Stress confidentiality	- Everything said in the interview is in confidence. The only reason confidentiality would be breached is if significant harm to others is mentioned. Participants should limit self-disclosure with this in mind
	- Tape will be destroyed after being transcribed
	- No one will be identified individually in the report
Set ground rules	- All views and responses are valid
	- There are no right and wrong answers
	- Please answer as fully with as much detail as possible – makes for richer data analysis.
	- It is helpful if you can give examples from your own or others experiences, but no need to mention personal details or names
	RECEIVE CONSENT AND TURN TAPE RECORDER ON

APPENDIX 12



Norfolk and Norwich NHS University Hospitals NHS Foundation Trust

Consent Form – Interviews

Patient Identification Number for this trial:

Study Centre:

Title of Project: 'The effects of a 12 month exercise intervention on patients diagnosed as 'intermediate' or 'high' risk for developing further polyps by their screening colonoscopy.'

Name of Researcher:

Please I	Initial	Box
1100301	muran	DUA

- I confirm that I have read and understand the information sheet dated (Version......) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- 3) I agree to the use of audio recording for analysis purposes, and the possible use of anonymous verbatim quotation in further publications.
- 4) I agree to take part in the above interview.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

APPENDIX 13

'Interview Debrief'

"Well providing that you have said everything that you wanted to, that is everything I personally wished to cover in the interview?

Ok. Just to reiterate then, I will now transcribe the interview onto a computer document, and then destroy all of the personal information so that the interview cannot be identified to you. Please feel free to contact me in the future and I will be happy to update you with how the research is progressing – you have my contact details don't you?

I will keep the tape until after the research project ends, just in case I need to go back to it at any point, but following that it will also be destroyed.

Thank you very much for coming to talk to me, and best wishes for the future."

Elevated Risk Participant Biographies

<u>Susan</u>

Susan was born in 1953 making her 60 years old at the time of interview. She lived with her cousin throughout childhood and thus played frequently in the local village; 'making dens' and 'skipping' whenever she could. As a child she was confident and enjoyed engaging in dance classes, however she has less fond memories of P.E. classes in school because she was picked last for the team games. This has impacted on her activity and confidence levels to this day with a real dislike for any group exercise or team sports. Susan has lived in both rural and urban environments. Although preferring the quietness of the countryside, she feels being in a city is easier for physical activity with more choice of exercise and better provision of cycle paths.

<u>James</u>

James was born in 1945 making him 68 at the time of interview. James had a happy childhood with many fond memories of playing with his friends and siblings in the local village. He has always enjoyed sport and was even selected for the school football team aged 14 – a hobby he continued throughout his childhood and up to the age of 28 when a knee injury stopped him from playing. Although now a non-smoker, James smoked until the age of 26 when he decided his finances could not support the habit. James spoke about a number of jobs throughout his life, starting with office and factory work, and ending with a lorry driving position. He claimed that he had witnessed a change in his lorry driving job which had become increasingly sedentary due to machinery – therefore he began recreationally playing squash in his 40s. James' wife suffered and subsequently died from cancer when they were both close to retirement age. This study, and his placement within the intervention group is 'his chance' to get back to doing something more active.

Bob

Bob was born in 1942 making him 71 at the time of his interview. As an only child he spent most of his childhood playing with local children from his school and village. Living rurally his whole life, he also spent many summers helping out local farmers with their harvest which he described as very physical. Bob struggled with the academic aspect of school, and was not particularly fond of the P.E classes either. He found understanding the rules and tactics difficult, so therefore his teachers would often give him the gardening or ground maintenance roles. When married, he spoke fondly of enjoying attending dances with his wife, however many of his jobs were spent driving and were quite sedentary. Unfortunately Bob has made

attempts to change his activity levels in the past by purchasing an exercise bike, and attending a local gym for advice however he is yet to find something which he really enjoys.

<u>Diane</u>

Diane was born in 1938 making her 76 at the time of her interview. Diane was bought up in London following the end of the Second World War which meant rationing was still rife. She remembers having to walk everywhere and using the spacious recreational grounds to play with friends. Diane was very active throughout her life, playing netball, hockey, and cricket and swimming regularly. She also was a member of the guide group and youth service, and played badminton to a very competitive level. Diane spoke of her desire to be a sports teacher, however this was frowned upon by her parents who encouraged her to get a 'proper job'. Eventually, she did fulfil her wishes and trained to be a teacher, however the degree resulted in less time to keep active, and she admitted her recent years had been very busy, but sedentary.

Margaret

Margaret was born in 1953, making her 60 years old at the time of interview. When questioned about her childhood, Margaret could not really recall playing outside, admitting that she was often kept inside either because of illness, or to help her mother look after her younger siblings. She was also rarely included in P.E. classes during school time as she had a heart condition, which left her with negative memories of exercise in general as it resulted in her getting bullied. Throughout Margaret's adult life, work was relatively active, looking after children and spending all of the time on her feet. Unfortunately Margaret admitted her motivation to do any form of exercise has been diminished since her husband passed away from cancer.

<u>Ryan</u>

Ryan was born in 1950, making him 64 at the time of the interview. Growing up for Ryan was full of playing with his best friend. Unfortunately he lost his best friend at an early age, and he suggested that this trauma impacted on his more introverted nature as a young child, and rebellious streak as a teenager. Due to his introverted nature which resulting in bullying, he suggested he was encouraged to start judo so that he may be able to defend himself – this developed into a hobby which would continue into most of his adult life at a competitive level. In his later years he suffers from arthritis (which he believes was caused by over-exercising as a teenager), this is preventing him from doing as much exercise as he would like to keep healthy.

David

David was born in 1948 making him 68 at the time of the interview. David spoke frequently about the impact of the war in his lifetime, feeling that the austerity experienced then had influenced his choices throughout life. He stated he did, and still continues to walk everywhere if he can, and still does not use a car unless absolutely necessary. He was a small child, and this impacted on his enjoyment of doing activity at school as he was never the fastest or strongest, however he has always been active and had a very labour intensive job. A severe injury in his adult life resulted in him having to 'learn to walk again' and increased his determination and motivation to be healthier and stronger through participating in this study.

<u>Terry</u>

Terry was born in 1946, making him 67 at the time of the interview. Living in a small town throughout his childhood meant there were always plenty of friends to play outside in the 'fields' or 'woods' with, however he did recall needing to walk or cycle everywhere. As a child he did not enjoy ball games as he always wore glasses and feared that he would be hit in the face. Being a scientist for the majority of his adult career he spent long periods of time on his feet, but this job became more desk bound and he started to notice himself gaining weight – a change he admittedly 'hated'. This resulted in him joining a number of active voluntary authorities and organisations to keep healthy in his later years. Terry was very clear that activity needed to be convenient and natural for him to enjoy it e.g. gardening.

Priscilla

Priscilla was born in 1945, making her 69 at the time of the interview. Having lived in the countryside her whole life, Priscilla stated she used to cycle everywhere which has resulted in her really disliking cycling now, finding it too 'uncomfortable'. Having always had a sedentary job she decided to 'try out' exercise classes in her 30's with friends, as she said she did them 'to have a good time'. This organised exercise did slow down however when her friends decided to stop attending, and she has been keen ever since to re-engage with activity as she feels much better and happier when exercising.

<u>Simon</u>

Simon was born in 1941, making him 72 at the time of his interview. Simon admits being (unusually) over-protected by his parents as a child, which meant he did not have as much freedom or active play as the other children in his village. This resulted in a rebellious streak towards the end of primary school, and increased popularity in secondary school. He began adult life with a relatively active job in a factory; however he disliked being inside so decided to join a farming apprenticeship scheme. Towards the later part of his career he became a

teacher in Kenya which was busy but not particularly active. He has a passion for flying, and more recently to pass his licence he needed to have a fitness assessment which provided increased motivation for behaviour change.

<u>Ray</u>

Ray was born in 1950 making him 64 at the time of the interview. Ray admitted to being a very active child; however he was the only interviewee who spoke about doing exercise (athletics) frequently with his father as an extra-curricular activity on top of school sport. As he held a sedentary office job for much of his early adult life he recreationally engaged in squash twice per week – however he did say that this was more of a social activity with friends, than for health benefits which were then unknown. His job then evolved to him being a cameraman which, given the heavy equipment and need to carry everything on his back, actually resulted in a number of work related injuries preventing any vigorous intensity exercise since. He now regards playing with his grandchildren as his main source of activity.

<u>Grace</u>

Grace was born in 1943 making her 71 at the time of the research interview. Being born on a farm and living in the countryside her entire life, Grace regarded activity as a natural and daily aspect of life. She often helped her father with the harvest as a teenager, but admitted the majority of her paid work was desk bound. As a hobby in her later years Grace flower arranges, and made a point of emphasising how active this job was as she would 'never sit still'. In her spare time Grace enjoyed spending time with the grandchildren and taking her dog on long walks which she felt must amount to fulfilling the current activity guidelines.

Lucy

Lucy was born in 1948, making her 66 at the time of the interview. Having had younger brothers Lucy admitted she was often involved in 'rough and tumble' and 'biked miles' with them to keep herself active. Despite this natural level of activity she put on weight after starting at secondary school, which made doing exercise difficult and uncomfortable. She also remarked that she was often put in goal for hockey which was 'humiliating'. Lucy also began working life in a very active job as a chef, which allowed her the chance to travel. She has lived abroad in warmer climates and suggested that the better weather improved her motivation to be outside. Of all the participants in the study, Lucy is the only 'current smoker'. A self proclaimed 'recluse' Lucy has suggested this study has given her the opportunity to realise 'exercise is possible – even for me'.

<u>Geoff</u>

Geoff was born in 1947, making him 67 at the time of the interview. Because of Geoff's childhood illnesses he was often held back from school sport, and was 'wrapped in cotton wool' by his parents, he was their only child. Activity in Geoff's life began when he was in secondary school, as he joined scouts and the air training corp. His passion for scouts lasted many years though, and even into his later years he runs numerous scout groups in the area. This has led Geoff to believe activity need not be in a gym environment, but outdoors, and achieved through walking and hiking. Until a recent illness prevented him from doing any activity at all, Geoff was an avid walker.

APPENDIX 15

Case Study – Coding

This appendix will outline the biography of one participant; 'Tom', and use his interview to illustrate how certain quotes were developed from their early stage codes, to larger categories and chapter concepts through the use of iterative analysis, reflective writing and memos.

<u>Tom</u>

Tom was born in 1942, making him 72 years old at the time of interview. Despite being an only child, he had many friends to play with and regarded himself as quite popular within the school and village. Much of the activity described within his childhood was creative play; however he was also selected to play football for both his primary and secondary school teams – something he was very proud of. Despite enjoying P.E. classes he much preferred the team games, as he suggested that it felt 'more natural'. Throughout his childhood and early adult life Tom maintained that he never did physical activity because of health reasons – they simply were not known, and instead he smoked; 'everyone smoked', until he was told he had high blood pressure which encouraged him to stop. Tom suggested he did not enjoy going to the gym because it felt 'forced' but that he was looking forward to finding out how to exercise 'properly' by being part of this programme.

Tom was approached to take part in this research study prior to his third screening colonoscopy, and consented because he thought it might 'help somebody' – his wife had recovered from colon cancer almost two decades ago. He remarked that the screening procedure was 'not too bad really', but that the surgeons had only ever found 'a few polyps in there' and that they were 'nothing to worry about'.

Tom was placed in the intervention group within the study, and this interview took place following his 3^{rd} exercise class with the other participants and research team. At the time of the interview Tom suggested he was enjoying the tailored nature of the programme, the social aspect with other participants and the benefit of having his wife attend with him.

The quotes below are followed by brackets containing the basic code given on N-Vivo:

"We played a lot, never thought of it as exercise though, it was just fun" (*Playing as a Child*)

"We never used to sit indoors, there wasn't anything to sit indoors for, there was no television...there was no need to be indoors, all the fun was outside" (Nothing to Distract)

Secondary Code: 'Childhood Play' (Memo)

It would seem that many participant memories of childhood were filled with play – being outside, making friends, and at times forging life skills such as leadership and team work. The idea that this

playing was 'exercise' or good for one's health was never realised with many just recalling the fact that there was 'nothing else to do'. Although studies have suggested that childhood activity levels have an impact upon adult activity levels (Telama 2005), it is interesting that all of these participants had highly active childhoods, yet, are still not meeting the current PA guidelines. This is an area worth greater exploration to attempt to understand why or where they activity levels changed. Could they have been unaware of the benefits, and thus, when their job started, they just had less time; or as they grew older, the fun and enjoyment aspect of playing games began to diminish?

"We would be doing stuff outside all the time, until it was practically dark, and as soon as the sun rose in the morning...we used to all go out together but there was no danger as there wasn't any traffic you see" (Less Transport)

"...your parents didn't know where you were half the time, but no one really cared – people weren't as afraid in those days" (*Being less Afraid*)

Secondary Code 'Perceptions of Safety' (Memo)

Participants recalled a time when the roads were safe, much safer than they are today. Not just because they have less transport on them, but also because the cars travel much slower. This change in transport may have impacted on an older person's choice to do exercise for fear of their safety in modern day society. This barrier has been expressed already in the work by Baert (2011), Van Stralen (2010) and Crombie (2004).

Another aspect of safety has also been mentioned in relation to crime. Instead of saying that today they fear for their personal safety, many participants spoke of a time when there was far less fear about what was out there. I wonder if this might be able to be related to technology, and exposure. Today the news about crime is highly accessible and I wonder if the aspects of technology, an increased awareness of crime, and the exposure to new stories has negatively impacted on an older person's choice (especially as they have lived through a different time), to be active.

"I guess I saw the impact of being outside and being active, it made me feel good, but we just did it because there was nothing else to do, not because we thought it was doing us any good" (*Doing PA for Health*)

"you smoked cigarettes and you seemed more grown up, I suppose we didn't realise then that it was bad for you! Much the same as exercise was good for you...that kind of health stuff wasn't well known" (*Smoking harm unknown*)

Secondary Code – 'Arrival of Health Advice' (Memo)

In response to my previous memo regarding childhood play, it appears my assumptions were correct in that these older individuals simply did not realise that PA was doing them any good, therefore, why would they continue into their adult years if they had families to support and a busy work life. N.B. I need to look into when gyms were a popular addition to society and whether this arrival may have come a little too late to become engrained in our participants lives, also I need to identify the first study to find a link between PA and health – may be Morriss in the 1950s?

Final Category – 'Changing Times' (Reflection – 10th July 2013)

Many of the participants in this study have spoken about how 'times have changed' from the era they were bought up in, and certainly from the era of their parents generation. Elements around childhood play, a lack of distraction then (or increased choice in modern day society due often to the impact of technological advances), and perceptions of safety/crime then and now, have all undoubtedly impacted on one's attitudes to engaging in PA, and feeling a great enough confidence to do organised exercise – in the often unfamiliar and forced nature of an exercise gym.

The idea that doing PA for health benefits is also a relatively new concept with many participants claiming that the types of activity they enjoyed were for fun and enjoyment, not for physiological benefit or disease risk reduction. This warrants the question, should we promote PA with these intrinsic motives in mind for an older population – so it is more likened to the fond memories of childhood play? Would that encourage not only initiation, but more importantly adherence to a PA programme?

Clearly the barriers mentioned within the literature around a lack of time or fear of injury are numerous, and completely relevant (and also found within this population). However I believe there are far deeper rooted barriers, centred around an older persons life history, the experiences they have had, and the numerous changes they have had to adapt to, which in the case of technology and sedentary living, have now become more normalised engrained into their lives than exercise.

Reasons for Study Participation (The Diagnosis)

"if it's gonna help somebody, or at least go some way in helping somebody in the future I was really happy to take part...I wasn't really thinking of myself I don't think"

"I just hope we can find some good stuff out, so people can be helped in the future, it all helps doesn't it...?"

Reflection – deciding to interview cancer survivors (10th Jan 2014):

Whilst answered in response to a question about study participation I feel that Tom (and many other elevated risk ppts) had participated in the study for purely altruistic means – not to improve <u>their</u> health, or make <u>them</u> feel any better. It would certainly be an interesting thought to look at the reasons for participation in the PA trial across a cancer survivor population to identify and differences, which may be likened to PA motivation and the teachable moment, or health certificate effect concepts.

Influence of Health Professional (The Diagnosis & An Opportunity Missed?)

"...the fact of a nurse saying something is enough to make to step back and think isn't it really. They are knowledgeable, you can trust them...you have to trust them"

"I remember the lovely chap who did my screening thing, he said, 'we have taken out a few little polyps, but they are all benign, so you have absolutely nothing to worry about'...so I guess at the time you think 'phew, I haven't got cancer', and you put it all to the back of your mind."

Reflection – deciding to interview health professionals (6th August 2012):

It is a difficult debate; should patients be told more about cancer risk following and elevated risk diagnosis – as is outlined in the study by Aronowitz, who claims people are being made into patients earlier and earlier. This ultimately increases anxiety for the future, and I am unsure as to whether this is absolutely necessary. However, what appears to be happening instead is the 'health certificate effect' whereby the word of a health professional is taken as absolute truth, and if the health professional plays polyps down, that is exactly how this will be perceived by the patient. These ideas and thoughts really need to be discussed with health professionals to get a clear of a picture as possible – I wonder if I should take in some example quotes to encourage discussion around whether more could be done to increase awareness of BOTH risk and the benefits of PA.

Faculty of Medicine and Health Student Conference, March 2012 – University of East Anglia

Poster Presentation

Miss Kelly Semper

Professor John Saxton & Dr Caitlin Notley

"A qualitative study exploring the experiences of living at elevated risk of colon cancer and the subsequent affect this may have on choices to partake in healthy lifestyle behaviours"

Background

Physical Activity participation may play a large role in reducing colon cancer (CC) risk (up to 24% reduced risk between the most and least active individuals – Wolin, 2009). Despite this, accelerometry data suggests only 6% of adult men, and 4% of adult women achieve the recommended 150 minutes of physical activity per week (NHS, 2010). There is a distinct lack of research surrounding an elevated risk patient population, and the desire to better understand the influences on PA participation in this group is becoming increasingly important to informed future health promotion strategies. Various psychological models, such as the 'health belief model', 'the Transtheoretical model' and phenomenons such as the 'teachable moment' and 'health certificate effect' will help to inform decision making processes throughout this research study.

<u>Methods</u>

Semi-structured interviews will be conducted with individuals at elevated risk of developing CC who are also enrolled onto a physical activity programme within the university. Narrative accounts will explore how attitudes towards PA have been shaped from early life to the present day. Also the impact of screening procedures and a subsequent change in health status will also be examined in reference to healthy lifestyle initiation.

Conclusions

Many personal, psychological and environmental barriers to physical activity are currently cited in past literature, however this research seeks to understand the influences in a less researched population of elevated risk, older adults. The use of narrative accounts will allow for participant life stories to inform the emergent findings.

A qualitative study exploring the experiences of living at elevated risk of colon cancer and the subsequent affect this may have on choices to partake in healthy lifestyle behaviours



Kelly Semper, John Saxton, Caitlin Notley: School of Allied Health Professions, UEA.

Rationale:

Despite a strong body of evidence, including a recent meta-analysis suggesting that lifestyle factors may play a large part in reducing colon cancer (CC) risk (up to 24% reduced risk - Wolin et al, 2009), accelerometry data suggest that adult males and females meeting the recommended 150 minutes of physical activity (PA) participation per week may be as low as 6% and 4% respectively (NHS, 2010).

Judging by the distinct lack of research surrounding this patient population, there is a need to better understand the experiences of those who are diagnosed at increased risk of CC after their screening colonoscopy, including the impact this has on their choice to partake in healthy lifestyle behaviours.

Health Belief Model (HBM) (Rosenstock, 1974):

Precontemplation Contemplation

change. J Consult Clin Psychol 51(3):390-5

Journal of Cancer, 100, 611-616.

Centre Lifestyles Statistics

References

Psychological models of motivation can offer some insight into the reasons why some individuals may decide to partake in PA. The HBM suggests that a persons demographics can have an effect on a number of variables, which in turn may all determine the likelihood of 'action':



change' for that behaviour to be implemented. Although these stages appear linear, the process is

far more fluid with the possibility of movement back and forth, depending on influential life events:

Action

Maintenance

Preparation

NHS 2010. Statistics on obesity, physical activity and diet: England, 2010. In: EASTWOOD, P. (ed.). The NHS Information

PROCHASKA, JO; DICLEMENTE, CC. (1983) Stages and processes of self-change of smoking: toward an integrative model of

ROSENSTOCK, I. (1974). Historical Origins of the Health Belief Model. Health Education Monographs. Vol. 2 No. 4

'Teachable Moment' vs. 'Health Certificate Effect':

Attending a cancer screening test can be a highly influential life event, and therefore the result could have the potential to change the way we behave. Those who attend screening due to a fear of illness may view the experience as a 'catalyst' to action known as a 'teachable moment' resulting in positive lifestyle changes. Conversely, if our screening results in a negative result (i.e. no evidence of cancer), this is often taken positively by the patient, and acts as a verification of current - sometimes unhealthy lifestyle habits, known as the 'Health Certificate Effect'.

Barriers and Facilitators to Physical Activity:

Barriers and facilitators to PA have been rarely explored in this population, however in similar groups such as diabetics and cancer sufferers, common factors usually fit into one of four categories:

Personal: A lack of time is a huge determinant alongside current health problems or injuries which may impact exercise behaviour

Psychological: Motivation impacts us hugely, whether we strive for normality, have negative perceptions or feel embarrassment.

Social: Advice we receive from health care professionals and support from a spouse or friend has the ability to effect behaviour choice

Environmental. The cost and locality of facilities, the weather outside and fears surrounding safety can reduce the likelihood of behaviour change.

Methodology: Transtheoretical Model (TTM) (Prochaska & Diclemente, 1983):

Relapse

Qualitative methods can be used to gain a deeper understanding of the multi-dimensional factors influencing PA behaviour in patients at elevated risk of CC. Many suggest that for lifestyle changes to be made, the individual must be at the correct 'stage of

Data Collection

Participants diagnosed at elevated risk of developing further colon polyps by their screening colonoscopy will be enrolled onto an Active Lifestyle Randomised Controlled trial, whereby purposeful selection of interview candidates will be made.

Semi-structured Interviews pre- and post-trial participation (12 months) will take place to explore: •Narrative accounts of how attitudes towards PA have been shaped from early life to present day •The impact of the screening procedure and subsequent diagnosis on current lifestyle choices WOLIN, K. Y., YAN, Y., COLDITZ, G. A. & LEE, I. M. 2009. Physical activity and colon cancer prevention: a meta-analysis. British Knowledge surrounding the benefits of PA in reducing CC risk ·Key barriers and facilitators to PA participation Focus groups will be conducted with trial participants and specialist health care professionals to:

•Gain insight into the guidance provided to those identified at elevated risk after a screening colonoscopy ·Address positive and negative experiences within the intervention design

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Qualitative Methods in Psychology Conference Abstract – Huddersfield, September 2013

Poster Presentation

Miss Kelly Semper, School of Health Sciences, University of East Anglia.

Professor John Saxton, Dr Caitlin Notley, Dr Charlotte Salter

<u>"If exercise is the answer...then why don't we do it? Using Narrative accounts to gain insight</u> <u>into exercise behaviour over a lifetime in patients at elevated risk of colon cancer."</u>

Background

Despite recent evidence suggesting that taking regular exercise could reduce ones risk of developing colon cancer by 24%, it is estimated only 5% of adults actually achieve recommended physical activity levels. By undertaking this research I aim to understand the reasons for and against exercise participation within patients diagnosed at elevated risk of developing colon cancer after their screening colonoscopy. Using the various determinants suggested within the Health Belief Model, I also intend to identify the impact an individual's perception of disease risk and severity with regards to exercise initiation.

Methods

Semi-structured qualitative interviews with approximately 16 patients diagnosed at elevated risk of developing colon cancer. Topics discussed will include patient narratives of previous experiences with physical activity, including any beliefs of attitudes which may have affected their choice to lead an active lifestyle as well as their thoughts on the screening procedure and elevated risk diagnosis. Data will be analysed using Constructivist Grounded Theory due to its explicit methodology for data analysis, yet its allowance for reflexivity and the awareness of the impact the researcher may have on participants and vice versa. The aim of this study is therefore to develop new theories surrounding behaviour change, especially physical activity participation in this, often over looked patient group. N-Vivo 10 will be used to help organise coding structures and hierarchies.

Discussion

This study I hope will begin to fill gaps within the current literature surrounding behaviour change in this patient population. By identifying specific reasons for and against exercise participation, as well as identifying areas in health promotion which could be improved upon, these findings could inform future researchers designing exercise interventions, as well as potentially tailor the health promotional advice given after screening examinations in order to encourage behaviour change in elevated risk individuals.

'If exercise is the answer...then why don't we do it?'

Using Narrative accounts to gain insight into exercise behaviour over a lifetime in patients at elevated risk of colon cancer.

Kelly Semper₁, John Saxton₁ Caitlin Notley₂ & Charlotte Salter₂ School of Rehabilitation Medicine₁ & Norwich Medical School₂, University of East Anglia

Background:

Despite evidence suggesting a 24% reduction in colon cancer risk through taking regular exercise (*Wolin*, 2009) it is estimated less that only 5% of adults over 60 years of age achieve the recommended weekly levels of physical activity (*HSE*, 2008).

Males and	Female	s Combin	ed
100 50 80 60 40		1	1
£ 20			
20 0	16-34	35-64	65+
Meets Recommendations	16-34 9.5	35-64 4.5	65+ 2.5
20 0 I Meets Recommendations	16-34 9.5 56.5	35-64 4.5 43	65+ 2.5 21





Patient Group:

Males and Females 60+ years old, identified at elevated risk of developing colon cancer through an NHS Bowel Cancer Screening examination.

Participants selected due to their involvement in a randomised controlled feasibility trial. Providing supervised exercise classes and motivation change workshops to those selected for the 'Active Lifestyle' arm of the intervention, compared to individuals within the 'Usual Care' arm who are asked to continue with their usual lifestyles.

Asked to attend one 60 minute semi-structured interview at the University where lifetime physical activity levels will be discussed as well as changing perceptions towards physical activity from childhood to the present day. The primary question asks for a <u>narrative account</u> of life time physical activity from all patients.

Why use Narrative Accounts?

Focuses on the construction of an individual's story: extremely relevant to my methodology of <u>constructivist grounded theory</u> (Charmaz, 2000),

Can allow for me (the researcher) to create a personal picture of the specific elements of a persons life which may or may not have affected their choice to do physical activity in order to probe on areas of importance throughout the remainder of the interview.



Preliminary Findings:









Environmental: Access to

Alongside these commonly reported themes, <u>socio-cultural perceptions</u> of ageing has been a *novel* element to my emerging ideas.

<u>'Changing Times'</u> has now become a common theme within my preliminary findings and focuses on elements such as the impact of technology or crime levels and altered perceptions of healthy living within my oatient population.

"...you have to understand, we live in a very different time now, when I was growing up we <u>had</u> to be active, we didn't do it for our health, there was just no other option..."

Positives of Narrative Accounts

- ✓ Free from my own personal biases
- ✓ Starting the interview with narrative accounts allowed for me to probe on areas specific to their life story afterwards
- ✓ Narrative accounts nicely link the past to the present which is extremely useful when needing to establish behaviours over a life span.
- ✓ Narratives are usually simple and coherent which aids both the researcher and interviewee.

 Narratives have a clear beginning, middle and end – which allowed me to structure my interview accordingly

Challenges within Narrative Interviewing

- Some people do not feel comfortable talking openly for a long period of time
- Possible Solution: Encourage openness and confidentiality immediately and provide encouraging gestures throughout narrative
- Individuals may have real difficulty giving a life time narrative due to a lack of memory, or indeed difficulties with following lengthy open questions e.g. Dyslexia.
- questions e.g. Dyslexia. Possible Solution: Split narrative into more manageable sections e.g. childhood, adolescence, adult life and retirement.
- Narratives can easily go off track and it is difficult to divert back to the relevant topic again

Possible Solution: open to discussion...

Division of Health Psychology Conference Abstract – Brighton, September 2013

Poster Presentation

Miss Kelly Semper, School of Health Sciences, University of East Anglia.

Professor John Saxton, Dr Caitlin Notley, Dr Charlotte Salter

<u>"If exercise is the answer...then why don't they do it?</u> <u>Preliminary findings from a qualitative study exploring lifetime physical activity levels in</u> <u>individuals at elevated risk of colon cancer"</u>

Background

Despite recent evidence suggesting that taking regular exercise could reduce ones risk of developing colon cancer by 24%, it is estimated only 5% of adults actually achieve recommended physical activity levels. By undertaking this research I aim to understand the reasons for and against exercise participation within patients diagnosed at elevated risk of developing colon cancer after their screening colonoscopy. Using the various determinants suggested within the Health Belief Model, I also intend to identify the impact an individual's perception of disease risk and severity with regards to exercise initiation, as well as explore whether a screening procedure could have the potential to elicit a 'Teachable Moment' rather than a 'Health Certificate Effect'; something frequently described post screening diagnosis.

Methods

Semi-structured qualitative interviews with approximately 18 patients diagnosed at elevated risk of developing colon cancer. Topics discussed will include patient narratives of previous experiences with physical activity, including any beliefs of attitudes which may have affected their choice to lead an active lifestyle, as well as their thoughts on the screening procedure and elevated risk diagnosis. Data will be analysed using Constructivist Grounded Theory.

Discussion

This study I hope will begin to fill gaps within the current literature surrounding behaviour change in this patient population. By identifying specific reasons for and against exercise participation, as well as identifying areas in health promotion which could be improved upon, future exercise interventions and even the advice given after screening examinations could be better tailored to suit the individual.



Ageing and Society Conference – 7th & 8th November 2014 (Manchester)

Oral Presentation

Miss Kelly Semper, School of Health Sciences, University of East Anglia

Professor John Saxton, Dr Caitlin Notley, Dr Charlotte Salter

"We never thought exercise was doing us any good...it was just a natural part of living': A Qualitative Exploration of Physical Activity Influences in Older Adults."

Short Description (up to 30 words):

In order to improve health and wellbeing within our largely sedentary ageing population delving deeper into the numerous socio-cultural influences for physical activity behaviour is of paramount importance.

Abstract (up to 200 words):

Background:

The numerous positive effects gained through engaging in physical activity (PA) in one's later years are now well documented; however, despite this, a recent report concludes that fewer than 3% of adults over the age of 65 years are achieving the recommended levels. This study attempts shed light upon the possible socio-cultural influences which may have an impact on PA behaviour within our ageing population.

Methodology:

Semi structured interviews with 24 adults over the age of 60 years, using an initial narrative component addressing lifetime PA levels and changing in perceptions of health.

Findings:

Although not achieving the official recommended PA guidelines most interviewees believed that they were active in more 'natural' ways; often likened to their childhood memories of never having to force PA. They also held many stereotypes, not only regarding what constitutes an 'active lifestyle' but also the types of people which may attend gyms or structured classes.

Conclusion:

Findings provide a unique insight and enhanced understanding into the more theoretical underpinnings of PA behaviour from a socio-cultural perspective allowing future policy makers in health promotion to design and implement increasingly relevant and therefore successful programmes by taking account of these pre-conceived attitudes and stereotypes.

Keywords: Active-ageing, Socio-cultural, Grounded Theor

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