Health Behaviour Change Among Teenage and Young Adult Cancer Survivors

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Declaration

I, Gemma Pugh, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.
Acknowledgements

Firstly, I owe a great deal of thanks to Dr Abi Fisher. I am forever grateful to her for allowing me the opportunity to do a PhD. I would also like to thank Dr Rachael Hough for always being so encouraging about my work. Together their constant support and genuine kindness has made doing this PhD better than I could have ever hoped. Thank you also to Dr Sarah Jackson for her input and advice over the past year. I could not have wished for a better supervisory panel.

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Abstract

There is growing recognition that teenage and young adult (TYA) cancer survivors should adopt a healthy lifestyle in order to reduce the impact a cancer diagnosis has upon growth and development as well as long-term health. There is a need for health behaviour change interventions to be developed for TYA cancer survivors’ in the UK which, in line with the National Cancer Survivorship Initiative, should be effective, inexpensive, and have the potential to be rolled out nationwide. In order to address this need, the aim of this thesis was to develop a health behaviour intervention specifically for TYA cancer survivors. Specifically this thesis includes: a systematic review of existing interventions targeting health behaviour change among TYA cancer survivors; data on the proportion of TYA cancer survivors meeting current health behaviour recommendations in comparison to TYAs within the general population (Study 1); and both quantitative and qualitative data on TYA cancer survivors interest in receiving health behaviour information and preference regarding the format, delivery, and timing of such information (Study 2 and Study 3). The results of the literature review and the results of studies 1-3 were combined with data on health professionals’ views of health behaviour intervention delivery to young people with cancer (Study 4) to inform the development of a collection of health behaviour change intervention resources containing comprehensive lifestyle information and behaviour change support tools. These intervention resources were then formatively evaluated by TYA cancer survivors and TYA health professionals for relevance, appeal and usability (Study 5). Results demonstrate TYA cancer survivors have a high level of interest in receiving health behaviour change support and would be open to engaging with the proposed intervention materials. The findings from this thesis contribute towards the development of a best practice health behaviour intervention for TYA cancer survivors. Such an intervention could be widely disseminated leading to an improvement in TYA cancer survivorship.
List of Publications


Pugh, G., Gravestock, H., Hough, R., Williams, K., & Fisher, A. (2017) *Lifestyle Advice Provision to Teenage and Young Adult Cancer Survivors: The Perspective of Health Professionals in the United Kingdom Supportive Cancer Care* [Epub ahead of print]


# Table of Contents

Table of Contents.............................................................................................................. 11  
List of Tables ...................................................................................................................... 17  
List of Figures ..................................................................................................................... 21  
List of Appendices .............................................................................................................. 23  

Chapter 1 Teenage and Young Adult Cancer Survivors: An Overview ............................ 25  
  1.1 Defining teenagers and young adults with cancer ...................................................... 25  
    1.1.1 Defining the ‘TYA’ age range ............................................................................. 25  
    1.1.2 Defining cancer survivors ............................................................................... 27  
    1.1.3 Distinguishing between TYA cancer survivors and TYA survivors of childhood cancer ........................................................................................................... 27  
  1.2 TYA cancer epidemiology ......................................................................................... 29  
    1.2.1 Incidence ......................................................................................................... 29  
    1.2.2 Survival .......................................................................................................... 29  
  1.3 Unique aspects of TYA cancer ................................................................................ 30  
    1.3.1 Distinct biological and clinical profile ............................................................. 30  
    1.3.2 Distinct developmental and psychosocial needs .............................................. 33  
  1.4 Current care structure for TYA cancer patients in the UK ....................................... 35  
  1.5 The long-term health and wellbeing of TYA cancer survivors ............................... 38  
    1.5.1 The long-term physical consequences of TYA cancer .................................. 39  
    1.5.2 The long-term psychosocial consequences of TYA cancer ......................... 42  
  1.6 Summary .................................................................................................................. 43  

Chapter 2 Health Behaviour Change Among TYA Cancer Survivors ............................... 45  
  2.1 The importance of promoting a healthy lifestyle among TYA cancer survivors ...... 45  
  2.2 Health behaviour guidelines for TYA cancer survivors ......................................... 46  
  2.3 Health behaviour and cancer survivorship .............................................................. 48  
    2.3.1 Physical activity .............................................................................................. 48  
    2.3.2 Diet .................................................................................................................. 55  
    2.3.3 Weight management ...................................................................................... 58  
    2.3.4 Smoking ......................................................................................................... 60  
    2.3.5 Alcohol consumption ..................................................................................... 62  
    2.3.6 Ultra-violet radiation and sun protection ....................................................... 65  
  2.4 Health behaviour change interventions for TYA Cancer Survivors ....................... 67  
    2.4.1 Methods ......................................................................................................... 67  
    2.4.2 Search strategy .............................................................................................. 67  
    2.4.3 Selection criteria ............................................................................................ 68  
    2.4.4 Data collection ............................................................................................... 68
2.4.5 Study quality ................................................................. 70
2.4.6 Results ........................................................................ 70
2.4.7 Discussion .................................................................. 87
2.5 Summary ....................................................................... 90
Chapter 3 PhD Aims .................................................................. 93
Chapter 4 Methodology ............................................................. 97
  4.1 Intervention development: existing frameworks & guidance .......... 97
  4.2 The use of behaviour change theory in intervention development ........ 99
  4.3 Patient and participant involvement (PPI) and user centred intervention design .. 104
  4.4 TYA cancer survivor health and lifestyle questionnaire ......................... 106
    4.4.1. Ethical approval ................................................................ 106
    4.4.2 Design and development ..................................................... 106
    4.4.3 Measures ....................................................................... 107
      Demographics and health characteristics ...................................... 107
      Physical Activity ................................................................... 107
      Diet and Nutrition .................................................................. 108
      Smoking ............................................................................... 108
      Alcohol consumption .............................................................. 108
      Sun related behaviour .............................................................. 109
      Weight status ....................................................................... 109
      Perception of health behaviour on current and future health .............. 109
      Health behaviour information and advice received .......................... 109
      Lifestyle information and advice preferences ................................. 109
    4.4.4 Participant eligibility .......................................................... 110
    4.4.5 Recruitment and sampling................................................... 110
  4.5 General population TYA health and lifestyle questionnaire ............... 113
    4.5.1 Ethical approval ............................................................... 113
    4.5.2. Design ........................................................................ 113
    4.5.3 Measures ....................................................................... 113
    4.5.4 Participant eligibility .......................................................... 113
    4.5.5 Recruitment ................................................................... 113
  4.7 Teenage and young adult cancer survivor interviews and focus groups ........ 115
    4.7.1 Ethical approval ............................................................... 115
    4.7.2 Participants & recruitment ................................................... 115
    4.7.3 Interview topic guide ........................................................ 115
  4.8 Teenage and young adult cancer health professionals survey ............... 116
    4.8.1 Ethical approval ............................................................... 116
    4.8.2 Design ........................................................................ 116
Chapter 5 Study 1 The Health Behaviours of TYA Cancer Survivors and General Population Controls

5.1 Background ................................................................................. 123
5.2 Aims ......................................................................................... 124
5.3 Methods .............................................................. 124
5.3.1 Population ........................................................................... 124
5.3.2 Measures .......................................................................... 124
5.4 Results .................................................................................... 125
5.4.1 Response rate ..................................................................... 125
5.4.2 Missing data ....................................................................... 127
5.4.3 Sample characteristics ......................................................... 128
5.4.4 The health behaviour status of TYA cancer survivors and general population TYAs ....................................... 132
5.4.5 TYA cancer survivors perception of their current health behaviour ............................................................. 138
5.4.6 TYA cancer survivors reported change in health behaviour since diagnosis .... 138
5.4.7 Perception of health behaviour on current and future health ................................................................. 141
5.5 Discussion .............................................................................. 144
5.6 Chapter summary ................................................................. 149

Chapter 6 Study 2 The Health Behaviour Information Needs and Preferences of Teenage and Young Adult Cancer Survivors .............................. 149
6.1 Introduction ............................................................................ 151
6.2 Aims ....................................................................................... 152
6.3 Methods ................................................................................ 152
6.3.1 Participants & recruitment .................................................. 152
6.3.2 Measures ........................................................................ 152
6.3.3 Statistical analysis ............................................................... 152
6.4 Results .................................................................................... 153
6.4.1 Response rate ..................................................................... 153
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.4.7 Barriers to providing lifestyle advice</td>
<td>201</td>
</tr>
<tr>
<td>8.5 Discussion</td>
<td>204</td>
</tr>
<tr>
<td>8.6 Chapter summary</td>
<td>207</td>
</tr>
<tr>
<td>Chapter 9 Study 5 The Development and User Evaluation of Health Behaviour Change Resources for Teenage and Young Adult Cancer Survivors</td>
<td>208</td>
</tr>
<tr>
<td>9.1 Introduction</td>
<td>208</td>
</tr>
<tr>
<td>9.2 Aims &amp; Objectives</td>
<td>209</td>
</tr>
<tr>
<td>9.3 Methods</td>
<td>209</td>
</tr>
<tr>
<td>9.3.1 Study design</td>
<td>209</td>
</tr>
<tr>
<td>9.3.2 Health behaviour change intervention resources for TYA cancer survivors</td>
<td>209</td>
</tr>
<tr>
<td>9.3.3 Format and modes of delivery</td>
<td>217</td>
</tr>
<tr>
<td>9.3.4 Measures</td>
<td>219</td>
</tr>
<tr>
<td>9.3.5 Population</td>
<td>219</td>
</tr>
<tr>
<td>9.3.6 Statistical analysis</td>
<td>219</td>
</tr>
<tr>
<td>9.4 Results</td>
<td>219</td>
</tr>
<tr>
<td>9.4.1 Response rate</td>
<td>219</td>
</tr>
<tr>
<td>9.4.2 Participant characteristics</td>
<td>219</td>
</tr>
<tr>
<td>9.4.3 Health behaviour information evaluation</td>
<td>222</td>
</tr>
<tr>
<td>9.4.4 Suggested improvements</td>
<td>230</td>
</tr>
<tr>
<td>9.4.5 Intervention resource evaluation</td>
<td>234</td>
</tr>
<tr>
<td>9.4.6 Acceptability and delivery</td>
<td>235</td>
</tr>
<tr>
<td>9.5 Discussion</td>
<td>237</td>
</tr>
<tr>
<td>9.6 Chapter summary</td>
<td>239</td>
</tr>
<tr>
<td>Chapter 10 General discussion &amp; conclusions</td>
<td>241</td>
</tr>
<tr>
<td>10.1 Thesis aims</td>
<td>241</td>
</tr>
<tr>
<td>10.2 Summary of main findings and their implications</td>
<td>241</td>
</tr>
<tr>
<td>10.2.1 Review of existing interventions for TYA cancer survivors</td>
<td>241</td>
</tr>
<tr>
<td>10.2.2 The health behaviour status of TYA cancer survivors and general population controls (Study 1)</td>
<td>243</td>
</tr>
<tr>
<td>10.2.3 TYA cancer survivors health behaviour change intervention needs and preferences (Study 2 &amp; Study 3)</td>
<td>246</td>
</tr>
<tr>
<td>10.2.4 Health professionals’ perspectives on the delivery of health behaviour information to TYA cancer survivors (Study 4)</td>
<td>248</td>
</tr>
<tr>
<td>10.2.5 The development of health behaviour intervention resources for TYA cancer survivors</td>
<td>250</td>
</tr>
<tr>
<td>10.3 Limitations</td>
<td>254</td>
</tr>
<tr>
<td>10.3.1 Recruitment</td>
<td>254</td>
</tr>
<tr>
<td>10.3.2 Sample size</td>
<td>255</td>
</tr>
<tr>
<td>10.3.3 Study design</td>
<td>256</td>
</tr>
<tr>
<td>10.3.4 Methodology</td>
<td>257</td>
</tr>
</tbody>
</table>
10.4 Further research .................................................................................. 258
10.5 Final conclusions ................................................................................ 259
References .................................................................................................. 261
Appendices ................................................................................................ 291
List of Tables

Table 1.1 Common age ranges adopted internationally to define young people with cancer .......................................................... 26
Table 1.2 Unique features of TYA cancer .......................................................................................................................... 31
Table 1.3 Key features of TYA cancer ............................................................................................................................... 37
Table 1.4 Potential late effects of cancer treatment by system and exposure Adapted from Nass et al., 2015 .................................................................................................................. 41
Table 2.1 Lifestyle guidance for teenage and young adult cancer survivors ................................................................. 47
Table 2.2 Effect sizes for meta-analysis of randomised controlled trials of physical activity in cancer survivors: physical health and function ........................................................................ 50
Table 2.3 Effect sizes for meta-analysis of randomized controlled trials of physical activity in cancer survivors: psychological health and function ........................................................................ 51
Table 2.4 Characteristics of included studies .................................................................................................................... 71
Table 2.5 Intervention outcomes ........................................................................................................................................ 78
Table 2.6 Component features of health behaviour interventions ................................................................................. 84
Table 2.7 Scores for risk of bias assessment (Cochrane Collaboration tool) for all included RCT health behaviour interventions (n=9) ................................................................................................................. 86
Figure 3.1 The development of a health behaviour intervention for TYA cancer survivors (PhD Study framework) .................................................................................................................. 94
Table 5.1 TYA cancer survivor health and lifestyle questionnaire recruitment efficacy .......................................................... 126
Table 5.2 General population TYAs health and lifestyle questionnaire recruitment efficacy .................................................. 126
Table 5.3 Proportion of missing data & littles missing completely at random outputs .................................................. 127
Table 5.4 Participant demographic and health characteristics ............................................................................................ 129
Table 5.5 Cancer and treatment characteristics of TYA cancer survivors ........................................................................ 130
Table 5.6 Health problems and weight status .................................................................................................................... 131
Table 5.7 Adjusted and unadjusted odds ratios for the association between treatment status and health behaviour .................................................................................................................. 136
Table 5.8 Reported perception of current lifestyle .................................................................................................................. 139
Table 5.9 Reported change in lifestyle since diagnosis ...................................................................................................... 140
Table 6.1 Participant characteristics ........................................................................................................................................ 154
Table 6.2 Health and treatment characteristics .................................................................................................................... 155
Table 6.3 Participant health problems ........................................................................................................................................ 156
Table 6.4 Participants description of the advice they had received in the past on each health behaviour .................................................................................................................. 160
Table 6.5 Preferences regarding the timing of health behaviour information delivery .......................................................... 165
Table 7.1 Participant characteristics ........................................................................................................................................ 171
Table 7.2 Lifestyle intervention content preferences .............................................................................................................. 181
Table 7.3 Lifestyle intervention format preferences .............................................................................................................. 185
Table 8.1 Participant Characteristics ........................................................................................................................................ 194
Table 8.2 Participant Characteristics: Professional Role ............................................................................................................ 195
Table 8.3 Percentage of health professionals overall and within each professional group aware of lifestyle guidance, enquiring about lifestyle and providing lifestyle advice to >75% of patients within their care (n=95)) .............................................................. 201
Table 8.4 Barriers and problems associated with the delivery of lifestyle information and advice to young people with cancer .................................................................................................. 202
Table 9.1 Content and rationale behind behaviour change techniques selected for inclusion within the intervention ........................................................................................................ 215
Table 9.2 Participant characteristics (TYA Cancer Survivors) .......................................................... 220
Table 9.3 Participant characteristics (TYA Health Professionals) ..................................................... 221
Table 9.4 TYA cancer survivors and TYA health professionals’ views on the standard of the health behaviour information ........................................................................................................... 227
Table 9.5 Feedback on the design and visual layout ........................................................................... 233
Table 9.6 TYA cancer survivors and TYA health professionals’ views on the appeal of discreet behaviour change techniques ........................................................................................................... 234
List of Figures

Figure 1.1 The care pathway for children and young people with cancer ................................................. 28
Figure 2.1 Flow diagram of search strategy results ...................................................................................... 69
Figure 3.1 The development of a health behaviour intervention for TYA cancer survivors (PhD Study framework) .................................................................................................................. 94
Figure 4.1 The COM-B model ..................................................................................................................... 103
Figure 4.2 The Behaviour Change Wheel and the COM-B model ................................................................. 103
Figure 4.3 Flow chart: Health and lifestyle questionnaire recruitment strategies ..................................... 103
Figure 5.1 Proportion of TYA cancer survivors and general population TYAs meeting current physical activity recommendations .......................................................................................... 133
Figure 5.2 Proportion of TYA cancer survivors and general population TYAs meeting current diet and nutrition guidelines ...................................................................................................... 134
Figure 5.3 Proportion of TYA cancer survivors and general population TYAs meeting current alcohol consumption, smoking and sun-safety health behaviour guidelines ........................................... 135
Figure 5.4 Perception of health behaviour on current health ..................................................................... 142
Figure 5.5 Perception of health behaviour on future health ........................................................................ 142
Figure 6.1 Proportion of TYA cancer survivors on treatment who received health behaviour advice since diagnosis and their interest in health behaviour information .................................................. 159
Figure 6.2 Proportion of TYA cancer survivors off treatment who received health behaviour advice since diagnosis and their interest in health behaviour information ............................................. 159
Figure 6.3 Sources TYA cancer survivors consult for information on each health behaviour .......... 163
Figure 7.1 Thematic map ............................................................................................................................. 173
Figure 8.1 Format of advice delivery ........................................................................................................... 200
Figure 9.1 Creative illustrations of the intervention resources ................................................................ 211
Figure 9.2 Intervention Formats .................................................................................................................... 218
Figure 9.3 Quality ratings of the TYA health behaviour change information ........................................... 223
Figure 9.4 Utility ratings of the TYA health behaviour change information .............................................. 224
Figure 9.5 Relevance ratings of the TYA health behaviour change information ........................................ 225
Figure 9.6 TYA cancer survivors and TYA health professionals’ views on the information on the benefits of a healthy lifestyle .................................................................................... 228
Figure 9.7 TYA cancer survivors and TYA health professionals’ views on the information on the risks of an unhealthy lifestyle ..................................................................................... 228
Figure 9.8 TYA cancer survivors and TYA health professionals’ views on the ‘ideas for everyday change’ ........................................................................................................................................ 229
Figure 9.9 TYA cancer survivors and TYA health professionals’ views on the information about forming new habits .................................................................................................................................. 229
Figure 9.10 Timing of health behaviour change intervention delivery ...................................................... 236
List of Appendices

Appendix 2.1 Published paper Journal of Adolescent and Young Adult Oncology .................. 291
Appendix 4.1 Intervention development frameworks .......................................................... 306
Appendix 4.2 Study approval letter – UCL ethics 6206/001 ................................................. 311
Appendix 4.3 Study approval letter – NHS ethics 15/LO/0764 ............................................. 313
Appendix 4.4 Health and lifestyle questionnaire ................................................................. 317
Appendix 4.5 Participant information sheet (health and lifestyle questionnaire) ................. 339
Appendix 4.6 Ethics amendment 6206/001 ........................................................................ 343
Appendix 4.7 General population TYA survey .................................................................. 345
Appendix 4.8 Participant information sheet (General population TYAs) ......................... 365
Appendix 4.9 Parent information sheet and consent form .................................................. 367
Appendix 4.10 Participant information sheet (Interviews and focus groups) ..................... 370
Appendix 4.11 Consent form: interview and focus group study ........................................ 375
Appendix 4.12 Focus group and interview schedule ............................................................ 376
Appendix 4.13 Ethics amendment – UCL ethics 4556/001 .................................................. 378
Appendix 4.14 Health professionals survey ........................................................................ 380
Appendix 4.15 Study approval letter – UCL ethics 6206/003 .............................................. 396
Appendix 4.16 TYA cancer survivor participant information sheet (Study 5) ..................... 397
Appendix 4.17 TYA health professionals participant information sheet (Study 5) ........... 398
Appendix 4.18 User evaluation of lifestyle intervention resources for teenage and young adult cancer survivors questionnaire ................................................................. 400
Appendix 4.19 Study 5 online survey screenshot ............................................................... 415
Appendix 5.1 Health behaviour data cleaning ..................................................................... 416
Appendix 5.2 Health behaviour scoring & cut-offs .............................................................. 417
Appendix 6.1 Published paper Journal of Adolescent and Young Adult Oncology ............ 427
Appendix 7.1. Published paper Cancer Nursing ................................................................. 436
Appendix 8.1 Published paper Supportive Cancer Care ..................................................... 446
Appendix 9.1 Health behaviour information and behaviour change support resources ...... 456
Appendix 9.2 Health behaviour behaviour change support resources ................................ 467
Appendix 10.1 Pan-London research fellowship ................................................................. 472
Chapter 1

Teenage and Young Adult Cancer Survivors: An Overview

There are currently over 2 million cancer survivors living in the UK; of these approximately 16,630 individuals are teenage or young adult (TYA) cancer survivors aged between 15 and 24 years\(^1\) (Maher et al., 2014). Although this is proportionally low and accounts for less than 2% of the total number of cancer survivors, the ongoing commitment by the National Institute of Clinical Excellence (NICE) to continue to reduce TYA cancer mortality means the number of young people living with and beyond cancer will continue to rise. Research now must focus on ways of improving the long-term survivorship of this unique population.

1.1 Defining teenagers and young adults with cancer

1.1.1 Defining the ‘TYA’ age range

As shown in Table 1.1, no consistent age range has been adopted internationally to define the ‘TYA’ group in the cancer survivorship literature or within clinical pathways. The overall lack of consensus of what the age range for TYA oncology should be, and the variation in the terminology used to define a TYA cancer survivor, stems from the fact the boundaries between childhood, adolescence, and adulthood are ambiguous and difficult to distinguish. In the first issue of the Journal of Adolescent and Young Adult Oncology (JAYAO), leading TYA cancer experts from a variety of professional backgrounds (oncology, haematology, nursing, and psycho-oncology) were invited to provide short pieces outlining their perspective on what age range should be adopted for TYA oncology and cancer care. From both clinical and supportive care standpoints, it was acknowledged that the complex biological and psychosocial developmental processes experienced during adolescence and young adulthood often do not occur in parallel to chronological age. Many contributors argued that the use of a set chronological age to define young people with cancer would be inappropriate, as typically the developmental age, psychosocial circumstance, and underlying biology of the cancer in question defines the treatment and care a young person will receive. For example, a TYA aged cancer patient diagnosed with a common paediatric malignancy (such as neuroblastoma or Wilms tumor) would be considered ‘old’ for their respective disease (which has a median age of diagnosis of < 5 years (Breslow et al., 1993) and would most likely benefit from paediatric oncology expertise, but not necessarily from treatment and care on a children’s ward by paediatric support services. Constraints imposed by a single rigid age bracket could (and in some cases do) lead to some young people with cancer not receiving the medical and psychosocial care and support they require. Specifically, in the past, accrual of TYAs to clinical

\(^1\) Data from the Macmillan- National Cancer Intelligence Network ‘Segmenting of the 2 million project’ were stratified by age, sex, time since diagnosis, national sub-geographies, deprivation and cancer type. Children, teenagers and young adults were segmented into two age categories: 0-14 years of age and 15-24 years of age. Data on the total number of TYA cancer survivors aged 13-24 years and the total number of adult aged cancer survivors of a diagnosis during adolescence or young adulthood of age have not been published.
trials has been impeded by stringent age cut-offs (Fern et al., 2014). One of the most significant achievements made to date by the National Cancer Research Institute Teenage and Young Adult Clinical Studies Group (NCRI TYA CSG) is the removal/ lowering of age eligibility criteria on adult cancer trials entering the National Institute for Health Research (NIHR) portfolio which has resulted in more young people being trial eligible. Similarly, increasing the age eligibility criteria for selected paediatric studies, such as UKALL2003, has led to a substantial increase in event free survival for TYA patients with acute lymphoblastic leukaemia (Hough et al., 2016).

As a combined result of these factors there is no call for a uniform definition of TYA to be adopted internationally. Instead, TYA oncology takes a patient-and-disease-orientated approach to treatment and publications or communications in the TYA field are required to define the rationale behind the use of any specific age range. This process not only takes into consideration the inter-variability among TYAs but also allows exploration of situations in which the entire age range (e.g. 13-39) can be considered as a whole, as well as situations where narrower age brackets (e.g. 13-18 vs 19-24 vs 24-39) may be more appropriate (Geiger and Castellino, 2011).

For the purposes of this thesis, 13-24 years will be used to define a ‘TYA cancer survivor’. This age range reflects the UK clinical age brackets set by the National Health Service (NHS) (NICE, 2005), and is the age-bracket supported by designated TYA cancer charities based within the United Kingdom (UK) (Teenage Cancer Trust, 2012).

**Table 1.1 Common age ranges adopted internationally to define young people with cancer**

<table>
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<tr>
<th>Country</th>
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<td>15-39</td>
</tr>
<tr>
<td>Canada</td>
<td>15-29</td>
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<tr>
<td>Australia</td>
<td>15-24</td>
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<tr>
<td>United Kingdom</td>
<td>13-24</td>
</tr>
<tr>
<td>Scandinavia</td>
<td>16-45</td>
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1.1.2 Defining cancer survivors

The term ‘cancer survivor’ originated in the mid-1980s, following the proposition by Fitzhugh Mullan that an individual is a cancer survivor from the moment of diagnosis and that there are three distinct phases of survival: ‘acute survival’, referring to survival during the period immediately after diagnosis, ‘extended survival’, referring to survival of the physical and psychological consequences of cancer treatment, and ‘permanent survival’, the point where recurrence is unlikely but the effects of treatment are still ongoing (Mullan, 1985). This characterisation of a cancer survivor articulates the common reality that those who have had successful cancer treatment often do not live a disease-free life, but are instead burdened by their diagnosis due to long-lasting physical and/or emotional side effects or consequences of treatment, and subsequently, do not identify completely with either the sick or the well (Ganz, 2005).

The meaning of the term cancer survivor and its connotations have been widely debated (Bell and Ristovski-Slijepcevic, 2013) as some hold the belief that a person cannot be a survivor until he or she lives to beyond 5 years post diagnosis (Feuerstein, 2007). The term survivor also carries a certain level of stigma with other labels such as ‘thrivor’ or ‘a person with a history of cancer’ being preferred by some who do not wish to identify with their diagnosis, and perceive ‘survivor’ as a negative label, tying them to a traumatic life event (Surbone et al., 2013). Understanding how an individual views themselves in the context of their cancer diagnosis is important, as there is some evidence that cancer identity is associated with long-term mental and physical well-being (Feuerstein, 2007). Among young people in particular, the formation of an empowering cancer-related-identity (e.g. survivor, thrivor, and conqueror) has been found to be associated with better psychosocial adjustment to cancer 1-year post diagnosis (Cho and Park, 2015).

For the purposes of this thesis, in consistence with existing survivorship literature, the National Cancer Institute (NCI) and Institute of Medicine (IOM) definition of cancer survivor will be adopted. This definition states ‘a person is defined as a cancer survivor from the time of diagnosis and for the balance of life’ (National Cancer Institute, 2015) and includes young people throughout the cancer care pathway displayed in Figure 1.1.

1.1.3 Distinguishing between TYA cancer survivors and TYA survivors of childhood cancer

The terms ‘teenager’, ‘adolescent’, ‘young adult’ and ‘young person’ are often used synonymously within the TYA cancer context. Often the term ‘TYA cancer survivor’ is used interchangeably to describe adults diagnosed with cancer during adolescence and young adulthood and those who are TYA-aged childhood cancer survivors. Specifically within observational studies, these individuals are often combined as a single population group, often confounding analyses (Marjerrison et al., 2016). Care has been taken throughout this thesis to distinguish between studies of TYA-aged cancer survivors, TYA-aged survivors of childhood cancers and adult survivors of cancer diagnosed in their TYA years.
Figure 1.1 The care pathway for children and young people with cancer

- Presentation
  - Referral
  - Diagnosis
- Holistic & Supportive Care
  - Treatment
  - Allied Treatment Services
    - Relationships
    - Housing
    - Transport
    - Finances
    - Education & work
    - Faith & spirituality
    - Physiotherapy
    - Dietetic
    - Occupational health
    - Speech and language
    - Ophthalmic
    - Orthotics and prosthetics
    - Art, music & drama therapy
    - Treatment summary
      - Holistic needs assessment
      - Cancer care review
      - Late effects management
      - Long-term follow up
- Survivorship & Rehabilitation
- Palliative Care
1.2 TYA cancer epidemiology

1.2.1 Incidence

The incidence of cancer during adolescence or young adulthood is relatively rare (Maher et al., 2014). Within Europe it is estimated that around 14,000 new cases of cancer are diagnosed among TYAs annually: of this figure approximately 2,200 TYA cancer diagnoses occur in the UK (Stark et al., 2015b, Stelianova-Foucher et al., 2015).

It is well-established that the incidence of cancer increases exponentially as a function of age. Between the years 2001 – 2005, 5,237 cancers were identified in the age group 0-12 years, 9,894 cancers identified in the TYA age group 13-24 years, and 131,802 cancers identified in the age group 24-49 years (Stark et al., 2015b). These numbers are comparatively small when considering that over 162,000 diagnoses occur annually among those aged over 50 years (Cancer Research UK, 2017). Even within the TYA age-bracket there is an age-related increase; 38% of cancers diagnosed among this age group occur among those aged 15-19 years of age and 62% of cancers are diagnosed among those aged 20-24 years (Cancer Research UK, 2017).

1.2.2 Survival

Although TYA cancers are relatively rare, in the UK cancer is still the leading cause of non-accidental death among young people (Geraci et al., 2007). However, the latest survival trend data indicate that the overall five-year cancer survival rate among TYAs, for all cancer types, has increased significantly from 75.5% in 1992-1996 to 82.2% in 2002-2006 in the UK (O’Hara et al., 2015). For some cancer types (Hodgkin lymphoma, melanoma, and thyroid carcinoma) survival now exceeds 90%. Despite these increases in survival, and although the mortality rate from cancer has declined across all age ranges in the past 25 years, the slowest rate of decline has occurred within the TYA age bracket (Gatta et al., 2009, Keegan et al., 2016). Specifically for some cancers (e.g. bone and soft tissue sarcomas) TYA cancer survival is poorer than that of children of the same tumour type (Lewis et al., 2014). TYAs with carcinomas of the cervix or breast have also been found to have worse 1 year survival than adults (Stark et al., 2015b). Unfavourable case-mix (e.g. multiple different cancers co-occurring), diagnostic delay, increased susceptibility to toxicity and issues around treatment compliance have been provided as explanations behind these differences in survival (Stark et al., 2015b, Fern et al., 2008, Kondryn et al., 2011). Current directive efforts, such as treatment decision-making based upon tumour biology/histology and increased clinical trial availability, are being made in attempt to reduce cancer mortality among the TYA age group (Stark and Lewis, 2013, Stark et al., 2015a, Bleyer et al., 2006).
1.3 Unique aspects of TYA cancer

1.3.1 Distinct biological and clinical profile

There is substantial evidence that cancer during adolescence or young adulthood is markedly different to cancer diagnosed during childhood or later in adulthood (Sender and Zabokrtsky, 2015, Barr et al., 2016). Most notably, the incidence of cancer type varies across the TYA age range such that TYA malignancies may be classified into one of three categories: ‘late paediatric cancer’ i.e. those which are more commonly seen in children such as medulloblastoma, hepatoblastoma and retinoblastoma; ‘true TYA cancers’ e.g. Hodgkins Lymphoma, osteosarcoma and Ewings’ sarcoma which peak in incidence during TYA years; and ‘early onset adult cancers’ which are more commonly observed in adults such as breast, bowel or prostate cancer (Barr et al., 2006). Table 1.2 provides an overview of the other distinctive biological and clinical features of TYA cancer and the implications these have in care for young people.
Table 1.2 Unique features of TYA cancer

<table>
<thead>
<tr>
<th>Feature, description, and implication in care</th>
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<tbody>
<tr>
<td><strong>Aetiology</strong></td>
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<tr>
<td>While cancers among infants and young children are strongly attributed to congenital factors and cancers among adults are strongly linked to environmental or lifestyle factors, very little is known about the causes of cancer among TYAs. In most instances, very few of the cancer diagnoses which occur within the TYA age range can be attributed to either congenital or environmental factors (Sender and Zabokrtsky, 2015). This often causes distress among young people at the point of diagnosis where typically a causal explanation behind their illness is being sought (Kent et al., 2012).</td>
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<tr>
<td><strong>Diagnostic delays</strong></td>
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<td>TYAs often experience a lengthy diagnostic journey (Fern et al., 2013a). Young people aged 16-24 are more likely to present via emergency referral and are twice as likely, when compared to older adults, to have three or more GP consultations before referral to a cancer specialist (Lyratzopoulos et al., 2012). Such delays in diagnosis are most commonly attributed to rarity of cancer in this age group, the complexity of presenting symptoms and insufficient awareness that cancer may occur in this age group. Often diagnostic delays can lead to the increased anxiety and distress among patients and may cause a delay in treatment initiation. Improved professional and public education about cancer symptoms among young people has the potential to reduce diagnostic delays (Kyle et al., 2013).</td>
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<tr>
<td><strong>Unique spectrum of cancer types, tumour biology and clinical behaviour</strong></td>
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<td>The majority (82%) of cancer cases among 15 to 19 year olds are non-epithelial cancers (e.g. central nervous system tumours, lymphomas and leukaemias) whilst among those aged 45+ years cancers are typically epithelial (e.g. carcinomas of the breast, bowel and lung) (Wu et al., 2010). Bone tumours, including osteosarcoma and Ewing sarcoma, are also common in TYA patients. Often the tumour biology and clinical behaviour of some cancer types seen in TYAs is not the same as in younger or older cancer patients (Bleyer et al., 2008, Tricoli et al., 2016). For example, the TEL-AM1 translocation is present in 50% of paediatric acute lymphoblastic leukaemia cases but only 10% of TYA cases (Moricke et al., 2005). Similarly, TYA breast cancer patients often present with ‘triple negative’ tumours; tumours which have limited expression of oestrogen, progesterone and human epidermal growth factor 2 receptors (Cleator et al., 2007). Variations in cancer histology provide the rationale behind precision medicine research for TYA cancer patients and the joint paediatric adult case review aspect of TYA cancer care to ensure that the most appropriate treatment protocol are administered.</td>
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Chapter 1

Table 1.2 Continued

**TYA patient biology**

Adolescence and young adulthood is a key time of biological growth and development. As a result, TYAs have a distinct physiological and pharmacological profile from children and adults. Age-related changes in pharmacology (e.g. drug clearance) may affect treatment efficacy and toxicity (Bleyer et al., 2008). Specifically among TYA Ewing sarcoma patients, gender-specific age-dependant changes have been associated with adverse chemotherapy side effects (Juergens et al., 2006). TYA patients treated with adult treatment regimens may also be under-treated relative to their biopharmalogical tolerance as typically dosage regimes within adult protocols are established from older adult populations who often have coexisting comorbidities (Bleyer et al., 2006). There is growing acknowledgement that treatment protocols developed for children or adults must not be assumed to be optimal for TYA-aged patients (Sender and Zabokrtsky, 2015). The multidisciplinary team (MDT) joint paediatric-adult care review of each TYA cancer case ensures the most appropriate treatment and dosage is given.
1.3.2 Distinct developmental and psychosocial needs

Adolescence and young adulthood are key stages of emotional, cognitive and social development. As outlined by Erikson’s Psychosocial Stage Theory, during adolescence and young adulthood, a young person is in the process of developing a secure personal identity and establishing personal values (Erikson, 1959). Peer relationships and social interactions gain increasing importance during this stage as an individual matures into an independent and autonomous young adult (Waterman, 1982). During this period hormonal changes associated with puberty manifest in the form of secondary sexual characteristics and body image becomes of increasing importance (Erikson, 1959). Brain maturation (neural proliferation and prefrontal cortex development) during adolescence and young adulthood contributes to the development of executive functioning, i.e. the ability to plan, respond to environmental cues, inhibit adverse reactions, and focus attention. The development of executive cognitive ability during TYA years leads to better judgement and decision making (Anderson et al., 2001). However, risk-taking behaviour is also common among TYAs, as independence is formed through the testing of boundaries imposed by parents and authority figures (Johnson et al., 2009).

A cancer diagnosis during this developmental time-point impacts on a variety of aspects of a young person’s life including body image, trust in health, self-esteem, education, and social relationships. For example, one prospective cohort study evaluating the behavioural and social outcomes of adolescent aged individuals within the Childhood Cancer Survivor Study found survivors (n=2,979, mean age: 14.8 years) were 1.5 times (99% Confidence Interval (CI) 1.1 -2.1) more likely than siblings (n=649, mean age 14.9 years) to display symptoms of depression or anxiety and 1.7 times (99% CI, 1.3-2.2) more likely to report trouble mixing with other young people (Schultz et al., 2007). Such problems could derail development and have lasting consequences into adulthood. Data from the 2009 Behavioural Risk Factor Surveillance System (BRFSS) survey indicate childhood cancer survivors (n=651; mean age: 33.49, Standard Deviation (SD): 8.36 years) had significantly lower life satisfaction (p<0.001) when compared to non-cancer peer controls (n=142,932; mean age: 38.27, SD: 8.64 years) (Phillips-Salimi et al., 2012).

During treatment, young people with cancer have increased dependence on parents and experience isolation from their peers (Haase and Phillips, 2004). As a method of coping with their diagnosis, young people may regress back to behaviours more common to young children (e.g. clingingness/ need to be comforted or soothed) and equally parents can become overprotective (Zebrack, 2011). One qualitative study exploring the experiences of parents (n=22) of TYA cancer patients (age 11-19 years at diagnosis) reported that parents found it challenging to allow their teenage or young adult child to exert autonomy and freedom without seeming ‘concerned’ or ‘hyper-vigilant’ (Lewis et al., 2015). However, although young people with cancer often describe wanting to be treated and addressed as adults, some TYAs with cancer may lack the cognitive or emotional skills to comprehend difficult information and make
treatment-related decisions (Epelman, 2013). Combined with previously described behaviour regression, the dichotomy between a desire for independence and the need to be cared for often intensifies young people’s distress towards their diagnosis and treatment (Gibson et al., 2010).

Treatment related side-effects such as weight gain or loss, alopecia, fatigue, acne and surgery scars commonly challenge a young person’s personal identity and self-image (Fan and Eiser, 2009). During a time where peer acceptance is viewed as paramount, such physical changes in appearance and challenges to self-image result in feelings of frustration, anger, anxiety, and isolation (Kent et al., 2012). Moreover, young people with cancer have reported being frustrated by the impact their diagnosis has had upon their ability to achieve developmental milestones such as finishing school, going to university, getting a good job, having lasting healthy relationships, and having children (Lewis et al., 2013, Hauken et al., 2013).

Addressing such psychosocial challenges and promoting resilience among young people with cancer has been at the heart of TYA cancer care since its inception in the early 1990s (Kelly et al., 2003). Understanding the coping strategies employed by TYA cancer survivors, and how these may contribute to psychosocial growth and resilience, has provided insight into how young people with cancer can best address the challenges faced during and after their diagnosis. Common coping strategies include positive thinking, self-talk, making jokes, asking questions, and seeking social, emotional and informational support (Decker, 2006). Problem-focused coping (e.g. information seeking to take control of the stressor) in comparison to emotional-focused coping (e.g. wishful thinking, and social withdrawal) was found to be associated with a greater sense of control and lower levels of distress among 76 child and TYA cancer survivors (mean age 14 years) in a mixed methods study (Sorgen and Manne, 2002). In contrast, unmet information and counselling support needs were found to be significantly associated with poorer health related quality of life, social and physical functioning over time among the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study (n=484, age range 15-39 years) (Smith et al., 2013). Within one study of TYA cancer survivors (n=53, age range: 16-30 years), after controlling for treatment status, an unmet information need was found to be a predictor of depression (Odds Ratio (OR) 0.487, P<0.001) (Dyson et al., 2012). Such findings underscore the importance of addressing the age-specific emotional and supportive care needs of young people with cancer. Interventions which facilitate empowerment and the development of resilience have the potential to improve the long-term psychosocial outcomes among TYA cancer survivors (Rosenberg et al., 2014).

However, much of the evidence on the psychosocial outcomes of TYA cancer survivors is either qualitative or cross-sectional (Barnett et al., 2016) and there is a lack of longitudinal data tracking psychosocial health outcomes among TYA cancer survivors over time (Millar et al., 2010). Thus, very little is understood of how the psychosocial profiles of TYA cancer survivors change over time as young people age and transition through the cancer pathway from treatment to survivorship. Nevertheless, it is widely accepted that the psychosocial needs of
TYA cancer survivors are not static and efforts to support young peoples’ psychological and social well-being must be adjusted over time to be age-appropriate and relevant to the individual (Barnett et al., 2016).

1.4 Current care structure for TYA cancer patients in the UK

Within the UK, national guidance (Children and Young People with Cancer, Improving Outcomes Guidance, CYPIOG) outlines the framework and mandates the quality of care that should be provided for every young person diagnosed with cancer (NICE, 2005). More recently, NHS England has defined TYA cancer service configuration standards which must be provided in order for these services to be commissioned (NHS England, TYA Cancer Service Specification, 2012). To date, compliance with these standards has been monitored by a national cancer peer review process (TYA Cancer Peer Review Measures). Table 1.3 outlines core principles of cancer care for children, teenagers and young people as outlined by CYPIOG and TYA cancer service specification. The UK model of TYA cancer care is based upon collaboration between paediatric and adult cancer specialists within specific TYA cancer units. There are 13 TYA principal treatment centres (PTCs) and over 25 TYA designated hospitals covering various geographical regions within the UK. Young people aged <19 years of age must be treated at a PTC and young people aged 19-24 years are given the option of place of treatment at either a PCT or designated TYA hospital closer to home. Irrespective of place of treatment, each young person must be discussed at the network TYA multidisciplinary team (MDT) meeting. The treatment and care a young person with cancer will receive is based on an assessment of their individual medical and holistic needs. Health professionals and service providers take into account factors such as a young person’s level of independence, maturity and clinical presentation (type of cancer, stage, new presentation or recurrence, potential treatment sequelae) when deciding treatment protocols and supportive care arrangements. Such an individualised approach to care is unique and balances the ‘care’ needs and ‘disease’ needs that a young person may have. This care structure and health services environment buffers the common and understandable fear and anxiety triggered by a cancer diagnosis. Ongoing review and update of national policy, specialist units and teams, service standards, professional education and research infrastructure ensure continual TYA cancer service progress occurs (Pearce, 2009, Teenage Cancer Trust, 2012).

In comparison to other European countries the coordinated care of TYA cancer patients within the UK is considered pioneering (Stark et al., 2015a, Vindrola Padrós et al., 2016). Within the UK the National Cancer Research Institute (NCRI) has a designated TYA clinical studies group (TYA CSG) which develops and delivers specific research relating to the challenges faced by young people. The UK also has a structured professional membership organisation (www.tyac.org.uk) which acts as a forum for TYA specific multi-professional education, support and service development. However, although the specialized care of TYA cancer patients has been mandated for almost a decade, there is no quantitative evidence that such age-specific services contribute to better cancer outcomes. This is concerning as such a lack of evidence
makes it challenging in the current economic climate for service providers to secure the financial investment to sustain and develop specialist TYA cancer services. The BRIGHTLIGHT study (a cohort of young people in England being followed up over 3 years) aims to identify the ‘added value’ which TYA cancer services bring (Taylor et al., 2015). This study aims to provide insight into the most valuable aspects of specialist TYA cancer care, whether specialist TYA cancer care affects cancer outcomes, and whether specialized TYA cancer care is economically beneficial. BRIGHTLIGHT closed to recruitment in 2016 and the forthcoming results are intended to inform organisational and clinical changes to improve the care and services for TYAs with cancer.
<table>
<thead>
<tr>
<th>Guideline Principle</th>
<th>Anticipated benefits to TYA cancer patients</th>
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<tr>
<td>Place of treatment</td>
<td>Treatment within a dedicated TYA cancer unit ensures improved quality of supportive care and psychosocial support for patients and their families. The delivery of some aspects of care closer to the family home also reduces the impact of cancer upon the wider family, reduces the burden of travel, reduce the associated costs of cancer, and increases patients and families satisfaction with care. Young people aged 19-24 years of age are given the option to make an informed decision about whether to receive care in a specialist centre (PTC) or closer to home.</td>
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<tr>
<td>Established cancer networks</td>
<td>Networks ensure the provision of well-coordinated care that meets the needs of TYA cancer patients at both local and national levels.</td>
</tr>
<tr>
<td>Multidisciplinary Teams</td>
<td>Multidisciplinary Teams (MDTs) ensure that the needs of a patient are considered from a range of different viewpoints and expertise. MDTs also promote open channels of communication and shared learning between professionals which in turn improves the probability of timely, appropriate and better continuity of care for the patient.</td>
</tr>
<tr>
<td>Continuity of care and assignment of a key worker</td>
<td>A key worker acts as the main point of contact for a young person and their family during treatment and beyond. The key worker provides clear and succinct information to the patient and their family, often in the form of a written care plan which minimises uncertainty and errors in treatment planning, improves patient trust, and improves patient satisfaction with care.</td>
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<tr>
<td>Evidence based treatment</td>
<td>Standardised treatment as set out in specified protocols should result in improved survival rates, lower morbidity and reduction in the intensity of therapy for some patients.</td>
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<tr>
<td>Access to research trials</td>
<td>Clinical trial research could improve outcomes among TYA cancer patients. Specifically, clinical trial access has the potential to reduce treatment related morbidities among good-risk disease patients and improve survival among young people with poor-risk disease.</td>
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<tr>
<td>Open communication between health professionals, young people and their families</td>
<td>Good communication between patients, their families, and professionals alongside patient access to age-appropriate relevant information ensures the best possible support is given to patients and their families. Open communication between health professional, young people and their families also promotes compliance.</td>
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</table>
1.5 The long-term health and wellbeing of TYA cancer survivors

As a result of the increasing number of TYAs surviving cancer, there is an increasing focus on the longer-term health and wellbeing of young people living with and beyond cancer. Large cohort studies such as the Childhood Cancer Survivor Study (CCSS) in the United States (US) (n=28,221) (Robison et al., 2002) and the British Childhood Cancer Survivor Study (BCCSS) (n=34,489) (Hawkins et al., 2008) provide much of the data regarding the long term health consequences of a cancer diagnosis during early life years. The CCSS is a cohort of cancer survivors who were diagnosed between 1970-1986 and were aged <21 years at diagnosis. The BCCSS is a cohort of individuals diagnosed before the age of 15 years in the UK between 1940-1991. Data within both cohorts was collected via postal questionnaires sent to eligible participants via their primary care physician or treating institution, and these data were then linked to national cancer registry data.

Despite the existence of these large childhood cancer survivor cohorts (which only include some adolescent cancer survivors) there is currently very little published or available prospective data on the long-term health and wellbeing of TYA cancer survivors (Woodward et al., 2011, Barr et al., 2016). This is a limitation to the TYA cancer field as outcomes from studies of long-term survivors of adult or childhood cancer such as the CCSS and BCCSS may not be directly extrapolated to TYAs due to the distinctive nature of cancer aetiology, cancer incidence, cancer biology and cancer treatment among TYAs. To address this, a TYA-specific cohort within the UK has been established. Titled ‘The Teenage and Young Adult Cancer Survivor Study’ (TYACSS), this cohort is the first in the world to investigate the specific aetiology of cancer outcomes among individuals diagnosed and treated for cancer during their TYA years. The TYACSS cohort comprises 200,945 individuals diagnosed with cancer between the age of 15 and 39, in England and Wales, between 1971 and 2006. Data on the participants within the cohort was gathered from the national death and cancer registries, the Hospital Episode Statistics for England, the Patient Episode Database for Wales and the Myocardial Ischaemia National Audit Project. To date, only two studies using TYACSS data have been published (Henson et al., 2016, Bright et al., 2017). The study published in late 2016 found the cardiac mortality risk among TYA cancer survivors was greater among survivors diagnosed between the age of 15 and 19 years of age than those who were diagnosed aged 35 to 39 years (Standardized Mortality Ratio, SMR: 4.2, 95% CI 3.4-5.2 for those aged 15-19 years; SMR 1.2, 95% CI 1.1-1.3 for those aged 35-39 years, p<0.001) whilst the study published in 2017 demonstrated cerebrovascular events were 40% higher than expected (Standardized Hazard Ratio, SHR=1.4, 95% confidence interval, 1.3-1.4). These results build upon evidence from the BCSS and CCSS that age at diagnosis and cancer type are key risk factors for subsequent cardiac and cerebrovascular mortality later in life among TYA cancer survivors.
1.5.1 The long-term physical consequences of TYA cancer

Although there is a large amount of heterogeneity between studies (e.g. differences in sample composition and treatment modality) conducted within the UK and the US (Hawkins et al., 2008, Robison et al., 2002) and conclusions from childhood cancer survivor studies should not be automatically extrapolated to TYA cancer survivors, several key points regarding the long-term survivorship of childhood and TYA cancer patients have emerged.

Firstly, childhood and TYA cancer survivors face a greater risk of mortality from either cancer recurrence or a second primary cancer. Within the CCSS, 57.5% of deaths at follow up (year 2002) were attributable to recurrent disease (Mertens et al., 2008) and data from the BCCSS indicate excess mortality at follow up (year 2006) to be 11 times greater than expected (SMR 10.7 95% CI 10.3-11.1) (Reulen et al., 2010). British Columbia cancer registry data has been used to examine the specific incidence of all-cause mortality and second malignant neoplasms (SMNs) among survivors of young adult cancer (n=1248) (Zhang et al., 2012). Results indicate long-term survivors of a young adult cancer diagnosis (diagnosed between the age of 20 and 24 years) have a mortality rate 6 times greater than the corresponding rate for the general population in British Columbia (SMR = 5.9; 95% CI, 4.9–6.9). Within this same study the mortality rate among Central Nervous System (CNS) tumour survivors was 23 times greater than the mortality rate among general population controls (SMR = 23.6; 95% CI, 15.1–35.1). Overall 53% of deaths within the cohort were attributed to the recurrence or progression of the original cancer diagnosis.

Secondly, there is substantial evidence that both childhood and TYA cancer survivors face a heightened risk of multiple chronic conditions due the short-term and long-term toxic effects of common cancer therapies. Table 1.4 outlines by system and exposure, common potential treatment late effects and chronic conditions experienced by young people with cancer. Evidence from the CCSS indicates that young people who have had a cancer diagnosis are 3.3 times more likely (95% CI 3.0-3.5) to have a chronic condition and 8.2 times more likely (95% CI, 6.9 -9.7) to have a condition defined as life threatening than their siblings (Oeffinger et al., 2006). Moreover, cumulative prevalence estimates indicate that nearly 95% of childhood and TYA cancer survivors will have a chronic health problem of some kind, and 80% will have a health problem classed as disabling or life threatening by the age of 45 (Hudson et al., 2013).

Although widespread organ dysfunction and frailty is common among TYA cancer survivors, it is important to note that the manifestation of chronic health problems within this group is dictated by individual treatment exposure and there are certain high risk groups for late effects onset. Specifically, secondary malignancies typically arise within body sites which were previous target sites for radiotherapy (Relling et al., 1999). Whilst data drawn from the BCCSS, CCSS, and TYACSS provide an invaluable insight into the long-term health outcomes of a cancer diagnosis during adolescence or young adulthood, these datasets lack detailed information on radiotherapy and chemotherapy exposure. Moreover, data on other
conventional risk factors for health outcomes, specifically health behaviours such as physical activity, diet, smoking, alcohol consumption and sun safety are also not available within these cohorts. As is the case among adult cancer survivors, it is likely that TYA cancer survivors’ elevated health risk is potentiated by a myriad of factors including genotype, the presence of other comorbidities and lifestyle behaviours (Robison and Hudson, 2014).
<table>
<thead>
<tr>
<th>System</th>
<th>Exposures</th>
<th>Potential Late Effects</th>
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<tbody>
<tr>
<td>Cardiovascular</td>
<td>Radiation Therapy</td>
<td>Myocardial infarction or stroke</td>
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<td></td>
<td>Anthracyclines</td>
<td>Congestive Heart Failure</td>
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<td>Platinums</td>
<td>Valvular disease</td>
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<td>Hypertension</td>
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<td>Pulmonary</td>
<td>Radiation Therapy</td>
<td>Restrictive lung disease</td>
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<td>Bleomycin</td>
<td>Pulmonary Fibrosis</td>
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<td>Carmustine/lomustine</td>
<td>Exercise Intolerance</td>
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<td>Renal/ Urological</td>
<td>Radiation Therapy</td>
<td>Renal Insufficiency or failure</td>
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<td></td>
<td>Platinums</td>
<td>Neurogenic bladder</td>
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<td>Isofamide/ cyclophosphamide</td>
<td>Dysfunctional voiding</td>
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<td>Haemorrhagic cystitis</td>
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<td>Glomerular Toxicity</td>
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<td>Tubular Dysfunction</td>
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<td>Radiation Therapy</td>
<td>Obesity</td>
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<td>Alkylating agents</td>
<td>Infertility and gonadal dysfunction</td>
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<td>Dyslipidaemia</td>
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<td>Insulin resistance and diabetes</td>
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<td>Musculoskeletal</td>
<td>Antimetabolite therapy</td>
<td>Osteopenia/ osteoporosis</td>
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<td>Radiation Therapy</td>
<td>Learning disabilities</td>
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<td>Cognitive Dysfunction</td>
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<td>Dysarthria</td>
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<td>Alkylating agents</td>
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<td>Whole body</td>
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<td>Second Malignancies</td>
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<td>Epipodophyllotoxins</td>
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1.5.2 The long-term psychosocial consequences of TYA cancer

Health-related quality of life (HRQL) is a broad and multidimensional construct which outlines the physical, psychological and social impact of disease-specific and treatment-related symptoms on an individuals’ self-perception of functioning. Constructs commonly measured as a proxy of HRQL include somatic symptoms, physical capability, psychological problems, social well-being, cognitive function and overall life satisfaction (Naughton and Shumaker, 2003). In comparison to those in the general population who have not had a cancer diagnosis, cancer survivors are much more likely to experience ‘poorer’ or impaired quality of life. These findings are consistent among both adult and TYA cancer survivors (Quinn et al., 2015, Wikman et al., 2011).

In analysis of the US-based Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) cohort (n=523; age at survey 15-41 years), TYA cancer survivors reported significantly worse HRQL across both physical and mental health scales than age-matched general population controls (Smith et al., 2013a). In addition, US National Health Interview Survey data indicate that adult-aged survivors of a cancer diagnosed during childhood, adolescence or young adulthood were significantly more likely to meet the criteria for serious psychological distress (OR= 4.23; 95% CI 2.08- 8.62) than a cancer-free control group (Phillips-Salimi and Andrykowski, 2013). Sleep disturbances are also common among TYA cancer survivors (Mulrooney et al., 2008) and in a study of 167 TYA survivors (mean age=20.08 years) who were followed-up approximately 12 years after diagnosis, sleep and fatigue problems were found to be strong predictors of depression (Daniel et al., 2015b).

Unmet service needs contribute to poorer HRQL among TYAs diagnosed with cancer. In particular, unmet pain management needs have been associated with worse overall social and physical functioning, and unmet physical or occupational therapy support needs have been found to be associated with poorer functioning across all HRQL domains (Smith et al., 2013b). Conversely, access to appropriate support and cognitive coping strategies have been found to be positively associated with TYA cancer survivor HRQL status. One study of Israeli-Jewish and Israeli-Arabic TYA cancer survivors (n=51, mean age: 21.45 years) found lower perceived vulnerability, greater optimism, and less fatalistic perspective was significantly related to greater overall HRQL (Stern et al., 2010).

Although the chronic physical health problems caused by cancer and its associated treatment are highly debilitating, cancer-related fatigue has been described as the ‘most prevalent and distressing’ of all symptoms experienced by TYA cancer survivors (Spathis et al., 2015). Such fatigue is defined as a ‘persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning’ (Mock et al., 2000) and is experienced by approximately 31–100% of young people living with and beyond cancer (Enskar and von Essen, 2007). Cancer-related fatigue often impacts significantly on a young person’s cognitive and physical function, limiting their ability to concentrate at school or work and take part in usual social activities both during and after treatment (Spathis et al., 2015). Within one study...
of 268 TYA-aged cancer survivors (mean age: 21.4 years; median age at diagnosis: 6.4 years), fatigued survivors had significantly poorer physical function, emotional function, school/work function, and psychosocial health (p<0.001) (Frederick et al., 2016). These findings are consistent with studies conducted among adults (Wagner and Cella, 2004) and highlight that the fatigue suffered by cancer survivors’ has an impact upon several quality of life domains. Among adult cancer survivors there is growing recognition that physical activity can alleviate fatigue both during and after active treatment (Mishra et al., 2012b, Mishra et al., 2012a). Within a meta-synthesis exploring the lived experience of cancer specific fatigue among children and adolescents, physical activity was consistently described as an effective coping strategy to relieve fatigue (Tomlinson et al., 2016). However the evidence base for the management of fatigue among TYA cancer survivors is scant; a systematic review of interventions to manage fatigue among TYA cancer survivors identified only 5 interventional trials which included fatigue as an outcome measure of interest (Spathis et al., 2015). Of these intervention studies, four investigated structured physical activity as part of the intervention and one investigated a self-coping intervention. Of these interventions only two (Keats and Culos-Reed, 2008, Atkinson, 2012) of the uncontrolled physical activity trials were found to have a significant effect on fatigue. Further research is required to establish causal factors of fatigue rather than factors simply associated with fatigue. Such data is imperative to informing the development of targeted interventions designed to manage the impact of fatigue on young people with cancer.

Data on the HRQL of TYA cancer survivors must also be interpreted with some degree of caution. Existing measures of HRQL may not adequately capture all the psychosocial domains relevant to TYA cancer survivors. One head-to-head comparison of the psychometric properties of cancer specific HRQL instruments, Quality of Life-Cancer Survivor (QOL-CS) and Quality of Life In Adult Cancer Survivor (QLACS), commonly used in TYA cancer survivor populations found the instruments to have poor construct validity and poor discriminant validity (Huang et al., 2012). There is a need to develop validated and reliable measures that quantify the impact of cancer upon TYA cancer survivors’ perceived sense of self, emotional development and autonomy development (Quinn et al., 2013). Moreover, much of the data on the long-term psychosocial well-being of TYA cancer survivors has been gathered from single centre surveys of homogenous TYA cancer survivors. Therefore caution should be applied when extrapolating the results of these studies to the general TYA cancer survivor population. No data on the HRQL status of TYA aged cancer survivors within the UK has been published to date (Quinn et al., 2015). It remains unclear whether modifiable factors such as treatment environment, supportive care services and health behaviour influence the HRQL of young people diagnosed with cancer in Britain.

1.6 Summary

A cancer diagnosis during adolescence or young adulthood is incredibly rare and young people diagnosed between the age of 13 and 24 years require specialist support to meet their
medical and psychosocial needs. Thanks to advancements being made in TYA cancer
treatment there is a growing number of young people living with and beyond their cancer
diagnosis. However, many TYA cancer survivors suffer from multiple physical and
psychosocial health problems during and after their cancer treatment. It is evident TYA cancer
survivors require specially tailored support from the point of diagnosis onwards.
Chapter 2

Health Behaviour Change Among TYA Cancer Survivors

As highlighted in Chapter 1 TYA cancer survivors are a unique population who require specialist care and support from the point of diagnosis onwards. This chapter presents the rationale behind investigating the health behaviours of TYA cancer survivors and includes trial and observational evidence linking health behaviours (physical activity, diet, smoking, alcohol consumption, and sun safety) to health outcomes among adult and TYA cancer survivors. Section 2.4 contains a systematic review of existing health behaviour change interventions conducted among TYA cancer survivors.

2.1 The importance of promoting a healthy lifestyle among TYA cancer survivors

Adolescence and young adulthood are key stages of development where many health-related habits and behaviours are established (Viner and Macfarlane, 2005, Nelson et al., 2008). While health behaviours (Tombor and Michie, 2017) during childhood are strongly influenced by parents, during early adolescence young people gain increasing autonomy and begin to make their own dietary and physical activity choices and often experiment with risky behaviours like alcohol consumption, smoking or drug use (Steinberg and Morris, 2001, Birch and Fisher, 1998, Kohl and Hobbs, 1998). Behaviours established during the period of growth from adolescence to young adulthood ‘track’ throughout the life-course and can cause the onset of later health problems in adulthood. For example, physical inactivity, poor dietary intake and high body fatness during childhood and adolescence has also been shown to continue into adulthood (Herman et al., 2009, Deshmukh-Taskar et al., 2006, Craigie et al., 2011). This is concerning as being overweight or obese at a young age has been found to be an independent predictor of later adulthood cardio-metabolic health status (Freedman et al., 2001, Park et al., 2013). Moreover, a systematic review of longitudinal cohorts (n=54 studies) reported that high levels of alcohol consumption in adolescence continue into adulthood and such drinking patterns associate with alcohol-related health problems including alcohol dependence in later life (McCannbridge et al., 2011b). Efforts to promote healthy lifestyle choices (i.e. sufficient physical activity, a healthy diet, abstinence from smoking and low levels of drinking) among adolescents and young adults have the potential to yield short-term

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2 A version of section 2.1 and section 2.2 of this chapter have been published in ‘A practical approach to the care of adolescents and young adults with cancer’ Edited by Chisholm, J. Soanes. L, Hough, R.

3 A version of section 2.4 has been published in the Journal of Adolescent and Young Adult Oncology (Appendix 2.1) Pugh, G., et al. (2016). “Health Behavior Change Interventions for Teenage and Young Adult Cancer Survivors: A Systematic Review.” J Adolesc Young Adult Oncol 5(2): 91-105.

4 Health behaviours are broadly defined as behaviours which influence the physical and psychosocial health and well-being of an individual (Tombor and Michie, 2017). For the purpose of this thesis the term health behaviour refers collectively to physical activity, dietary intake, tobacco use, alcohol consumption and UV exposure.
improvements in health and well-being and prevent the manifestation of non-communicable diseases later in life (Sothern et al., 1999, Viner and Macfarlane, 2005).

As outlined within Chapter 1, TYA cancer survivors are at increased risk of current and future health problems when compared to their peers. Given that individual levels of cumulative environmental exposure to carcinogens is directly proportional to age, and in most incidents it takes two or more decades for environmentally-related cancers to manifest, it is unsurprising that cancers strongly linked to lifestyle related carcinogens (i.e. smoking, alcohol consumption and sunlight exposure) are more commonly observed in adults than in TYAs (Tricoli et al., 2016). Efforts to reduce exposure to such carcinogens (especially sunlight exposure) among children and TYAs are therefore unlikely to reduce the incidence of cancer among young people, but will reduce the risk of cancer occurring when young people age and are adults (Bleyer and Barr, 2007). Existing evidence from studies of adult-aged cancer survivors during and after treatment suggest that the adoption of healthy lifestyle habits may prevent or ameliorate some of the health risks faced by individuals who have had a cancer diagnosis (Demark-Wahnefried et al., 2006). As a result there is growing attention towards the needs and lifestyle challenges of young people with cancer (Daniels et al., 2015). Healthy lifestyle choices such as being sufficiently active and eating a healthy diet could substantially improve the long-term survivorship and quality of life of TYA cancer survivors, whereas health risk behaviours (e.g. smoking, drinking and tanning) may exacerbate TYA cancer survivors’ underlying risk of chronic disease and of secondary malignancy (Clarke and Eiser, 2007).

2.2 Health behaviour guidelines for TYA cancer survivors

Table 2.1 outlines the lifestyle guidance as set out by the Children’s Oncology Group (COG) for TYA cancer survivors. The focus of this guidance is to improve quality of life and decrease the likelihood of health problems among childhood, adolescent and young adult cancer survivors. The guidance document stipulates that childhood and TYA cancer survivors should have access to enhanced follow-up care which promotes a healthy lifestyle, encourages ongoing monitoring of health status, and facilitates late effects identification and intervention (The Childrens Oncology Group, 2008). In lieu of insufficient age-specific evidence, the lifestyle guidance set out by the COG for TYA cancer survivors is based upon, and does not differ substantially from, guidance outlined by the American Cancer Society (Rock et al., 2012) and the World Cancer Research Fund (WCRF, 2007) for adult cancer survivors. All three sets of guidance note that the nutritional needs and physical activity capabilities of TYA cancer survivors may change over time and are likely to be dictated by individual factors such as diagnosis type, treatment status, and age. As such, all sets of guidance advocate that the individual needs of any cancer survivor are considered before attempts to change behaviour are encouraged or undertaken.
Table 2.1  Lifestyle guidance for teenage and young adult cancer survivors

<table>
<thead>
<tr>
<th>Health Behaviour</th>
<th>Guidance (Childrens’ Oncology Group, 2008)</th>
</tr>
</thead>
</table>
| Physical Activity | Check with healthcare team before starting an exercise plan or taking part in a new sport or recreational activities.  
For adults – engage in moderate physical activity >30minutes/day for >5days per week.  
For children and adolescents – Engage in >60 minutes of moderate to vigorous physical activity for >5days per week. |
| Diet | Choose a variety of foods from all the food groups (grains, vegetables, fruits, oil, milk, meat & beans).  
Use the steps to a healthier you guide to develop a well-balanced diet and activity plan. (www.mypyramid.gov) |
| Fruit/ Veg | Eat > 5 servings of fruit and veg per day, including citrus fruits and dark green and deep yellow vegetables.  
When drinking juice choose 100% fruit or vegetable juice and limit to 4oz per day. |
| Milk/Dairy | Choose low-fat milk and dairy products |
| Meat | Limit intake of red meat and substitute with fish, poultry and beans  
When eating meat, select leaner, or smaller portions |
| Fibre | Eat plenty of high-fibre foods, such as whole grain breads, rice, pasta and cereals |
| Fat | Decrease the amount fat in meals by baking, broiling or boiling foods.  
Limit fried or high fat foods |
| Sugar | Limit refined carbohydrates, including pastries, sweetened cereal, soft drinks and sugar |
| Salt Intake | Avoid salt cured, smoked, charbroiled and pickled foods |
| Alcohol | Limit alcoholic drinks to <2 drinks per day for men and <1 drink per day for women. |
| Smoking | Do not smoke |
| Sun Safety | Limit the amount of time in the sun especially between 10am and 2pm.  
Regularly using sunscreen with a sun protection factor of 15 or more  
Cover up in the sun and do not actively try and tan. |
2.3 Health behaviour and cancer survivorship

2.3.1 Physical Activity

Physical activity, defined as ‘any bodily movement produced by skeletal muscles which results in energy expenditure’ (Caspersen et al., 1985), is a well-established key component of primary and secondary prevention of non-communicable diseases such as coronary artery disease, hypertension, type 2 diabetes, stroke and osteoporosis (Booth and Hargreaves, 2011, Lee et al., 2012). Physical activity guidelines have been published in the UK to provide scientifically informed guidance on the dose of physical activity different age groups of the population should perform (Woods and Mutrie, 2012). The public health recommendation that young people (<18 years of age) should accumulate ≥300 mins of moderate intensity activity or ≥150 vigorous intensity activity and adults (>18 years of age) should accumulate ≥150 minutes of moderate intensity activity, or ≥75 minutes of vigorous intensity physical activity, over the course of a week stems from several systematic reviews which have identified this as the quantity of physical activity required to ameliorate health, increase fitness and prevent the onset of chronic disease (O'Donovan et al, 2010; Warburton et al, 2010).

There is a growing body of convincing evidence that physical activity plays an important role in the primary prevention of cancer among adults. Several systematic reviews of prospective and observational studies have concluded that meeting the physical activity recommendations reduces an individuals’ risk of developing colon, breast and endometrial cancer by 20-60% (Kohler et al., 2016, Kushi et al., 2012). Moreover, among adults there is evidence supporting a beneficial role for physical activity on cancer outcomes (Schmid and Leitzmann, 2014). For example, one large meta-analysis of 22 prospective cohort studies of breast cancer survivors (n=123,574; Mean age: ~50 years) found greater physical activity participation reduced both all cause and breast cancer specific mortality, (Hazard Ratio, HR=0.52, 95% CI: 0.43-0.64; HR=0.59, 95% CI: 0.45-0.78, respectively) (Lahart et al., 2015). Similarly, within the Melbourne Collaborative Cohort Study (n=41,528) colorectal cancer survivors (n=526) who were inactive had poorer overall and disease specific survival than those who were exercisers (overall survival HR: 0.77, 95% CI: 0.58-1.03; disease specific survival: HR: 0.73, 95% CI: 0.54-1.00) (Haydon et al., 2006). Similar findings have been reported within cohort studies of prostate cancer survivors (Kenfield et al., 2011). However, evidence of the effect of physical activity on mortality, survival and cancer recurrence is currently limited to observational studies only and therefore, alongside other limitations such as the use of self-report measures of health behaviour, the direction of causality cannot be determined. The Colon Health and Life-long Exercise Change (CHALLENGE) Trial, an ongoing RCT which aims to assess the effect of a 3 year physical activity intervention on colorectal cancer survival will provide the first evidence to address this gap (Courneya et al., 2008).

On the other hand, there is consistent evidence from both observational studies and randomized controlled trials (RCTs) that physical activity improves physical and psychological health and well-being of individuals both during and after cancer treatment. The results of two
meta-analyses of randomised controlled trials assessing the impact of physical activity on parameters of physical health and well-being among adult cancer survivors are summarised in Table 2.2 and Table 2.3 respectively. These meta-analyses build upon earlier narrative reviews (Friedenreich, 2001, Courneya, 2003) describing the positive effects of physical activity by providing an insight into the magnitude of the effect. Moreover, by limiting the inclusion criteria to RCTs these meta-analyses provide a more accurate estimate of effect size. As per Cohen’s classification criteria for effect size (where an effect size <0.2 is small, an effect size of 0.5 is moderate and an effect size >0.8 is large) physical activity during treatment has a small to moderate effect on dimensions of physical and psychological health (Speck et al., 2010). Post-treatment, physical activity has a large effect on lower body strength and upper body strength; a moderate effect on aerobic fitness, HRQL and fatigue; and a small effect on body strength, weight, and anxiety (Speck et al., 2010, Fong et al., 2012, Mishra et al., 2012a, Mishra et al., 2012b). In adult cancer survivors the mechanisms through which physical activity improves cancer outcomes have been identified as favourable changes in natural killer cell function, circulating levels of insulin, insulin like growth factor (IGF), C-reactive protein, interleukin 6, and tumour necrosis factor alpha (McTiernan, 2008). From the standpoint of psychosocial health a recent meta-synthesis of qualitative research (n=40 studies: total number of participants, n=604) exploring cancer survivors’ perspectives of the impact of physical activity on their quality of life found physical activity positively impacted upon survivors physical, psychological, social, and spiritual well-being (Burke et al., 2017). Collectively such data on both the physical and psychological benefits of physical activity during and after cancer treatment support the utility of physical activity interventions in improving health outcomes among cancer survivors.
Table 2.2 Effect sizes for meta-analysis of randomised controlled trials of physical activity in cancer survivors: physical health and function

<table>
<thead>
<tr>
<th>Author</th>
<th>Speck et al., 2010</th>
<th>Fong et al., 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of studies within review</td>
<td>n=66</td>
<td>n=39</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Weighted Mean Effect Size (95% CI)</th>
<th>Pooled Estimate (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>During Treatment Post Treatment</td>
<td>Post Treatment</td>
</tr>
<tr>
<td><strong>Physiological Markers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insulin-like growth factor (ng/mL)</td>
<td>-</td>
<td>-0.31 (-0.59 to 0.03)</td>
</tr>
<tr>
<td>Insulin (pmol/L)</td>
<td>-</td>
<td>-0.05 (-0.31 to 0.20)</td>
</tr>
<tr>
<td>Glucose (mmol/L)</td>
<td>-</td>
<td>-0.03 (-0.37 to 0.30)</td>
</tr>
<tr>
<td>Homeostatic model assessment</td>
<td>-</td>
<td>0.03 (-0.25 to 0.30)</td>
</tr>
<tr>
<td><strong>Physical Function</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiovascular Fitness</td>
<td>0.33 (0.08 to 0.57)</td>
<td>0.32 (0.036-0.59)</td>
</tr>
<tr>
<td>Six Minute Walk Test (m)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper Body Strength</td>
<td>0.39 (0.12 to 0.65)</td>
<td>0.99 (0.67 to 1.32)</td>
</tr>
<tr>
<td>Lower Body Strength</td>
<td>0.24 (0.07 to 0.41)</td>
<td>0.90 (0.12 to 1.68)</td>
</tr>
<tr>
<td>Left handgrip (kg)</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Right handgrip (kg)</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Sit and reach (cm)</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td><strong>Body Composition</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BMI</td>
<td>-0.07 (-0.30 to -0.16)</td>
<td>-0.14 (-0.22 to -0.05)</td>
</tr>
<tr>
<td>Body Weight</td>
<td>-0.25 (-0.49 to 0.00)*</td>
<td>-0.18 (-0.31 to 0.06)*</td>
</tr>
<tr>
<td>Waist:Hip Ratio</td>
<td>-</td>
<td>-0.01 (-0.04 to 0.02)</td>
</tr>
<tr>
<td>% Body Fat</td>
<td>-0.25 (-0.48 to -0.02)</td>
<td>-0.18 (-0.31 to 0.05)</td>
</tr>
<tr>
<td>Fat Mass</td>
<td>-0.19 (-0.40 to 0.02)</td>
<td>-0.25 (-0.57 to -0.07)</td>
</tr>
<tr>
<td>Lean Mass</td>
<td>0.12 (-0.24 to 0.47)</td>
<td>0.13 (-0.08 to 0.34)</td>
</tr>
</tbody>
</table>

*aSignificant to at least <0.05*  
**Peak oxygen consumption (mL/kg/min)**  
*bLeg Press (kg, 1 repetition maximum)**  
*cBench press (kg, 1 repetition maximum)**
<table>
<thead>
<tr>
<th>Author</th>
<th>Number of Studies within Review</th>
<th>Outcome</th>
<th>Mean Effect Size</th>
<th>Pooled Estimate (95% CI)</th>
<th>Standardized Mean Difference (95% CI)</th>
<th>Standardized Mean Difference (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td><strong>During Treatment</strong></td>
<td></td>
<td><strong>Post Treatment</strong></td>
<td><strong>During Treatment</strong></td>
<td><strong>Post Treatment</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Global Quality of Life</td>
<td>0.13 (-0.005 to -0.26)</td>
<td>0.29 (0.03 to 0.54)</td>
<td>0.33 (0.12 to 0.55)</td>
<td>0.48 (0.16 -0.81)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pain</td>
<td>-0.33 (-1.32 to 0.66)</td>
<td>-0.12 (-0.71 to 0.47)</td>
<td>-1.03 (-1.16 to 3.21)</td>
<td>-0.29 (-0.55 to -0.04)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vigour</td>
<td>0.22 (-0.18 to 0.61)</td>
<td>0.17 (-0.30 to 0.64)</td>
<td>-1.0 (95% CI)</td>
<td>-1.0 (95% CI)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fatigue</td>
<td>-0.01 (-0.35 to 0.33)</td>
<td>-0.54 (-0.90 to -0.19)</td>
<td>-1.0 (-1.8 to -1.0)</td>
<td>-0.38 (-0.57 to -0.18)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Depression</td>
<td>0.06 (-0.26 to 0.38)</td>
<td>-0.30 (-0.65 to 0.05)</td>
<td>-4.1 (-6.5 to -1.8)</td>
<td>-0.55 (-0.87 to -0.22)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Anxiety</td>
<td>-0.21 (-0.39 to 0.03)</td>
<td>-0.43 (-0.88 to 0.03)</td>
<td>-0.7 (-3.4 to 2.1)</td>
<td>-0.46 (-0.81 to -0.11)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social Function</td>
<td>0.11 (-0.15 to 0.36)</td>
<td>0.07 (-0.13 to 0.27)</td>
<td>3.4 (95% CI)</td>
<td>0.54 (0.03 to 1.05)</td>
</tr>
</tbody>
</table>

*SMDs from baseline to 12 weeks follow up. SMDs for other study time points e.g. 6 month or 12 month follow up are reported within the original article.
However although promising, there are limitations in the existing literature on the benefits of physical activity among cancer survivors. As previously mentioned understanding of survival benefits is currently from observational data and the vast majority of RCT physical activity intervention studies focus solely on breast, prostate and colorectal cancer survivors. Moreover, there is a notable lack of objective measurement of physical activity in these studies. Future research should attempt to overcome these existing limitations to the evidence base. More insight is required into the optimal mode, frequency and duration of physical activity for cancer survivors and the effect of physical activity on the survival outcomes of different cancer groups.

In comparison to the literature concerning adult cancer survivors, the available literature on the benefits of physical activity for children and TYAs with cancer is relatively limited. Nevertheless, it has been suggested that physical activity could have the same (if not more) benefits for young people affected by cancer (Barnes and Demark-Wahnefried, 2014, Gilliam and Schwebel, 2013). For example, data from 1,187 adult survivors of childhood Hodgkin lymphoma in the CCSS cohort (mean age: 31 years at the time of analysis; median years since diagnosis: 16.7 years) indicated those meeting national vigorous intensity exercise guidelines (≥3 bouts of vigorous intensity exercise/week of ≥20 minutes in duration) had 51% reduced risk of cardiovascular events in comparison to not meeting the guidelines (RR 0.49, 95% CI 0.31-0.76) (Jones et al., 2014). In a sub-sample (n=365; mean age: 28.5 years; range: 18.4-44.6 years) of the St Jude Lifetime Cohort, resistance training more than once per week was associated with a 2.8% increase in lean muscle mass (Boland et al., 2016). Similarly the Dutch Quality of Life in Motion Study found that among young people with cancer (n=60, aged 8-18 years) each additional minute of physical activity per day (measured by Actical® accelerometers) resulted in 0.05 ml/kg.min increase in cardiorespiratory fitness and each additional minute of sedentary time per day led to a decrease in cardiorespiratory fitness by 0.06 ml/kg.min (Braam et al., 2015). Moreover, linear associations (β=0.17, p<0.01) have been found between physical activity and HRQL among TYA aged childhood cancer survivors (n=215, mean age=18 years, mean age at diagnosis=8.8 years) (Paxton et al., 2010). Another study investigating the association between physical activity and sleep in 50 cancer survivors (aged 8-18 years) found a strong correlation between physical activity (measured by accelerometry) and sleep efficiency (r=0.31, p=0.03) (Orsey and Wakefield, 2016). Combined, these findings suggest that physical activity is a potential effective strategy to in reduce the negative physical and psychosomatic consequences of cancer treatment (Walter et al., 2015). However, such observational evidence does not provide an insight into the direction of the association between physical activity and health among TYA cancer survivors. In order to test for a causal association, RCTs of physical activity interventions are required.

However, to date very few trials have examined the impact of physical activity on health outcomes among young people with cancer. A narrative review of physical activity interventions specifically targeting young people with cancer reported only nine empirical
studies of exercise or physical activity interventions designed for TYA cancer survivors (Barnes et al., 2015). None of these studies reported any negative outcomes or adverse events, suggesting that physical activity is at least safe and feasible for cancer survivors of this age. Three of these studies (Keats and Culos-Reed, 2008, Gilliam and Schwebel, 2013, Jarvela et al., 2012) reported small, but significant, post-intervention improvements in participant strength and endurance; three studies (Hartman et al., 2009, Jarvela et al., 2012, Huang et al., 2014) reported physical activity to have a positive effect on body composition and weight status; one study (Keats and Culos-Reed, 2008) reported significant HRQL improvements; and the remaining two studies (Rabin et al., 2011, Li et al., 2013) reported significant improvements in mood and self-efficacy. Only one study (Cox et al., 2005, Hudson et al., 2002) reported no significant improvement in physical activity behaviour; however the null outcome of this intervention was most likely due to the fact this study was a multi-behaviour intervention targeting and did not measure physical activity using validated measures.

A more recent systematic review of 12 physical activity interventions conducted during the intense treatment phase among children and adolescents with cancer also concluded that physical activity interventions during this stage of the cancer continuum are feasible, acceptable and safe (Grimshaw et al., 2016). Of the included studies, the majority included a physical activity intervention which was tailored to the specific needs of the patient, supervised and delivered in an inpatient setting. Overall, across the intervention studies physical activity was found to have a favourable effect on aerobic capacity, body composition, emotional function, muscle strength, motor performance and psychosocial health. However, akin to the studies conducted among TYA cancer survivors post-treatment, the majority of studies included within the review by Grimshaw and colleagues had methodological limitations, such as insufficient power to detect significant effects of physical activity on health outcomes and difficulties in participant recruitment and retention.

Moreover, although the outcomes of physical activity trials suggest that activity is safe, often young people who have complex conditions (e.g. cardiac or pulmonary dysfunction, surgery, neurological impairment, high levels of pain, central nervous system tumour, and cognitive impairments) were excluded from participating in the formal physical activity intervention trial limiting the extent to which results may be extrapolated to the whole TYA cancer population. The physical activity interventions reported within these reviews also varied considerably in terms of what exercise was prescribed and how frequently the intervention took place. As such, akin to the adult literature, there is currently insufficient evidence to quantify the optimal mode, frequency, and duration of physical activity for TYA cancer survivors (Braam et al., 2013, Baumann et al., 2013, Stolley et al., 2010). Nevertheless, it is clear there are a number of considerable benefits to promoting physical activity among young people with cancer.

However, existing data suggest that a large proportion of TYA cancer survivors do not meet physical activity guidelines (Belanger et al., 2012, San Juan et al., 2011, Stolley et al., 2010). Data on the physical activity behaviours of TYA cancer survivors during treatment are limited.
but studies have shown that the physical activity levels of TYAs drop significantly following a cancer diagnosis and typically do not return to pre-diagnosis levels of activity following treatment completion. For example, Keats and colleagues asked TYA cancer survivors (n=97, mean age: 17.3 years) to retrospectively recall their physical activity behaviour from the point of diagnosis and found that the frequency and duration of moderate and strenuous physical activity dropped from 3-4 session per week pre-diagnosis to 0-1 during treatment (p<0.0005) and rose to only 1-2 sessions per week post treatment (Keats et al., 2006). In one study of 40 childhood cancer haematopoietic stem cell transplant survivors (mean age: 12.5±3.2 years) more than two thirds of participants reported spending 3 or more hours per day on sedentary activities during leisure time (Bogg et al., 2015). In addition, data from the recent Dutch ‘Quality of Life in Motion’ study report that TYA cancer survivors within the sample (n=60, mean age: 13.8 years) were sedentary for more than 80% of all waking hours (median 869/1080 min per day) (Braam et al., 2015). A German study investigating the physical activity behaviours of young people receiving cancer treatment found a larger reduction in physical activity among adolescent aged participants (>14 years) during in patient stays when compared to children (4-13 years old) (87% reduction in children vs 95% reduction in adolescents) (Gotte et al., 2014). Among long term TYA survivors within the CCSC (n=2648, mean age: 28.7 years) 44.2% of 18-24 year olds and 55.8% of 25-34 year olds did not meet Centre for Disease Control recommendations of being active for more than 30 min per day on more than 5 days of the week (Florin et al., 2007). Data from the CCSS also indicated survivors were significantly less likely to meet physical activity recommendations than their siblings (OR=1.2; 99% CI=1.1 – 1.3) (Ness et al., 2009). One cross-sectional survey of 74 young adult cancer survivors (mean age = 22.9 years) found more than half retrospectively rated their fitness as ‘much worse’ or ‘not quite as good’ compared to pre-diagnosis (Murnane et al., 2015).

However, existing data on the physical activity levels and sedentary behaviours of TYA cancer survivors should be considered in light of several limitations. Firstly the majority of studies have been conducted using self-report physical activity questionnaires (Tudor-Locke and Bassett Jr, 2004); self-report levels of physical activity tend to be over-estimated. Moreover, most of the data presented here have been generated from studies conducted within the United States; the physical activity behaviours of British TYA cancer survivors remain to be explored. Similarly, further work is required to explore how physical activity interventions may be integrated and adopted into standard clinical practice as there is some confusion among health professionals on the safety of prescribing exercise to young people with cancer (Grimshaw et al., 2016, Spreafico et al., 2014).
2.3.2 Diet

Although the quantity of the evidence is limited, and quality of the evidence is variable, there is general consensus that among the general population a diet rich in fruit and vegetables, complex whole grains, and lean proteins prevents the development of chronic health problems such as glycaemia, high blood pressure and cardiovascular disease, and can prevent the manifestation some cancers (Katz and Meller, 2014). Specifically, the World Cancer Research Fund have concluded there to be ‘convincing’ evidence that there is a link between red and processed meat consumption and colorectal cancer; ß-carotene supplementation and lung cancer; and aflatoxins and liver cancer (WCRF, 2011). In comparison to the 1990s when a very reductionist approach to diet was taken (i.e. where there was a heavy focus on single components of dietary intake) an overall healthy diet high in fruit, vegetables, fibre and lean protein is now considered better than a dietary pattern characterized by extreme intake (or extreme restriction) of specific foods or food groups (Hoffmann, 2003, Katz and Meller, 2014). As a result the dietary guidelines by governments and non-profit organizations centre around individuals consuming a balanced diet of all the major food groups (WCRF & AICR, 2007).

Among adult cancer survivors diet and nutrition is recognized as an important element of care and is considered key in the secondary prevention of cancer and the promotion of improved outcomes (Demark-Wahnefried et al., 2008). However, the evidence-base is limited and challenges in the accurate and reliable measurement of dietary intake and nutrition have led to challenges in interpreting the research investigating the link between diet and cancer outcomes. One meta-analysis of 117 prospective cohort studies investigating the effect of diet on mortality and cancer recurrence among adult cancer survivors (total participants: n=209,597) found that good dietary intake was inversely associated with all-cause mortality (Relative Risk, RR, 0.78; 95% CI, 0.72–0.85) but not cancer recurrence (RR, 0.87; 95% CI, 0.68–1.11). Similarly, within the same meta-analysis a Western dietary intake (characterised as being high-fat, high-sugar, rich in snacks or unhealthy foods) was associated with increased risk of all-cause mortality (RR, 1.46; 95%CI, 1.27–1.68) but not cancer recurrence (RR, 1.21; 95% CI 0.69–2.13; I² =81%; post-diagnosis RR, 1.34; 95% CI, 0.62-2.92; I²=85%) (Schwedhelm et al., 2016). These findings differ somewhat from the findings of the European Prospective Investigation into Cancer and Nutrition Study (a study of nearly 400,000 adults) which reports that death from chronic disease and cancer mortality is 34% lower among cancer survivors who have healthy diet (characterized by high fruit and veg intake, complex wholegrains and lean proteins) than cancer survivors with a poor diet (Vergnaud et al., 2013). However, within both of these studies diet-quality was summarized into a single index with each component given the same weighting, potentially causing under-estimation of effect size.

To truly determine the effect of dietary intervention on cancer outcomes large RCTs are required but existing RCTs investigating the effect of change in diet on cancer-related outcomes are few in number and have produced mixed results. For example the Women’s Healthy Eating and Living (WHEL) study; a dietary intervention comprising telephone counselling, cooking classes and print materials; including over 3,000 female participants...
found no difference in breast cancer incidence or mortality between the intervention and the control group over the whole study period from 1995 to 2006 (mean follow up period: 7.3 years) (Pierce et al., 2007). Conversely, the Women’s Intervention Study (WINS) study; a dietary intervention study focused on investigating the effect of reducing fat intake on relapse-free survival among female breast cancer survivors; found over the follow up period (median: 60 months) those in the intervention group were less likely to have experienced a breast cancer recurrence than the control group (Hazard Ratio: 0.76; 95% CI 0.60 – 0.98; p= 0.077). The mixed results potentially arise from the differences in study populations (the WINS study included only women who were post-menopausal whilst the WHEL study included women aged 18 to 70 years of age); recruitment and follow up time periods (the WINS study enrolled women one year post diagnosis whereas the WHEL study enrolled women up to four years from diagnosis meaning the WHEL study, relative to the WINS study did not account for cancer recurrence in the first four years from diagnosis); and weight loss between intervention and control groups (the effect of the WINS study on cancer recurrence may be due to the effect the intervention had upon weight status rather than the dietary change) (Pierce et al., 2007, Chlebowski et al., 2006). Additional studies are required to clarify the association between dietary intake and cancer outcomes.

Although evidence linking diet to cancer outcomes is limited, there is potential that common treatment-related side effects experienced by TYA cancer survivors (specifically weight gain, weight loss and muscular atrophy) could be mitigated or managed through effective dietary interventions (Barnes and Demark-Wahnefried, 2014, Ladas, 2014, Phillips-Salimi et al., 2012). Specifically adherence to a Mediterranean diet has been found to be associated with lower body mass index (BMI) (p=0.04), lower visceral adiposity (p=0.07), lower subcutaneous adiposity (p<0.001) and a 31% (OR 0.69, 95% CI 0.50, 0.94) risk reduction in developing metabolic syndrome among TYA-aged childhood cancer survivors (n=117, mean age: 24 years; mean time since diagnosis: 17.6 years) (Tonorezos et al., 2013). Among survivors from the St Judes Lifetime Cohort (n=365, mean age: 28.5 years), 1g higher protein intake per kilo of body mass per day was found to associated with a 7.9% increase in lean muscle mass (Boland et al., 2016). Such findings, although cross-sectional, suggest young people with cancer may benefit from optimising dietary intake.

However, only 3 RCT intervention studies (Rai et al., 2008, Cox et al., 2005, Mays et al., 2011c) have investigated the effect of dietary change on health outcomes among TYA-aged cancer survivors (Cohen et al., 2016). None of these studies investigated metabolic or cardiovascular outcomes and only one of these studies (Rai et al., 2008) included body composition as an outcome. Within the study conducted by Rai and colleagues at the 36 month follow up there was no significant difference in bone mineral density (measured with a DEXA scan) between the intervention (n=141, calcium and Vitamin D supplementation plus nutritional education) and the control group (n=134, education only) (MD -0.05; 95% CI -0.26
The null finding may be in part due to the poor adherence to behaviour intervention and the self-report methods of dietary assessment used.

In common with studies investigating physical activity, data on dietary patterns gathered from self-report food frequency questionnaires is subject to a high level of biased reporting and systematic error (Natarajan et al., 2010). A recent validation of self-reported methods to quantify dietary intake among childhood cancer survivors (n=16, mean age= 11.7 years) found food frequency questionnaires significantly underestimate absolute dietary intake when compared to 24-hour diet recalls and doubly labelled water (Zhang et al., 2015a). As a result of such data collection limitations and lack of trials there is currently insufficient evidence to draw conclusions about the role of nutrition and dietary intake on health and cancer outcomes among TYA cancer survivors. Further studies are needed to quantify the relationship between dietary intake and health outcomes among TYA cancer survivors and establish whether nutrition may directly or indirectly affect cancer outcomes. Nevertheless, evidence among adult cancer survivors, and the emerging observational evidence among TYA cancer survivors, does suggest diet is a core part of healthy survivorship and that it is reasonable to recommend TYA cancer survivors to have as healthy a diet as possible.

However, although limited to a few studies, existing evidence does suggest that dietary patterns and nutritional intake among young people with cancer are typically poor. Cross-sectional data have indicated that more than half of TYA cancer survivors do not meet national dietary recommendations (Badr et al., 2013, Hansen et al., 2014, Larcombe et al., 2002). For instance, one study of TYA aged childhood cancer survivors (n=209; mean age=20.3 years) in the United States found 79% of young people did not meet recommended daily fruit intake, 68% fell below guidelines for calcium intake, and 84% fell below guidelines for dietary fat intake (Demark-Wahnefried et al., 2005b). Worryingly, previous studies of young people with cancer have found that energy intake often exceeds energy expenditure by more than 10% (Cohen et al., 2012) and energy intake from sweets can be up to 70% higher than recommended (Tylavsky et al., 2010). Data from the Diet and Acute Lymphoblastic Leukaemia Treatment (DALLT) study (an embedded prospective cohort study of patients being treated on the Dana-Faber Cancer Institute ALL Consortium Protocol 05-001) found more than 50% of child and adolescent acute lymphoblastic leukaemia (ALL) patients (n=640) exceeded calorie intake recommendations for their age and gender (Ladas et al., 2016). Such data emphasizes the need to provide TYA cancer survivors with nutrition and diet intervention from the point of diagnosis onwards. However, there are currently no data on if, and how, the nutrition and dietary intake habits of TYA cancer survivors change throughout the cancer pathway and whether TYA cancer survivors have any motivation to change their dietary intake.
2.3.3 Weight Management

Obesity, defined as an excessive accumulation of body weight resulting in BMI >30 kilograms of body weight per square metre of height (kg/m²), and overweight body status (BMI 25-29 kg/m²) results from energy imbalance caused by greater energy intake than expenditure (Hall et al., 2012). Obesity is a known risk factor for multiple chronic conditions and several cancer types (Kopelman, 2007). In 2007 the World Cancer Research Fund concluded that there was convincing and plausible mechanistic evidence linking excessive body fat (BMI) to increased risk of oesophageal, gallbladder, pancreatic, kidney, colorectal, postmenopausal, ovarian and endometrial cancers (Basen-Engquist and Chang, 2011, WCRF & AICR, 2007). Worldwide, high BMI is estimated to account for 481,000 cancer diagnoses each year (Arnold et al., 2015).

Among adult cancer survivors, obesity at diagnosis and weight gain post diagnosis has been found to be a risk factor for poor treatment efficacy, poorer survival outcomes (recurrence and all-cause mortality) and to increased risk of treatment related complications and chronic health conditions (Demark-Wahnefried et al., 2012, McTiernan, 2008, Siegel et al., 2010, Allott et al., 2013, Bracci, 2012, Protani et al., 2012). The newly established Breast Cancer WEight Loss Study (BWEL Study) aims to test whether overweight or obese breast cancer survivors who intentionally lose weight following a lifestyle intervention program have a lower rate of cancer recurrence. Data from this study will establish if weight loss interventions influence survival outcomes and if weight management interventions should form part of routine breast cancer treatment (Alliance for Clinical Trials in Oncology., 2017).

Weight gain and obesity are very common among young people who have had a cancer diagnosis. One meta-analysis of survivors of childhood ALL found the prevalence of obesity among survivors 5-9 years post treatment (n=14 studies, mean/median age= 13.2 – 19.4 years) ranged between 29%- 69%; and the prevalence of obesity among survivors more than 10 years post treatment (n=5 studies, mean/median age= 20.5=24.1 years) to be within the range of 34 – 46% (Zhang et al., 2015b). These figures are comparatively high when compared to the prevalence of overweight and obesity among general population adolescents which is estimated to be between 22-25% in Europe (Bibiloni et al., 2013).

The high prevalence of obesity and TYA cancer survivors’ elevated risk of weight gain is a cause for concern as many of the long-term physical, metabolic, and endocrine effects of TYA cancer such as cardiovascular dysfunction, hypertension, and glucose intolerance are heavily influenced by weight status (Guh et al., 2009). Additionally, among young people with cancer, specifically those who have had a diagnosis of leukaemia, obesity has been associated with poorer overall and event-free survival (Amankwah et al., 2016, Butturini et al., 2004). In one study of high-risk ALL patients (n=2008; age range: 0- 21 years) being obese at diagnosis was associated with greater treatment related toxicity. However, encouragingly, in individuals whose weight status returned to healthy BMI ranges during treatment, this risk of poor event-free survival and treatment-related toxicity was mitigated (Orgel et al., 2014). This study provided evidence that, unlike previous reports, survival and treatment-related toxicity is not
solely influenced by weight status at diagnosis but is moderated by weight status during treatment.

Earlier age at diagnosis, an ALL diagnosis, cranial radiation, glucocorticoid exposure, growth hormone deficiency and female gender have been identified as high risk groups for weight gain and obesity (Gibson et al., 2016, Garmey et al., 2008). The link between cranial radiation and weight gain is thought to arise from inadvertent damage to the hypothalamic region of the brain. Radiation-related damage to the hypothalamus impairs the production and regulation of appetite-related hormones such as ghrelin and leptin leading to increased energy intake and subsequent weight gain (von Deneen and Liu, 2011). In recognition of this, and the multitude of other adverse side effects caused by prophylactic cranial radiation, cranial radiation has now been omitted from most contemporary cancer treatment protocols. However, steroids are often prescribed to young people undergoing cancer treatment. Steroids, specifically glucocorticoids, result in dose-response increase in appetite and hence energy intake (Jansen et al., 2009, Reilly et al., 2001). Typically, contemporary protocols for ALL involve the administration of glucocorticoids during the induction, re-induction and maintenance phases of treatment. The Australian and New Zealand Childrens’ Oncology Group (ANZCHOG) ALL-Study-8 treatment protocol differed in that glucocorticoids were not administered to patients during maintenance therapy. Findings from longitudinal (7 years) follow up of patients (n=184, age range at diagnosis: 1.1 – 17.9 years) treated on this protocol indicate patients gained weight during treatment and that this weight gain persisted 7 years post treatment such that the prevalence of overweight and obesity at 7 years was 27.7% (Touyz et al., 2017). These findings indicate that the removal of cranial radiation and glucocorticoids during maintenance therapy do not attenuate young people’s elevated risk of weight gain during cancer therapy, suggesting that health behaviours (dietary intake and physical activity levels) may influence weight trajectories in children and teenagers treated for cancer. It is plausible that whilst treatment-related energy imbalance may be unavoidable, health behaviours especially high levels of energy consumption (high calorie intake) and low levels of energy expenditure (low levels of physical activity) are likely to amplify energy imbalance and lead to further weight gain. For example, findings from CCSS (n=9283) indicate that adult survivors of childhood cancer who are physically active have a reduced risk of obesity than those who were inactive (RR, 0.90; 95% CI 0.82-0.97) (Green et al., 2012). Likewise, high intake of fruit, vegetables, fish and legumes has been found to be associated with significantly lower adiposity and BMI among young adult aged survivors of childhood ALL (n=117, mean age: 23 years; mean years since treatment: 17.5) (Tonorezos et al., 2013). There is growing recognition that addressing the weight status of TYA cancer patients and TYA-aged survivors of cancer throughout the cancer care pathway has the potential to prevent morbidity and mortality within this population group (Armstrong et al., 2013, Zhang and Parsons, 2015). However, no studies have investigated if young people with cancer are motivated to manage their weight and how and when weight advice should be delivered.
2.3.4 Smoking

Smoking is the most preventable cause of lung cancer and was linked to 60,000 cases (19.4%) of all newly diagnosed cancer cases in the UK in 2010 (Parkin et al., 2011). It is well established that smoking causes a plethora of chronic diseases including stroke, gum disease, high blood pressure, heart disease, pneumonia, hardening of the arteries, chronic lung disease, asthma and bone thinning (Office of the Surgeon General, 2004). Second-hand smoke exposure and passive smoke exposure (where an individual unintentionally inhales the smoke from another person’s cigarette) have also been found to be associated with increased risk of chronic disease. For example, a recent meta-analysis of studies investigating the association between second-hand smoke and health outcomes found second-hand smoke exposure significantly increases an individual’s risk of stroke (RR: 1.35, 95% CI 1.22-1.50), ischaemic heart disease (RR: 1.27, 95% CI 1.10-1.48) and coronary obstructive pulmonary disease (RR: 1.66, 95% CI: 1.38-2.00) (Fischer and Kraemer, 2015). As a result of the well-established strong link between smoking and chronic disease, legislative action (TV and advertising bans, tobacco taxes, anti-smoking campaigns and e-cigarettes) by the British Government has been taken in an attempt to improve public health (Department of Health 2015).

Tobacco use is often initiated during adolescence and is heavily influenced by peers, socio-economic status and level of educational attainment. Although there is no evidence that smoking causes the types of cancer commonly diagnosed in young people; lifetime tobacco use initiated during adolescence or young adulthood is likely to influence cancer risk in adulthood. Data from the US Surgeon Generals Report on smoking among adolescence indicate over 80% of adolescents who smoke will continue to smoke well into adulthood and over a third of these individuals will suffer from a health defect as a result of their smoking (National Center for Chronic Disease Prevention and Health Promotion (US) Office on Smoking and Health, 2012). Preventing smoking initiation during adolescence is therefore a key public health priority (Department of Health 2015).

Among adult cancer survivors, smoking and tobacco use has been strongly associated with increased risk of cancer recurrence and second primary lung cancer (HR: 6.69, 95% CI: 2.00-22.42) (Bishop et al., 2014). Furthermore smoking has been found to cause treatment-related complications and exacerbate common treatment-related side-effects such as mucositis, weight loss, and fatigue (Gritz et al., 2014). In general, particularly among head and neck cancer survivors, individuals who smoke following a cancer diagnosis have poorer physical and emotional health compared to non-smokers (Karam-Hage et al., 2014, Garces et al., 2004).

Although data is limited the effects of smoking are likely to be equally as bad, if not worse, for young people who have been treated for cancer, as smoking may exacerbate cardiopulmonary toxicities and respiratory infection risks associated with thoracic radiation exposure and some antineoplastic therapies (Klosky et al., 2007). Among male adult-aged survivors of childhood
ALL (n=862, mean age 31.3 years) smoking is associated with low bone mass density (OR:1.71 95% CI: 1.02-2.85) and increased frailty (OR 2.97 95% CI 1.56-5.67) (Wilson et al., 2016). Data on survivors of TYA cancer (n=1019, diagnosed between the age of 15 and 39) drawn from the 2012 to 2014 National Health Interview Study indicate survivors who smoked suffered from more comorbidities (OR, 1.62; 95% CI 1.06 – 2.47; P = 0.03) and had poorer self-reported health (OR, 0.34; 95% CI, 0.22-0.54; P <0.001) than survivors who were never smokers (Kaul et al., 2016).

Data on smoking patterns among TYA cancer survivors is limited. Some studies indicate that the prevalence of smoking among childhood and TYA cancer survivors is lower than general population controls (Observed/Expected: 0.72, 95% CI 0.69-0.75) (Emmons et al., 2002) whereas other studies have shown no significant difference between survivors and population control groups (Larcombe et al., 2002, Kahalley et al., 2012). Such discrepancies in findings can be attributed to variation in smoking status measures used, recall bias and use of convenience sampling. However, a recent meta-analysis of smoking among childhood cancer survivors, siblings and age-matched peers found survivors of childhood cancer (defined as young people diagnosed <21 years of age) were less likely to smoke than siblings (OR 0.68, 95% CI 0.49-0.96) or peers (OR 0.54, 95% CI 0.42-0.77) (Marjerrison et al., 2016). These findings are consistent with previous narrative reviews within this field (Rabin, 2011, Clarke and Eiser, 2007). This meta-analysis also pooled the incidence of risk-taking behaviour among childhood cancer survivors and concluded 22% (95% CI 0.19-0.26) of young people with a cancer history were smokers. It is likely that the prevalence of smoking is higher as most studies included within the pooled analysis were comprised of cancer survivors participating in long-term follow up survivorship programs who may be interested in health to a greater extent than young people who are lost to follow up or choose not to participate in such lifestyle related research. Moreover, there is evidence that individuals of a low socio-economic status (a group who are more likely to initiate smoking at a younger age) are less willing to respond to survey based health research (Milam et al., 2016).

Recent longitudinal data from the CCSS indicate an approximate fall from 19% to 16% in smoking prevalence among cancer survivors within the cohort from baseline (data collection: 1994-1999) to long-term follow-up (data collection: 2003) (Gibson et al., 2015). These results reflect both normal age related declines in smoking behaviour and suggest population-wide public health efforts to reduce smoking have been somewhat effective among long-term adult-aged TYA cancer survivor in the United States. However, without true estimates of the prevalence of smoking behaviour among TYA cancer survivors, professionals and researchers within the TYA cancer field face challenges in creating, targeting and evaluating smoking interventions for this age group of cancer survivors.
2.3.5 Alcohol Consumption

Irrespective of the type of alcoholic drink, the causal association between alcohol consumption and poor health is exponential without a threshold effect (Connor, 2017); the more alcohol an individual drinks the more likely they are to suffer from a serious chronic condition or a cancer diagnosis. Several comprehensive systematic reviews by the World Cancer Research Fund, The American Institute for Cancer Research, and the Global Burden of Disease Alcohol Group have concluded that lifelong excessive alcohol consumption is associated with increased risk of myocardial dysfunction, liver damage, osteoporosis, and cancers of the oral cavity, larynx, oesophagus, breast, and colon (WCRF, AICR, 2007). Alcohol consumption alone is thought to account for 4% of the total global burden of disease (Rehm et al., 2009). Data from the Million Women's cohort (n=1,280,296) indicate that for every additional 10g alcohol consumed (equivalent to one extra drink per day per person) there is an increase in the excessive incidence of breast cancer, head and neck cancer, and rectal cancer giving a total excess of 15 cancer diagnoses per 1000 women per day (Allen et al., 2009).

Although the specific biological mechanisms underlying the association between alcohol consumption and cancer risk are mixed, the pooled effect sizes observed within epidemiological studies are consistent and are considered biologically plausible (Connor, 2017). Because of the cumulative weight of the epidemiological evidence linking alcohol consumption to poorer health outcomes, Public Health England have taken a series of measures (taxation, marketing regulation, managing the social drinking environment, and providing information and education) to reduce alcohol consumption in an attempt to reduce the incidence of chronic disease and cancer among the British population (PHE, 2016).

Adolescents and young adults are recognised as a high-risk population group for alcohol consumption. Data pooled from nine UK-based cohorts (n=59,397) indicate that alcohol consumption rises during adolescence and peaks during young adulthood at the age of 25 (Britton et al., 2015). One large-scale survey of English adolescents (n=5,700) found 89% of 15-16 year olds had had an alcoholic drink within their lifetime and 39% reported drinking on a weekly basis. 66% of adolescents surveyed also reported that they drank to be intentionally drunk at least once a month (Bremner, 2011). This is concerning as there is consistent evidence that alcohol consumption during adolescence and young adulthood can lead to anti-social behaviour, unintentional injuries, and can have a negative effect on neurocognitive development (Welch et al., 2013, Lopez Caneda et al., 2014). There is also evidence that excessive alcohol consumption in adolescence continues into adulthood and can lead to lifelong alcohol dependence (McCambridge et al., 2011). However, there is very little evidence concerning the effect of adolescent alcohol consumption on later adulthood health and well-being. This is due to the sparsity of prospective data assessing drinking patterns among the TYA age-group and subsequent health outcomes >10 years later (McCambridge et al., 2011). As a result causal inferences between alcohol consumption during TYA years and long-term adulthood health cannot be drawn. Nevertheless, given the weight of the
evidence linking alcohol to poor health outcomes in general; and the fact that adolescent drinking patterns persist throughout the life course; efforts to prevent excessive drinking habits among TYAs are warranted as a means to reduce the incidence of alcohol related health problems among adults.

Research on the long-term health consequences of alcohol consumption post cancer diagnosis is inconclusive. A recent systematic review of prospective and case control studies (n=16; n= 35, 690 participants) investigating alcohol consumption in relation to risk of breast cancer recurrence concluded that there was a only suggestive association between alcohol consumption and breast cancer recurrence (Simapivapan et al., 2016). Within studies investigating alcohol consumption and mortality among colorectal cancer survivors, prediagnosis alcohol consumption was not associated with colorectal cancer-specific mortality whilst there was a modest association between post-diagnosis drinking and colorectal cancer-specific mortality (RR 1.27, 95% CI, 0.87-1.86) (Yang et al., 2017). Among head and neck cancer survivors, continued alcohol consumption of 2.3 drinks per day was associated with a significant increased risk of mortality (RR: 2.7, 95% CI 1.2-6.1) when compared to non-drinkers. This is unsurprising given that alcohol is a known risk factor for cancers of the pharynx, larynx, thyroid gland, and oesophagus (Mayne et al., 2009). Post-diagnosis alcohol consumption has also been found to be associated with diabetes and ischemic heart disease among adult colorectal cancer survivors (Hawkes et al., 2011).

Among TYA cancer survivors, heavy drinking is thought to exacerbate underlying asymptomatic liver disease, particularly among patients who have undergone hematopoietic stem cell transplants (Bleyer and Barr, 2007). However, akin to the adult cancer survivorship literature, a limited number of studies have investigated the relationship between alcohol consumption and health outcomes among young people who have had a cancer diagnosis. Data from the St Judes lifetime cohort indicate moderate alcohol consumption is associated with low bone mass density (OR 2.09; 95% CI, 1.14-3.83) among female survivors of childhood ALL (n=426) (Wilson et al., 2016). However, due to the cross-sectional design of these studies it not possible to ascertain the direction of the association between alcohol consumption and health outcomes among TYA cancer survivors. Without prospective data on alcohol behaviour and health status it is unclear whether alcohol consumption is a modifiable risk factor for cancer recurrence, second primary cancer or the onset of comorbidities among TYA cancer survivors. More research in this area, specifically intervention studies investigating whether reduction in alcohol consumption or alcohol cessation lead to better health outcomes, are required.

The evidence concerning patterns of alcohol consumption among TYA cancer survivors is mixed and confounded by country-specific laws concerning alcohol purchase, recall bias, and variability in the classification of alcohol consumption. The reported prevalence of binge drinking among TYA cancer survivors varies widely from 8%-54% (Bauld et al., 2005, Lown et al., 2008). Meta-analysis of comparative studies indicate childhood and TYA cancer survivors
are less likely to report binge drinking (OR 0.77, 95% CI 0.68-0.88) when compared to siblings, but equally likely to binge drink when compared to peers (OR 0.97, 95% CI 0.38-2.49) (Marjerrison et al., 2016). However, one cross-sectional survey of TYA cancer survivors (n=178; mean age: 25.2 years) in the UK found that when looking at alcohol consumption over a week, although TYA cancer survivors within this sample were less likely to binge drink, both male and female TYA cancer survivors (43% & 68%, respectively) reported higher levels of light drinking (i.e. up to 8 units over a week) than controls or siblings (Larcombe et al., 2002).

It has been hypothesized that TYA cancer survivors may engage in health risk behaviours (e.g. smoking and drinking) to cope with life stressors or as a method of normalization (Martin and Kadan-Lottick, 2012). Moreover, although there is no quantitative evidence to support the notion, it has previously been suggested that the observed differences in smoking and alcohol consumption behaviours between TYA cancer survivors and general population TYAs may be reflective of a less active social life among survivors (Larcombe et al., 2002). Factors associated with binge drinking among TYA cancer survivors include male gender, educational status, substance use-related coping style, and worse parent-reported family functioning (Rebholz et al., 2012, Szalda et al., 2013).

Although the studies regarding the drinking behaviours of TYA cancer survivors are heterogeneous in terms of sample composition and outcome, given the weight of the epidemiological evidence linking alcohol to poor health outcomes in general, health behaviour interventions designed specifically for TYAs targeting alcohol consumption are required. In addition, young people with cancer have previously expressed a specific desire for more information and guidance on safe drinking practices (Fern et al., 2013b).
2.3.6 Ultra-Violet Radiation and Sun Protection

Ultraviolet radiation (UVR), is emitted naturally from the sun in the form of light. UVR exposure triggers DNA damage which manifests in the form of erythema (skin reddening/sun-burn) and lasting pigmentation of the skin (suntan). Excessive UVR exposure and poor skin care practices are the predominant cause of common skin cancers such as cutaneous malignant melanoma, basal-cell carcinoma and squamous-cell carcinoma. Based upon the weight of the epidemiological evidence underpinning the association between UVR exposure and skin cancer incidence and the well-defined causal mechanisms linking UVR exposure to skin cancer development, the International Agency for Research on Cancer (IARC) has classified UVR radiation as carcinogenic to humans (IARC, 2012). This has led to stringent public health guidance stipulating that individuals must avoid too much sun, use sun-protection and never use sunbeds (Greinert et al., 2015, The Childrens Oncology Group, 2008). Recommendations to avoid excessive UVR and sun-light exposure include seeking shade, wearing light clothing to cover exposed skin, and applying sunscreen at regular intervals. Data from the CCSS indicate young people who have undergone cancer treatment with radiotherapy are at a 6.3-fold increased risk of melanoma and non-melanoma skin cancers (Perkins et al., 2005). Safe sun practices as stipulated within the European Code against Cancer and by the Children’s Oncology Group (contained within Table 2.1) may mitigate some of this risk for survivors of a childhood or TYA cancer diagnosis.

However, TYAs are notorious for poor sun-protection practices. During adolescence and young adulthood intentional tanning and sunbathing practices increase whilst sunscreen and sun protection drop (Quatrano and Dinulos, 2013). Within one large scale cross-sectional study of Scottish adolescents (n=2173, Mean Age: 12.4 years) 51% of young people reported a single incident of sunburn the previous summer of whom 38% reported sunburn on more than one occasion (Kyle et al., 2014). Girls were significantly more likely to report an incident of sunburn when compared to boys (p<0.001) with nearly two-thirds (57.8%, n=611) of girls reporting sunbathing regularly to try and get a tan. Of those who were regular sunbathers 47.4% (n=289) reported using oils to try and help the tanning process. It was clear that intentional tanning was associated with cosmetic motives with a fifth of adolescents reporting that having a suntan made them feel better about themselves and that being tanned made them feel more attractive to others (22.7% and 18.8%, respectively). Similar results were found in a cross-sectional survey exploring Irish students (n=822, mean age: 22 years) attitudes to tanning where 63.9% reported an intention to get a tan next summer with 82.8% of those reporting that having a tan made them feel healthier (Flannery et al., 2016). Given the well-established link between UVR exposure and skin cancer risk it is evident that behavioural interventions to target deliberate tanning and poor sun protection practices are required for young people within the British Isles just as much as they are for young people living in warmer climates.
Data on sun exposure or sun protection practices among TYA cancer survivors are extremely limited but do suggest that young people with cancer engage in high-risk sun behaviour. One study conducted in the United States in mid-Atlanta found that non-adherence to skin protection was the most common poor lifestyle behaviour among TYA cancer survivors (n=175, mean age: 14.2 years; time since diagnosis: 9 years) (Tercyak et al., 2006). Results from Project REACH, conducted within the Dana-Faber Cancer Institute in the Boston, Massachusetts, found that 29% of TYA cancer survivors (n= 44/153; mean age: 26 years; time since diagnosis: 14 years) reported >5 hours per week of tanning or reported using a sun bed twice within the last year (Zwemer et al., 2012). However, when compared to siblings, adult-aged childhood cancer survivors are significantly less likely to report sunbathing (RR =0.92 95% CI =0.89-0.95) within the past year than siblings (Buchanan et al., 2009). This finding suggests TYA-aged and adult-aged childhood or TYA cancer survivors may be more aware of the importance of sun-safe behaviours in preventing cancer recurrence. However, there is no concrete evidence to suggest that perceived risk of cancer recurrence is associated with improved health behaviour choice among TYA cancer survivors. Nevertheless, despite the lack of evidence, it is generally considered that health promotion efforts which incorporate counselling regarding the risks of sun exposure among TYAs may prompt an affective behavioural response, and trigger positive behaviours change, which in turn may mitigate TYA cancer survivors risk of malignant and non-malignant melanoma occurring as second primary cancers (Murphy, 2013).
2.4 Health Behaviour Change Interventions for TYA Cancer Survivors

As outlined within Section 2.3, among adult cancer survivors and the general population, poor health behaviours (inactivity, poor dietary intake, smoking, alcohol consumption, and sun exposure) are linked to worse health outcomes. Among TYA cancer survivors, there is growing evidence that the same holds true and that healthy lifestyle choices among young people who have had a cancer diagnosis could improve long-term health. Nonetheless, in spite of this, the majority of cross-sectional studies indicate that the health behaviours of TYA cancer survivors are generally poor with most studies reporting insufficient levels of physical activity, poor dietary intake and engagement in risky health behaviours such as smoking, drinking and tanning. As demonstrated among adult cancer survivors it is unlikely TYA cancer survivors will spontaneously improve their health behaviours, or adopt healthier lifestyle choices, without intervention (Williams et al., 2013).

The efficacy of health behaviour interventions piloted among long-term childhood cancer survivors and adult cancer survivors has been reviewed previously, (Barnes and Demark-Wahnefried, 2014, Brier et al., 2015, Stolley et al., 2010). However, until very recently, TYA aged cancer survivors have been largely neglected within health behaviour research. As a result, very little is currently understood about the best setting and timing to initiate a health behaviour intervention among young people affected by cancer.

The aim of this systematic review was therefore to synthesize the literature published to date on health behaviour interventions targeting physical activity, diet, smoking, alcohol consumption and/ or sun behaviours among TYA aged cancer survivors.

2.4.1 Methods

A search was originally conducted in November 2014 for studies written in English and published in peer reviewed journals describing the outcome of an intervention targeting health behaviour change in TYA cancer survivors. The search was repeated in August 2017.

2.4.2 Search Strategy

Health behaviours of interest were physical activity, diet, tobacco use (smoking), alcohol consumption and sun exposure (and all permutations of these behaviours). The following search terms were applied to CINAHL PLUS, Embase, Medline, and PsycInfo bibliographic databases: cancer patient* or cancer survivor* AND aerobic* or exercis* or fitness or gym* or physical* or sport* or diet* or energy intake or food* or fruit* or nutrition* or veg* not VEGF or drink* or cigarette* or alcohol or smok* or tobacco* or sun* or ultraviolet* AND random* or RCT or trial or intervention AND Teen* or Adolescen* or TYA or AYA or Young Adult. The search strategy was developed in consultation with a research librarian at University College London. Authors of studies selected for review were contacted enquiring as to whether they knew of

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5 The contents of Section 2.3 has been published as Pugh, G., Gravestock, H. L., Hough, R. E., King, W. M., Wardle, J., & Fisher, A. (2016). Health Behavior Change Interventions for Teenage and Young Adult Cancer Survivors: A Systematic Review. Journal of Adolescent and Young Adult Oncology, 5(2): 91-105. (Appendix 2.1)
any additional health behaviour interventions targeting TYA cancer survivors conducted as a randomized control trial (RCT) or otherwise, which were either published or unpublished.

2.4.3 Selection Criteria

As the aim of this PhD is to develop a health behaviour intervention for TYA cancer survivors it was necessary that the principal outcome measure reported within included manuscripts was health behaviour change (i.e. magnitude of increase or decrease in the frequency of targeted health behaviours). Studies investigating the effect of a health behaviour intervention (e.g. structured physical activity sessions) on cognitive, biological or nutrient outcomes were excluded. Participants of interest were those between the ages of 13 and 24 years of age defined as a teenager, adolescent or young adult cancer survivor. However, given inconsistencies in the TYA age bracket between countries, and in order to capture all relevant literature, studies wherein participants were i) described as TYA cancer survivors and ii) the mean age of the participant group fell below 30 years were also included for review. Given the lack of behavioural research within this area, intervention studies wherein the mean age of participants fell slightly above or below the lower and upper ends of this criterion bracket were also included for review. In addition, no studies were excluded based upon participants’ treatment status or position upon the cancer care continuum. This is in alignment with the National Cancer Institute, World Cancer Research Fund and American Institute of Cancer Research definition of cancer survivor described in Chapter 1, Section 1.1.2.

2.4.4 Data Collection

The results of the search are presented in Figure 2.1. 1311 studies were identified within the original search, a further 331 studies where identified in the updated search conducted in August 2017. The titles and abstracts of all articles were individually screened by myself to assess eligibility for inclusion. Full text versions of articles that potentially met the inclusion criteria were subsequently retrieved and screened to assess eligibility for inclusion. After independent screening included and excluded studies were reviewed by myself and my primary supervisor (Dr Abi Fisher) and any discrepancies were resolved by discussion. A total of 13 intervention studies, comprising 15 articles, were included for full review. Data and information regarding sample characteristics, intervention design methodology, and intervention outcomes pertaining to health behaviour change were extracted from the original studies. Data from each study was summarized and aggregated: meta-analysis was not possible due to the wide variation of outcome measures used within studies.
Figure 2.1 Flow diagram of search strategy results

- **Articles identified through database searching** (n=1642)
- **Articles after duplicates removed** (n=1441)
- **Records screened** (n=1441)
- **Full-text articles assessed for eligibility** (n=68)
- **Articles included for qualitative synthesis** (n=15)
- **Records excluded** (n=54)

**Reasons for exclusion (n=54)**
- Review paper or protocol study (n=14)
- Report of baseline trial data or cross-sectional data only (n=1)
- No health behaviour change summary measures (focus on cognitive/biological/nutrient outcomes) (n=11)
- Focus on mediators of health behaviour change (n=3)
- Mean age of participants <13 or >30 years (n=18)
- Non-cancer survivors TYAs (n=5)
- Meeting Abstract (n=2)
2.4.5 Study Quality

The methodological quality of the included RCT studies was measured using the Cochrane Collaboration risk of bias tool which allows evaluation of study quality based on six key criteria; random sequence generation, allocation concealment, blinding, incomplete outcome data, selective reporting and other sources of bias. Each study was rated low risk, unclear or high risk for each category of bias. Within this review a study was considered to have a high risk of bias if two thirds or more of the criteria were scored as high risk.

2.4.6 Results

Characteristics of included studies are summarized in Table 2.4. Of the thirteen studies included nine were two armed randomized control trials with the remainder being either a one arm feasibility trial (n=3) or repeated measures longitudinal design (n=1). The majority of studies (n=9) were conducted in the United States with the remaining four studies being conducted in Canada, China, Finland and Germany.

In total, 1232 participants (n= 522 male, n= 711 female) were recruited across all studies. The smallest sample included 10 participants (Keats and Culos-Reed, 2008) and the largest 266 (Cox et al., 2005, Hudson et al., 2002). Typically participants were between the age of 13 and 18 years however three studies (Berg et al., 2014, Belanger et al., 2014, Li et al., 2013) specifically recruited young adult participants over the age of 18. All studies included both female and male participants with most studies successfully recruiting more females than males. Ten of the thirteen studies reported details of ethnicity, in these, exact numbers were generally not given, but the majority of participants recruited were reported to be White/Caucasian.

Cancer survivors of haematological malignancies were the most commonly recruited with two studies (Huang et al., 2014, Jarvela et al., 2012) specifically recruiting acute lymphoblastic leukaemia (ALL) survivors (n=55). Within studies wherein time since diagnosis, time since treatment or age at diagnosis was reported we are able to infer that the majority of participants across the included studies were diagnosed with cancer during their childhood before the age of 12 years.

The primary aim of the majority of studies was to establish the feasibility and efficacy of novel interventions promoting health behaviour change amongTYA aged cancer survivors. Five intervention studies solely aimed to change physical activity, one addressed diet and nutrition, one addressed smoking and tobacco use and six addressed multiple health behaviours in unison. Of the six studies that addressed multiple health behaviours, one targeted physical activity and diet, two addressed smoking and alcohol consumption, one addressed diet and sun exposure and two addressed physical activity, diet, smoking and alcohol health behaviours.
Table 2.4 Characteristics of included studies

<table>
<thead>
<tr>
<th>Author</th>
<th>Study Design</th>
<th>Participants</th>
<th>Target Behaviour</th>
<th>Intervention</th>
<th>Control</th>
<th>Health Behaviour Outcome Measures</th>
</tr>
</thead>
</table>
| Quiddle et al., 2016 | Singe-arm feasibility trial | N=23 Median age: 20 years Median age of cancer diagnosis: 16.0 years | Diet | Intense individually tailored nutritional counseling from a registered dietician. All recommendations were based upon the German Nutrition Society (DGE) dietary recommendations. Counselling messages were reinforced via a telephone call at weeks 2 and 6. | NA      | Diet: European Prospective Investigation into Cancer and Nutrition (HEI-EPIC)  
Significant improvement in overall diet quality.  
Significant improvements in drinks, vegetables, fruits, cereals, dairy products and sweets/snacks/alcohol.  
Non-significant improvement in meat or fat/oil intake. |
| Huang et al., 2014 | RCT            | N=38 Median Age: 13 years Median Age at diagnosis: 5 years | Multiple Health Behaviour Change (diet and PA) | Weight maintenance intervention tailored for cancer survivors providing weekly nutritional and PA goals and skills. | Lower intensity general weight management intervention. | PA: Actigraph accelerometers  
Diet: Youth adolescent questionnaire  
Non-significant improvements in weight or weight-related behaviour. |
### Table 2.4 Continued

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>N</th>
<th>Age/Time Since Diagnosis</th>
<th>PA</th>
<th>Description</th>
<th>Outcome Measure</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belanger et al., 2014</td>
<td>RCT</td>
<td>212</td>
<td>18-39 years; 18-29 years: N=55 (25.9%)</td>
<td>PA</td>
<td>Targeted PA guidance including advice about how to engage in PA, tips on how to make PA enjoyable, how much PA is recommended, how to determine PA intensity, guidance to recognize PA opportunities, and information about goal setting.</td>
<td>One page leaflet of Canadian physical activity guidelines (CPAG).</td>
<td>Targeted PA guidance had no significant effect on PA min/wk at 3 months follow up. Exploratory analysis revealed that amongst those achieving &gt;300min/wk PA at baseline, the targeted physical activity guidance had a significant effect on PA at 3 months follow up.</td>
</tr>
<tr>
<td>Berg et al., 2014</td>
<td>One-arm feasibility trial</td>
<td>24</td>
<td>Mean Age: 23.38 years; Mean time since diagnosis: 10.71 years</td>
<td>PA</td>
<td>Web-based intervention involving 6 weeks of bi-weekly emails encouraging reporting of health behaviours. Following input of health behaviour participants were routed to tailored graphical depictions of their health behaviour habits and video messages, participants were also offered incentives for participation to the intervention.</td>
<td>N/A</td>
<td>PA: 7 day PA recall. Smoking &amp; Alcohol: 7 day recall. Frequency of PA, smoking and drinking (days) did not significantly improve at 12 week follow-up. Frequency of binge drinking was significantly reduced at 6 week follow-up but was not maintained at 12 weeks.</td>
</tr>
<tr>
<td>Valle et al., 2013</td>
<td>RCT</td>
<td>86</td>
<td>Mean Age: 30.8 years; Mean time since diagnosis: 58.2 months</td>
<td>PA</td>
<td>FIT-NET. Facebook based intervention including goal setting, self-monitoring content, and social support.</td>
<td>Facebook-based self help comparison. Lower level of intervention with no feedback, goals setting or progression tracking.</td>
<td>Change in minutes/week of MVPA, Light PA, total PA and body weight were significantly greater in FIT-NET intervention group versus comparison control.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>N</td>
<td>Age</td>
<td>Major Findings</td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Li et al., 2013</td>
<td>RCT</td>
<td>71</td>
<td>9-16 yrs</td>
<td>4 day integrated adventure-based training and health education program. Educational talks included discussing the benefits of PA, exploring how to overcome barriers to PA and creating a personal PA action plan with the guidance of health care professionals. Same amount of time and attention as intervention but no PA educational content. Invited to attend 4 days of leisure activities. Intervention group reported significantly higher levels of PA and higher PA self-efficacy than baseline at 9 months and in comparison to controls.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hollen et al., 2013</td>
<td>RCT</td>
<td>243</td>
<td>14-19 yrs</td>
<td>Individually tailored risk behaviour counselling including modules on decision making, smoking, alcohol use, an interactive substance use module and a health status module. Intentional control group received standard care and a sham CD-ROM related to study skills at baseline. Smoking and Alcohol: Periodic assessment of drug use among youth, the decision making quality scale (DMSQ) and risk motivation questionnaire (RMQ). Substance use risk behaviour was not reported. The intervention resulted in a significant effect between treatment groups for total risk motivation score for alcohol.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Jarvela et al., 2012</td>
<td>One arm feasibility trial</td>
<td>17</td>
<td>16-30 yrs</td>
<td>Illustrated home based exercise program followed up by 2 week telephone counselling and motivation. Intervention program was not effective in significantly increasing PA index.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2.4 Continued

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>N, Age, Mean Age, Mean time since diagnosis</th>
<th>Intervention</th>
<th>Control</th>
<th>Diet: Bone health behaviours comprising of milk consumption frequency &amp; 24 hour calcium recall.</th>
<th>Sun Safety: Sun safety behaviour scale assessing sunscreen use, and UV exposure avoidance.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mays et al., 2011a</td>
<td>RCT</td>
<td>N=75, Age: 11-21 yrs Mean Age: 14.2 years Mean time since diagnosis: 9.0 years</td>
<td>Multiple Health Behaviour Change (Diet, Physical Activity and Sun Safety)</td>
<td>Control waiting list.</td>
<td>In comparisons to control milk consumption frequency, past month calcium supplementation, days in past month with calcium supplementation and total sun safety behaviours were significantly improved at follow up in intervention group.</td>
<td></td>
</tr>
<tr>
<td>Mays et al., 2011b</td>
<td></td>
<td></td>
<td>A half-day, group based, interactive workshop that included messages and skill building exercises addressing relevant risk reducing and health promoting behaviours.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keats and Culos-Reed., 2008</td>
<td>Repeated measures longitudinal design</td>
<td>N=10, Age:14-18 yrs Mean Age: 16.2 years Mean time since diagnosis: 62.5 months</td>
<td>PA 90 minutes educational and exercise sessions once a week for 16 weeks. 8 weeks exercise &amp; education; 8 weeks exercise only.</td>
<td>N/A</td>
<td>PA: Godin leisure time exercise Questionnaire.</td>
<td>Significant increase in PA from baseline to mid-program but not maintained post-program or at 3 month follow up.</td>
</tr>
</tbody>
</table>
Table 2.4 Continued

<p>| Cox et al., 2005, Hudson et al., 2002 | N= 266, Age: 12-18 yrs Mean age of intervention group: 15.09 years Intervention group time from diagnosis: 10.95 years | Multiple Health Behaviour Change (PA, Diet, Smoking &amp; Alcohol Consumption). Health behaviour training in health goal chosen by the survivor and encouragement to make a commitment to a health goal for ensuing year. Health behaviour training session included a review of the advantages and disadvantages of the health behaviour, an explanation of how to engage in the health behaviour, problem solving of potential barriers, and an encouraged commitment to engage in the health behaviour. Participants were also given reinforcement at 3 and 6 months via telephone. | Lower intensity intervention: Self-examination teaching, targeted late effects screening, clinical assessment (physician/nurse practitioner) and late effects risk counselling. PA &amp; Diet: Health practice frequency subscale. Significant decrease in junk food consumption in the intervention group. Smoking abstinence remained unchanged. No effect on physical activity or alcohol use. |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>N</th>
<th>Age</th>
<th>Intervention Description</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tyc et al., 2003</td>
<td>RCT</td>
<td>103</td>
<td>10-18 yrs</td>
<td>Risk counselling intervention providing late-effects counselling, educational video, goal setting, physician feedback, tobacco literature and follow-up telephone counselling at 1 and 3 months by a research nurse.</td>
<td>Brief tobacco risk advice counselling that is commonly incorporated into routine medical care (Standard Care)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(10-13 yrs, N=40, 14-18 yrs N=63)</td>
<td></td>
<td>Smoking: Knowledge perceived vulnerability, intentions and perceived positive effects of tobacco use sub-scales. Significant increase in knowledge perceived vulnerability, and lower intention to smoke scores at 12 months. No significant difference at 6 months across all measures. No change in smoking status.</td>
</tr>
<tr>
<td>Hollen et al., 1999</td>
<td>RCT</td>
<td>64</td>
<td>13-21 yrs</td>
<td>Integrated information specific to cancer survivors workshop detailing info specific to survivorship, decision making skills, risk behaviours and social support from peers and healthcare professionals. Educational component lasted one day and the social component lasted overnight.</td>
<td>Standard Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>44% of the sample were diagnosed before the age six years.</td>
<td></td>
<td>Smoking &amp; Alcohol: Periodic assessment of drug use among Youth</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>The effect of the intervention for improving smoking behaviour and alcohol behaviour was not significant at 1, 6, or 12 month follow up post intervention. Significant effect on decision making and motivation.</td>
<td></td>
</tr>
</tbody>
</table>

**RCT:** Randomized Controlled Trial, **PA:** Physical Activity, **MVPA:** Moderate Vigorous Physical Activity
Table 2.5 displays the outcomes of all included interventions. Of the thirteen included studies all were deemed to be practical and feasible methods of promoting behaviour change among young people who have been diagnosed with cancer. However, only seven (54%) were successful in significantly changing target health behaviour. Within these studies the reported mean change in health behaviour from baseline or difference between intervention group and control was typically small. Three intervention studies although not achieving significant behaviour change did have a significant effect on mediators of health behaviour.

Table 2.6 outlines component features and delivery methods of included interventions. There was wide variation in the combination of component features used within the interventions contained within this review. As a result, collectively reviewing the content and component features of all studies was difficult given the heterogeneity of intervention characteristics and outcome measures. Nevertheless, patterns and trends relating to intervention delivery emerged.

Half (n=6) of all included studies promoted health behaviour change remotely meaning the intervention was delivered without face-to-face interaction with the researchers conducting the intervention. Within six studies phone calls were used as a means to provide additional counselling or motivation to intervention participants at various time points throughout the intervention. A third (n=4) of the interventions were computer based and delivered online via specifically designed websites, CD-ROMs, existing social networking websites, or email reminders. Only one intervention used text messaging to deliver intervention reminders. Four interventions included day long workshops which aimed to facilitate health behaviour change by facilitating informed decision making, creation of an action plan, and skill building exercises. Printed materials were often used to support information received during workshops or counselling sessions.

Eleven of the thirteen interventions incorporated an aspect of emotional or social support either in the form of one-to-one contact with a research nurse/ dietician, a facilitated group sessions, or opportunity to interact with other young people who have also had a diagnosis of cancer. Only one study targeted health behaviour change with the support of the family. Seven of the interventions provided individually tailored information to the participant in the form of personalized behavioural counselling, feedback or motivation. Online platforms (e.g. private Facebook groups) were utilized as novel methods of incorporating aspects of social support into the intervention.
Table 2.5 Intervention outcomes

<table>
<thead>
<tr>
<th>Study</th>
<th>Intervention Component</th>
<th>Baseline Scores</th>
<th>Follow Up Score</th>
<th>Control Group</th>
<th>Mean Change</th>
<th>Outcome measure (Measurement Point)</th>
<th>Significant Change (P Value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quiddle et al., 2016</td>
<td>HEI-EPIC*</td>
<td>47.0</td>
<td>65.0</td>
<td>-</td>
<td>-</td>
<td>12 weeks</td>
<td>P&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>BMI</td>
<td>21.4</td>
<td>20.4</td>
<td>-</td>
<td>-</td>
<td>12 weeks</td>
<td>0.218</td>
</tr>
<tr>
<td></td>
<td>Quality of Life</td>
<td>83.3</td>
<td>83.3</td>
<td>-</td>
<td>-</td>
<td>12 weeks</td>
<td>0.332</td>
</tr>
<tr>
<td></td>
<td>Blood Pressure (mmHg)</td>
<td>110/70</td>
<td>110/75</td>
<td>-</td>
<td>-</td>
<td>12 weeks</td>
<td>0.015/0.605</td>
</tr>
<tr>
<td></td>
<td>Waist to hip ratio (WHR)</td>
<td>0.80</td>
<td>0.77</td>
<td>-</td>
<td>-</td>
<td>12 weeks</td>
<td>0.349</td>
</tr>
<tr>
<td>Huang et al., 2014</td>
<td>Daily Amount of MVPA</td>
<td>76 min/day</td>
<td>87 min/day</td>
<td>Baseline: 44 min/day</td>
<td>+11 min/day*</td>
<td>4 months</td>
<td>0.65**</td>
</tr>
<tr>
<td></td>
<td>Diet</td>
<td>2002 kcal/day</td>
<td>1748 kcal/day</td>
<td>Baseline: 1775</td>
<td>-254 kcal/day*</td>
<td>4 months</td>
<td>0.24**</td>
</tr>
<tr>
<td>Belanger et al., 2014</td>
<td>Total Physical Activity</td>
<td>215 min/wk</td>
<td>240 min/wk</td>
<td>-</td>
<td>+69 min/wk</td>
<td>1 month</td>
<td>0.19**</td>
</tr>
<tr>
<td></td>
<td>Total Physical Activity</td>
<td>228 min/wk</td>
<td>285 min/wk</td>
<td>-</td>
<td>+8 min/wk</td>
<td>3 months</td>
<td>0.81**</td>
</tr>
<tr>
<td>Study</td>
<td>Intervention Component</td>
<td>Baseline Scores</td>
<td>Follow Up Score</td>
<td>Control Group</td>
<td>Mean Change</td>
<td>Outcome measure (Measurement Point)</td>
<td>Significant Change (P Value)</td>
</tr>
<tr>
<td>---------------------</td>
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<td>-----------------------------</td>
</tr>
<tr>
<td></td>
<td>Days of moderate cardio exercise</td>
<td>2.57</td>
<td>2.61</td>
<td>-</td>
<td>-</td>
<td>6 weeks</td>
<td>0.90</td>
</tr>
<tr>
<td></td>
<td>Days of vigorous cardio exercise</td>
<td>1.74</td>
<td>1.74</td>
<td>-</td>
<td>-</td>
<td>6 weeks</td>
<td>0.99</td>
</tr>
<tr>
<td></td>
<td>Days of strength training</td>
<td>1.00</td>
<td>1.39</td>
<td>-</td>
<td>-</td>
<td>6 weeks</td>
<td>0.35</td>
</tr>
<tr>
<td></td>
<td>Days of drinking</td>
<td>5.00</td>
<td>5.55</td>
<td>-</td>
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MVPA: moderate vigorous physical activity. MET h/wk: Physical Activity Index calculated as a multiple of the resting metabolic rate (MET) by multiplying the mean frequency, duration and intensity of weekly leisure time physical activity. *mean change calculated from raw data by first author (GP) **Significance calculated between treatment groups *HEI-EPIC: A sum score of <40 indicates a bad diet, >40-64 points a moderate and >65 points good dietary behaviour.
Table 2.6 Component features of health behaviour interventions

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*Studies underlined are those which were successful in changing one or more health behaviour. **peer group support was delivered using an online social networking website. No face to face communication took place. ***studies which had a significant effect on mediators of health behaviour
The content and format of four interventions had been developed and designed by the researchers working in consultation with young people (Huang et al., 2014, Berg et al., 2014, Belanger et al., 2014, Mays et al., 2011b, Mays et al., 2011a). The intervention content of one study was guided by a specially commissioned advisory group (Li et al., 2013). One intervention programme piloted by Mays and colleagues was explicitly developed following the PRECEDE-PROCEED health planning model (Donze and Tercyak, 2006). A range of theoretical models were used as a basis for behaviour change in many of the interventions. One third of the intervention studies (Huang et al., 2014, Hollen et al., 2013, Mays et al., 2011b, Mays et al., 2011a, Tyc et al., 2003) included within this review provided education and personalized risk counselling regarding the latent effects of cancer diagnosis and treatment to participants.

The duration of interventions ranged from a single half day group session to 12 months where intervention materials were delivered at scheduled time points. The number of contacts (including delivery of intervention, baseline and follow-up measures) made by the research team to the participant also varied across studies but was not associated with the duration of the intervention study. Interventions which were delivered remotely using modern communication technologies such as the internet or telephone typically had more information delivery contact points than interventions delivered by other methods.

Due to heterogeneity between intervention characteristics no clear relationship could be drawn between intervention efficacy or outcome and intervention content, delivery, theoretical design or duration. However, of the interventions which significantly changed behaviour five out of six included social support in the form of peer group interaction, one-to-one counselling or telephone support from a nurse, health coach or member of the research team conducting the intervention. Interventions which were successful in achieving significant behaviour change were also heavily incentivized. Within studies wherein participant evaluation was reported most interventions were generally received positively by young people.

A breakdown of the methodological quality classifications for each included RCT is displayed in Table 2.7. Only one RCT was deemed to be at low risk of bias with the remaining being deemed to be at moderate risk of bias.
Table 2.7 Scores for risk of bias assessment (cochrane collaboration tool) for all included RCT health behaviour interventions (n=9)

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<th>Low risk of bias</th>
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2.4.7 Discussion

The findings of this systematic review highlight the novel and diverse range of intervention design and delivery methods used to promote health behaviour change among TYA aged cancer survivors. Six of the thirteen interventions included within this review were successful in changing health behaviour. However, the relationship between intervention efficacy or outcome and intervention content, delivery mode, or theoretical design was undiscernible due to the heterogeneity of intervention characteristics. Although the number of eligible studies identified was limited due to the lack of research within this area trends emerged relating to the delivery and content of health behaviour interventions designed specifically for TYA aged cancer survivors.

Firstly, just over half of the interventions were delivered remotely. The majority of remotely-delivered interventions were either computer based or involved a mail out of paper based intervention materials. This is in keeping with previous studies investigating the intervention preferences of TYA aged cancer survivors (Badr et al., 2013, Demark-Wahnefried et al., 2005a, Rabin et al., 2013b). Remote intervention delivery within this population may be especially beneficial given that TYA cancer survivors often have time consuming obligations (e.g. studying and working) and physical limitations (e.g. chronic fatigue) which may limit their engagement and interest in health promotion activities (Goette et al., 2014, Wright et al., 2013). In recent years websites and mobile applications have emerged as promising and innovative approaches to remote intervention delivery (Elliot et al., 2013, Gray et al., 2005). Two intervention studies included within this review used online features of pre-existing social network websites and specifically designed websites to deliver the health behaviour intervention to young people. Such websites and mobile phone applications which create an easily accessible and enriched information environment (e.g. additional videos, links, or testimonials), facilitate behaviour tracking, tailor feedback, and provide an aspect of peer support are worth further investigation within the context of health behaviour change. Moreover, utilization of online recruitment strategies may overcome the recruitment and adherence challenges typically faced by researchers within this area (Flanagan et al., 2015, Rabin et al., 2013a).

Nevertheless, although interventions delivered remotely have emerged as promising strategies to lifestyle promotion among TYA cancer survivors, social, emotional and instrumental support, from healthcare professionals, friends, and family was a key feature of many of the health behaviour interventions included within this review. However, due to the variation in social support formats between interventions it was not possible attribute social support with intervention efficacy or outcome. As in healthy adolescent and young adult population groups it is likely that as a young person who has had a diagnosis of cancer transitions from adolescence to adulthood family influence upon behaviour decreases as young people often seek direct and indirect support from close friends or peers (Decker, 2007). Previous studies support the notion that social support is key and have found social influences
to be independent predictors of health behaviour among general population TYAs and young people managing chronic conditions such as Type 1 diabetes (Bruening et al., 2012, Merianos et al., 2016). In one study of adolescents cancer survivors aged 12-16 years, family and peer support for physical activity was found to be significant predictor of time spent in moderate-vigorous physical activity whilst only family physical activity levels and family support for physical activity were found to be predictors of physical activity among cancer survivors aged 8-12 years (Gilliam et al., 2012). Having friends with poor diets has also previously been cited as a barrier to healthy eating by young people who have experienced cancer (Arroyave et al., 2008). Efforts to deliver health information and support to TYA aged cancer survivors should take into account this transitional phenomenon and potentially target social groups as mediators of behaviour change.

Many of the interventions identified within this review included goal-setting and self-monitoring as part of the behaviour change programme. Self-monitoring and feedback (awareness of standards and efforts) allow individuals to track their progress and compare their current behaviour to the specific goal they have set. In line with social cognitive theory self-monitoring and feedback on behaviour develops self-efficacy through validating the individuals’ belief that they are capable of carrying out the behaviour (enactive attainment) (Bandura, 2004). Interventions targeting physical activity and dietary behaviour change among adults which include self-monitoring in combination with either goal-setting, goal review, and feedback have been found to be more effective at prompting behaviour change than interventions not including these techniques (Michie et al., 2009). Similarly, within a meta-analysis of physical activity and dietary behaviour change apps targeted towards adolescents, self-monitoring was found to be a significant univariate predictor of physical activity behaviour change among adolescents (Brannon and Cushing, 2015). Moreover, within a formal expert consensus study which aimed to identify behaviour change techniques and engagement strategies worthy of inclusion within a smartphone app designed to reduce excessive alcohol consumption, self-monitoring was ranked the most likely effective component of a smartphone app to targeting alcohol consumption (Garnett et al., 2015). It is therefore suitable to suggest that goal setting and self-monitoring be included as cornerstone behaviour change techniques within a health behaviour intervention designed specially for TYA cancer survivors.

The incorporation of personalized risk counselling regarding the latent effects of cancer diagnosis and treatment into the health education component of the intervention was a common feature in several studies. Explicitly emphasizing health risk and long term consequences of cancer diagnosis and treatment has been identified as alternative means of promoting health behaviour change among young adult survivors as greater understanding of risk may motivate young people to adopt healthier lifestyles (Ford et al., 2014a). Such interventions which support the development of autonomous motivation and decision making may be more effective in promoting health behaviour change among TYA cancer survivors.
than strategies and theories which take a more directive approach to changing knowledge and beliefs (D’Agostino et al., 2011).

A wide range of psychological theories (Trans-theoretical model, Theory of Planned Behaviour, Theory of Reasoned Action, Social Cognitive Theory, Experimental Learning Theory, Theory of Decision Making, Classic Change Theory, The Health Belief Model, the Precede-Proceed Model, Conflict Model of Decision Making, and Cognitive Theory) formed the basis of existing health behaviour change interventions piloted among both TYA and adult cancer survivors. Although there is evidence that theory based health promotion interventions may help improve intervention outcomes (Glanz and Bishop, 2010), this review could not demonstrate a link between the theoretical basis and the outcome of any included studies. Aside from the decision-aid piloted by Hollen and colleagues, the majority of studies did not provide a full description of how the chosen behaviour change theory was operationalized in intervention design or in the measurement and analysis of intervention outcomes. This may be due to length limitations in journal articles or may, as suggested by Painter and colleagues (2008), be due to theory being used superficially in behaviour change research (Painter et al., 2008). The poor use and reporting of theoretical constructs in intervention design has led to doubt over the effect of theory-based interventions on behaviour change outcomes (Pinto and Floyd, 2008).

This review highlights the diverse range of health behaviour interventions which are practical and viable ways of promoting a healthy lifestyle among young people who have had a cancer diagnosis. Encouragingly, interventions which were designed in consultation with young cancer survivors showed promising results. The inclusion of TYA cancer survivors within research design is an important step in advocating patient centred care which supports and respects young peoples’ autonomy and independence (Zebrack, 2014). No studies included within this review reported any adverse outcomes. Many intervention studies included within this review reported promising results suggesting that if the intervention was replicated with sufficient power significance could be achieved. Although some studies reported that compliance to the intervention protocol was low this was typically anticipated and strategies such as incentives were used to maximize participant attrition. In one particular intervention study despite a third of participants not complying fully with the boosters features of the intervention 90% rated all evaluation criterion positively (Hollen et al., 2013). Overall, participant enthusiasm and engagement with the intervention studies was high. This is reflective of the interest young people have previously reported in receiving health behaviour change information and support (Murnane et al., 2015).

Several limitations in intervention study design and reporting of results must be addressed. Firstly, a large proportion of studies included within this review addressed physical activity as the target health behaviour; more insight is required in relation to smoking, alcohol consumption and specifically dietary health behaviour change among TYA cancer survivors. Brief descriptions of intervention design within studies limited the stratification of potential
effective components of the intervention and limited the interpretation of methodological quality with few studies proving clear information on the randomization procedure or blinding at outcome assessment. When considering the results of the interventions as a collective it is important to note the small sample size and variable adherence rates within several studies which limit the power to detect significant effects in analyses. The generalizability of the reported outcomes of the interventions conducted by Huang et al (2014) and Jarvela et al (2012) are also limited as haematological malignancies, although common, only account for a small amount of the variety of cancer diagnosis’ observed in TYA cancer survivors. Few studies followed out a long term follow up of health behaviour change making it unrealistic to draw conclusions about the long term efficacy of these interventions to produce durable health behaviour changes. In addition, most behaviour change outcomes were measured subjectively suggesting that results should be interpreted with caution considering evidence that young people are proxy to high level of response bias, specifically during the self-report of smoking and alcohol behaviours. A small number of potentially informative studies may also have been excluded from analysis despite including young people between the age of 13 and 24 as the mean age of the sample may have been >30 years. Specific research into the health behaviours and lifestyle choices of teenage and young adult cancer survivors is limited and hence many of the citations used within this review may in fact refer to teenage and young adult aged childhood cancer survivors. Care has been taken where necessary to emphasize this.

A cancer diagnosis and treatment are often viewed as a ‘teachable moment’\(^6\) for behaviour change because of the unique impact diagnosis and treatment has upon an individuals’ motivation to learn about, adopt and maintain positive health behaviours (Demark-Wahnefried et al., 2005a, McBride et al., 2003). However, the majority of the interventions identified within this review were conducted among young people who had completed their cancer treatment. Very little is currently understood about whether a cancer diagnosis during adolescence or young adulthood is ‘teachable moment’ and if this point is related to stage of treatment, age or individual. Further investigation into the changes TYA cancer survivors make to their health behaviour following their diagnosis is required to establish at what time point within the cancer journey health behaviour intervention should be delivered to maximum effect. Equally, further investigations into the information and support preferences of young people who have had a cancer diagnosis is required to clarify the suitability of various modes of intervention delivery. In turn this will provide evidence of the most effective means of promoting health behaviour change among TYA aged cancer survivors’.

2.5 Summary

Supporting and encouraging TYA aged cancer survivors to lead a healthy lifestyle may help reduce the impact of treatment late effects upon both their current and long term health. While

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\(^6\) A teachable moment is defined as ‘a naturally occurring health event thought to motivate individuals to spontaneously adopt risk-reducing health behaviours’ (McBride et al., 2003)
several interventions designed specifically for TYA cancer survivors have shown promising results, further work is required to evaluate how best to promote health behaviour change to young people who have had a cancer diagnosis. Development of such interventions should occur in partnership with both TYA cancer consumer groups and TYA cancer professionals in order to ensure that interventions are developed and designed to have the greatest impact.
Chapter 3

PhD Aims

Current evidence (summarised in Chapter 1) indicates that young people who have had a cancer diagnosis face a risk of cancer recurrence, a heightened risk of second primary cancer, chronic disease, fatigue, and emotional distress throughout their life-course. As described in Chapter 2, a healthy lifestyle could prevent the onset and development of treatment related side-effects and improve quality of life among TYA cancer survivors; but there are gaps in the literature. The small number of existing health behaviour interventions conducted among TYA cancer survivors have shown promising results. However, most of these interventions were small pilot or feasibility studies and none were conducted in a UK health-care setting. Many of these interventions were also resource intensive and did not provide sufficient long-term follow-up of health behaviour change. There is a need for health behaviour change interventions to be developed for TYA cancer survivors’ in the UK which, in line with the National Cancer Survivorship Initiative, should be effective, inexpensive, and have the potential to be rolled out to TYA cancer survivors nationwide.

In order to address this need, the aim of this thesis was to develop a health behaviour intervention specifically for TYA cancer survivors. As it is well recognized that poor intervention design can impede the overall uptake and effect of an intervention, several frameworks (summarised in Chapter 4) have been published to assist researchers and practitioners to develop interventions in a logical evidence based way. As shown in Figure 3.1 the development of the health behaviour intervention for TYA cancer survivors within this thesis has been guided by the Behaviour Change Intervention Design Process (Michie et al., 2014) and the 6 Steps to Quality Intervention Design (6SQuiD) (Wight et al., 2015). The reasons for selecting these frameworks are described in Chapter 4. Study 1 was carried out to define and understand TYA cancer survivors’ health behaviour whilst studies 2, 3 and 4 were carried out to identify intervention functions and options for delivery and implementation. Chapter 9 of this thesis provides greater detail of how the results of studies 1-4 have contributed to the development of the health behaviour change intervention for TYA cancer survivors. The design and purpose of Study 5 reflects Step 5 of the 6SQuiD framework and incorporates Yardleys and colleagues (2015) person based approach to the development and evaluation of the acceptability and feasibility of intervention functions. The methods used within each study of this thesis are described in Chapter 4.
Figure 3.1 The development of a health behaviour intervention for TYA cancer survivors (PhD Study framework)
The specific aims of each study contained within this thesis were as follows:

**Chapter 5, Study 1**
- Compare the health behaviours of TYA cancer survivors to general population controls.
- Examine differences between TYA cancer survivors and general population TYAs perception of health behaviour on current and future health.
- Determine the proportion of TYA cancer survivors who report making changes to their health behaviour following their cancer diagnosis and establish if TYA cancer survivors perceive the need to change their health behaviour.

**Chapter 6, Study 2**
- Establish TYA cancer survivors past experience of, and interest in receiving health behaviour information.
- Identify TYA cancer survivors’ preferences regarding the format, delivery, and timing of health behaviour information.

**Chapter 7, Study 3**
- To explore TYA cancer survivors’ motivation behind lifestyle related behaviour change, and their preferences regarding lifestyle information and health behaviour change intervention delivery.
- Identify barriers and facilitators to health behaviour change among young people affected by cancer.

**Chapter 8, Study 4**
- Explore health professionals awareness of health behaviour guidance, level of health behaviour advice provision and views on the format and delivery of health behaviour advice to TYA cancer survivors.
- Identify health professionals perceived barriers to providing health behaviour advice.

**Chapter 9, Study 5**
The existing literature within this field (Chapter 1 and Chapter 2) and the results from studies 1 to 5 (Chapters 5-8) of this thesis were used to inform the development of a health behaviour intervention. These resources were evaluated by both TYA cancer survivors and health professionals in Study 5 in order to:
- Determine if the health behaviour information developed as part of the proposed intervention meets the needs of TYA cancer survivors and health professionals.
- Establish TYA cancer survivors and health professionals receptivity to proposed health behaviour intervention resources.
- Examine TYA cancer survivors and health professionals receptivity to the inclusion of discrete behaviour change techniques within the intervention resources.
Chapter 4
Methodology

This chapter summarises existing literature concerning complex intervention development, the use of theory in intervention development, the role of patient and participant involvement and the methods used within each study of this thesis.

4.1 Intervention Development: Existing Frameworks & Guidance

Intervention development refers to: ‘the decision-making processes, methods and findings which occur between the idea or inception of an intervention until it is ready for formal feasibility, pilot or efficacy testing prior to full trial or evaluation’ (Hoddinott, 2015). There are a number of intervention development frameworks which currently exist to guide researchers in their approach to intervention design, development and evaluation. As outlined in Appendix 4.1 these include The UK Medical Research Council (M.R.C) Framework for Complex Intervention Development (Craig and Petticrew, 2013); The Intervention Mapping Framework (Bartholomew et al., 1998); The PRECEDE-PROCEED Model of Intervention Development (Green and Kreuter, 2005); Six Simple Steps to Quality Intervention Development (6SquID) (Wight et al., 2015); and The Behaviour Change Intervention Design Process (Michie et al., 2014). These frameworks are designed to support systematic and rigorous intervention development and prevent type II errors occurring due to weak design or poor implementation of the intervention. The accompanying guidance to each of these intervention development frameworks emphasize that intervention development be considered an iterative process with theoretical, empirical and practical information being integrated into the final intervention.

However, despite the widespread use and various merits of these approaches to the development of interventions, these frameworks have a number of limitations. The MRC guidance has been criticised for not providing elaboration or detail on the three stages of intervention development (identifying the evidence base/identifying or developing theory/modelling process and outcomes) and specifically providing little guidance on the exact tasks which should be undertaken within each stage of the development process (Wight et al., 2015). Moreover, the MRC Complex Intervention Framework has been criticised for overlooking the importance of context and being heavily focused towards evaluation. Similarly, the Intervention Mapping framework does not specifically call for consideration of wider social, environmental, and policy factors which may influence the target behaviour of the intervention or the overall translation of the intervention into practice. Akin to the PRECEDE-PROCEED Model of

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* A poster detailing the proposed studies contained within this thesis was presented at the National Cancer Intelligence Network Cancer Outcomes Conference, Belfast, 2015.

Intervention Development, The Intervention Mapping Framework has also been criticised for being a lengthy and highly prescriptive approach to intervention development which is reliant on financial and human resources (i.e. money, technical skill and time); factors of which are often in short supply in public health settings.

Consequently a ‘best’ or ‘gold-standard’ approach to behavioural intervention design and development has not been recognized or agreed-upon (Czajkowski et al., 2015) and often the early stages of complex intervention development covered within these frameworks are not reported (Hoddinott, 2015). This has led to a lack of transparency within the literature regarding the decisions that were made at early stages of the intervention development process and a large amount of ‘research waste’ wherein poor interventions are developed and fully evaluated at a high cost (Chalmers et al., 2014). Moreover, bias is also often present within intervention development. Often public health interventions are developed by researchers and expert panels who are cognitively homogenous in their ideas and thinking. Although intervention development is widely viewed as an iterative process such ‘group-thinking’ can lead to counter-arguments being rationalized and disagreements remaining unvoiced which in turn can lead to premature conclusions, the collection and reporting of only confirmatory data and un-expected findings being attributed to operational flaws rather than the design of the intervention itself. Although there exists stringent guidance on reducing bias within systematic reviews and intervention trials little is known on how to reduce bias, group-thinking and ‘It seemed like a good idea at the time’ style thinking in intervention development (Atkins and Michie, 2015, Higgins et al., 2011).

In an attempt to overcome the limitations of existing intervention development frameworks, reduce bias, and improve the clarity of intervention design and development, Wright and colleagues have proposed six simple steps to quality intervention development (6SquiD) (Wight et al., 2015). Step 1: define and understand the problem and its causes; Step 2: identify which causal or contextual factors are modifiable, which have the greatest scope for change, and who would benefit most; Step 3: decide on the mechanisms of change; Step 4: clarify how these will be delivered; Step 5: test and adapt the intervention; and Step 6: collect sufficient evidence of effectiveness to proceed to a rigorous evaluation. The first four steps of the 6SquiD framework focus on the rationale and thought process behind the purpose of the intervention and the specific contents of the intervention. Step 5 ‘testing and adapting the intervention’ encourages researchers to carry out a formative evaluation in order to clarify key issues such as acceptability to the target population, operational feasibility and how to maximise the reach of the intervention ahead of full scale pilot testing (Step 6). It is thought that if these steps are followed uncostly evaluations or the implementation of unpromising interventions can be avoided (Wight et al., 2015). These steps to intervention development outlined by Wright and colleagues are not dissimilar to the steps contained within the ‘Conceptual framework for planning and intervention-related research’ proposed by de Zoysa
and colleagues in the late 1990s’ and the behaviour change intervention design process more recently proposed by Michie and Colleagues in 2014.

As outlined within Figure 3.1 the studies conducted within this thesis map onto the 6 steps for quality intervention development framework, and the behaviour change intervention design process. These frameworks are analogous to one another and place emphasis upon firstly identifying and understanding key behavioural issues (Study 1 of this thesis) and secondly identifying how the behaviour change intervention should be delivered (Studies 2-4 of this thesis). These steps in intervention development are important as they articulate the need for the intervention in the first instance and when and how such an intervention would be best delivered to the target population. Such data ensures the ensuing intervention is not redundant and will be engaging for target users.

4.2 The use of behaviour change theory in intervention development

A notable similarity between the approaches to intervention development outlined within Section 4.1 is the encouragement of the use of behaviour theory as a means to enhance intervention efficacy (Glanz and Bishop, 2010). Theory-based interventions draw upon recognised psychological theories or models which suggest constructs and mediators of behaviour which could form intervention targets to be addressed by the overall intervention. Such theories are also useful to explain and predict behaviour and intervention outcomes. The incorporation of behavioural theory into interventions is supported by several systematic reviews and meta-analyses which have found theory based behaviour change interventions to be more effective at improving health behaviour than those which are not theory based (Glanz and Bishop, 2010). For example, Avery and colleagues investigated the application of behavioural theory in dietary interventions aimed at cancer prevention and found all interventions which were theory-based (n=10) significantly improved diet quality whereas only half (n=15/30) of the interventions which were not explicitly theory based improved dietary outcomes (Avery et al., 2013). Moreover, a recent meta-analyses of 82 RCTs targeting physical activity behaviour change among the general adult population found theory based interventions had a greater effect than non-theory based interventions (d=0.31, 95% CI:0.24-0.37) (Gourlan et al., 2016). Similarly, within one systematic review exploring the use of computer based interventions to reduce alcohol use among TYAs, a greater proportion of interventions which were based upon a specific theoretical framework reported significant behaviour outcomes than interventions which targeted a specific theoretical construct of behaviour or intervention technique (Tebb et al., 2016). The efficacy of theory-based interventions may be due to the use of theory as a guide to ensure the intervention targets the specific mediators of the target behaviour of the intervention, or may be due to theory-based interventions being developed with greater care, fidelity and structure (Glanz and Bishop, 2010). However, as discussed in Chapter 2, there is a lack of consistency in the way in which theory has been used within existing health behaviour change interventions for TYA cancer survivors. This has also been shown in behaviour change studies conducted among adult...
cancer survivors (Bourke et al., 2013). Moreover, even in instances where an intervention has been developed based on theory, the single chosen theory often does not consider all possible influences on behaviour. For example, the commonly used Theory of Planned Behaviour (TPB)\(^8\) (Ajzen, 1991) and Health Belief Model (HBM)\(^9\) (Janz and Becker, 1984) do not comprise any reference to the influence of impulsivity, self-control or emotional processing. Whilst conversely, the Transtheoretical Model of Behaviour (TTM)\(^{10}\) (Prochaska and Velicer, 1997) includes no reference to the influence of social or environmental factors on an individual’s readiness to undertake behaviour change. In response to the limitations of existing theories the COM-B model of behaviour change (Figure 4.1) and Behaviour Change Wheel (Figure 4.2) were developed in 2011 following a synthesis of existing behaviour change theories (Michie et al., 2011b).

As per the COM-B model of behaviour change, behavioural interventions must enhance an individuals’ capability to regulate the target behaviour; maximise opportunities for an individual to support self-regulation of the target behaviour; and increase individuals’ motivation to engage in the desired target behaviour (Michie et al., 2011b, Abraham et al., 2009). This model recognises that health behaviour is multidimensional and centres upon the premise that an individuals’ capability to change their health behaviour (e.g. become more active, stop smoking, have a healthier diet) is determined by both their physical and psychological capability; that an individual will only carry out a behaviour or change their behaviour if the opportunity is presented within either their physical environment and/or social environment; and that an individuals’ motivation to carry out a change in behaviour is influenced by self-conscious planning and evaluation (reflective motivation) and emotional desires, reactions and impulses (automatic motivation). As shown in Figure 4.2 these components of health behaviour are interactive, for example an increase in knowledge (psychological capability) of the benefits of physical activity for cancer survivors is likely to increase motivation to seek opportunities to be active. Addressing these six tenets (physical capability, psychological capability, physical opportunity, social opportunity, reflective motivation and automatic motivation) of behaviour is likely to lead to an increase in receptivity to health and lifestyle information and health behaviour change intervention efficacy.

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\(^8\) The Theory of Planned Behaviour is a psychological theory which proposes that attitude (either negative or positive), subjective norms, and perceived behavioural control affect an individual intention and subsequently motivation to carry out a behaviour (Ajzen, 1991).

\(^9\) The Health Belief Model is a model which posits that health behaviour is predicted by perceived threat of a behaviour and perceived effect of the behaviour. The model recognises that perceived threat of a behaviour is influenced by perceived susceptibility and perceived seriousness of the behaviour and that perceived benefits and barriers influence an individuals’ appraisal of the effectiveness of behaviour. The model also recognises that self-efficacy and stimuli (cues to action) influence behaviour (Janz & Becker. 1984).

\(^{10}\) The Trans-theoretical Model of Behaviour, sometimes referred to as the Stages of Change (SoC) Model, subdivides individuals into five categories of motivational readiness: i) pre-contemplation, ii) contemplation, iii) preparation, iv) action and v) maintenance. The model centres on the premise that individuals at the same stage of behaviour change would benefit from similar interventions to overcome barriers to behaviour change (Prochaska & Velicer, 1997).
In order to address these six tenants of behaviour, the COM-B model is surrounded within the behaviour change wheel by nine intervention functions and seven policy functions. These nine intervention functions (education, persuasion, incentivisation, coercion, training, enablement, modelling, environmental restructuring, and restrictions) are means by which an intervention may change behaviour and are often referred to as the ‘active-ingredients’ of an intervention. The seven policy functions (guidelines, environmental/social planning, communication/marketing, legislation, service provision, regulation and fiscal measures) represent wider societal and environmental decisions which could be made by authorities to support the delivery of the intervention in a wider public health context. Combined the Behaviour Change Wheel and COM-B model provide a comprehensive theoretical framework upon which to base intervention development. So much so, that the National Institute for Health and Care Excellence (NICE) guidance for development of individual level behaviour change interventions recommends understanding the target intervention behaviour in the context of the COM-B model (National Institute of Clinical Excellence, 2014). However, it is important to note there has been some suggestion that the Behaviour Change Technique Taxonomy, the COM-B model, and Behaviour Change Wheel whilst useful in creating clarity and systematisation of reporting in behaviour change literature, may reduce the variability of theory being applied in health and research (Ogden, 2016).

As highlighted in the published systematic review in Chapter 2, a wide range of psychological theories (Trans-theoretical model, Theory of Planned Behaviour, Theory of Reasoned Action, Social Cognitive Theory, Experimental Learning Theory, Theory of Decision Making, Classic Change Theory, The Health Belief Model, the Precede-Proceed Model, Conflict Model of Decision Making, and Cognitive Theory) have formed the basis of existing health behaviour change interventions piloted among both TYA and adult cancer survivors (Pugh et al., 2016). These interventions commonly attempted to prompt behaviour change by improving the knowledge and skills of young people and often included self-regulatory strategies to behaviour change (e.g. problem solving, planning and normative feedback) and/or one-to-one behavioural support. Such strategies to behaviour change are resource intensive and are often considered transient as behaviour change is often not sustained once the intervention ceases.

Habit formation has been proposed as an effective strategy to self-sustained behaviour change (Nelson et al., 2008). Habit formation is defined as: ‘repeating a chosen behaviour in the same context, until it becomes automatic and effortless’ (Gardner et al., 2012). Making healthy lifestyle choices habitual (i.e. an automatic set of actions triggered in specific contexts due to learned associations between cues and actions) is considered to ‘cement’ behaviour patterns over time. Repeating the same action in the same context (context-dependent repetition) forms and reinforces context-behaviour associations within an individuals’ memory. As the number of the context-dependent actions increase over time a new habit begins to form; as more time surpasses and the number of times the newly formed habit is repeated, the habit becomes increasingly resistant to intentional deliberative actions and is less reliant
on memory, attention and motivation making the behaviour automatic (Lally et al., 2011). The
shift of behaviour being dependent upon willpower and motivation (reflective cues) to being
impulsive and automatic means the behaviour is no longer reliant upon conscious control.
Therefore, whilst behaviour change may initially be the product of intention and motivation,
after repeating the behaviour in a stable context the behaviour will become habitual and
second-nature. Given behaviours developed during adolescence and young adulthood often
persist into adulthood, the habit model of behaviour change provides a reasonable means to
provide young people with lifestyle advice (Gardner et al., 2012, van Genugten et al., 2016).
Figure 4.1 The COM-B model

Figure 4.2 The Behaviour Change Wheel and the COM-B model
4.3 Patient and participant involvement (PPI) and user centred intervention design

Aside from the use of theory, a second important feature of the various intervention development frameworks outlined within section 4.2 is the frequent emphasis upon the importance of researchers and public health practitioners taking a user centred and phased approach to intervention development. Incorporating feedback from both users and stakeholders at all stages of the intervention design process means the ensuing intervention is more likely to be accepted by patient groups and successfully integrated into usual practice (Brett et al., 2014b). Moreover, there is some (albeit weak) evidence that an intervention will have greater odds of being successful (i.e. achieving behaviour change) if the users and stakeholders of an intervention are active participants within the planning and development stages of the intervention itself (Brett et al., 2014a).

The person-based approach (PBA) to intervention development established by Yardley and colleagues (2015) outlines a systematic approach to addressing and incorporating the views of target users within intervention development. The person-based approach centres around understanding the behaviours, needs, and perspectives of the user population and grounding the contents of the intervention in the psychosocial context in which the intervention will be used (Yardley et al., 2015b). The evaluation and acceptability phases of the PBA framework particularly focus towards understanding users’ acceptance, engagement, trust, and satisfaction with the specific behaviour change techniques incorporated into the intervention. Suggested activities which should be undertaken as part of the PBA to intervention development include: consultation with experts, members of user groups, and other stakeholders; observation of real-life context of intended health care product; creation of personas, scenarios, use cases; creation and usability testing of prototype product; mixed methods process analyses of implementation (reach, fidelity, context effects) and in-depth analysis of mediators and moderators of intervention efficacy. As per the theory of self-determination (Ryan and Deci, 2000)11 understanding and incorporating users’ needs and perspectives into the intervention design process supports an individuals need for autonomy and a sense of competence which will ultimately enhance their perceived relatedness to, and support for, the intervention. It is considered that a person-based approach to intervention development will optimize users’ autonomous motivation to use the final intervention and overcome the common problem of low uptake and adherence commonly encountered during intervention piloting and evaluation. However, it is worth noting that the PBA approach to intervention development is time consuming and reliant on patient engagement. Moreover, the guidance on the PBA approach to intervention development does not specify how best to interpret conflicting results.

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11 The Theory of Self-Determination is a theory of motivation which centres on social and cultural factors which facilitate or undermine an individuals’ engagement in activities (Ryan and Deci, 2000).
In the context of TYA cancer research there is a continual drive to involve young people in research design and development. Including TYA cancer survivors views in intervention development in particular ensures the ensuing intervention meets the needs of young people and prevents any disparity between young peoples and professional perception of patient need (Taylor et al., 2011).

In reflection of the benefits behind the person-based-approach to intervention development, a strong user centred approach has been taken towards the development and design of all studies within this PhD thesis. An oral presentation of the protocol for this PhD thesis was presented to the groups and organisations listed below. All feedback and comments from academics, health professionals, and young people with cancer during these presentations contributed to the planning, development and methodology of the studies contained within this thesis.

- London Cancer Network, North Thames TYA Cancer Network Coordinating Group (September, 2014)
- University College Hospital, London, Clinical Trials Group (September, 2014)
- CLIC Sargent Young Peoples Reference Group (December, 2014)
- National Cancer Research Institute (NCRI), Psychosocial Oncology & Survivorship Clinical Studies Group (CSG), Lifestyle and Behaviour Change Sub-Group (January, 2015)
- NCRI, Teenage & Young Adult CSG (October, 2015)
- Surrey University, Cancer Care Research Group, Invitation from Dr Lisa Mcann (February, 2016)
PhD Methods

4.4 TYA cancer survivor health and lifestyle questionnaire

Data from the TYA Cancer Survivor Health and Lifestyle Questionnaire are presented in Chapter 5 (Study 1) and Chapter 6 (Study 2).

4.4.1. Ethical Approval

Ethical approval for this study was provided by both University College London Research Ethics Committee reference: 6206/001 and London Hampstead NHS Research Ethics Committee reference: 15/LO/0764. Study approval letters are contained within Appendix 4.2 and Appendix 4.3 respectively.

4.4.2 Design and development

The Health and Lifestyle Questionnaire was developed to gather novel data regarding the health behaviours and intervention preferences of TYA cancer survivors within the UK. The questionnaire was based on an ongoing large-scale health behaviour survey of breast, prostate and colorectal cancer survivors ‘ASCOT’ that is being conducted by University College London in partnership with London Cancer (Beeken, 2016). The ASCOT survey was adapted by me, in partnership with CLIC Sargent and TYA cancer specialists (Rachael Hough, Consultant Haematologist; Wendy King, TYA Nurse Consultant; and Helen Gravestock, CLIC Sargent Research and Policy Manager) to be relevant to TYAs. As detailed in section 4.4 the protocol and outline of the survey was also presented to several TYA cancer professional and patient groups. Young people, TYA cancer health professionals, and researchers working within the TYA field were invited to provide comments on the design of this study and provide feedback on the content of the questionnaire. Some health professionals thought exploring illicit drug and sexual behaviours would have been a useful addition to the survey. Although these topics were considered important, it was agreed that these were beyond the scope of this PhD. One cancer survivorship expert (Dr Gill Hubbard) suggested the addition of a sun-related health behaviour measure, which led to the inclusion of the items regarding tanning, sun-burn and sun-bed use in the questionnaire.

The questionnaire was piloted with 8 TYA cancer patients attending an out-patient clinic at University College Hospital, London (UCLH). They were asked to read through the questionnaire and provide comments and feedback on the content of the survey and their understanding of each individual question. Overall, they were enthusiastic about the study concept, thought the study would be very beneficial to young people with cancer, and felt the questionnaire was easy to complete. However, many commented on the length of the survey as being too long. Some very minor structural and content changes were made to the survey following this feedback.
4.4.3 Measures

The full version of the TYA Cancer Survivor Health and Lifestyle questionnaire is provided in Appendix 4.4. In order to maximise participants likelihood of completing the survey it was available online or on paper. The paper version of the questionnaire was professionally designed to fit with the visual identity of CLIC Sargent. In addition, in order to enhance recruitment participants could complete the survey anonymously, but also had the option to provide contact details for follow-up interviews.

Demographics and health characteristics

Participants were asked to report their age, sex, highest level of educational attainment, marital status, current living arrangement, and ethnicity. Participants were asked to report what type of cancer they were diagnosed with and the date of their diagnosis. Participants were also asked to report their stage at diagnosis, current treatment status, time since treatment completion, and any health problems (other than cancer) they suffer from. Due to the nature of the recruitment methods used within this study it was not possible to access young peoples’ clinical records to gather this diagnostic or health information.

Physical Activity

A modified version of the Godin Leisure Time Exercise Questionnaire (GLTEQ) was used to assess physical activity (Godin et al., 1986). The GLTEQ asks participants to report on average how often they engage in mild, moderate and strenuous exercise for at least 15 minutes or more in a typical week during free time. Whilst it is acknowledged that an objective measure of physical activity would have been preferable (Reilly et al., 2008) this was not feasible for this study due to lack of available resources. However, the GLTEQ has been used in similar studies of TYA cancer survivors (Wright et al., 2013, Gilliam et al., 2012) and has demonstrated reliability and validity within the oncology research setting (Amireault et al., 2015). In one study of childhood leukaemia survivors (n=28; mean age= 10.7 years, range 5.7 – 14.7 years) physical activity measured by GLETQ Leisure Score correlated to physical activity measured by accelerometer (r=0.57; p<0.005) (Tillmann et al., 2002). The modifications to the original measure were minor and involved the addition of a single item to collect information regarding the average duration (in minutes) of each exercise intensity. This modification is common with over 80% of published articles using the GLETQ in oncology research reporting a similar small amendment to the original questionnaire (Amireault et al., 2015).

Participants were also asked to report how their current physical activity levels compare to before their cancer diagnosis and whether they thought they should do more, less or not change the amount of physical activity they do.
Diet and Nutrition

A modified version of the Dietary Instrument for Nutrition Education (DINE) food frequency questionnaire (FFQ) was used to assess dietary intake (Roe et al., 1994). Items contained within the original DINE FFQ were reviewed, compared to the National Diet and Nutrition Survey (NDNS), compared to the Low Income Diet and Nutrition Survey (LIDNS) and adapted by a clinical research dietician (Dr Helen Croker) to ensure all items contained within the FFQ were relevant to young people and up-to-date. The adapted DINE questionnaire contains 12 questions to assess dietary fibre intake, 21 questions to assess total fat intake, 3 questions to assess red meat intake, 1 question to assess processed meat intake, and 7 questions to assess sugar intake. The full list of questions and associated dietary group are contained within Appendix 5.2.

Participants were also asked to report frequency of fruit and vegetable consumption. The two-item fruit and vegetable consumption measure used within the health and lifestyle questionnaire has been used previously (Steptoe et al., 2004, Wolf et al., 2009) and has shown sufficient construct validity when compared to objective measures (bio-markers plasma ascorbic acid, beta-carotene and alpha-tocopherol 24-hour urinary potassium excretion) of fruit and vegetable consumption, (Cappuccio et al., 2003).

Participants were also asked to report how their diet is now in comparison to before cancer, and if they have made efforts to change their diet since their cancer diagnosis.

Smoking

Smoking status was determined using questions adapted from the Health Survey for England (Craig, 2009). Participants were asked to report if they currently smoke cigarettes and if so, how many per day. Smokers were asked to report if they ever tried to quit smoking before their cancer diagnosis and if they have tried to quit smoking since their cancer diagnosis. Those who reported not smoking were asked to report if they had ever smoked regularly in the past.

Alcohol consumption

Alcohol intake was assessed using three questions taken from the Alcohol Use Disorders Identification Test Consumption (AUDIT-C) scale (Bush et al., 1998). The 3 item AUDIT-C measure has been found to be a valid and sufficiently accurate measure (Sensitivity Score: 0.88, 95% CI 0.83-0.93) of alcohol consumption and binge drinking among young adult and adolescent age groups (Cortés-Tomás et al., 2016, Knight et al., 2003). Participants were asked to report frequency of alcohol consumption, the number of units consumed on a typical day of drinking and frequency of binge drinking within the past year. Participants were also asked to report how their alcohol consumption compares to before their cancer diagnosis, and if they have any desire to decrease the amount of alcohol they currently consume.
Sun Related Behaviour

Three items taken from a sun health behaviour instrument developed in New Zealand (Wright et al., 2008) and used to assess sun-related behaviours in Scottish adolescents (Kyle et al., 2014) were used to assess incidence of sun-bathing, incidence of sun-burn and use of high-street sunbeds over the past year. The inclusion of these items were based upon correspondence with Dr Gill Hubbard (Reader, University of Stirling). To date, there has been no data published on the reliability or validity of these single items.

Weight Status

In order to determine young peoples’ weight status self-reported height and weight were recorded. Participants were also asked to report how their weight compares to before their cancer diagnosis, and whether they would currently like to lose, gain or keep their weight the same. Similar to physical activity data, whilst it is acknowledged that an objective measure of weight would have been preferable (Sherry et al., 2007) this was not feasible for this study due to lack of available resources.

Perception of health behaviour on current and future health

Participants were asked to report the extent to which they felt each health behaviour (eating a balanced diet, not smoking, exercising regularly, avoiding alcohol, eating fruit and vegetables, avoiding red or processed meat, maintaining a healthy weight and looking after their skin in the sun) were important to their current and future health. Response options were on a 5 point Likert scale from ‘Not at all important’ to ‘Very important’.

Health behaviour information and advice received

Participants were asked to report if they have ever been given information or advice on physical activity, diet, alcohol consumption, or smoking since being diagnosed with cancer. Those who indicated that they had received lifestyle advice were asked to provide specific details of the advice they were given and who had provided the advice. Participants were also asked to report if they thought of the amount of lifestyle advice they had received was too little, too much or about right.

Lifestyle information and advice preferences

Participants were asked to recall if since their diagnosis a health professional had ever given them any direct advice about physical activity, diet, weight management, alcohol consumption or smoking. The advice young people received was recorded in by an open response question asking participants to record the details of the advice they were given. Young people were asked to report their level of interest in receiving information and advice on all health behaviour topics covered within this study. Participants were also asked to indicate if they would have taken up the offer of lifestyle advice at the end of their initial treatment and whether they would take up the offer now. Response options were ‘yes definitely’, ‘yes probably’, ‘probably not’, ‘definitely not’, and ‘not sure’. Young people were asked to select from a pre-determined list
where they seek information or support for each health behaviour. The list included friends, parents, printed materials, YouTube, websites online, telephone helplines, or health professionals. Participants were asked to report when they thought the best time to offer health behaviour information to young people would be (Before treatment starts/ during treatment/ immediately after treatment/ 3-5 months after treatment/ 6-12 months after treatment/ more than 1 year after treatment) and their level of interest in various advice formats (short leaflet/ long leaflet/ internet information/ mobile or tablet app/ DVD or video information/ telephone call from a health professional/ one individual counselling session/ multiple individual counselling sessions/ one group session/ multiple group sessions). These answer options were based upon existing information delivery format options identified within the systematic review of existing health behaviour interventions for young people with cancer reported in Chapter 2.

4.4.4 Participant Eligibility

Any young person between the age of 13 and 25 who had been diagnosed with cancer at any point in their lifetime was eligible to complete the survey; this included young people aged 13-25 years of age who had been diagnosed with cancer during their childhood (aged 0-12 years). Young people with cancer were eligible to complete the survey regardless of treatment status. In line with the National Cancer Institute (NCI) definition of a cancer survivor (NCI, 2015), the inclusion criteria was deliberately kept broad in order to capture a rich picture of the health behaviours of a wide cross-section of TYA cancer survivors, rather than limiting to specific age or disease groups.

4.4.5 Recruitment and Sampling

The Health and Lifestyle questionnaire was available to young people with cancer in electronic online and paper format between May 2015 and April 2016. Figure 4.4 displays a flowchart of the recruitment strategies employed within this study. In brief, TYA cancer survivors were either recruited through University College Hospital, London (UCLH) or project partners, CLIC Sargent. Young people who completed the survey at UCLH did so during normal clinic waiting times. The link to the online version of the survey was advertised upon the CLIC Sargent website, Twitter page and Young Peoples’ Network Facebook group. Paper copies of the questionnaire were also handed out by social workers affiliated to or employed by CLIC Sargent. In addition, all young people who had previously volunteered in research for CLIC Sargent and had expressed an interest in participating in future research were sent paper copies of the survey accompanied by a free-post envelope.

All young people who were given the survey in clinic at UCLH, or received a physical copy of the survey in the post via CLIC Sargent, also received a participant information sheet detailing why they were being invited to complete the survey and take part in this study (Appendix 4.5). Young people who followed the online link to the survey were routed to an electronic version of the same participant information sheet and asked to confirm that they had read it prior to
the beginning of the survey. By completing and returning the survey young people were consenting to their anonymous data being used for analysis.
Figure 4.3 Flow chart: Health and lifestyle questionnaire recruitment strategies

University College London Hospital

Eligible participants identified during MDT meeting

Participants receive the survey via a paper version during their usual visit to clinic or sign-posted to an online version.

CLIC Sargent

Online Version

Paper Version

The link to the online survey was available online via the CLIC Sargent website, Twitter account and young people’s Facebook page. Reminders and notifications about the survey link were sent out at various time-points.

CLIC Sargent Social Workers

CLIC Sargent social workers handed physical copies of the survey to young people within their care. Each survey was accompanied by a participant information sheet and a free post envelope to return to the study team at UCL.

CLIC Sargent Young Peoples Panel

Young people who had given CLIC Sargent their contact details as an expression of interest in taking part in research were mailed a physical copy of the survey in the post accompanied by a participant information sheet and...

Participants complete the survey without providing contact details.

Anonymous survey data included within analysis.

Participants complete the survey and provide contact details.

Invited to participate in Study 2
4.5 General population TYA health and lifestyle questionnaire

Data from the general population TYA Health and Lifestyle Questionnaire is presented in Study 1.

4.5.1 Ethical Approval

Ethical approval for this study was provided by University College London Research Ethics Committee reference number: 6206/001. The approved amendment request to the original ethics application is outlined in Appendix 4.6.

4.5.2 Design

The general population TYA survey (Appendix 4.7) was based upon the Health and Lifestyle Questionnaire as described in Section 4.5. Minor changes were made to the TYA Cancer Survivors version of the Health and Lifestyle Questionnaire. The primary difference between the survey for TYA cancer survivors and TYAs’ within the general population was the removal of all questions relating to cancer diagnoses and experience of treatment. As the original survey had previously been piloted among TYA cancer survivors, it was not considered necessary to pilot the survey among adolescents and young adults within the general population.

4.5.3 Measures

Demographics and health characteristics

Participants were asked to report their age, sex, highest level of educational attainment, marital status, current living arrangement, and ethnicity. Participants were also asked to report if they were experiencing any health problems, if they had a family history of common health difficulties.

Health Behaviour

The same measures of health behaviour (physical activity, diet, smoking, alcohol consumption and sun safety) as outlined within Sections 4.5.3 were adopted within the survey.

The same questions on perception of current health behaviour were also used within the survey.

4.5.4 Participant eligibility

Any young person between the age of 13 and 24 years of age within the general population of the United Kingdom was eligible to complete the survey. The inclusion criteria was deliberately kept broad in order to capture a rich picture of the health behaviours of a wide cross-section of TYAs residing within the UK rather than limiting to specific age or demographic groups.

4.5.5 Recruitment

The Health and Lifestyle questionnaire was available to young people in electronic online and paper format between May 2016 and January 2017. In brief, young people were either
recruited online through social media, youth networks or websites directed towards teenagers and young adults. Paper versions of the survey were made available to young people through schools and University College London. Participants who completed the survey at school did so during normal school hours either during assembly or form group tutorial time. Participant information sheets are displayed in Appendix 4.8; Parental information sheets and consent opt-out forms are displayed in Appendix 4.9.
4.7 Teenage and young adult cancer survivor interviews and focus groups

Data from the TYA Cancer Survivor Interviews and Focus Groups is presented in Study 4, Chapter 8.

4.7.1 Ethical Approval

Ethical approval for this study was provided by University College London Research Ethics Committee reference number: 6206/001. Study approval letters are contained within Appendix 4.2 and Appendix 4.3.

4.7.2 Participants & Recruitment

Participants were TYA cancer survivors who had completed the Health and Lifestyle Questionnaire outlined within section 4.2 of this chapter. Figure 4.4 displays an overview of the recruitment strategies employed for the Health and Lifestyle Questionnaire. All survey responses were anonymous, but participants who completed them had the option to express interest in being involved in a qualitative study focussing on the development of a lifestyle intervention for TYA cancer survivors by leaving contact details. If a young person indicated interest in taking part in either a focus group or interview, they were sent an information sheet (Appendix 4.10) and consent form (Appendix 4.11). Young people had the option to choose the method of participation most convenient to them (a focus group or telephone interview). It was hoped that by proposing a combination of participation methods there would be increased interest.

All interviews and focus groups were conducted by myself between July 2015 and January 2016. All participants provided informed written consent prior to the commencement of the interview or focus group. Young people received a £15 online shopping voucher for their participation.

4.7.3 Interview topic guide

The interviews and focus group followed the same semi-structured interview guide (Appendix 4.12) which centred around three main themes: i) what a healthy lifestyle means ii) past experiences of receiving, asking and searching for lifestyle advice and iii) preferences relating to lifestyle information delivery with regard to content, format and delivery. Participants were prompted when necessary and encouraged to share their thoughts and experiences openly.
4.8 Teenage and young adult cancer health professionals survey

Data from the survey of TYA cancer health professionals is presented in Study 5, Chapter 9.

4.8.1 Ethical Approval

This study was approved by University College London Ethics Committee (reference 4456/001), (Appendix 4.13).

4.8.2 Design

Data were collected via an anonymous online survey.12 The development and design of the survey was based on previous work carried out by Williams and colleagues, who assessed knowledge and predictors of lifestyle advice in health professionals working with adult breast, prostate and colorectal cancer patients (Williams et al., 2015). The survey was adapted for use among TYA specialists in consultation with several health professionals working directly with young people with cancer, (Helen Gravestock, CLIC Sargent, Research and Policy Manager; Michelle Vernon, CLIC Sargent, Lead social worker; Wendy King, Nurse Consultant).

4.8.3 Participants

Health professionals (oncologists, haematologists, surgeons, cancer nurses and allied health professionals) working directly with TYA cancer patients in the UK were eligible to complete the survey.

4.8.4 Recruitment

The web link to the survey was cascaded through the mailing lists of several UK based professional and charitable bodies specialising in the care of TYA cancer patients. The survey was also circulated by existing contacts within the NHS, London Cancer Network and the National Cancer Research Institute Teenage and Young Adult Clinical Studies Group (NRCI TYA CSG). Several reminders about the survey were posted upon the TYAC website and sent to services staff employed or affiliated with CLIC Sargent. TYAC is a professional organisation within the UK which aims to unite professionals working with young people with cancer and CLIC Sargent is a UK based cancer charity specialising in caring for and supporting young people, and their families, affected by cancer. By following the online link and completing the survey participants consented to the use of their anonymous data.

4.8.5 Measures

The full survey is shown in Appendix 4.14. Demographic questions included those relating to professional speciality and place of work. Professional speciality questions included professional group, length of time in current role, length of time working with young people, best fit description of patient age group, and patient cancer group. Place of work questions

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12 https://www.surveymonkey.com/r/8BQH63W
investigated hospital affiliation (principal treatment centre/designated hospital/other) and regional affiliation.

Awareness of lifestyle recommendations and guidelines was assessed using the question: ‘Are you familiar with any guidelines specifically for cancer patients for any of the following lifestyle topics?’ Lifestyle topics included physical activity, diet, weight management, smoking, alcohol consumption and sun safety. In order to determine knowledge and awareness of the wide array of lifestyle recommendations and guidance available, this was followed by the open response question ‘Do you remember the name of the guidelines or who produced them?’.

TYA health professionals’ level of provision of lifestyle advice was determined by two questions: ‘With what percentage of your patients do you enquire about the following lifestyle topics?’ and ‘With what percentage of your patients do you give advice about the following lifestyle topics?’ Reported patient interest in lifestyle information was determined by the question: ‘How many of your patients ask you for information on the following topics’. Response options for all of the above questions for each lifestyle topic were ‘none’, ‘1-25%’, ‘26-50%’, ‘51-75%’, ‘>75%’. Lifestyle topics listed in order were physical activity, diet, weight management, smoking, alcohol consumption and sun safety.

Delivery of lifestyle advice was assessed by the question; ‘If you were to give advice on the following lifestyle topics, what form does this advice usually take?’. Response options included ‘giving verbal advice’, ‘giving written advice e.g. leaflet/pamphlet’, ‘referring to a website’, ‘referring to another health professional’ or ‘other’.

Perceived barriers were assessed using ‘Would any of the following factors put you off giving your patients advice?’ Response options were based upon barriers previously reported within the literature in adult cancer survivors (O’Hanlon and Kennedy, 2014, Spellman et al, 2013, Anderson et al, 2013) and included; ‘Don’t think advice would change their behaviour’, ‘not convinced it would affect cancer outcomes’, ‘lack of clear guidelines’, ‘felt I was being judgemental of their choices’, ‘patient too frail or unwell’, ‘lack of patient interest’, ‘lack of time’, ‘none of the above’, or ‘other’. Perceived problems in providing lifestyle information to patients were explored by the question ‘Would you perceive any problems in providing information to your patients?’ (yes/no) followed by an open response question for further details.

In order to explore TYA health professionals’ opinions about the format and delivery of lifestyle information, the following questions were asked: ‘From your experience which format do you think patients would like lifestyle information to be in? Response options included ‘leaflet or pamphlet’, ‘website’, ‘mobile app’, ‘other’. This was followed directly by a question exploring when this advice should be delivered to young people including ‘before treatment’, ‘during treatment’, ‘0-6 months’ ‘post-treatment’, ‘6-12 months post treatment’, or ‘12+ months post treatment’.
4.9 User Evaluation of a Health Behaviour Intervention for TYA Cancer Survivors

The overall development process, and specific details of how the findings from studies 1-5 of this PhD thesis contributed to the development of the intervention resources outlined within Study 5 is contained within Chapter 9. As highlighted in Section 4.2 feasibility and piloting testing is a core step of the intervention development process (Campbell et al., 2007). Carrying out a formative evaluation can provide insight into key issues which may affect the efficacy of a larger scale pilot trial such as: acceptability of the intervention to the target group; acceptability of the intervention to stakeholders and delivery organisations; if the content of the intervention is satisfactory to meet the needs of the target population; and if intervention format and delivery methods are appropriate. Such findings can help identify how best to maximise the uptake and adherence to the intervention and determine if training is required for target groups, stakeholders, and delivery organisations before they use the intervention (Wight et al., 2015). The informal testing and user evaluation stages of intervention development is often not reported or are 'hurried' due to lack of time or resources but formative evaluation studies can improve the overall uptake and effectiveness of an intervention (Czajkowski et al., 2015).

4.9.1 Ethical Approval

Ethical approval for this study was provided by University College Research Ethics Committee reference 6206/003. Study approval letters are contained within Appendix 4.15

4.9.2 Design

Written health behaviour information and illustrations (shown in Appendix 9.1 and Appendix 9.2) of health behaviour change techniques (goal setting, action planning, self-monitoring, prompts, feedback and social support) and illustrations of behaviour change intervention resources (an app, a website and leaflets) were incorporated into an online evaluation survey (Appendix 4.18). A screenshot of what the illustrations and survey appeared like in the online survey is included in Appendix 4.19.

4.9.3 Participants

TYA Cancer Survivors: Any young person between the age of 13 and 24 years who has a cancer diagnosis within their lifetime was eligible to participate. This included young people within this age bracket who received their cancer diagnosis during their childhood (aged 0-12 years). In alignment with the National Cancer Institute definition of cancer survivor young people were eligible to participate irrespective of their treatment status.

TYA Health Professionals: Any health professional (oncologists, haematologists, surgeons, cancer nurses and allied health professionals) working directly with TYA cancer patients within the UK were eligible to participate.
4.9.4 Recruitment

TYA Cancer Survivors: Young people living with and beyond cancer were recruited through project partners, CLIC Sargent. Adverts for the study were posted upon the CLIC Sargent website, twitter page, and young peoples’ network Facebook page.

TYA Health Professionals: A recruitment email was sent to all health professionals who completed the earlier health professionals survey study (Study 4, Chapter 9). The recruitment advert was also circulated by existing contacts within the NHS, London Cancer Network, National Cancer Research Institute Teenage and Young Adult Clinical Studies Group (NCRI TYA CSG), Teenage Cancer Trust and CLIC Sargent.

Participant information sheets (Appendix 4.16 and 4.17) outlining the purpose of the study were included on the first page of the online survey.

4.9.5 Incentives

Each young person who participated in the online survey was eligible to enter a prize draw for £50 Amazon gift voucher. There was no incentive available for health professionals.

4.9.6 Measures

The questions contained within the TYA cancer survivor and TYA health professionals’ survey are contained within Appendix 4.18. Both the TYA cancer survivor and TYA health professionals online evaluation survey consisted of two parts. Within Part 1 participants (both TYA cancer survivors and health professionals) were asked to review and evaluate the written information on physical activity, diet, smoking, alcohol consumption and sun safety for standard, quality, and relevance. Within Part 2 of the online evaluation survey, participants were asked to review and evaluate the illustrations of the proposed behaviour change techniques and intervention delivery resources for appeal and usability. Each of the questions within the survey was guided by items contained within the Ensuring Quality Information for Patients (EQIP) tool (Moult et al., 2004). The EQIP tool is a validated information assessment tool which was developed during three annual rounds of health care leaflet auditing by the Patient Information Group at Great Ormond Street Childrens’ Hospital. The original scale is intended for use by health professionals to rank the quality of written patient information; questions contained within both the TYA cancer survivor and health professionals’ survey were based upon each of the quality criterion contained within the original scale.

Cassie Davis (CLIC Sargent, Information Manager) and Stephanie Jury-Dale (CLIC Sargent, Information Officer) were invited to provide comments on the design of this study and provide feedback on the content of both the young peoples and health professionals versions of the evaluation survey. Overall they were impressed with the design of the study and noted that the EQIP scale questions were not dissimilar to the questions they ask when evaluating written information resources in house at CLIC Sargent. Both Cassie and Steph were confident that the evaluation process outlined within this study was sufficient to meet the Information
Standard Accreditation (ISA) of CLIC Sargent. Cassie and Steph suggested a minor change to the wording of one of the questions originally contained within the EQIP scale. The original question asking ‘Is the information short and concise? Yes/No’ was changed to ‘Is the information written at the right level? Yes/No’.

**Demographic & Health Information**

**TYA Cancer Survivors:** Participants were asked to report their age, sex, highest level of educational attainment, marital status, current living arrangement, and ethnicity. TYA cancer survivors were also be asked to report what type of cancer they were diagnosed with, the date of their diagnosis, the stage of their cancer at diagnosis, their current treatment status, and any health problems (other than cancer) they suffer from.

**TYA Health Professionals:** Health professionals were be asked to report their professional speciality, length of time in current role, length of time working with young people with cancer, best fit description of patient age group, patient cancer group and place of work.

**Part 1. Information Evaluation**

**Perceived quality of the Information**

TYA cancer survivors and health professionals were asked to rate the quality information on each health behaviour topic as either very good quality, good quality, neither high or low quality, low quality or very low quality.

**Perceived relevance of the information**

TYA Cancer Survivors perceived relevance of the information on each health behaviour was determined by two questions: ‘How useful is this information on to you?’ and ‘Do you think young people need this kind of information’. Professionals perceived relevance of the information on each health behaviour was determined by two similar questions ‘How useful do you think the information is to young people with cancer’ and ‘Do you think young people with cancer need this kind of information?’. The response options for the first question were ‘Very useful; quite useful; neither useful or unhelpful; unhelpful; and very unhelpful’ and response options for the second question were ‘Yes, very much; yes; neither yes or no; no; or no this information is relevant’ in both the TYA and health professional versions of the evaluation survey.

**Perceived standard of the information and suggested improvements**

Both TYA cancer survivors and health professionals were also asked to answer a series of questions exploring the standard of the written health behaviour information. These questions were ‘Is it clear what the information was about?’ ‘Do you understand the language being used?’ ‘Is the information written at the right level?’ and ‘Is the information written in a tone which you think is appropriate (i.e respectful and non-judgemental?)’. Response options were ‘Yes’, ‘Partly’ and ‘No’. Within an open response question both TYA cancer survivors and
health professionals were asked comment on how they thought the information on each health behaviour could be improved. TYA cancer survivors and health professionals were also asked to rate the extent to which the written information met their information need on each health behaviour topic. Response options were on a five-point likert scale from ‘Not at all’ to ‘Very Much’. A single question asking participants to rate the extent to which they liked or disliked the information on the benefits of a healthy lifestyle, the information on the risks of an unhealthy lifestyle, the ideas for everyday change sections and the information on forming news habits was also asked. Participants were also asked to comment within an open response box on any further information they would like to see included about each of the health behaviour topics.

Part 2. Intervention Resource Evaluation

As outlined earlier illustrations of health behaviour change techniques (goal setting, action planning, self-monitoring, prompts, feedback and social support) and illustrations of behaviour change intervention resources (an app, a website and leaflets) were incorporated into the second section of the survey.

The appeal of the resources

Participants were asked to rate how appealing they found the idea of each behaviour change techniques illustrated: ‘How appealing do you find the idea of [insert behaviour change technique e.g. goal setting]’. Response options were ‘very appealing; quite appealing; not appealing; not at all appealing’.

Usability of the intervention resources

For each behaviour change technique a single question was used to explore whether young people believed they would use the intervention resources as intended to change each individual health behaviour: ‘For each health behaviour listed below (list included physical activity, diet, smoking, alcohol consumption and sun safety) how likely are you to [insert behaviour change technique e.g. goal setting]. Response options were ‘not at all likely’, ‘maybe’ and ‘very likely’. Participants were also asked to rank each of the behaviour change techniques in order of preference and rank how likely they thought they would be to use the intervention materials if they were available today. Response options were ‘extremely likely’, ‘very likely’, ‘somewhat likely’ ‘not so likely’ and ‘not at all likely’. TYA cancer survivors were asked whether or not they would recommend the resources to another young person with cancer and health professionals were asked whether or not they would signpost young people within their care to the intervention resources. Response options were ‘no not at all’, ‘maybe’ and ‘definitely, yes’. Participants were also asked to select which format (leaflet, website or app) of the intervention resources they would be most likely to use. Within two separate open response questions participants were asked to comment on each of the resources in turn and identify features they liked and disliked.
Potential efficacy of a behaviour change intervention for TYA cancer survivors

TYA cancer survivors were asked to consider the written health behaviour information and the intervention resources together and consider whether combined the resources would be effective at helping them to i) be more active ii) have a healthier diet iii) quit smoking iv) limit your alcohol consumption and v) improve sun safe behaviours.

Suggested improvements

Suggestions for improvement were collected within open response questions. Participants were asked to consider the intervention resources as a collective and comment on aspects they liked the most, aspects they disliked, and how they thought the intervention resources could be improved overall.

4.10 Statistical analyses, results & methodological limitations

The statistical analyses, results, and specific methodological limitations of each study are outlined in the relevant study chapters.
Chapter 5

Study 1

The Health Behaviours of TYA Cancer Survivors and General Population Controls

5.1 Background

As discussed within Chapter 1 TYA cancer survivors are at a significantly higher risk of health problems than members of the general population (Hudson et al., 2013, Oeffinger et al., 2006). However, as highlighted in Chapter 2, there is growing evidence that positive health behaviours (particularly physical activity) may improve physical and psychosocial health outcomes among young people with cancer both during and after cancer treatment (Smith et al., 2014, Rustler et al., 2017, Baumann et al., 2013). As such, and in keeping with the Childrens’ Oncology Group long-term follow up recommendations for young people with cancer, TYA cancer survivors are encouraged to be as physically active as possible, eat a healthy diet and abstain from smoking, drinking and tanning (The Childrens Oncology Group, 2008).

However, as highlighted in Chapter 2, of the few studies which have investigated the health behaviour status of TYA cancer survivors, the majority have been conducted in the US and predominantly explored the health behaviour status of long-term survivors of a cancer diagnosed during childhood. Findings generally indicate that these cancer survivors have low levels of physical activity, consume relatively poor diets, drink moderate to large quantities of alcohol and engage in health risk behaviours such as smoking and intentional tanning (Belanger et al., 2012, Stolley et al., 2010, Ladas, 2014, Marjerrison et al., 2016, Zwemer et al., 2012, Tercyak et al., 2006). Only one study regarding the health behaviours of TYA cancer survivors (n=178) in the UK has been published to date (Larcombe et al., 2002). This study found TYA cancer survivors (mean age at time of study: 25.2 years, mean age at diagnosis: 8.2 years) to have a lower health behaviour index score when compared to either general population controls or siblings, suggesting TYA cancer survivors practice better health behaviours than their peers. However, the survey instruments used to gather data on health behaviour within the study were non-validated and by calculating a health behaviour index score as the primary outcome measure Larcombe and colleagues limited the extent to which findings may be compared to findings from other studies of TYA cancer survivors or studies of TYAs within the general population.

Data presented in this chapter was presented orally at the Adolescent and Young Adult Cancer Congress, Edinburgh, December 2016
There is therefore a need to fully explore the current health behaviours of TYA aged cancer survivors within the UK and to establish the extent to which the health behaviours of young people with cancer differ to the general population. There is especially need to explore the health behaviours of TYA cancer survivors undergoing cancer treatment as there is very little published data concerning the health behaviours of young people receiving active cancer therapy. Such data is important to inform an understanding of how cancer affects the lifestyles of TYAs and how behaviour change interventions may be best tailored to the needs of young people with cancer. Similarly, it is important to understand if young people with cancer have made, or perceive the need to make, positive changes to their lifestyle following their cancer diagnosis. Such data will provide insight into how motivated TYA cancer survivors are to changing their health behaviour.

5.2 Aims
As described in Chapter 3, the aims of this study were to:

i) Compare the health behaviours of TYA cancer survivors to general population controls

ii) Examine differences between TYA cancer survivors and general population TYAs perception of health behaviour on current and future health.

and;

iii) Determine the proportion of TYA cancer survivors who report making changes to their health behaviour following their cancer diagnosis and establish if TYA cancer survivors perceive the need to change their health behaviour.

5.3 Methods
5.3.1 Population
Recruitment and data collection methods are outlined within Chapter 4, Section 4.4

5.3.2 Measures
Participant demographics and data on health behaviours of interest (physical activity, diet, smoking, alcohol consumption and sun safety), change in health behaviour status since diagnosis, and perception of the importance of health behaviour was collected using the TYA health and lifestyle questionnaire shown in Appendix 4.4.

5.3.3 Statistical Analyses
Age (≤18 years/≥18 years), ethnicity (White British/ Other), treatment status (currently receiving treatment: OT-TYACS/not receiving treatment: OFT-TYACS), and number of health problems (no health problems/ one health problem/ two or more health problems) were all dichotomised for the main analyses. Individual data on weight status, physical activity, diet, alcohol consumption, smoking, and sun related behaviour were scored and dichotomised according to whether young people were meeting WCRF and COG recommendations as
outlined within Table 2.1 of Chapter 2. The scoring procedure and cut-offs applied to each health behaviour are as outlined within Appendix 5.2.

Descriptive statistics were produced to determine the proportion of participants meeting current health behaviour guidelines and the proportion of TYA cancer survivors who report making changes to their lifestyle following their cancer diagnosis. Descriptive statistics were also produced to define the extent to which participants viewed each individual health behaviour as important to their current and future health. Statistical comparisons between the three groups of participants: On-Treatment TYA cancer survivors (OT-TYACS), Off-treatment TYA cancer survivors (OFT-TYACS), and general population TYAs (GP-TYAs) were made using chi-squared tests and logistic regression analysis for categorical variables and non-parametric Mann-Whitney tests for continuous variables. Multivariable models were adjusted for age and gender.

Statistical assumptions were checked. For the multivariable logistic regression models the variance inflation factor (VIF) and tolerance statistic (TS) were checked to ensure multicollinearity did not exist between the predictor variables. If VIF>10 and TS<0.2, multicollinearity was deemed present; where this was the case it is been indicated in the text (Field, 2009). Cross-tabulation tables were also produced to check the expected frequencies and independence of the data to ensure that each entity (participant & outcome measure) featured only once in the contingency table. Where more than 20% of cells had an expected frequency of below 5, Fishers exact tests were used. Again, where this is the case it is indicated in the text.

5.4 Results

5.4.1 Response rate

Table 5.1 provides an overview of the number of TYA cancer survivors from each recruitment strategy. In total 299 young people with cancer began the survey and completed at least one section. The total reach of the survey cannot be estimated given the disparate nature of the recruitment strategy. However, the sample size accrued in this study is comparable to other single institution efforts to gather cross-sectional data on TYA cancer survivors (Larcombe et al., 2002, Belanger et al., 2012, Badr et al., 2013).

Table 5.2 provides an overview of the number of general population TYA participants from each recruitment strategy. Again, the total reach of the survey cannot be estimated given the disparate nature of each recruitment strategies employed. In total 704 young people began the survey and completed at least one survey item. Unfortunately, due to time constraints (each paper questionnaire takes approximately 15 minutes to code and enter) it was not possible to enter all of the data from general population TYAs in the timeframe of my PhD. Data from a random sample of 370 was entered and has been used within this study.
### Table 4.1 TYA cancer survivor health and lifestyle questionnaire recruitment efficacy

<table>
<thead>
<tr>
<th>Recruitment Route</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>University College Hospital, London</td>
<td>98</td>
</tr>
<tr>
<td>CLIC Sargent online link</td>
<td>165*</td>
</tr>
<tr>
<td>CLIC Sargent social workers</td>
<td>25</td>
</tr>
<tr>
<td>CLIC Sargent mail out</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>299</strong></td>
</tr>
</tbody>
</table>

*A total of 300 surveys were returned but one participants data was excluded from the analysis as they were 26 years of age.

### Table 4.2 General population TYAs health and lifestyle questionnaire recruitment efficacy

<table>
<thead>
<tr>
<th>Recruitment Route</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schools</td>
<td>590</td>
</tr>
<tr>
<td>Online</td>
<td>114</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>704</strong></td>
</tr>
</tbody>
</table>
5.4.2 Missing data

From the original sample of 299 TYA cancer survivors and 321 general population TYAs who had started the Health & Lifestyle Questionnaire 36 TYA cancer survivors and 49 general population TYAs did not complete any of the items contained within any of the health behaviour measures. These individuals were excluded from analyses leaving a total sample of 263 TYA cancer survivors and 321 general population TYAs for analyses. Littles Missing Completely at Random (LMCAR) test was performed to evaluate the patterns of missing data within each measure of health behaviour for each group. Table 5.3 displays the proportion of missing data and output for each LMCAR test. For all measures of health behaviour in both groups, any residual missing data points were deemed to be missing completely at random (MCAR), as there were no significant systematic difference (p>0.005) between missing and observed values indicating no key demographic differences between completers and non-completers of the survey items. However, there was a large amount of variation in the proportion of missing data between the health behaviour measures; this is likely due to participants experiencing questionnaire fatigue and completing the earlier parts of the survey then stopping before they had finished. Within both the online and paper versions of the survey, the measures of physical activity behaviour appeared first, followed by diet, smoking, alcohol consumption and sun safety. When the proportion of missing data missing is greater than 5% the use of the expectation maximization algorithm to compute missing data introduces biased estimates to the data set (Sterne et al., 2009). Therefore, combined with the knowledge that the missing data is due to survey drop out and not uniform non-response to survey items, other than the imputation of data based upon logical reasoning carried out during the data cleaning stage described in Appendix 5.1 available case analysis was carried out.

Table 4.3 Proportion of missing data & littles missing completely at random outputs

<table>
<thead>
<tr>
<th>Health Behaviour</th>
<th>LMCAR Output</th>
<th>% Missing Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>TYA Cancer Survivors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical activity</td>
<td>$X^2=15.376$, df=0, p=0.052</td>
<td>4.2-4.6</td>
</tr>
<tr>
<td>Diet</td>
<td>$X^2=52.449$, df=256, p=1.000</td>
<td>6.1-12.5</td>
</tr>
<tr>
<td>Smoking</td>
<td>$X^2=0.374$, df=2, p=0.829</td>
<td>13.7-25.6</td>
</tr>
<tr>
<td>Alcohol consumption</td>
<td>$X^2=2.437$, df=4, p=0.656</td>
<td>12.5-15.2</td>
</tr>
<tr>
<td>Sun Safety</td>
<td>$X^2=7.165$, df=2, p=0.028</td>
<td>12.5-12.9</td>
</tr>
<tr>
<td>General Population TYAs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Activity</td>
<td>$X^2=31.466$, df=36, p=0.0684</td>
<td>0.0-0.3</td>
</tr>
<tr>
<td>Diet</td>
<td>$X^2=25.200$, df=1355, p=0.000</td>
<td>1.6-13.4</td>
</tr>
<tr>
<td>Smoking</td>
<td>$X^2=0.434$, df=1, p=0.510</td>
<td>2.8-33.6</td>
</tr>
<tr>
<td>Alcohol consumption</td>
<td>$X^2=3.781$, df=7, p=0.805</td>
<td>2.8-3.1</td>
</tr>
<tr>
<td>Sun Safety</td>
<td>$X^2=0.956$, df=2, p=0.620</td>
<td>2.8-3.1</td>
</tr>
</tbody>
</table>
5.4.3 Sample characteristics

Participant characteristics are displayed in Table 5.4. TYA cancer survivors on-treatment had an average age of 19 years (Standard deviation (SD)=3.06) and TYA cancer survivors off-treatment had an average age of 20 years (SD=2.78). TYA cancer survivors in both groups were predominantly female (n=46, 55.4%, on-treatment; n=109, 62.9%, off treatment), white British (n=63, 75.9%, on-treatment; n=134, 77.0%, off treatment), and living at home with their immediate family (n=64, 77.1%, on-treatment; n=125, 71.8%, off treatment). Most TYA cancer survivors (n=33, 39.8%, on-treatment; n=76, 43.7%, off treatment) reported being in full-time education, however 37.3% (n=31) of TYA cancer survivors on treatment reported being unable or too ill to work or study.

General population TYAs had an average age of 17 years (SD=3.1) were predominantly female (n=249, 77.6%), in full time education (n=248, 77.3%) and living at home with their immediate family (n=257, 80.1%). General population TYAs were significantly younger than TYA cancer survivors (mean difference: 2.89, p<0.0001) and were more likely to be female ($X^2 (1, n=584) = 22.66, p<0.001$) and be from a non-white British ethnic background.

Table 5.5 outlines the cancer and treatment characteristics of TYA cancer survivors. The most common cancer diagnoses were haematological malignancies (n=154, 59.2%), bone tumours (n=26, 10%) and soft tissue sarcomas (n=22, 8.5%). Average age at diagnosis was 16.5 years (SD=4.43). At the time of survey completion, the majority of respondents (n=146, 56.1%) had finished cancer treatment and with more than half reporting that they were between 1-5 years from treatment completion (56.1% n=79).

Table 5.6 outlines health problems and weight status of all study participants. TYA cancer survivors were more likely to report one or more health problems than general population TYAs (82% vs 37%, $X^2 (2, n=578 = 13.17, p=0.001$). The most common health difficulties among TYA cancer survivors both on and off treatment were extreme fatigue and mental health problems. Just over half of TYA cancer survivors (n=144, 54.8%) were a healthy weight. The proportion of young people classed as being either overweight or obese was significantly greater among TYA cancer survivors than the general population (30.4% vs 9.6%; $X^2 (4, n=584) =70.07, p<0.001$).
<table>
<thead>
<tr>
<th></th>
<th>TYA Cancer Survivors On Treatment</th>
<th>TYA Cancer Survivors Off Treatment</th>
<th>General population TYAs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=83</td>
<td>n=174</td>
<td>n=321</td>
</tr>
<tr>
<td><strong>Age (Mean±SD)</strong></td>
<td>19±3.06</td>
<td>20.0±2.78</td>
<td>17 ± 3.1</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>55.4 (46)</td>
<td>62.9 (109)</td>
<td>249 (77.6)</td>
</tr>
<tr>
<td>Males</td>
<td>44.6 (37)</td>
<td>37.4 (65)</td>
<td>72 (22.4)</td>
</tr>
<tr>
<td><strong>Educational Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GSCE/ Standard Grade/ School Cert</td>
<td>65.1 (54)</td>
<td>68.4 (119)</td>
<td>157 (48.9)</td>
</tr>
<tr>
<td>Vocational Qualifications (e.g NVQ1 +2)</td>
<td>18.1 (20)</td>
<td>11.5 (20)</td>
<td>8 (2.5)</td>
</tr>
<tr>
<td>A-Level/ Higher School Cert</td>
<td>38.6 (32)</td>
<td>52.9 (92)</td>
<td>46 (14.3)</td>
</tr>
<tr>
<td>Bachelor Degree</td>
<td>8.4 (7)</td>
<td>18.4 (32)</td>
<td>30 (9.3)</td>
</tr>
<tr>
<td>Masters/PhD/PGCE</td>
<td>0 (0)</td>
<td>5.2 (9)</td>
<td>17 (5.3)</td>
</tr>
<tr>
<td>Still studying</td>
<td>41.0 (34)</td>
<td>33.9 (59)</td>
<td>200 (62.3)</td>
</tr>
<tr>
<td>No Formal Qualifications</td>
<td>4.8 (4)</td>
<td>1.1 (2)</td>
<td>7 (2.2)</td>
</tr>
<tr>
<td>Other</td>
<td>8.4 (7)</td>
<td>5.7 (10)</td>
<td>10 (3.1)</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed full-time</td>
<td>6.0 (5)</td>
<td>21.8 (38)</td>
<td>19 (5.9)</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>14.5 (12)</td>
<td>22.4 (39)</td>
<td>23 (7.2)</td>
</tr>
<tr>
<td>Self-employed</td>
<td>0 (0)</td>
<td>1.7 (3)</td>
<td>5 (1.6)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4.8 (4)</td>
<td>5.7 (10)</td>
<td>26 (8.1)</td>
</tr>
<tr>
<td>Full-time education</td>
<td>39.8 (33)</td>
<td>43.7 (76)</td>
<td>248 (77.3)</td>
</tr>
<tr>
<td>Part-time education</td>
<td>6.0 (5)</td>
<td>4.6 (8)</td>
<td>3 (0.9)</td>
</tr>
<tr>
<td>Unable or too ill to work/study</td>
<td>37.3 (31)</td>
<td>13.2 (23)</td>
<td>1 (0.3)</td>
</tr>
<tr>
<td>Voluntary work</td>
<td>9.6 (8)</td>
<td>6.9 (12)</td>
<td>20 (6.2)</td>
</tr>
<tr>
<td><strong>Living Arrangement</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>2.4 (2)</td>
<td>6.9 (12)</td>
<td>16 (5)</td>
</tr>
<tr>
<td>With my partner</td>
<td>10.8 (9)</td>
<td>9.2 (16)</td>
<td>13 (4)</td>
</tr>
<tr>
<td>With immediate family</td>
<td>77.1 (64)</td>
<td>71.8 (125)</td>
<td>257 (80.1)</td>
</tr>
<tr>
<td>Other family</td>
<td>3.6 (3)</td>
<td>0.6 (1)</td>
<td>6 (1.9)</td>
</tr>
<tr>
<td>With friends</td>
<td>4.8 (4)</td>
<td>11.5 (20)</td>
<td>25 (7.8)</td>
</tr>
<tr>
<td>Residential Care</td>
<td>1.2 (1)</td>
<td>0 (0)</td>
<td>3 (0.9)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>75.9 (63)</td>
<td>77.0 (134)</td>
<td>41.1 (132)</td>
</tr>
<tr>
<td>White Irish</td>
<td>1.2 (1)</td>
<td>1.1 (2)</td>
<td>1.2 (4)</td>
</tr>
<tr>
<td>Black African</td>
<td>4.8 (4)</td>
<td>2.9 (5)</td>
<td>6.5 (21)</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>1.2 (1)</td>
<td>1.1 (2)</td>
<td>1.2 (4)</td>
</tr>
<tr>
<td>Indian</td>
<td>2.4 (2)</td>
<td>1.7 (3)</td>
<td>8.1 (26)</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>1.2 (1)</td>
<td>2.9 (5)</td>
<td>4.4 (14)</td>
</tr>
<tr>
<td>Pakistani</td>
<td>1.2 (1)</td>
<td>2.9 (5)</td>
<td>3.1 (10)</td>
</tr>
<tr>
<td>Chinese</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>4.4 (14)</td>
</tr>
<tr>
<td>Mixed White and Black African</td>
<td>0 (0)</td>
<td>0.6 (1)</td>
<td>1.6 (5)</td>
</tr>
<tr>
<td>Mixed White and Black Caribbean</td>
<td>2.4 (2)</td>
<td>0.6 (1)</td>
<td>1.2 (4)</td>
</tr>
<tr>
<td>Mixed White and Asian</td>
<td>1.2 (1)</td>
<td>0.6 (1)</td>
<td>3.7 (12)</td>
</tr>
<tr>
<td>Other</td>
<td>6.0 (5)</td>
<td>8.0 (14)</td>
<td>21.8 (70)</td>
</tr>
</tbody>
</table>

*Data on treatment status missing for 6 participants **Where percentages do not equal 100% this was due to participants selecting all that applied
## Table 4.5 Cancer and treatment characteristics of TYA cancer survivors

<table>
<thead>
<tr>
<th>Cancer Diagnosis</th>
<th>TYA Cancer Survivors On Treatment</th>
<th>TYA Cancer Survivors Off Treatment</th>
<th>TYA Cancer Survivors Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=83 % (n)</td>
<td>n=174 % (n)</td>
<td></td>
</tr>
<tr>
<td><strong>Cancer Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lymphoma</td>
<td>22.9 (19)</td>
<td>31.5 (62)</td>
<td>31.5 (81)</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>34.9 (29)</td>
<td>24.1 (42)</td>
<td>27.6 (71)</td>
</tr>
<tr>
<td>Bone tumour</td>
<td>7.2 (6)</td>
<td>10.9 (19)</td>
<td>9.7 (25)</td>
</tr>
<tr>
<td>Soft tissue sarcoma</td>
<td>15.7 (13)</td>
<td>5.7 (10)</td>
<td>8.9 (23)</td>
</tr>
<tr>
<td>CNS tumour</td>
<td>10.8 (9)</td>
<td>6.9 (12)</td>
<td>8.2 (21)</td>
</tr>
<tr>
<td>Germ cell tumour</td>
<td>0 (0)</td>
<td>5.2 (9)</td>
<td>3.5 (9)</td>
</tr>
<tr>
<td>Carcinoma</td>
<td>3.6 (3)</td>
<td>4.6 (8)</td>
<td>4.3 (11)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>2.4 (2)</td>
<td>1.1 (2)</td>
<td>1.6 (4)</td>
</tr>
<tr>
<td>Other</td>
<td>4.8 (4)</td>
<td>8.0 (14.0)</td>
<td>7 (18)</td>
</tr>
<tr>
<td><strong>Age at diagnosis (Mean±SD)</strong></td>
<td>17.0±4.1</td>
<td>16.2±4.5</td>
<td>16.4 ± 4.4</td>
</tr>
<tr>
<td>0-12 years</td>
<td>10.7 (8)</td>
<td>15.1 (25)</td>
<td>12.6 (33)</td>
</tr>
<tr>
<td>13-18 years</td>
<td>45.3 (34)</td>
<td>54.8 (91)</td>
<td>48.9 (127)</td>
</tr>
<tr>
<td>19-24 years</td>
<td>44.0 (33)</td>
<td>30.1 (50)</td>
<td>32.2 (84)</td>
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<tr>
<td>Missing data</td>
<td>9.6 (8)</td>
<td>4.6 (8)</td>
<td>6.2 (16)</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>56.9 (33)</td>
<td>57.4 (70)</td>
<td>57.2 (103)</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>51.8 (29)</td>
<td>46.9 (58)</td>
<td>50.3 (87)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>94.6 (70)</td>
<td>97.5 (156)</td>
<td>96.6 (226)</td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>5 (2)</td>
<td>8.7 (8)</td>
<td>7.6 (10)</td>
</tr>
<tr>
<td>Active surveillance</td>
<td>5 (2)</td>
<td>8.9 (8)</td>
<td>7.7 (10)</td>
</tr>
<tr>
<td>None</td>
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<td>1.1 (1)</td>
<td>1.6 (2)</td>
</tr>
<tr>
<td>Not sure</td>
<td>5 (2)</td>
<td>1.1 (1)</td>
<td>2.4 (3)</td>
</tr>
<tr>
<td>Other</td>
<td>12 (10)</td>
<td>13.7 (24)</td>
<td>13.6 (36)</td>
</tr>
<tr>
<td><strong>Time Since Treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;3 months from finishing treatment</td>
<td>-</td>
<td>13.2 (23)</td>
<td>-</td>
</tr>
<tr>
<td>4-11 months since finishing treatment</td>
<td>-</td>
<td>19 (33)</td>
<td>-</td>
</tr>
<tr>
<td>1-5 years since finishing treatment</td>
<td>-</td>
<td>46 (80)</td>
<td>-</td>
</tr>
<tr>
<td>&gt;5 years since finishing treatment</td>
<td>-</td>
<td>5.7 (10)</td>
<td>-</td>
</tr>
<tr>
<td>On active surveillance</td>
<td>-</td>
<td>12.1 (21)</td>
<td>-</td>
</tr>
<tr>
<td>I don’t know</td>
<td>-</td>
<td>0.6 (1)</td>
<td>-</td>
</tr>
<tr>
<td>Missing data</td>
<td>-</td>
<td>3.4 (6)</td>
<td>-</td>
</tr>
</tbody>
</table>

*Where percentages do not equal 100% this was due to participants selecting all that applied

**Data from those off treatment only (n=174)**
### Table 4.6 Health problems and weight status

<table>
<thead>
<tr>
<th>Health Problems</th>
<th>TYA Cancer Survivors On treatment N=83</th>
<th>TYA Cancer Survivors Off treatment N=174</th>
<th>General Population TYAs N=321</th>
</tr>
</thead>
<tbody>
<tr>
<td>Osteoporosis</td>
<td>0.0 (0)</td>
<td>4.0 (7)</td>
<td>0.3 (1)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>4.8 (4)</td>
<td>1.7 (3)</td>
<td>0.6 (2)</td>
</tr>
<tr>
<td>Asthma</td>
<td>10.8 (9)</td>
<td>8.6 (15)</td>
<td>13.4 (43)</td>
</tr>
<tr>
<td>Irregular heart rhythm</td>
<td>7.2 (6)</td>
<td>5.7 (10)</td>
<td>1.9 (6)</td>
</tr>
<tr>
<td>Extreme fatigue</td>
<td>31.3 (26)</td>
<td>29.9 (52)</td>
<td>6.2 (20)</td>
</tr>
<tr>
<td>Mental health problems</td>
<td>16.9 (14)</td>
<td>20.1 (35)</td>
<td>14.3 (46)</td>
</tr>
<tr>
<td>Lung disease</td>
<td>0.0 (0)</td>
<td>1.1 (2)</td>
<td>0.3 (1)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>1.2 (1)</td>
<td>2.3 (4)</td>
<td>0.6 (2)</td>
</tr>
<tr>
<td>Any other heart trouble</td>
<td>1.2 (1)</td>
<td>1.7 (3)</td>
<td>0.9 (3)</td>
</tr>
<tr>
<td>Another cancer</td>
<td>2.4 (2)</td>
<td>1.1 (2)</td>
<td>0.3 (1)</td>
</tr>
<tr>
<td>Sensory Impairment</td>
<td>1.2 (1)</td>
<td>5.2 (9)</td>
<td>1.2 (4)</td>
</tr>
<tr>
<td>Other</td>
<td>34.1 (28)</td>
<td>35.1 (61)</td>
<td>7.8 (25)</td>
</tr>
<tr>
<td><strong>Body Fatness</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obese</td>
<td>13.3 (11)</td>
<td>12.1 (21)</td>
<td>2.5 (8)</td>
</tr>
<tr>
<td>Overweight</td>
<td>18.1 (15)</td>
<td>18.4 (32)</td>
<td>6.5 (21)</td>
</tr>
<tr>
<td>Healthy weight</td>
<td>50.6 (42)</td>
<td>56.3 (98)</td>
<td>51.4 (165)</td>
</tr>
<tr>
<td>Underweight</td>
<td>7.2 (6)</td>
<td>4.6 (8)</td>
<td>19 (61)</td>
</tr>
<tr>
<td>Missing data</td>
<td>10.8 (9)</td>
<td>8.6 (15)</td>
<td>20.6 (66)</td>
</tr>
</tbody>
</table>
5.4.4 The health behaviour status of TYA cancer survivors and general population TYAs

Figure 5.1 presents the proportion of TYA cancer survivors meeting current physical activity recommendations made by the Childrens’ Oncology Group (COG). Adjusted and unadjusted odds ratios for the association between treatment status and health behaviour are presented in Table 5.7. TYA cancer survivors who had finished treatment were more likely to meet current physical activity recommendations (p<0.001) than those undergoing treatment (30.1% vs 52.3%, respectively), however there was no significant difference between TYA cancer survivors off treatment and TYAs within the general population (52.3% vs 54.8%, respectively).

Figure 5.2 presents the proportion of participants within each group meeting the current COG and World Cancer Research Fund diet and nutrition recommendations. Less than 40% of TYA cancer survivors and general population TYAs were meeting recommendations for fat intake, sugar intake, and fibre intake. In contrast, a high proportion (>80%) of participants met current recommendations for red meat intake of no more than 500g per week. Less than a quarter of TYA cancer survivors and general population TYAs met current fruit and vegetable recommendations of more than five portions per day. As shown in Table 5.7 there was no significant difference in the dietary intake between TYA cancer survivors on-treatment and those who were off-treatment. On the other hand, in comparison to general population TYAs, TYA cancer survivors were significantly less likely (p<0.005) to meet fat intake, sugar intake and processed meat guidelines than general population TYAs.

Figure 5.3 displays the proportion of TYA cancer survivors and general population TYAs meeting alcohol consumption, smoking and sun-safety guidelines. Approximately one-third of TYA cancer survivors (n=18, 31.8%) and general population TYAs (n=76, 34.9%) aged between 13 and 17 years at the time of the survey reported under-age drinking. Among young adult participants (those aged 18-24 years at the time of the survey) most participants (>80%) were meeting the recommendations of no more than 2 alcoholic drinks per day. However, analyses of the AUDIT-C measure indicated a large proportion of young adult cancer survivors and general population TYAs were binge drinking i.e. regularly consuming 5 or more drinks on one occasion (Cortés-Tomás et al., 2016). TYA cancer survivors who were off treatment were more likely to report binge drinking than general population TYAs (OR=3.26, 95% CI 2.12 - 5.02, p<0.001). Very few TYA cancer survivors and general population TYAs were current smokers. Those who were smoked an average of 8.6±3.17 and 9±1.9 cigarettes per day (TYA cancer survivors and general population TYAs, respectively). A significantly larger proportion (p<0.005) of general population TYAs (n=41,15.9%) reported smoking in the past when compared to TYA cancer survivors (n=19, 7.2%). Less than a third of participants met current sun safety guidelines. 36% (n=95) TYA cancer survivors and 48.6% (n=156) of general population TYAs reported intentionally tanning whilst 36.1% (n=95) of TYA cancer survivors and 46.1% (n=148) general population TYAs reported severe sun-burn in the past year. Encouragingly, very few young people within either group reported using sun-beds (5.9% and 8.4% respectively).
Figure 4.3 Proportion of TYA cancer survivors and general population TYAs meeting current physical activity recommendations

Proportion (%)

0 10 20 30 40 50 60 70 80 90 100

OT-TYACS  OFT-TYACS  GP-TYACS
Figure 4.4 Proportion of TYA cancer survivors and general population TYAs meeting current diet and nutrition guidelines
Figure 4.5 Proportion of TYA cancer survivors and general population TYAs meeting current alcohol consumption, smoking and sun-safety health behaviour guidelines.
Table 4.7 Adjusted and unadjusted odds ratios for the association between treatment status and health behaviour

<table>
<thead>
<tr>
<th></th>
<th>Physical Activity (n=577)</th>
<th>Fat Intake (n=440)</th>
<th>Fibre Intake (n=521)</th>
<th>Sugar Intake (n=460)</th>
<th>Red-Meat Intake (n=545)</th>
<th>Processed Meat (n=550)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Un-Adjusted</td>
<td>Adjusted</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Odds Ratio (95% CI)</td>
<td>Odds Ratio (95% CI)</td>
<td>Odds Ratio (95% CI)</td>
<td>Odds Ratio (95% CI)</td>
<td>Odds Ratio (95% CI)</td>
<td>Odds Ratio (95% CI)</td>
</tr>
<tr>
<td>GP-TYAs</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>OFT—TYA</td>
<td>0.35 (0.21, 0.59)</td>
<td>1</td>
<td>0.21 (0.81, 0.54)</td>
<td>1</td>
<td>0.38 (0.21, 0.68)**</td>
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</tr>
<tr>
<td>OT-TYA</td>
<td>0.89 (0.62, 1.29)**</td>
<td>0.39 (0.22, 0.68)**</td>
<td>0.54 (0.21, 1.36)**</td>
<td>0.38 (0.21, 0.68)**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fat Intake (n=440)</td>
<td>GP-TYAs</td>
<td>1</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>OFT—TYA</td>
<td>1.48 (0.83, 2.64)</td>
<td>1</td>
<td>3.41 (1.08, 10.77)*</td>
<td>1</td>
<td>0.781 (0.44, 1.38)</td>
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</tr>
<tr>
<td>OT-TYA</td>
<td>1.41 (0.90, 2.21)</td>
<td>0.80 (0.45-1.41)</td>
<td>3.33 (1.05, 10.55)*</td>
<td>0.781 (0.44, 1.38)</td>
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<td>Fibre Intake (n=521)</td>
<td>GP-TYAs</td>
<td>1</td>
<td>1</td>
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<td>1</td>
</tr>
<tr>
<td>OFT—TYA</td>
<td>1.77 (1.17, 2.69)*</td>
<td>1</td>
<td>1.62 (0.99, 2.67)*</td>
<td>1</td>
<td>0.949 (0.52, 1.71)</td>
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<tr>
<td>OT-TYA</td>
<td>1.68 (0.98, 2.88)*</td>
<td>0.87 (0.47-1.59)</td>
<td>1.55 (0.86, 2.81)</td>
<td>0.949 (0.52, 1.71)</td>
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<td>Sugar Intake (n=460)</td>
<td>GP-TYAs</td>
<td>1</td>
<td>1</td>
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<td>1</td>
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<tr>
<td>OFT—TYA</td>
<td>1.91 (1.25, 2.90)**</td>
<td>1</td>
<td>1.84 (1.14, 2.95)***</td>
<td>1</td>
<td>1.444 (0.78, 2.66)</td>
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</tr>
<tr>
<td>OT-TYA</td>
<td>2.78 (1.58, 4.91)****</td>
<td>1.47 (0.80-2.71)</td>
<td>2.71 (1.47, 4.97)****</td>
<td>1.444 (0.78, 2.66)</td>
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</tr>
<tr>
<td>Red-Meat Intake (n=545)</td>
<td>GP-TYAs</td>
<td>1</td>
<td>1</td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td>OFT—TYA</td>
<td>0.56 (0.29, 1.08)</td>
<td>1</td>
<td>0.93 (0.21, 4.08)</td>
<td>1</td>
<td>1.882 (0.79, 4.45)</td>
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</tr>
<tr>
<td>OT-TYA</td>
<td>1.04 (0.50, 2.13)</td>
<td>1.84 (0.78-4.32)</td>
<td>1.59 (0.39, 6.49)</td>
<td>1.882 (0.79, 4.45)</td>
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<tr>
<td>Processed Meat (n=550)</td>
<td>GP-TYAs</td>
<td>1</td>
<td>1</td>
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<td>1</td>
<td>1</td>
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<tr>
<td>OFT—TYA</td>
<td>1.63 (1.11, 2.40)*</td>
<td>1</td>
<td>5.01 (1.93, 13.01)****</td>
<td>1</td>
<td>1.195 (0.66, 2.13)</td>
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</tr>
<tr>
<td>OT-TYA</td>
<td>2.18 (1.30, 3.64)**</td>
<td>1.33 (0.76, 2.32)</td>
<td>6.06 (2.32, 15.84)****</td>
<td>1.195 (0.66, 2.13)</td>
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</tr>
</tbody>
</table>

*aOR adjusted for age and gender  *p<0.05  **p<0.005  ***p<0.01  ****p<0.001*
<table>
<thead>
<tr>
<th></th>
<th>Un-Adjusted</th>
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<tbody>
<tr>
<td></td>
<td>Odds Ratio</td>
<td>Odds Ratio</td>
<td>Odds Ratio</td>
<td>Odds Ratio</td>
</tr>
<tr>
<td></td>
<td>(95% CI)</td>
<td>(95% CI)</td>
<td>(95% CI)</td>
<td>(95% CI)</td>
</tr>
<tr>
<td>Fruit &amp; Veg (n=527)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP-TYAs</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OFT—TYA</td>
<td>1.73 (0.90, 3.31)</td>
<td>1</td>
<td>2.11 (0.69, 6.43)</td>
<td>1</td>
</tr>
<tr>
<td>OT-TYA</td>
<td>1.62 (0.99, 2.65)</td>
<td>1.06 (0.51, 2.20)</td>
<td>2.15 (0.68, 6.75)</td>
<td>0.961 (0.45, 2.02)</td>
</tr>
<tr>
<td>Smoking (n=533)</td>
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</tr>
<tr>
<td>GP-TYAs</td>
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<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OFT—TYA</td>
<td>1.95 (0.91, 4.18)</td>
<td>1</td>
<td>2.1 (0.94, 4.68)</td>
<td>1</td>
</tr>
<tr>
<td>OT-TYA</td>
<td>1.04 (0.46, 2.36)</td>
<td>0.53 (0.19, 1.44)</td>
<td>1.1 (0.49, 2.73)</td>
<td>0.533 (0.19, 1.46)</td>
</tr>
<tr>
<td>Alcohol Consumption (Units) (n=490)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP-TYAs</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OFT—TYA</td>
<td>0.94 (0.39, 2.25)</td>
<td>1</td>
<td>0.92 (0.36, 2.35)</td>
<td>1</td>
</tr>
<tr>
<td>OT-TYA</td>
<td>0.22 (0.02, 1.68)</td>
<td>0.23 (0.02, 1.90)</td>
<td>0.19 (0.02, 1.58)</td>
<td>0.209 (0.02, 1.73)</td>
</tr>
<tr>
<td>Binge Drinking (n=523)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP-TYAs</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OFT—TYA</td>
<td>3.06 (2.03, 4.61)</td>
<td>1</td>
<td>3.26 (2.12, 5.02)</td>
<td>1</td>
</tr>
<tr>
<td>OT-TYA</td>
<td>1.1 (0.68, 2.02)</td>
<td>0.38 (0.21, 0.69)</td>
<td>1.26 (0.72, 2.2)</td>
<td>0.404 (0.21, 0.74)**</td>
</tr>
<tr>
<td>Sun Safety (n=536)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP-TYAs</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OFT—TYA</td>
<td>0.65 (0.41, 1.03)</td>
<td>1</td>
<td>0.76 (0.45, 1.29)</td>
<td>1</td>
</tr>
<tr>
<td>OT-TYA</td>
<td>0.47 (0.27, 0.83)</td>
<td>0.94 (0.51, 1.74)</td>
<td>0.56 (0.31, 1.04)</td>
<td>1.03 (0.55, 1.93)</td>
</tr>
</tbody>
</table>

*OR adjusted for age and gender *p<0.05 **p<0.005 ***p<0.01 ****p<0.001
5.4.5 TYA cancer survivors perception of their current health behaviour

Table 5.8 outlines participants’ perception of their current health behaviour. Most TYA cancer survivors (both on and off treatment) and general population TYAs felt they should do more physical activity and over half felt they should have a healthier diet. Approximately one-third of participants felt they needed to lose weight whilst 40% of TYA cancer survivors who had completed treatment and general population TYAs did not think they needed to change their weight. Less than 10% of young people thought they should drink less.

5.4.6 TYA cancer survivors reported change in health behaviour since diagnosis

Table 5.9 displays TYA cancer survivors reported change in health behaviour since diagnosis. Most TYA cancer survivors reported that their physical activity levels were lower and their weight greater than before their cancer. However, 42.2% (n=65) of TYA cancer survivors who had completed their main treatment reported having a healthier diet than before their cancer diagnosis. A similar proportion (41%, n=43) of TYA cancer survivors who were undergoing cancer treatment at the time of the survey reported that they drank less alcohol since their diagnosis. Of those who reported smoking (n=17) most were attempting to quit with approximately half indicating the quit attempt had been initiated following their diagnosis.
### Table 4.8 Reported perception of current lifestyle

<table>
<thead>
<tr>
<th>Weight Status</th>
<th>TYA Cancer Survivors On Treatment</th>
<th>TYA Cancer Survivors Off Treatment</th>
<th>General Population TYAs</th>
<th>Group Differences</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think I should be trying to lose weight</td>
<td>36.1 (30)</td>
<td>45.4 (79)</td>
<td>34 (109)</td>
<td></td>
</tr>
<tr>
<td>I think I should be trying to gain weight</td>
<td>14.5 (12)</td>
<td>10.3 (18)</td>
<td>10.6 (34)</td>
<td>$X^2 (6) = 12.59, p=0.050$</td>
</tr>
<tr>
<td>I don’t think I need to change my weight</td>
<td>41.0 (34)</td>
<td>40.2 (70)</td>
<td>40.8 (131)</td>
<td></td>
</tr>
<tr>
<td>Don’t Know</td>
<td>7.2 (6)</td>
<td>3.4 (6)</td>
<td>10.9 (35)</td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td>1.2 (1)</td>
<td>0.6 (1)</td>
<td>3.7 (12)</td>
<td></td>
</tr>
</tbody>
</table>

#### Physical Activity

| I think I should do more physical activity          | 70.7 (58)                         | 71.1 (123)                        | 67.0 (215)               |                   |
| I think I should do less physical activity          | 2.4 (2)                           | 2.3 (4)                           | 2.5 (8)                  |                   |
| I don’t think I need to change my physical activity | 20.7 (17)                         | 25.4 (44)                         | 24.9 (80)                | $X^2 (6) = 9.63, p=0.141$ |
| Don’t know                                         | 6.1 (5)                           | 0 (0)                             | 4.4 (14)                 |                   |
| Missing data                                       | 0 (0)                             | 1.2 (2)                           | 1.2 (4)                  |                   |

#### Diet

| I think I should have a healthier diet              | 55.8 (43)                         | 53.2 (82)                         | 53.3 (171)               |                   |
| I don’t think I need to change my diet             | 31.2 (24)                         | 39.6 (61)                         | 33.0 (106)               | $X^2 (6) = 9.41, p=0.151$ |
| Don’t know                                         | 9.1 (7)                           | 4.5 (7)                           | 10.6 (34)                |                   |
| Missing Data                                       | 2.6 (2)                           | 1.9 (3)                           | 3.1 (10)                 |                   |

#### Alcohol Consumption

<p>| I think I should drink less                         | 6 (5)                             | 5.7 (10)                          | 9.3 (30)                 |                   |
| I don’t think I need to change my alcohol consumption | 62.7 (52)                        | 63.8 (111)                        | 76 (244)                 | $X^2 (4) = 9.65, p=0.915$ |
| Don’t know                                         | 8.4 (7)                           | 6.9 (12)                          | 9.3 (30)                 |                   |
| Missing Data                                       | 21.9 (19)                         | 23.6 (41)                         | 5.3 (17)                 |                   |</p>
<table>
<thead>
<tr>
<th></th>
<th>OT-TYACS n=83</th>
<th>OFT-TYACS n=174</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td><strong>Weight Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than before cancer</td>
<td>50.6 (42)</td>
<td>59.2 (103)</td>
</tr>
<tr>
<td>About the same as before cancer</td>
<td>24.1 (20)</td>
<td>23.0 (40)</td>
</tr>
<tr>
<td>Less than before cancer</td>
<td>24.1 (20)</td>
<td>17.8 (31)</td>
</tr>
<tr>
<td>Missing data</td>
<td>1.2 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Physical Activity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than before cancer</td>
<td>16.9 (14)</td>
<td>28.9 (50)</td>
</tr>
<tr>
<td>About the same as before cancer</td>
<td>14.5 (12)</td>
<td>25.4 (44)</td>
</tr>
<tr>
<td>Less than before cancer</td>
<td>66.3 (55)</td>
<td>44.5 (77)</td>
</tr>
<tr>
<td>Missing data</td>
<td>2.4 (2)</td>
<td>1.2 (1)</td>
</tr>
<tr>
<td><strong>Diet</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthier than before cancer</td>
<td>31.2 (24)</td>
<td>42.2 (65)</td>
</tr>
<tr>
<td>About the same as before cancer</td>
<td>44.2 (34)</td>
<td>44.2 (68)</td>
</tr>
<tr>
<td>Less healthy than before cancer</td>
<td>22.1 (17)</td>
<td>11 (17)</td>
</tr>
<tr>
<td>Missing data</td>
<td>1.6 (2)</td>
<td>2.6 (4)</td>
</tr>
<tr>
<td><strong>Alcohol Consumption</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than before cancer</td>
<td>8.4 (7)</td>
<td>27.0 (47)</td>
</tr>
<tr>
<td>About the same as before cancer</td>
<td>27.7 (23)</td>
<td>28.2 (49)</td>
</tr>
<tr>
<td>Less than before cancer</td>
<td>41.0 (34)</td>
<td>20.1 (35)</td>
</tr>
<tr>
<td>Missing data</td>
<td>22.9 (19)</td>
<td>24.7 (43)</td>
</tr>
<tr>
<td><strong>Smoking</strong></td>
<td>n=8</td>
<td>n=9</td>
</tr>
<tr>
<td>Tried to quit since cancer diagnosis</td>
<td>50.0 (4)</td>
<td>44.4 (4)</td>
</tr>
<tr>
<td>Not tried to quit since cancer diagnosis</td>
<td>50.0 (4)</td>
<td>55.6 (5)</td>
</tr>
</tbody>
</table>

*Only smokers included in analyses
5.4.7 Perception of health behaviour on current and future health

Figure 5.4 displays participants’ perception of health behaviour on current health and Figure 5.5 displays participants’ perception of health behaviour on future health. Most TYA cancer survivors and general population TYAs perceived looking after their skin in the sun, maintaining a healthy weight, eating a balanced diet, eating plenty of fruit and vegetables, not smoking and exercising regularly as ‘very’ or ‘somewhat’ important to their current and future health. In contrast less than 30% perceived avoiding red or processed meat as important to their current or future health. TYA cancer survivors were more likely to view not smoking, avoiding alcohol, and looking after their skin in the sun as important to their current health than general population TYAs (p<0.005). There was no significant difference in TYA cancer survivors and general population TYAs views on the importance of smoking, weight, fruit and vegetable intake, red meat intake and alcohol consumption on future health but TYA cancer survivors were more likely to view eating a balanced diet and being physical activity as important to future health than general population TYAs (p<0.05).
Figure 4.6 Perception of health behaviour on current health

Sun Skin Care $X^2 (2) = 11.23, p=0.004$

Weight $X^2 (2) = 3.67, p=0.160$

Red & Processed Meat Consumption $X^2 (2) = 1.85, p=0.395$

Fruit & Vegetable Intake $X^2 (2) = 1.85, p=0.395$

Alcohol Consumption $X^2 (2) = 14.62, p=0.001$

Smoking $X^2 (2) = 13.60, p=0.001$

Balanced Diet $X^2 (2) = 2.55, p=0.276$

Physical Activity & Exercise $X^2 (2) = 0.76, p=0.682$

- Very Important
- 4
- 3
- 2
- Not at all Important
- Missing Data
Figure 4.7 Perception of health behaviour on future health status

**Sun Skin Care** $\chi^2 (2) = 3.29, p=0.193$

**Weight** $\chi^2 (2) = 3.33, p=0.197$

**Red & Processed Meat Consumption** $\chi^2 (2) = 3.33, p=0.197$

**Fruit & Vegetable Intake** $\chi^2 (2) = 0.013, p=1.00$

**Alcohol Consumption** $\chi^2 (2) = 5.59, p=0.060$

**Smoking** $\chi^2 (2) = 7.04, p=0.003$

**Physical Activity & Exercise** $\chi^2 (2) = 6.69, p=0.041$

**Diet** $\chi^2 (2) = 5.95, p=0.041$
5.5 Discussion

The primary aim of this study was to compare the health behaviours of TYA cancer survivors to general population controls. This study also aimed to compare TYA cancer survivors perception of health behaviour on current and future health to general population controls. Results suggest that despite the importance of health behaviour in cancer survivorship (Siegel et al., 2015, Daniel et al., 2015a, Rabin, 2009), TYA cancer survivors in the UK have a similar health behaviour status to TYAs within the general population in that they are largely inactive, consume diets low in fibre, lean meat and fruit and vegetables, and regularly binge on alcohol. Nevertheless, reassuringly a high proportion of TYA cancer survivors and general population TYAs perceived leading a healthy lifestyle as important to their current and future health, and held a desire to be more active and have a healthier diet. Collectively these results suggest that TYA cancer survivors need, and would be receptive to, health behaviour change interventions.

Results from this study indicate that a substantial proportion of TYA cancer survivors and general population TYAs do not meet current physical activity recommendations. The finding that the majority (>70%) of TYA cancer survivors who were undergoing active treatment at the time of the survey do not meet physical activity guidelines may in part be explained by physical limitations resulting from their cancer therapy. Often young people undergoing cancer treatment are hospitalized for long periods of time, require isolation due to depressed immune systems, suffer from severe infections and experience a high level of fatigue (Sender and Zabokrtsky, 2015). These factors, combined with the influence of parents and carers sometimes taking a 'rest is best' approach and discouraging physical activity, may limit TYA cancer patients ability to be active during treatment (Goette et al., 2014, Spreafico et al., 2014). Nevertheless, the finding of no marked difference in physical activity between TYA cancer survivors off treatment and general population TYAs suggest young people with cancer make some effort to get back to the same level of activity they had prior to their cancer diagnosis. The non-significant difference between TYA cancer survivors and general population TYAs physical activity levels is in keeping with a recent systematic review of studies comparing the physical activity levels of children and adolescents with Type 1 diabetes, cardiovascular disease, or chronic respiratory disease and healthy population controls (Elmesmari et al., 2017). The finding of a non-significant difference in this study, and within the systematic review by Elmesmari and colleagues, suggest the intrapersonal, interpersonal and environmental barriers to physical activity which explain low levels of physical activity among the general population.  

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14 Intrapersonal factors associated with physical activity include: negative emotions, attitudes, and beliefs; and low levels of perceived benefit, self perception and physical capability.

15 Interpersonal factors associated with physical activity include: social support, peer support, societal attitude, and social norms

16 Environmental factors associated with physical activity include: availability of resources to be active, built environment, access to physical activity resources, and local and national policies supporting physical activity.
population may also apply equally to young people living with a chronic health condition (Ginis et al., 2016).

Compared to general population TYAs, TYA cancer survivors within this study consumed diets which are high in fat, sugar and processed meats. Existing cross-sectional studies have reported similar results indicating the TYA cancer survivor population have poor diet quality (Badr et al., 2013, Cohen et al., 2012, Landy et al., 2013, Love et al., 2011). For individual food groups, among both TYA cancer survivors and the general population fruit and vegetable intake was strikingly poor with less than a quarter of young people meeting the current recommendations of 5 portions per day. Others have confirmed these findings: for example a cross-sectional study of twenty-two acute lymphoblastic leukaemia and lymphoma survivors (mean age: 11.7 years) reported that only 22% met green vegetable intake recommendations (Zhang et al., 2015d) and a cross-sectional study of long term survivors of childhood cancer (n=209, mean age:20.3 years) found only 21% met fruit intake recommendations (Demark-Wahnefried et al., 2005b). The finding that approximately 70% of TYA cancer survivors did not meet recommendations for fibre, fat or sugar intake is similar to previous studies which have investigated the contribution of macro-nutrients to energy intake among young people with cancer (Zhang et al., 2015d, Badr et al., 2013, Tylavsky et al., 2010). Within this current study the high proportion of TYA cancer survivors meeting current recommendations for red meat intake of no more than 500g per week is most likely explained by the high intake of processed meat observed. Existing studies examining the dietary intake of TYA aged cancer survivors have not explicitly investigated red meat versus processed meat intake but there is evidence that childhood cancer survivors consume a low ratio of unsaturated fats to saturated fat (Zhang et al., 2015d).

Overall, the finding that TYA cancer survivors have poor dietary intake is concerning as diet and nutrition are established risk factors for cardiovascular disease, diabetes and obesity onset (Katz and Meller, 2014). Specifically, among TYA cancer survivors, poor nutritional intake has been found to exacerbate metabolic syndrome (Tonorezos et al., 2013). The finding that TYA cancer survivors (both on and off-treatment) were significantly less likely than general population TYAs to meet sugar, fibre, processed meat and fruit and vegetable recommendations was expected as several reviews discussing diet and nutrition among paediatric and TYA cancer survivors indicate young people with cancer crave energy dense foods high in sugar or salt during treatment (Barnes and Demark-Wahnefried, 2014, Ladas, 2014). Although these cravings are thought to be an acute response to cancer therapies such as glucocorticosteroids there is evidence that on completing treatment young people have difficulty reversing unhealthy eating habits and often suffer lasting changes in taste preference which interfere with their ability to consume certain foods (Arroyave et al., 2008). Dietary intake data gathered within this study supports this notion and emphasizes the need to discourage junk food consumption among TYA cancer patients, particularly those undergoing active cancer treatment.
The finding that approximately 30% of TYA cancer survivors were obese or overweight and more than half indicated their current weight was greater than before diagnosis is concerning. However it is unclear if weight gain observed among childhood and TYA cancer survivors is due to the effects of cancer treatment, increased energy intake and/or decreased physical activity (Jansen et al., 2009). There is a need to investigate the extent to which health behaviour contributes to weight gain among TYA cancer survivors and address whether health behaviour interventions may overcome the impact cancer treatment has upon the body composition of young people (Barnea et al., 2015, Zhang and Parsons, 2015). Such data are crucial in determining how best to address the weight status of young people with cancer.

Encouragingly, very few young people within this study reported being either a current or former smoker and the number of smokers within this study was lower than the estimated proportion (22% (95% CI 0.19 - 0.26)) of childhood cancer survivors engaging in smoking (Marjerrison et al., 2016). Whilst there was no difference in the prevalence of smoking between TYA cancer survivors and general population TYAs within this study, high levels of alcohol consumption (particularly binge drinking) were observed in both groups. Moreover, a third of TYA cancer survivors and general population TYAs aged between 13 and 17 years of age reported under-age drinking. These data are reflective of results are in keeping with The European School Survey Project on Alcohol and Other Drugs (ESPAD), which found 45% of males and 36% of females aged between 15 and 16 years in the UK, France, Finland, Denmark, and Belgium, binge drink regularly (Hibell et al., 2009). Such patterns of binge, and under-age drinking, among young people are again a cause for concern as these behaviours are strongly linked to health and social problems (World Health Organization, 2014, Viner and Taylor, 2007). The finding that fewer TYA cancer survivors who were on active treatment reported binge drinking, most likely reflects the ill health of young people with cancer during treatment and their social isolation away from friends and peers. Worryingly, very few young people reported a desire to change their levels of alcohol consumption, despite recognising that limiting alcohol consumption is important to current and future health status. Such data suggests TYA cancer survivors health beliefs and attitude towards alcohol consumption (specifically binge drinking) do not necessarily influence risk behaviour as might have been expected.

Within this study, the sun safety behaviours of TYA cancer survivors reflected the health behaviours of general population TYAs (Flannery et al., 2016, Kyle et al., 2014) and data from studies of childhood cancer survivors in the United States which indicate non-adherence to skin protection is common (Zwemer et al., 2012, Tercyak et al., 2006). Although a very small proportion of young people within either the cancer survivor or general population group reported using a sun-bed within the past 12 months, intentional tanning and sun-burn were frequently reported and less than a third of young people were classified as meeting current sun skin care recommendations. Deliberate tanning and poor sun skin care practices among
both TYA cancer survivors and general population TYAs are concerning given the well-established link between UVR exposure and skin cancer (Greinert et al., 2015). Previous research among adolescents and young adults have found that young people intentionally seek a tan for cosmetic values (Zwemer et al., 2012). Similar to alcohol consumption, although TYA cancer survivors are aware of the importance of looking after their skin in the sun for current and future health; the finding that young people with cancer still engage in these risk behaviours suggest affective attitude (i.e. how enjoyable young people find the behaviour) overrides, and has a stronger influence on behaviour, than instrumental health belief. However, consideration must also be given to social and environmental factors, which are also known to influence health behaviour choice among young people with cancer (Cox, 2011).

The non-significant difference in health behaviour status between TYA cancer survivors who were off treatment and general population TYAs may be because TYA cancer survivors make positive changes to their health behaviour after their diagnosis and treatment. 28% of young people who had finished cancer treatment reported that they had increased their levels of physical activity and 42% reported their diet was healthier than before cancer. These findings, combined with the finding that most TYA cancer survivors felt they should be more active, eat a healthier diet and lose weight, support the hypothesis that a cancer diagnosis and its subsequent treatment may be a ‘teachable moment’ (i.e. an event which increases an individual’s motivation to improve their health behaviour). However, as demonstrated by TYA cancer survivors poor health behaviour status, the adoption and maintenance of healthy lifestyle choices during and after cancer treatment is unlikely to occur without intervention.

Reassuringly, a large proportion of TYA cancer survivors and general population TYAs identified regular exercise, having a balanced diet, fruit and vegetable intake, smoking abstinence, maintaining a healthy weight and looking after their skin in the sun as important to both current and future health. However, very few young people believed that red or processed meat intake was important to their current or future health; nevertheless this likely reflects the low level of awareness surrounding the impact of red meat consumption on health outcomes (Cancer Research UK, 2016). When compared to general population TYAs, young people with cancer were more likely to perceive abstaining from risk behaviours (alcohol consumption, smoking and tanning) as important to current health suggesting TYA cancer survivors have a heightened risk perception of these behaviours and are conscious of the importance of making the right choices and taking responsibility for their own health. However, despite that fact that the majority of TYA cancer survivors agreed that health behaviour was important to current and future health, findings from this study indicate that young people are largely inactive, consume poor diets, and engage in smoking, drinking and tanning. It is likely that TYA cancer survivors, despite their awareness of the importance of health behaviour, rationalize poor lifestyle choices with cognitive strategies such as ignoring information about the riskiness of their behaviour and rationalizing their decision by outweighing the short-term gain with long-term risks of the behaviour (Woodgate et al., 2015, Larsman et al., 2012). As per health
promotion programmes conducted among general population TYAs health behaviour interventions and education programmes for young people with cancer should not solely focus on the provision of health behaviour education but also must challenge how young people process the information (Woodgate et al., 2015). Case scenarios have been proposed as useful mean to effectively communicate risk information to adolescents and young adults. Examples of other TYA cancer survivors deliberating the benefit/risks of leading a healthy lifestyle or dealing with a variety of barriers have been noted as useful self-reflective and educative tools to empower young people to be more aware of their beliefs and behaviours.

Although this is the largest study to date to report on the health behaviour status of TYA cancer survivors in the United Kingdom, this study has a number of limitations. Firstly, data on TYA cancer survivors change in sun-related health behaviours since diagnosis was not collected. Moreover, although the measures of health behaviour used within the Health and Lifestyle questionnaire have been validated and used within other studies, the data gathered was self-reported and therefore subject to recall bias and inaccuracies due to under and over reporting. For example, data from a comparative study of subjective self-reported physical activity and objectively measured physical activity among TYA cancer survivors (n=28; mean age=13.8±2.8 years; 3.4±2.0 months post cancer diagnosis) indicate young people with cancer, similar to general population TYAs, severely over-estimate their levels of physical activity when self-reporting (Götte et al., 2017, Vanhelst et al., 2017). Similarly, young people with cancer (n=22, mean age 11.2 years) have been found to over-estimate food intake when using self-report food frequency questionnaires in comparison to 24-hour dietary recalls (Zhang et al., 2015a). It is recognized that similar levels of over or under-reporting occur within measures of other health behaviours, particularly weight and alcohol consumption. Therefore, as the proportion of young people meeting current health behaviour recommendations was calculated from self-reported data, it is possible that the proportion of TYA cancer survivors and general population TYAs meeting current health behaviour recommendations may be even lower than estimated.

Moreover, it is likely that health behaviour status may vary by diagnosis and therapeutic regimen. Unfortunately, due to the small sample size it was not possible to sub-classify TYA cancer survivors by cancer type or treatment exposure. Future studies should investigate in closer detail the specific impact of these factors on health behaviour status so that health behaviour interventions may be modified and adapted to meet the needs of young people of different cancer types. Thought must also be given to when health behaviour interventions should be initiated among TYA cancer survivors. The finding that the health behaviour status of TYA cancer survivors during treatment is poor suggests interventions introduced early during treatment or as a young person approaches the end of therapy may be beneficial in preventing the commonly observed declines in physical activity and dietary quality.

Unfortunately, there were some important differences in the characteristics of TYA cancer survivors compared to general population TYAs, with young people in the general population
being significantly younger and more likely to be female. These differences are most likely due to the recruitment methods. General population TYAs were mainly recruited via schools and higher education institutions whilst the recruitment of TYA cancer survivors was highly targeted and conducted through UCLH and CLIC Sargent. As with most health research, it is likely that the respondents to the survey were more health conscious and interested in lifestyle issues than those who did not respond to the recruitment adverts. For this reason, it is likely that the proportion of young people who perceive health behaviour as important to current and future health, and the proportion of TYA cancer survivors and general population TYAs meeting current health behaviour recommendations may again be lower than presented within this study.

5.6 Chapter summary

Overall, this study expands our current understanding of the health behaviours of TYA cancer survivors and specifically provides detail on TYA cancer survivors perception of health behaviour on current and future health. Taken together, these data indicate that TYA cancer survivors do not adhere to current health behaviour guidelines and engage in behaviours which have the potential to exacerbate their risk of ill-health and future health problems. The finding that TYA cancer survivors have a desire to change their health behaviour and perceive health behaviour as important to both current and future health is encouraging and further strengthens the rationale behind a specifically designed health behaviour intervention for young people with cancer.
Chapter 6

Study 2

The Health Behaviour Information Needs and Preferences of Teenage and Young Adult Cancer Survivors

6.1 Introduction

As described within Chapter 2 there is increasing recognition that healthy lifestyle choices such as physical activity, good dietary intake, smoking abstinence, and moderate alcohol consumption contribute to better health outcomes among young people who have been diagnosed with cancer, specifically within the context of late-effects management (Smith et al., 2014, Slater et al., 2015, Spector et al., 2015). However, Chapter 5 (Study 1) provides cross-sectional evidence that the health behaviours of TYA cancer survivors within the U.K are generally poor with very few young people meeting current health behaviour recommendations. Nevertheless, despite the poor health behaviours of TYA cancer survivors many young people correctly identify healthy lifestyle choices as important to both their current and future health and indicate a desire to make positive changes to their health behaviour. These data support the need to develop a health behaviour intervention for TYA cancer survivors.

Education has been identified as a core intervention function in behaviour change (Michie et al., 2011b). As per the COM-B model of behaviour change discussed in Chapter 4, education and the provision of information serve to improve an individual's psychological capability (i.e. knowledge and understanding of the target behaviour) and reflective motivation (i.e. self-conscious intention to carry out the target behaviour) (Michie et al., 2014). It is important that health behaviour interventions developed specifically for TYA cancer survivors are reflective of the information needs of young people with cancer as interventions which contain information which is vague or confusing will lead young people to be sceptical of the importance of health behaviour and resistant to the idea of behaviour change (Nagler, 2014, Tan et al., 2015). Yet, studies investigating the information needs of TYA cancer survivors, like studies exploring health behaviour status, have predominantly been conducted in the United States among long-term survivors of childhood malignancies (Arroyave et al., 2008, Wu et al., 2015, Murnane et al., 2015). Furthermore much of the qualitative and quantitative evidence concerning the information needs and preferences of TYA cancer survivors have focused on late-effects management and psychosocial issues such as fertility, education, and relationships (Barakat et al., 2016, Nass et al., 2015, Morgan et al., 2010, Zebrack, 2008). As

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17 A version of this Chapter has been published in the Journal of Adolescent and Young Adult Oncology (Appendix 6.1) Pugh, G., et al. (2017). "The Health Behavior Information Needs and Preferences of Teenage and Young Adult Cancer Survivors." *J Adolesc Young Adult Oncol* 6(2): 318 - 326
a result, there is limited understanding of TYA cancer survivors specific interest in, or experience of, receiving health behaviour information. Similarly, as discussed in Chapter 2 there is very little understood about who should provide TYA cancer survivors with health behaviour information; and when and how such information should be delivered. Historically it has been thought that health behaviour change programmes are best delivered to young people after they have finished their treatment (Rabin, 2009). However, there is mounting evidence that the best window to offer TYA cancer survivors behaviour change support could occur during cancer treatment as addressing TYA cancer survivors health behaviour early may help young people deal better with the long-term physical or psychosocial impact of their cancer treatment (Gupta et al., 2013, Barnes et al., 2016).

6.2 Aims

As described in Chapter 3, this study aimed to firstly, establish TYA cancer survivors past experience of, and interest in receiving health behaviour information and secondly; identify their preferences regarding the format, delivery, and timing of such information.

6.3 Methods

6.3.1 Participants & recruitment

Recruitment and data collection methods are outlined in Chapter 4, Section 4.4. In brief, TYA cancer survivors were recruited though University College London Hospital (UCLH) and project partners CLIC Sargent between May 2015 and April 2016.

6.3.2 Measures

Participant demographics and data on the health behaviour advice TYA cancer survivors had received in the past; their level of interest in receiving health behaviour information, and their thoughts on when and how health behaviour information should be delivered to young people with cancer were gathered by questions contained within the Health and Lifestyle Questionnaire (Appendix 4.4).

6.3.3 Statistical analysis

Littles Missing Completely at Random test was performed to evaluate the patterns of missing data (Craig and Petticrew, 2013). Descriptive statistics to were used to i) characterise participants and examine the cancer history and health status of the sample; ii) determine the proportion of TYA cancer survivors who reported receiving health behaviour advice and their views on the amount of advice they were given; and iii) gauge TYA cancer survivors interest in lifestyle information and preferences regarding information delivery. Logistic regression models were used to explore associations between participant characteristics (age, sex, age at diagnosis, treatment status, and number of health problems) and both past experience of receiving advice (received vs not received) and interest in advice (interested vs not interested) on each behaviour. Chi-Square analyses were performed to examine potential differences in
TYA cancer survivors preferences regarding the timing of information delivery. Open-response answers were coded line-by-line and analysed according to Elo and Kynas’ (2008) process of content analysis (Elo and Kyngäs, 2008). In total, 441 individual open response comments were analysed. Second coding was carried out by Dr Sarah Jackson. Cohens Kappa was run to determine the inter-rater reliability of the content analysis.

6.4 Results

6.4.1 Response rate

A total of 294 TYA cancer survivors started the Health and Lifestyle Questionnaire and provided at least one answer to a question contained within the survey; unfortunately due to survey drop out only 216 TYA cancer survivors provided data on key variables required for this study. Within this study any residual missing data points were deemed to be missing completely at random (MCAR) as there were no systematic differences between missing and observed values ($X^2 = 0.00$, df=0, $p>0.05$) indicating no key demographic differences between completers and non-completers. Any residual missing data were imputed based upon simple means; a total of 40 individual data points (0.5% of the total data set) were imputed. There was a good level of inter-rater agreement on qualitative data (Cohen’s Kappa >0.6; $p<0.005$).

6.4.2 Sample characteristics

Participant characteristics are displayed in Table 6.1. Overall, participants (n=216) had an average age of 20 years (standard deviation (SD) = 2.85; range 13-25 years), were predominantly female (n=130, 60%), white British (n=183, 85%) and living at home with their immediate family (n=163, 75%). Most participants (n=91, 42%) reported still being in full-time education, however 38.2% (n=26) of TYA cancer survivors who were undergoing cancer treatment at the time of the survey reported being either unable or too ill to work.

Table 6.2 outlines the health and treatment characteristics of all participants. Overall, the most common cancer diagnoses were haematological malignancies (lymphoma/leukaemia) (n=126, 59%), bone tumours (n=22, 10%) and soft tissue sarcomas (n=20, 9%). Average age at diagnosis was 16.8 years (SD=4.0; range of age at diagnosis: 0-24 years). Two thirds (n=141, 65%) reported suffering from one or more health problems other than their original cancer diagnosis. Table 6.3 displays the range of health problems suffered by participants. The most common health difficulties experience by both TYA cancer survivors on treatment and off treatment were extreme fatigue and mental health problems.
Table 4.1 Participant characteristics

<table>
<thead>
<tr>
<th></th>
<th>TYA Cancer Survivors On Treatment n=68</th>
<th>TYA Cancer Survivors Off Treatment n=142</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td><strong>Age (Mean±SD)</strong></td>
<td>20.0±2.9</td>
<td>19.0±2.7</td>
</tr>
<tr>
<td><strong>Age Range</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13-18 years</td>
<td>30.9 (21)</td>
<td>28.9 (41)</td>
</tr>
<tr>
<td>19-25 years</td>
<td>69.1 (47)</td>
<td>71.1 (101)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>42.6 (29)</td>
<td>38.0 (54)</td>
</tr>
<tr>
<td>Females</td>
<td>57.4 (39)</td>
<td>62.0 (88)</td>
</tr>
<tr>
<td><strong>Educational Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GSCE/ Standard Grade/ School Cert</td>
<td>20.6 (14)</td>
<td>19.7 (28)</td>
</tr>
<tr>
<td>Vocational qualifications (e.g. NVQ1 +2)</td>
<td>8.8 (6)</td>
<td>6.3 (9)</td>
</tr>
<tr>
<td>A-Level/Higher School Cert</td>
<td>35.3 (24)</td>
<td>39.4 (56)</td>
</tr>
<tr>
<td>Bachelor degree</td>
<td>7.4 (5)</td>
<td>14.8 (21)</td>
</tr>
<tr>
<td>Masters/PhD/PGCE</td>
<td>0 (0)</td>
<td>4.9 (7)</td>
</tr>
<tr>
<td>Still studying</td>
<td>14.7 (10)</td>
<td>6.3 (9)</td>
</tr>
<tr>
<td>No formal qualifications</td>
<td>4.4 (3)</td>
<td>1.4 (2)</td>
</tr>
<tr>
<td>Other</td>
<td>8.8 (6)</td>
<td>7.0 (10)</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed full-time</td>
<td>7.4 (5)</td>
<td>20.4 (29)</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>13.2 (9)</td>
<td>21.1 (30)</td>
</tr>
<tr>
<td>Self-employed</td>
<td>0 (0)</td>
<td>1.4 (2)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>5.9 (4)</td>
<td>4.9 (7)</td>
</tr>
<tr>
<td>Full-time education</td>
<td>38.2 (26)</td>
<td>43.7 (62)</td>
</tr>
<tr>
<td>Part-time education</td>
<td>5.9 (4)</td>
<td>4.9 (7)</td>
</tr>
<tr>
<td>Unable or too ill to work</td>
<td>38.2 (26)</td>
<td>15.5 (22)</td>
</tr>
<tr>
<td>Voluntary work</td>
<td>8.8 (6)</td>
<td>6.3 (9)</td>
</tr>
<tr>
<td><strong>Living Arrangement</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>1.5 (1)</td>
<td></td>
</tr>
<tr>
<td>With my partner</td>
<td>7.4 (5)</td>
<td>9.2 (13)</td>
</tr>
<tr>
<td>With immediate family</td>
<td>82.4 (56)</td>
<td>73.2 (104)</td>
</tr>
<tr>
<td>Other family</td>
<td>4.4 (3)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>With friends</td>
<td>2.9 (2)</td>
<td>12.7 (18)</td>
</tr>
<tr>
<td>Residential care</td>
<td>1.5 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>79.4 (54)</td>
<td>78.2 (111)</td>
</tr>
<tr>
<td>Non-White</td>
<td>20.6 (14)</td>
<td>21.8 (31)</td>
</tr>
</tbody>
</table>

*Where percentages do not equal 100% this was due to participants selecting all that applied.
Table 4.2 Health and treatment characteristics

<table>
<thead>
<tr>
<th>Health</th>
<th>TYA Cancer Survivors On Treatment</th>
<th>TYA Cancer Survivors Off Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cancer Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lymphoma</td>
<td>25.0 (17)</td>
<td>35.9 (51)</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>32.4 (22)</td>
<td>24.6 (35)</td>
</tr>
<tr>
<td>Bone tumour</td>
<td>8.8 (6)</td>
<td>10.6 (15)</td>
</tr>
<tr>
<td>Soft tissue sarcoma</td>
<td>20.6 (14)</td>
<td>3.5 (5)</td>
</tr>
<tr>
<td>CNS tumour</td>
<td>8.8 (6)</td>
<td>5.6 (8)</td>
</tr>
<tr>
<td>Germ cell tumour</td>
<td>0 (0)</td>
<td>6.3 (9)</td>
</tr>
<tr>
<td>Carcinoma</td>
<td>0 (0)</td>
<td>4.2 (6)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>1.5 (1)</td>
<td>0.7 (1)</td>
</tr>
<tr>
<td>Other</td>
<td>11.8 (8)</td>
<td>12.0 (17)</td>
</tr>
<tr>
<td><strong>Age at diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean±SD</td>
<td>17.2±3.68</td>
<td>16.6±4.03</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>42.6 (29)</td>
<td>37.3 (53)</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>38.2 (26)</td>
<td>31.0 (44)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>92.6 (63)</td>
<td>89.4 (127)</td>
</tr>
<tr>
<td>Hormone Therapy</td>
<td>2.9 (2)</td>
<td>3.5 (5)</td>
</tr>
<tr>
<td>Active Surveillance</td>
<td>1.5 (1)</td>
<td>2.8 (4)</td>
</tr>
<tr>
<td>None</td>
<td>0 (0)</td>
<td>0.7 (1)</td>
</tr>
<tr>
<td>Not Sure</td>
<td>1.5 (1)</td>
<td>0.7 (1)</td>
</tr>
<tr>
<td><strong>Time Since Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Still receiving treatment</td>
<td>100 (68)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>&lt;3 months from finishing treatment</td>
<td>-</td>
<td>15.5 (22)</td>
</tr>
<tr>
<td>4-11 months since finishing treatment</td>
<td>-</td>
<td>19.7 (28)</td>
</tr>
<tr>
<td>1-5 years since finishing treatment</td>
<td>-</td>
<td>45.8 (65)</td>
</tr>
<tr>
<td>&gt;5 years since finishing treatment</td>
<td>-</td>
<td>4.9 (7)</td>
</tr>
<tr>
<td>On active surveillance</td>
<td>-</td>
<td>14.1 (20)</td>
</tr>
</tbody>
</table>

*Where percentages do not equal 100% this was due to participants selecting all that applied.
### Table 4.3 Participant health problems

<table>
<thead>
<tr>
<th>Health Problems</th>
<th>TYA Cancer Survivors On Treatment</th>
<th>TYA Cancer Survivors Off Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=83 (% (n))</td>
<td>n=174 (% (n))</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>0 (0)</td>
<td>4.9 (7)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2.9 (2)</td>
<td>2.8 (4)</td>
</tr>
<tr>
<td>Asthma</td>
<td>10.3 (7)</td>
<td>9.9 (14)</td>
</tr>
<tr>
<td>Irregular heart rhythm</td>
<td>5.9 (4)</td>
<td>7.0 (10)</td>
</tr>
<tr>
<td>Extreme fatigue</td>
<td>33.8 (23)</td>
<td>28.9 (41)</td>
</tr>
<tr>
<td>Mental health problems</td>
<td>16.2 (11)</td>
<td>19.0 (27)</td>
</tr>
<tr>
<td>Lung disease</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>1.5 (1)</td>
<td>2.1 (3)</td>
</tr>
<tr>
<td>Any other heart trouble</td>
<td>1.5 (1)</td>
<td>2.1 (3)</td>
</tr>
<tr>
<td>Another cancer</td>
<td>2.9 (2)</td>
<td>1.4 (2)</td>
</tr>
<tr>
<td>Sensory Impairment</td>
<td>1.5 (1)</td>
<td>4.2 (6)</td>
</tr>
</tbody>
</table>
6.4.3 Health behaviour advice received since diagnosis

Figure 6.1 and Figure 6.2 displays the proportion of participants who reported receiving advice on each health behaviour since their cancer diagnosis. Approximately 60-70% of TYA cancer survivors reported receiving advice on physical activity and diet and approximately 45% reported receiving advice on weight. The majority (≥70%) reported receiving no advice on smoking or alcohol consumption.

Participants open response answers describing the advice they had received in the past are shown in Table 6.4. Much of the health behaviour advice participants reported receiving was general advice about maintaining a healthy lifestyle, however many participants reported receiving specific advice that related to cancer management. Specifically, participants reported being told to remain active during and after their treatment to help with recovery and to manage cancer-related fatigue. With regard to diet, advice often centred on weight management with many participants reporting that the advice they received was predominantly about calorie intake. Most TYA cancer survivors reported that they were actively discouraged from smoking and that they were advised to either not drink or reduce the amount they drink.

TYA cancer survivors who reported being ≥18 years of age at diagnosis were more likely to report having received advice on diet (OR=1.82, 95% CI 1.02-3.23, p=0.04) and weight (OR=2.61, 95% CI 1.43-4.75, p=0.002) than those aged <18 years at diagnosis. Unsurprisingly, TYA cancer survivors ≥18 years of age at the time of the study were more likely than TYA cancer survivors aged <18 to report receiving advice on smoking (OR=0.377, 95% CI 0.18-0.78, p=0.009) and alcohol consumption (OR=0.402, 95% CI 0.18-0.85, p=0.018). There were no other significant relationships between participant characteristics and the receipt of lifestyle advice.

The majority (n=170, 79%) felt that the amount of information they had received in the past was ‘about right’. Only 19% (n=42) felt they had not received enough information and 2% (n=4) thought they had been given too much information.

6.4.4 Interest in health behaviour information

Seventy-one percent of participants (n=153) reported that they would take up the offer of health behaviour information, advice and support if given the opportunity. The most commonly desired topic of advice was physical activity, closely followed by weight, and diet (Figure 6.1 and Figure 6.2). Less than a quarter of TYA cancer survivors reported an interest in advice on smoking and alcohol consumption.

TYA cancer survivors aged >18 were significantly less likely than 13-18 year-old TYA cancer survivors to report being interested in advice on diet (OR=0.41, 95% CI 0.18-0.89, p=0.024) and general lifestyle (OR=0.42, 95% CI 0.18-0.96, p=0.040), while females in comparison to males were more likely to be interested in advice on alcohol consumption (OR=1.62, 95% CI 0.76-3.46, p=0.209). There were no other significant relationships between age, gender, age
at diagnosis, current treatment status, number of health problems and interest in advice on each health behaviour.
Figure 4.8 Proportion of TYA cancer survivors on treatment who received health behaviour advice since diagnosis and their interest in health behaviour information

Figure 4.2 Proportion of TYA cancer survivors off treatment who received health behaviour advice since diagnosis and their interest in health behaviour information
Table 4.4 Participants’ description of the advice they had received in the past on each health behaviour

<table>
<thead>
<tr>
<th>Physical Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Resume normal activities when able and importance of exercising a few times a week’ (Female, Age 20, Lymphoma)</td>
</tr>
<tr>
<td>‘I was advised to ensure I exercised regularly to remain healthy’ (Female, Age 21, Lymphoma)</td>
</tr>
<tr>
<td>‘When going to gym let the instructor know about my previous condition to allow me a specialised work out to suit’ (Female, Age 25, Aplastic Anaemia)</td>
</tr>
<tr>
<td>‘Listen to your body, avoid weight bearing and high impact exercise due to AVN in knees and bone infarcts in legs. Try to be as active as pain allows.’ (Female, Age 24, Leukaemia)</td>
</tr>
<tr>
<td>‘Encouraged it, said if I was up to it then it would aid recovery’ (Female, Age 23, Lymphoma)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diet</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Due to treatment I had a neutropenic diet plan for a long time. Foods that were safe to eat when neutropenic.’ (Female, Age 22, Leukaemia)</td>
</tr>
<tr>
<td>‘Said to monitor this [diet] with my weight, as chemo had a big impact on these through affecting my diabetes’ (Male, Age 23, Lymphoma)</td>
</tr>
<tr>
<td>‘When on chemo, how to gain weight I had lost’ (Female, Age 17, Wilms Tumour)</td>
</tr>
<tr>
<td>‘Was told about taste buds changing and to keep calorie intake up’ (Female, Age 19, Leukaemia)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Weight Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Where I should be on the scales and advice on how to get there, told I should think about losing weight.’ (Female, Age 21, Lymphoma)</td>
</tr>
<tr>
<td>‘When first being given the all clear, I was underweight due to treatment. Advice was given on how to increase my weight, options available such as enshake etc.’ (Female, Age 24, Lymphoma)</td>
</tr>
<tr>
<td>‘Try to lose some weight to help with my prosthetic leg and walking’ (Female, Age 21, Bone Tumour)</td>
</tr>
</tbody>
</table>

Participant characteristics are displayed in brackets
Table 6.4 continued

**Alcohol Consumption**

“When I got the all clear I was told to be careful with my alcohol intake to protect my liver.’ (Female, Age 21, Lymphoma)

‘Limit daily alcohol consumption and limit tablets if feeling drunk’ (Male, Age 18, Un-Specified Cancer Type)

‘Don’t binge drink’ (Male, Age 19, Lymphoma)

**Smoking**

‘Just to keep not smoking’(Female, Age 23, Lymphoma)

‘Don’t do it ever (even though I do not smoke) - lungs already had enough and can cause more cancer’ (Female, Age 17, Lymphoma)

‘Dangers of smoking. What risks they add for poor health.’ (Female, Age 22, Leukaemia)
6.4.5 Sources from which TYA cancer survivors seek health behaviour information

Figure 6.3 outlines the range of sources TYA cancer survivors report consulting for information on each health behaviour topic. TYA cancer survivors typically sought information on physical activity and diet from websites online, whilst health professionals were the preferred source of information on weight, smoking, alcohol consumption and general lifestyle advice. Very few TYA cancer survivors (<15%) indicated that they would seek health behaviour information from their friends, parents, telephone helplines, or YouTube. Nonetheless, a greater proportion of TYA cancer survivors reported asking for advice or information from their friends rather than their parents about smoking (11% vs. 5%) and alcohol consumption (15% vs 7%).
Figure 4.3 Sources TYA cancer survivors consult for information on each health behaviour

- Friends
- Parents
- Health Professionals

Respondents (%)

- Printed Materials
- YouTube
- Websites Online
- Telephone Helplines

- Physical Activity
- Diet
- Weight
- Smoking
- Alcohol Consumption
- General Lifestyle Information
6.4.6 Preferences regarding health behaviour information delivery

The vast majority of participants reported that they would prefer health behaviour information to be available online (n=190, 88%) or in the form of app (n=184, 85%) and indicated a preference for short information leaflets over longer booklets (78% vs 66% respectively). Sixty-eight percent (n=147) reported that they would be interested in one individual counselling session. Group counselling sessions and a telephone call from a health professional were found to be the least popular formats of advice and information delivery.

Seventy-six percent (n=108) of TYA cancer survivors who had finished their cancer treatment felt that if given the opportunity they probably would have taken up the offer of information and support on health behaviour at the end of their main treatment. Table 6.5 displays TYA cancer survivors preferences on the best time to offer health behaviour information to young people with cancer. Unsurprisingly TYA cancer survivors on treatment at the time of the study reported a greater interest in receiving advice during the treatment phase of the cancer continuum, particularly before treatment begins (35% vs 21%, X² (5, N=210) =17.807, exact p=0.002). No other participant characteristics were found to predict timing preference. As a collective sample, most participants (29%, n=62) felt health behaviour information and advice would be best provided immediately after treatment; a similar proportion of participants felt health behaviour information would be best provided before treatment starts (n=56, 26%), during treatment (n=39, 18%), and 3-5 months after treatment (n=45, 21%).
Table 4.5 Preferences regarding the timing of health behaviour information delivery

<table>
<thead>
<tr>
<th>When do you think would be the best time to offer information about lifestyle to young people diagnosed with cancer?</th>
<th>TYA Cancer Survivors On Treatment (n=68)*</th>
<th>TYA Cancer Survivors Off Treatment (n=142)*</th>
<th>Total Sample (n=216)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before treatment starts</td>
<td>35 (24)</td>
<td>21 (30)</td>
<td>26 (56)</td>
</tr>
<tr>
<td>During treatment</td>
<td>23 (16)</td>
<td>16 (23)</td>
<td>18 (39)</td>
</tr>
<tr>
<td>Immediately after treatment</td>
<td>31 (21)</td>
<td>27 (39)</td>
<td>29 (62)</td>
</tr>
<tr>
<td>3-5 months after treatment</td>
<td>9 (6)</td>
<td>26 (37)</td>
<td>20 (45)</td>
</tr>
<tr>
<td>6-12 months after treatment</td>
<td>0 (0)</td>
<td>9 (12)</td>
<td>6 (12)</td>
</tr>
<tr>
<td>More than 1 year after treatment</td>
<td>2 (1)</td>
<td>1 (1)</td>
<td>1 (2)</td>
</tr>
</tbody>
</table>

*data on treatment status missing for 6 participants. TYACS: TYA Cancer Survivors
6.5 Discussion

Interventions which contain relevant health behaviour information have the potential to improve physical activity, dietary, smoking and alcohol practices of TYA cancer survivors by increasing knowledge and awareness of the importance of healthy lifestyle choices; improving positive attitude and intentions towards positive health behaviour choices, and acting as a cue to positive behaviour change (Rabin, 2009, Hollen et al., 2007). However, findings from this study indicate that TYA cancer survivors often do not receive health behaviour information or advice as part of routine care; particularly on sensitive health topics such as weight management, smoking and alcohol consumption. TYA cancer survivors were predominantly interested in information on physical activity, diet and weight management and reported seeking advice from health professionals and websites. No consensus was reached as to when information or advice on health behaviour should first be provided, with fairly equal proportions of TYA cancer survivors indicating that health behaviour information should be provided before treatment, during treatment and after treatment.

TYA cancer survivors high level of interest in receiving information on physical activity, diet, and weight management is encouraging and reflects findings from previous research exploring the long-term follow up preferences and psychosocial support needs of young people with cancer (Murnane et al., 2015, Gibson et al., 2015, Barakat et al., 2016, Zebrack, 2008). Moreover, TYA cancer survivors descriptions of the advice they had received in the past indicate health professionals do make some effort to discuss health behaviour with their patients.

However, the finding that very few TYA cancer survivors report past experience of receiving, or any interest in receiving, information on smoking and alcohol consumption is concerning given the well-established risks these behaviours have on current and future health (Wilson et al., 2016). Previous narrative reviews exploring the risk-taking behaviours of TYA cancer survivors have acknowledged that counselling TYA cancer survivors on smoking and alcohol consumption is a challenge given that experimentation with such behaviour is often a standard part of youth culture (Morgan et al., 2010). One qualitative study exploring the late effects information needs of adult-aged survivors of childhood and adolescent cancer identified ambivalence to receiving health risk information as a core theme (Lie et al., 2015). Participants in the study indicated they were passive towards the importance of receiving detailed information on late effects during adolescence, and were only aware of the importance of being fully informed about health risks faced by TYA cancer survivors in hindsight as adults. A similar notion may apply to information on smoking and alcohol consumption. Previous intervention studies conducted among TYA-aged childhood cancer survivors have reported intensive late-effects counselling, containing explicit information on the risks of tobacco use, to be effective at improving health knowledge and lowering intentions to smoke (Tyc et al., 2003). As such, it is clear that despite TYA cancer survivors apparent disinterest in information on smoking and
alcohol consumption, efforts to provide TYA cancer survivors with such information should be continued.

TYA cancer survivors within this study most commonly reported seeking information and support on health behaviour from either health professionals or websites. This was to be expected given the close and trusting relationships young people with cancer often have with health professionals (Gibson et al., 2012) and the prolific use of the internet among TYAs in general (Gross, 2004). The finding that TYA cancer survivors seek information directly from health professionals confirm findings from a recent cross-sectional survey exploring the support service preferences of TYA cancer survivors (n=102) wherein 82.8% of young people reported they seek information on their cancer and what can be done about it directly from professionals (Abrol et al., 2017). Similarly, the finding that TYA cancer survivors seek information online is supported by existing research which indicates 70 – 90% of young people with cancer have regular access to a laptop, smartphones, or a tablet (Abrol et al., 2017, Moody et al., 2015). However, a recent systematic review of technology-based lifestyle interventions piloted among childhood and TYA cancer survivors found only six interventions that were delivered via digital mediums such as websites, mobile apps, emails, text messages or games consoles, highlighting the paucity of digital interventions available to TYA cancer survivors (Kopp et al., 2016).

The finding that TYA cancer survivors are interested in health behaviour information throughout the cancer care pathway from diagnosis to survivorship strengthens the rationale for developing easily accessible, readily available, health behaviour information resources for young people with cancer. However, it remains to be explored whether the precise moment at which a young person with cancer would be most receptive to health behaviour information is related to current age, age at diagnosis or treatment status. We were unable to find any association between these factors and interest in health behaviour information, suggesting that the ‘teachable moment’ for health promotion among TYA cancer survivors may be governed by intra-individual factors. Even so, there is some evidence that health behaviour interventions delivered to TYA cancer survivors may be most effective in preventing the onset and development of health problems if delivered during treatment and in the early stages of survivorship care prior to the onset of treatment-related comorbidities or noted declines in health behaviour (Barnes et al., 2016). Early introductions to health promotion efforts may trigger behaviour change among some TYA cancer survivors and prime intentions to change behaviour among those who are not ready or unreceptive towards lifestyle change (Demark-Wahnefried et al., 2006, Demark-Wahnefried et al., 2005a).

This study highlights a number of key factors that should be considered when developing health promotion interventions for young people with cancer. Namely, it provides a useful insight into TYA cancer survivors past experience of, and overall interest in, receiving health behaviour information. This study also presents some of the first data on how and when such
information should be provided to young people with cancer. However, these results should be considered in light of several limitations. Firstly, due to the nature of recruitment it is not possible to gather data on non-responders or use data submitted by TYA cancer survivors who completed only small parts of the survey. Secondly, akin to the majority of existing health behaviour interventions the sample within this study was predominantly white and aged between 19-25 years. Moreover, the possibility of response bias within the sample is high as it is likely that those who responded to the health and lifestyle survey are those who are already engaged in health promotion efforts. As such, coupled with the cross-sectional nature of the study design, the findings may not generalize to the TYA cancer survivor population as a whole. In addition, the study only investigated the information needs and preferences of TYA cancer survivors with regard to physical activity, diet, smoking, and alcohol consumption. Many young people with cancer report a need for information and support on sun safety, sexual health, fertility and recreational drug use. Exploring TYA cancer survivors past experience and preference for the timing, delivery and format of receiving advice on these topics is a much needed direction for future research.

6.6 Chapter summary

TYA cancer survivors are highly interested in health behaviour information available throughout the cancer pathway from the point of diagnosis. Specifically, young people with cancer are more interested in information on physical activity, diet and weight management than information on smoking or alcohol. It is therefore likely that young people with cancer require additional support from health professionals on sensitive health topics such as smoking and alcohol consumption. Further research is required to understand what motivates young people to lead a healthy lifestyle and identify specific features a health behaviour intervention which might be particularly appealing to young people with cancer.
Chapter 7

Study 3

The Health Behaviour Information Preferences of Teenage and Young Adult Cancer Survivors: A Qualitative Study

7.1 Introduction
As detailed within Chapter 6 (Study 2) TYA cancer survivors demonstrate a high level of interest in receiving health behaviour information. Results indicate that more than 70% of young people with cancer are interested in advice on a healthy lifestyle with the majority (63%) reporting they would have liked the opportunity for information, advice and support on making lifestyle changes at the end of their main treatment. However, although the findings from Study 2 are encouraging, information provision is passive, and unlikely to prompt behaviour change without the incorporation of behaviour change techniques or understanding of the underlying motives behind lifestyle change (Michie et al., 2011a). Therefore, identifying barriers and facilitators to health behaviour change among TYA cancer survivors is central to the design and development of interventions for this age group. Similarly gathering data on the health behaviour intervention format and delivery preferences of young people with cancer, from a patient-centred perspective will ensure the final intervention is acceptable, appealing and relevant. Such insight will increase the likelihood that young people with cancer will engage with the health behaviour intervention resources being provided (Zebrack, 2014).

7.2 Aim
The aim of this study was to explore TYA cancer survivors’ motivation behind lifestyle related behaviour change, and their preferences regarding lifestyle information and health behaviour change intervention delivery. In addition, this study aimed to identify barriers and facilitators to health behaviour change among young people affected by cancer.

7.3 Method
7.3.1 Population
Participant recruitment and data collection methods are discussed within Chapter 4 Section 4.7. A sample of 13 young people participated within this study (n=10, interview participants: n=3, focus group participants).

18 A version of this chapter has been published in Cancer Nursing (Appendix 7.1) Pugh, G., et al. (2017). “The Lifestyle Information and Intervention Preferences of Teenage and Young Adult Cancer Survivors: A Qualitative Study.” Cancer Nurs. doi: 10.1097/NCC.0000000000000508. [Epub ahead of print]
7.3.2 Measures

Participant demographics and data on health status, time since diagnosis and treatment status were gathered from the health and lifestyle questionnaire as outlined in Chapter 4, Section 4.5. As detailed within Chapter 4, Section 4.7 each interview and focus group was centred on the same topic guide contained within Appendix 4.7.

7.3.3 Analysis

Qualitative data was transcribed full-verbatim and checked for accuracy during the familiarisation phase of the six-phase process of thematic analysis as outlined by Braun and Clarke, 2006. In the familiarisation phase each interview/focus group recording and transcript was listened to and reviewed simultaneously. An initial list of codes and themes were generated from this process and several meetings between the study team (GP, Dr Abigail Fisher, and a psychologist Dr Rebecca Beeken) were held in order to refine these lists until a single list of codes and relating themes was agreed upon. Each core theme and any related sub-themes were then discussed with a TYA cancer expert (Dr Rachael Hough) for affirmation and identification of missing themes. An independent researcher (Jessica Haddrell) second coded the focus group transcript and three of the interview transcripts to ensure the each theme worked in relation to each coded extract. All qualitative data analysis was carried out in NVivo version 11.0. To ensure conceptual clarity, the final report and generation of results was guided by the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007). Percentage agreement and Cohens Kappa were calculated to determine the inter-rater reliability of the analysis.

7.4 Results

7.4.1 Response rate

Following the health and lifestyle questionnaire (n=294), 93 young people left their contact details indicating interest in participating in this subsequent qualitative study. Of these young people, 10 responded to one of the three recruitment emails sent inviting them to take part in this study. Three young people were recruited via CLIC Sargents participation team. Interviews typically lasted 30 minutes in duration (range: 19mins 41 seconds – 43 mins 16 seconds). The focus group lasted approximately 1.5 hours and was arranged at a time convenient to the group member using existing non-clinical meeting facilities within CLIC Sargents London head office.

7.4.2 Sample characteristics

Characteristics of all participants are displayed in Table 7.1. The mean age of the sample was 22.9 years (range: 17-25 years) and the majority of participants were female (n=9, 70%). Mean age at diagnosis was 18.6 years. One participant was a TYA cancer survivor of a cancer diagnosed during childhood. Most participants (n=6, 46%) had been diagnosed with a haematological malignancy such as a leukaemia or lymphoma. Of those who provided full data (n=10/13) the majority (n=8, 80%) were no longer receiving active cancer treatment however
50% (n=4) of these young people had finished active cancer treatment less than a year before this study.

Table 4.6 Participant characteristics

<table>
<thead>
<tr>
<th>Participant Demographics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age at diagnosis (years)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;13 years</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>13-18 years</td>
<td>4 (31%)</td>
</tr>
<tr>
<td>18-24 years</td>
<td>8 (61%)</td>
</tr>
<tr>
<td><strong>Cancer Type</strong></td>
<td></td>
</tr>
<tr>
<td>Leukaemia</td>
<td>2 (15%)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>4 (31%)</td>
</tr>
<tr>
<td>Carcinoma</td>
<td>4 (31%)</td>
</tr>
<tr>
<td>CNS Tumour</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (15%)</td>
</tr>
<tr>
<td><strong>Treatment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Still receiving cancer treatment</td>
<td>2 (15%)</td>
</tr>
<tr>
<td>Less than 3 months since treatment</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>Between 4-11 months since treatment</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>1-5 years since treatment</td>
<td>5 (38%)</td>
</tr>
<tr>
<td>On active surveillance</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>Missing data</td>
<td>3 (23%)</td>
</tr>
</tbody>
</table>
7.4.3 Themes

Three core themes emerged from the interviews and the single focus group; i) cancer as a catalyst to lifestyle behaviour change; ii) factors influencing health behaviour change and iii) health behaviour information preferences. Figure 7.1 provides an overview of the thematic map generated within this study. There was a good level of inter-rater agreement on emerging themes (Mean weighted percentage agreement: 99.14%; mean weighted Kappa: 0.89).
Figure 4.9 Thematic map

Cancer as a catalyst to behaviour change

- Attempts to change lifestyle
- Motivation behind interest in lifestyle change
- Regaining normalcy
- Regaining control over health
- Heightened awareness of health
- Impact of cancer and cancer treatment on lifestyle choice

Factors Influencing Health Behaviour Change

- Cognitive Factors
  - Self-efficacy
  - Confidence
  - Knowledge & Skills

- Social Factors
  - Immediate family influence

- Peer-support

- Cancer-related physical changes
  - Treatment-related side effects
  - Physical changes following cancer treatment (scaring, body composition, hair loss)

- Practical Factors
  - Resource availability
    - Unmet Lifestyle Information Needs
    - Confusion/ uncertainty from unclear or lack of advice
Figure 7.1 continued

Health Behaviour Information and Intervention Preferences

**Information Content**
- Range of lifestyle topics
- Information about late effects
- Specific TYA cancer lifestyle information
- Recognition of individual needs
- Non-judgemental information

**Resource Format**
- Range of formats
- Accessible (optional to dip in and out/ easy to reach/find)
- Age-appropriate
- Visual Features (attractive/ non-patronizing)
- Concise Information

**Timing & Delivery**
- When/timing (Pre/During/Post Treatment)
- Who (Reliable/ Trustworthy Sources)
7.4.4 Cancer as a catalyst and barrier to lifestyle behaviour change

Young people indicated that their cancer diagnosis was often the underlying reason behind interest in lifestyle information and the catalyst behind any attempts to lead a healthier lifestyle. Leading a healthy lifestyle was seen by participants as a positive way of feeling better about themselves, regaining normality, regaining control of their health, and managing treatment related side-effects of cancer treatment including cancer recurrence:

‘It makes you feel as like you have some control if you can at least exercise and have some control over your diet. If you can’t do anything else then at least it’s something you can do.’ (Female, Aged 24, Diagnosed aged 21, Bowel Cancer)

‘The only thing for me now is to live like healthy because I want to be healthy. I don’t want anything to… I don’t want to go through anything that I’ve just been through again...’ (Female, Aged 22, Diagnosed aged 9, Thyroid Cancer)

Participants also reported that following their cancer diagnosis and treatment a healthy lifestyle was now generally more important to them; participants also voiced an increased awareness of the importance of lifestyle for long-term health. This heightened awareness of health was often attributed to the impact of their cancer diagnosis on life outlook:

‘I think being diagnosed with cancer you tend to be a bit more aware afterwards because you sort of don’t take your health for granted as much, I think.’ (Female, Aged 17, Diagnosed age 17, Wilms Tumour)

‘You know that you, you’ve got to take care of your body because, you know, this was, it’s like a scare really, I’ve had like a scare to my body that I need to make sure that everything is working fine, I’m putting good stuff in there and… you know, I just need to feel like I, I feel good about myself, eating the right foods and exercising.’ (Female, Aged 22, Diagnosed aged 9, Thyroid cancer)

With reference to smoking and tanning, young people often indicated aversion to smoking ‘cause obviously its causes cancer...’ and increased awareness of the risks of tanning and sun exposure. Often young people indicated that their cancer and their treatment led them to be more conscious of their alcohol consumption but some admitted being ‘probably what you’d call a binge drinker’. Two participants specifically indicated that they drink less now following their cancer diagnosis as they considered ‘more important things in life’ and ‘life too short to be unhealthy’. Young people typically did not bring these behaviours (smoking, drinking or tanning) up within discussion unless prompted.
7.4.5 Factors influencing health behaviour change

It was evident that cognitive factors such as individual health beliefs, self-efficacy, and confidence often contributed to TYA cancer survivors’ health behaviour and engagement with health and lifestyle information:

“Sometimes you have low self-esteem and you don’t want to… it’s not that the information isn’t engaging, it’s more how you feel in yourself” (Female, aged 24, diagnosed age 21, Hodgkin’s lymphoma)

Peer and social support were found to be the main facilitators of confidence and self-efficacy among young people. Young people often talked about the influence their immediate family and social network had upon their lifestyle both during and after treatment:

‘Obviously, when I was ill, I think even though I was kind of 17, 18, you do become more dependent on your parents, so providing them with the information about a diet or food or any exercise you can do, it is good because there are days that you might not feel up to go and exercise during that time, but actually I often found that it was my mum that was like, “Right, we’ll go for a walk,” trying to find ways to engage me in it.’ (Female, aged 24, diagnosed age 17, Hodgkin’s lymphoma)

Participants also emphasised the need for peer support to come from other young people of a similar age and position to them. Many young people looked to identify with other TYA cancer survivors and described wanting to know more about their lifestyles and what was ‘normal’ for them.

‘You just kind of think, well, they understand, um, and I think it’s a lot easier to get the information into your head when it’s another person’s story. Like, telling it rather than just someone whose job it is to write the information, it’s coming from someone who’s been through a similar situation….. ’ (Male, Aged 23, Diagnosed age 21, Hodgkin Lymphoma).

All participants viewed education on the benefits of a healthy lifestyle and guidance on making lifestyle changes as important. Young people often reported that goals and progress monitoring would be useful motivational tools to encourage young people to sustain positive health behaviour changes:

‘Personally, I found, like, having a goal to work towards is really helpful, um, and you can…. if you can sort of track it along the way. So, it’s always really helpful to be able to see that you’re making progress. That gives you a nice confidence boost and stuff like that.’ (Female, Aged 24, Diagnosed aged 18, CNS Tumour).

‘I think I quite like to feel a sense of achievement. So if I’m, sort of, noting down what I’m doing, I can kind of remind myself that, ‘Oh, I’ve done this today, that’s a good thing to have done,’ kind of thing. So that… I think making a record, erm, can be a good way of forming habits, because, yeah, you… You keep doing it and you keep reminding yourself that you’re doing it...’
and it makes you feel good kind of thing, yeah.’ (Female, Age 22, Diagnosed age 21, HLH/Chronic Active EB Virus)

Participants generally supported the notion that any changes should be made gradually in order to sustain health behaviour change over-time:

‘I think I’ll slowly try and... I’m not going to change it straight away, because I think I’ll find that really hard, but what I’m trying to do is try and change a few meals slowly, otherwise I think I’ll just crave my diet how it used to be.’ (Female, Aged 24, Diagnosed age 23, Hodgkin Lymphoma).

Young people often acknowledged that a healthy lifestyle could be of benefit to everyone:

‘I think a lot of people, yeah, they’re disillusioned and think they can’t exercise at all. But even a little bit is good for you. So it’s just kind of making the best of what you’ve got, and being able to make a bit of time to keep active’ (Male, Aged 23, Diagnosed age 21, Hodgkin Lymphoma)

Despite the high level of interest in leading a healthy lifestyle many young people described challenges they had faced in attempts to change their health behaviour. Young people talked openly about the difficulty of having to navigate a ‘new body’ post treatment that is ‘not the same as what it was pre-treatment’. Often treatment related side effects or late effects were the main barrier to improving lifestyle behaviours, specifically diet or exercise related behaviours:

‘I tried to… with my diet, I tried to gradually reintroduce healthier foods and things, but I’ve had loads of problems with that and just haven’t been able to really, on and off. And with exercise, because of my surgery, I wasn’t really sure what I could do, because they cut through my stomach muscles, so I had to be really careful about hernias and things.’ (Female, Aged 24, Diagnosed age 21, Bowel Cancer)

Many young people openly discussed the impact cancer treatment had upon their appetite, diet, and weight. Young people were often frustrated by treatment related fluctuations in weight and failed attempts to maintain or reach a healthy body weight. Dietary habits and food preferences formed during treatment were often outlined as one of the biggest challenges to changing diet related behaviours:

‘I’d ate so much junk when I was on steroids that I just... it just became a habit, and I never broke it, really. So it’s taken, like, six, seven years for me to break the unhealthy eating I was doing for two and a half years. (Female, Aged 25, Diagnosed age 15, Acute Lymphoblastic Leukaemia).

Specifically regarding physical activity, many participants shared that cancer and its associated treatment had led to a loss of confidence in their ability to exercise:
"I don't know. I was very active before I was diagnosed, and then during that time I lost… you do lose your confidence because […] muscle wastage and things like that." (Female, aged 24, diagnosed age 17, Hodgkin lymphoma)

Another participant explained feeling self-conscious around other young people in public places such as local gyms because of cancer related physical changes in his appearance such as ‘hair loss’ and ‘a fatter face cause of steroids or whatever…’. In addition, young people often viewed themselves as different to other young people who had not had cancer:

"I'd never dreamt of going to the gym with… I don't mean to say ordinary people, but people of good health because I would have felt like such an outsider." (Female, aged 24, diagnosed age 17, Hodgkin lymphoma)

Geographical, financial, and time related barriers to leading a healthy lifestyle were also mentioned by young people who indicated that travelling to support groups, paying for gyms, and preparing or cooking healthy meals as barriers to being active and eating healthily. Barriers relating to reducing alcohol consumption, quitting or abstaining from smoking, or being safe in the sun were not openly discussed suggesting young people were typically unaware of extraneous factors influencing these behaviours.

Although some young people did have a positive experience most participants within this study reported a high level of dissatisfaction with the lifestyle information they had received in the past. Young people typically reported previously receiving very brief information about lifestyle from health professionals; often this advice was given within the context of treatment or during discussions about late effects management:

"I had kind of like an end-of-treatment, like, meeting with my consultant. I don't know... I don't think he does it with everyone, but he offered to do it with me because I was particularly worried about finishing. .. just did say, like, "Make sure you look after yourself." Like, "Don't smoke, don't go on a sun bed. You know, don't eat unhealthily, because you're at higher risk of being obese after the treatment and stuff." (Female, Aged 25, Diagnosed age 15, Acute Lymphoblastic Leukaemia).

However, young people often reported that health professionals were not forthcoming with information about lifestyle and that either no information was given or that the information they were given was vague and out of context. One young person discussed an incident when a health professional was caught off guard by their request for specific information about sun safety:

"I did ask the doctor about, you know, "Was it okay to be in the sun?" ....I think it was a question that they weren't really... I don't know if he'd been that, sort of, prepared for the question. He kind of was like, […] Oh, you'll be okay without sun cream if you're outside for just a little while,' which didn't really kind of answer... I'd quite like to have known, you know,
what I... How... You know, can I... Can I sit in the sun in the summer, for instance? Erm, so, yeah…’. (Female, Aged 22, Diagnosed aged 21, HLH/ Chronic Active EB Virus).

Some young people also reported that information about late effects and long term management of cancer was not openly discussed with them by health professionals. This caused a high level of distress among young people.

‘Mmm. Because, like, when I was diagnosed with the AVN [Avascular Necrosis], it was so shocking, like, I was literally so so... so, so shocked because, um, I... they didn't really tell me anything about late effects. They didn't tell me anything when I was diagnosed, or when I'd finished, so it was really, like... it was just really surprising, and then...Like, I've seen statistics that say, like, it's so much more common than they're making out, and they're still really guarded about telling you.’ (Female, Aged 25, Diagnosed age 15, Acute Lymphoblastic Leukaemia).

‘At the time during treatment, I don't specifically remember being given that kind of information. It's only when I've then asked about stuff that then maybe other things have been mentioned.’ (Female, Aged 24, Diagnosed aged 23, Hodgkin Lymphoma).

Lack of information from health professionals often prompted young people to search elsewhere for information, most commonly online:

‘So the first thing I done was went on the internet, googled it.’ (Female, Aged 24, Diagnosed age 17, Hodgkin Lymphoma)

‘I think the only challenge was not really knowing what to do, so not knowing…obviously, I know it's quite easy… it felt quite easy to think that you should kind of avoid fatty foods and things like that, but it's more the information. So I would go online a lot.’ (Female, Aged 24, Diagnosed age 17, Hodgkin Lymphoma)

Young peoples’ level of satisfaction with information found themselves varied. Some reported finding useful recipes and blogs from other cancer survivors whilst others reported struggling to find any age appropriate resources or any information relevant to their needs. Young people had strong views that there was not enough information readily available for young people with cancer that focused on TYA specific issues.

‘When you finished treatment you sort of feel a bit… not abandoned, but you are sort of on your own dealing with it yourself, trying to manage. You know, you feel like you are in charge of your own health again, which can be a bit of a responsibility. It would be nice to be able to have someone saying, you know, giving you a bit of guidance.’ (Female, Aged 24, Diagnosed age 21, Bowel Cancer).

‘I suppose with my condition, I've tried to look about, what, um, sensible exercise would be, but there's literally no information anywhere…’ (Female, Aged 25, Diagnosed age 15, Acute Lymphoblastic Leukaemia).
The lack of clear guidance or information from health professionals and online sources led to feelings of confusion and uncertainty among young people on how to, and when to, safely make lifestyle changes following their cancer diagnosis. Specifically, young people were often unsure about the effects of alcohol and its interaction with their treatment status:

‘Yeah, because, um, I would like to know, you know, can I drink, will it affect me, you know, does it relate to like what kind of cancer I had, is too much… having too much bad for me? Probably anyway. But just, just in general like if, if I wanted to go out with my friends would I have a drink, because I don’t, I don’t know, I don’t know, if that makes sense, I don’t really know if I’m allowed to or not’ (Female, Aged 24, Diagnosed aged 18, CNS Tumour).

7.4.6 Lifestyle Advice Preferences

**Content**

Participant’s ideas concerning the content of lifestyle information are displayed in Table 7.2. Young people were interested in lifestyle information on a range of topics. Specifically young people were interested in lifestyle information that was integrated with other information topics such as late effects management and maintaining normalcy.

‘And when they are telling you all these side effects, I think that’s then for me when I’d want to know about the healthy lifestyle and how to keep fit and healthy, eat healthily.’ (Male, Age 25, Diagnosed age 21, testicular cancer).

Young people often expressed that they wanted lifestyle information which specifically related to their cancer diagnosis and the effects it had had, interest in specific information on weight maintenance was also common.
Table 4.7 Lifestyle intervention content preferences

**Range Of Lifestyle Topics**

‘Like, um, healthy food tips, what maybe we should be eating now, like something to do with alcohol and smoking, um, if it’s relevant to them. Um, you know, just about like why is it not good for you and, you know, this is why we should stop and…’ (Female, Age 22, Diagnosed age 22, Thyroid Cancer)

‘Um, just stuff like diet, kind of how to deal with changes in appearance, and like, how your lifestyle's going to change, physical activity, stuff on education, if you’re going to be going back into education, or if you’re thinking of going into it. Just, kind of, a bit of everything, cover all bases.’ (Male, Age 23, Diagnosed age 21, Hodgkins Lymphoma)

‘Maybe a bit more about sort of drinking and smoking and going out stuff.’ (Male, Age 23, Diagnosed age 21, Hodgkins Lymphoma)

**Lifestyle Information Specific To The Impact And Effects Of TYA Cancer**

‘Like what you can advise which would help your weight not fluctuate as much when you are not able to be as active as you used to be. That might be quite helpful’ (Male, Age 20, Diagnosed age 19, Acute Lymphoblastic Leukaemia)

‘And I suppose you’d have different sections. I think a neutropenic section would be really useful. Erm, and then, erm, maybe, like, a trying to gain weight section and also like a trying to lose weight section because if you’ve been on steroids’ (Female, Age 22, Diagnosed 21, HLH/ Chronic Active EB Virus).

‘Like, more about, um, what the impact of my lifestyle now might have in the future’ (Female, Age 22, Diagnosed age 20, Hodgkin Lymphoma).

‘I think there needs to be more information, because some people might want information about a healthier lifestyle, on chemotherapy what foods are good and what foods are bad.’ (Male, Age 25, Diagnosed age 21, Testicular Cancer)

‘I don’t know, things relevant to the different kind of cancer that young people often have. I know bowel cancer isn’t very common, so it probably wouldn’t be on there, but there are some that are really common to young people, so specialised information on how they should exercise and what they should do, especially if they had restrictions and stuff like that.’ (Female, Age 24, Diagnosed age 21, Bowel Cancer)
Table 7.2 Continued

**Recognition Of Individual Needs**

"It’s quite hard when your body, kind of, changes without... When you... And you have no control over it. It’s... It’s... You're not the per... You don't look like the person you used to look like. Erm, and I think sort of just kind of acknowledging that when you talk about, ‘Oh, if you need to lose weight, or if you need to gain weight,’ erm, I just... I think maybe acknowledging that at the beginning of the section. Just saying, you know, ‘Yeah, we... This is really hard, but, you know, don't worry, you could lose the weight again,’ or, ‘you'll put on the weight again. Here's some helpful tips of how to do that,’ kind of thing.’ (Female, Age 22, Diagnosed 21, HLH/ Chronic Active EB Virus).

‘Just the general how to look after myself. I mean, I know how to look after myself, obviously, but recommendations for specific types of cancer. I mean, I've got a brain tumour, so I'll say I wasn't affected. But things that would be specific to me. Whereas someone who, say, had Hodgkin lymphoma might be completely different. You can't just give everyone the same information and just hope it works out.’ (Female, Age 24, Diagnosed Age 18, Benign Meningioma)

'I think the thing as well - because all cancers are different and so are treatments, and also the way that you respond is different - I feel like sometimes the information in the booklet can be quite generic and might not apply to all situations.’ (Female, Age 24, Diagnosed age 23, Hodgkins Lymphoma)

Like... I know this sounds weird, but, sometimes when you're reading, like, a general leaflet, you're kind of like, ‘Yeah, this is all well and good, but what about someone who's been through treatment or diagnosis and stuff?’ (Female, Age 25, Diagnosed age 15, Acute Lymphoblastic Leukaemia).
‘Like when you are not able to exercise and that kind of thing, what effect… because obviously you want to eat healthily, but at the same time you need to manage the weight a bit. So maybe like what you can advise which would help your weight not fluctuate as much when you are not able to be as active as you used to be. That might be quite helpful’ (Male, Age 20. Diagnosed age 19, Acute Lymphoblastic Leukaemia).

Many participants also expressed an interest in specific information about socialising, particularly drinking. Participants highlighted strongly that the content of lifestyle information for TYA cancer survivors should be relevant to the needs of young people with cancer. Consistent with this theme, participants were also strongly interested in information that took into account their own individual needs as survivors of specific cancers.

**Format**

Participant’s ideas concerning lifestyle information format are displayed in Table 7.3. Young people considered the pros and cons of various formats of lifestyle information delivery. Participants spoke openly about elements of information delivery that had strongly disliked in the past and how they thought lifestyle information should be made available to young people with cancer nowadays. Overall, young people were interested in information presented in a variety of formats that could be accessed depending upon their needs at any given time. Information delivered online or via mobile applications appealed to TYA cancer survivors as these formats were perceived as more accessible and appealing to young people:

‘For this generation, it has to all move to digital because that’s the way this generation is moving forward.’ (Male, Age 25, Diagnosed age 21, testicular cancer).

‘Erm, well, I think the good thing about a website is that it’s always, like… Unlike with booklets, erm, it… The website would always be there. Erm, whereas you might get given booklets at the start and then by the time you actually need the advice the booklet might have got lost.’ (Female, Age 22, Diagnosed 21, HLH/ Chronic Active EB Virus)

However, several young people acknowledged that online information is only seen if it is being actively searched for. In such instances young people highlighted the need for information to be available in multiple formats including in the form of counselling from health professionals:

‘I think online it tends to be… you only see it then if you go looking for it…. Like when I was diagnosed, my CLIC Sargent social worker came in and she just gave me loads of leaflets and just said, “Look through these,” and then I looked through them, whereas I wouldn’t have gone onto a website and looked at it myself, really’ (Male, Age 20, Diagnosed age 19, Acute Lymphoblastic Leukaemia).

Participants during discussion regarding the design and presentation of lifestyle information indicated that information should be concise, accessible, attractive and age-appropriate. Young people wanted lifestyle information that was easy to find and easy to navigate. Specific
features such as designated topic sections, lists and interactive online features such as hyperlinked content and the ability to ‘pin’ or ‘like’ favourites appealed.

Young people expressed frustration at having to sift through ‘endless’ information resources in the past. Short articles or information presented in ‘chunks that you can read one by one’ were preferred. Participants also emphasized the need for lifestyle information resources to be designed specifically for ‘young people rather than children’. Many of the participants emphasized the need for making sure both the content and format of health and lifestyle information was neither patronizing nor ‘sugar-coated’. Visual features such as use of colour, infographics and imaginative page layout were suggested by young people as being key aspects of lifestyle information design and format.
Table 4.8 Lifestyle intervention format preferences

<table>
<thead>
<tr>
<th>Range Formats</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Or even if you just have the little business cards with the address on, just say, ‘Oh here you go, it’s all on there if you want it,’ or, ‘We’ve got an app.’ Because, I mean, that’s the thing, isn’t it, this generation, you don’t read.’ (Female, Age 24, Diagnosed age 18, Benign Mengioma)</td>
</tr>
<tr>
<td>‘Um, nothing too long. Like, it’s got to be, like, easy to read, like, concise, um... I’m trying to think what else. Like, accessible as well, I suppose. Not just like a leaflet, but if you can get it online or... available in different ways.’ (Female, Age 25, Diagnosed age 21, Hodgkins Lymphoma)</td>
</tr>
<tr>
<td>‘I think having a leaflet with the website on will kill two birds with one stone, so then they’ve got the leaflet rather than printing out loads and loads of leaflets. Because I remember getting information when I was having radiotherapy, I was saying, “What am I going to do with all these leaflets? I don’t need all these.” Because they had the website on the bottom, I was like, “Well I can just go online and look at it. I don’t need it all kind of printed out.’ (Female, Age 24, Diagnosed age 18, Benign Mengioma)</td>
</tr>
<tr>
<td>‘I prefer like that communication where you can talk really, answer questions, because you can’t really ask anybody a question when you read a leaflet.’ (Female, Aged 22, Diagnosed age 9, Thyroid Cancer)</td>
</tr>
<tr>
<td>‘I do use mobile apps pretty, quite a lot, so I think that would be pretty useful because you can just go on your phone and have a little look instead of like looking at a book or something, because some people like things to read and then some people like looking on their phone for information.’ (Female, Aged 22, Diagnosed age 9, Thyroid Cancer)</td>
</tr>
<tr>
<td>‘Just because, you know, everyone is glued to their phones, and especially if you’re in hospital having treatment, or you’ve had treatment or whatever, it can just be quite good to kind of pick up your phone and just scroll through stuff to kill some time. I think an app would be really good.’ (Female, Age 23, Diagnosed age 21, Hodgkin Lymphoma).</td>
</tr>
</tbody>
</table>
Table 7.3 Continued

<table>
<thead>
<tr>
<th>Accessible, Easy To Digest &amp; Concise</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘I’d like the thought of looking at a little… like looking at a little book and just like looking at little facts and stuff about what you can eat and, do you know?’ (Female, Aged 22, Diagnosed age 9, Thyroid Cancer)</td>
</tr>
<tr>
<td>‘A bit like a section in the little booklet, maybe, and then you just jump to the bit like… you know, that’s ideal… what you’re… what, what you do, so you’ (Female, Aged 22, Diagnosed age 9, Thyroid Cancer)</td>
</tr>
<tr>
<td>‘Almost like an interactive website, almost like a Pinterest, with all different tabs, just because I think it would help to target the audience’ (Female, Age 24, Diagnosed age 17, Hodgkin Lymphoma)</td>
</tr>
<tr>
<td>‘I liked the fact that I just had something to read and quickly access.’ (Female, Age 24, Diagnosed age 23, Hodgkin Lymphoma).</td>
</tr>
<tr>
<td>‘I think probably like little bite-sized bits of information with, then, kind of an option to go into a more detailed bit if you’d like to kind of read into it yourself a bit more then, would be best in general.’ (Male, Age 23, Diagnosed age 21, Hodgkin Lymphoma).</td>
</tr>
<tr>
<td>‘Um, I like the idea of infographics. I find them, just, they’re always, like, quite a good thing to have, like, kind of tying in to the nice, concise bits of information.’ (Female, Age 23, Diagnosed age 21, Hodgkin Lymphoma).</td>
</tr>
<tr>
<td>‘If I don’t want to read it all, but I just want to read a certain section, then I’d just want it to be easily found. I like the use of headings, so I’d just think, ‘Oh right, that’s the bit I want to read right now.’ quite small. Easy to take in, especially when you are going through treatment and stuff, you don’t want to read a massive article.’ (Female, Aged 24, Diagnosed age 21, Bowel Cancer).</td>
</tr>
<tr>
<td>‘Not so you feel like it’s going to be a long list of things for you to read through and it wasn’t like really sinking in. So maybe something that’s quite punchy, I guess.’ (Male, Aged 20, Diagnosed age 19, Acute Lymphoblastic Leukaemia).</td>
</tr>
</tbody>
</table>
Delivery

No consensus on when the best time to provide health behaviour information to young people with cancer was reached. Participants often contemplated their own experience of receiving and searching for lifestyle information and considered the impact such information might have had if it had been received at a different time point. Often young people felt that the correct time for lifestyle information delivery was dependent upon an individual’s frame of mind concerning their diagnosis, treatment status, and prognosis and that such information may be best delivered as and when a person is ‘ready’. Young people were often acutely aware of the risk taking mind-set of young people and acknowledged that information delivered at the wrong time point can sometimes fall upon deaf ears. Participants stressed the importance of not being overwhelmed with information and that they were more receptive to information if advice was offered in a supportive and open manner:

‘I can understand why not all information is given at once, because otherwise you do feel a bit bombarded. I feel like if they just said it in the way of, ‘Obviously you don’t need to take this on board straight away,’ but just, ‘Things to consider over the next few months, if you want to.’ (Female, Age 24, Diagnosed aged 23, Hodgkin Lymphoma)

Young people also indicated that access to the information should be volitional:

If somebody’s kind of lectured you about it, and if you’re kind of being told, “Oh yeah, go check this out, go check this out, go check this out,” sometimes you just kind of think, “Oh, well, I don’t really want to look at that.” So I think, if they could be given a resource pack, maybe, to go and look into themselves… (Male, Age 23, Diagnosed aged 21, Hodgkin Lymphoma).

Throughout all interviews and focus groups young people indicated a strong preference for information that was ‘sensible’ and ‘legitimate’ from reliable and trustworthy sources. Young people commonly cited well-known TYA cancer charities in the UK as the best sources of information and that they would prefer information endorsed by health professionals specializing in TYA care who ‘know what they are talking about’
7.5 Discussion

Findings from this study highlight the need for readily available age-appropriate health information on a wide-range of health topics for TYA cancer survivors. Such information should be incorporated into a health behaviour change interventions developed and designed specifically for young people with cancer.

In this study young people often described their cancer diagnosis as the primary reason behind their interest in lifestyle information and engagement in health behaviour change. Many young people reported an increased perception of personal health risk after their cancer diagnosis, and viewed adopting healthy lifestyle behaviours as a positive self-management strategy. This suggests a cancer diagnosis may trigger an affective re-evaluation of health status among TYA cancer survivors and potentially prime young people towards making healthier lifestyle choices. Data from study 1 on TYA cancer survivors reported change in health behaviour since diagnosis and perception of health behaviour on current and future health support this notion. However, as demonstrated among adult cancer survivors: it is unlikely that behaviour change will occur, or be sustained over time, among TYA cancer survivors without intervention (Demark-Wahnefried et al., 2005a, Williams et al., 2013). Lifestyle information and behaviour change delivery strategies should therefore capitalize upon young peoples’ engagement in receiving health behaviour information.

Despite the high level of engagement with lifestyle related topics, young people within this study often described numerous barriers to health behaviour change. Specifically, many young people outlined that cancer-related physical changes had negatively impacted their confidence and self-efficacy towards being physically active. This is consistent with previous reports indicating that the greatest psychosocial challenge faced by young people who have had cancer is the adjustment to physical and mental limitations resulting from their diagnosis and treatment (Barakat et al., 2016). Content analysis of messages posted on an online forum for TYA cancer survivors confirm these findings that treatment related physical changes or physiological problems (such as gastrointestinal issues) limit lifestyle choice, promote anxiety, and diminish self-efficacy among young people with cancer (Love et al., 2013).

Nevertheless, social support, goal setting, and self-monitoring in the form of behaviour tracking emerged as facilitators of both self-efficacy and health behaviour change within this study. Young people often discussed the importance of social connectedness and the impact such support had upon their motivation and confidence to make, and sustain, positive changes to their health behaviour. Specifically young people discussed the importance of social comparison and the value of knowing about the challenges other young people with a cancer faced when making lifestyle changes. Such findings support the overwhelming evidence concerning TYA cancer survivors need for social support both during and after treatment (Zebrack, 2011), and reflect the importance of peer influence and social norms on adolescent and young adult health behaviour (Sallis, 2000). The emergence of goal-setting and self-
monitoring as key facilitators of behaviour change among young people with cancer is consistent with findings from previous research conducted among adult aged cancer survivors (Bourke et al., 2013). Moreover, within one online-based physical activity intervention for TYA cancer survivors analyses revealed that young people who monitored their behaviour the most via the online log and set more weekly goals reported greater physical activity levels (Valle et al., 2013). The application of behaviour tracking and goal setting to health behaviours other than physical activity warrants exploration as there is limited evidence concerning the feasibility and acceptability of diet, drinking, smoking or sun safety self-monitoring among TYA cancer survivors.

Within this study young peoples’ account of their experience and satisfaction of receiving and searching for information on physical activity, diet, drinking, smoking and sun safety was often negative reflecting the lack of lifestyle information or behaviour change resources available for TYA cancer survivors. This is concerning given the emerging importance of promoting health behaviour among young people with cancer (Barnes and Demark-Wahnefried, 2014) and the strong correlation between unmet information needs and poor health related quality of life among TYA cancer survivors (Gupta et al., 2013, Smith et al., 2013). Young people with cancer have previously reported lifestyle information as being ‘overlooked’ and specifically raised concerns about the impact of health professionals failing to address the consequences of alcohol consumption during treatment (Fern et al., 2014). Addressing the specific lifestyle information needs of young people with cancer is important as information provision is a core part of supportive cancer care (Taylor et al., 2013).

TYA cancer survivors indicated a desire for information which covered a range of health and lifestyle topics. Specifically young people were interested in lifestyle information which was age-appropriate and specific to their needs as TYA cancer survivors. A desire for lifestyle information which included reference to side-effects or late effects management was also common. This is reflective of previous reports detailing young peoples’ high level of interest in discussing health behaviour during late effects consultations (Michel et al., 2009). In addition, consistent with previous research exploring intervention design and delivery preferences TYA cancer survivors within this study specified that lifestyle information and health behaviour change interventions should be readily available and continually accessible (Rabin et al., 2013b, Belanger et al., 2012). Young people within this study also specified that lifestyle information should be available in multiple formats to suit individual differences. Participants discussed the explicit advantages of lifestyle information available online highlighting the accessibility of this format of information and intervention delivery. However, young people acknowledged that information available solely in digital formats lack the personal support from health professionals, immediate family, and social networks that they require. This is reflective of parent and professional opinion expressed within previous research exploring the user requirements and considerations of web-based self-management for TYA cancer survivors: parents and health professionals both stressed the importance of online information
resources not replacing face-to-face consultations and interactions with either peers or health professionals (Moody et al., 2015).

No consensus as to when the most appropriate time to introduce health behaviour information to young people with cancer was reached. However, it was generally agreed that although health behaviour change may not occur immediately it would be beneficial to introduce TYA cancer survivors to the concept of lifestyle change as early as possible in the cancer care pathway. Such early introductions to lifestyle and health behaviour change information may trigger behaviour change among some young people and prime those who are not ready for lifestyle change (Coa et al., 2015).

A major strength of this study is the inclusion of young peoples’ perspectives on drinking, smoking and sun safety. The relevance of these behaviours to TYA cancer survivors is often overlooked within studies which typically address diet and physical activity. However, this study has a number of limitations. Firstly, very few young people answered our call for participants despite having indicated an interest in taking part after completing the health and lifestyle questionnaire reported in Chapter 5 and 6. Specifically no young people under the age of 18 participated within this study. A mixed method qualitative approach was taken and incentives were introduced to this study as a means to enhance participation, these decisions were based upon previous reports detailing the recruitment difficulties typically faced within TYA cancer research (Rabin et al., 2013a, Hendricks-Ferguson et al., 2013). Although there were no differences between the qualitative data generated from the interviews and focus group, social barriers during the focus group may have reduced the likelihood of an individual sharing an experience or idea. It would also be reasonable to suggest that the young people who took part within this study were engaged with health and lifestyle information and as a result the possibility of response bias is high and findings may not generalize to the TYA cancer survivor population as a whole. Further research to clarify the lifestyle information needs and health behaviour interventions preferences of TYA cancer survivors with low levels of engagement is required.

7.6 Chapter summary

TYA cancer survivors are highly motivated to make lifestyle changes following their cancer diagnosis and treatment and have a preference for readily available age-appropriate health behaviour information covering a wide-range of health topics. Tailored health behaviour change interventions designed specifically for young people with cancer must consider the numerous barriers young people with cancer encounter when making lifestyle related changes. Health behaviour change interventions which incorporate or facilitate social support, goal setting and behaviour tracking have the potential to effectively improve young peoples' self-efficacy regarding healthy lifestyle choices. Lifestyle information resources must be piloted in unison with TYA cancer survivors and health professionals in order to effectively evaluate their acceptability.
Chapter 8

Study 4

Health Behaviour Advice Provision to Teenage and Young Adult Cancer Patients: The Perspective of Health Professionals

8.1 Introduction

As outlined within Chapter 6 (Study 2) the majority of TYA cancer survivors turn to health professionals for advice and guidance on lifestyle related behaviours. Moreover, in Chapter 7 (Study 3) several participants stressed the importance of receiving lifestyle advice from trustworthy and reliable sources such as health professionals and specialist TYA cancer charities. However, many young people felt that the guidance they had been given from health professionals about health behaviour was unclear, brief and in some instances confusing.

As discussed within Chapter 2 specific health recommendations written for TYA cancer survivors are contained within the Childrens’ Oncology Group (COG) long-term follow-up guidelines for survivors of childhood, adolescent and young adulthood cancers. Specifically, health professionals are advised to provide health behaviour counselling to young people within the context of late-effects management, especially when regarding the treatment of cardiac problems and metabolic syndrome. While there are currently no formal guidelines for TYA cancer survivors receiving treatment, there is general consensus that health professionals caring for young people with cancer have a duty to advocate the importance of healthy lifestyle choices throughout the cancer care pathway (Daniel et al., 2015a).

However, studies of health professionals working within adult oncology settings suggest that awareness of the importance of health behaviour is generally low and that professionals perceive numerous barriers to providing such advice to their patients. For example, a study of 460 health professionals working with adult breast, prostate and colorectal cancer patients in the UK demonstrated that not believing lifestyle would affect cancer outcome was associated with lower odds (OR<0.48, p<0.05) of giving lifestyle advice (Williams et al., 2015). Previous studies of health professionals working with adult cancer survivors have also shown lack of knowledge, lack of time, and patient sensitivity to be perceived barriers to providing lifestyle advice (O’Hanlon and Kennedy, 2014, Spellman et al, 2013, Anderson et al, 2013).

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19 A version of this chapter has been published in the journal of Supportive Cancer Care (Appendix 8.1) Pugh, G., et al. (2017). “Lifestyle advice provision to teenage and young adult cancer patients: the perspective of health professionals in the UK,” Support Care Cancer, doi: 10.1007/s00520-017-3814-5. [Epub ahead of print]
Little is known about TYA health professionals’ familiarity with lifestyle guidance, and their current practices regarding the delivery of lifestyle advice to young people within their care. In addition, there is currently no data on TYA cancer specialists’ views of how and when the best time in the cancer care pathway to deliver such advice would be.

8.2 Aim

As described in Chapter 3, the aim of this study was to explore health professionals’ awareness of health behaviour guidance, level of health behaviour advice provision and views on the format and delivery of health behaviour advice to TYA cancer survivors. Health professionals’ perceived barriers to providing lifestyle advice were also explored.

8.3 Methods

8.3.1 Participants & Recruitment

Participant recruitment and data collection methods are discussed in Chapter 4, Section 4.8.

8.3.2 Measures

Participant demographics and data on awareness of lifestyle recommendations, level of advice provision, and delivery of lifestyle advice were collected using the health professionals’ survey as detailed within Chapter 4, Section 4.8.

8.3.3 Analyses

All survey responses were downloaded and transferred to statistical package SPSS Version 22. Descriptive statistics were produced to describe the demographics of respondents and the proportion of health professionals overall and within each professional group who were familiar with lifestyle guidance, and reported enquiring about health behaviour and providing advice to the majority (>75%) of their patients. Descriptive statistics were also produced to report health professionals’ perceived barriers to providing lifestyle advice and views on the format and delivery of such advice. Exact significance tests for Pearson’s chi-square analyses were performed to examine potential differences between professional groups regarding familiarity with lifestyle guidance, enquiry about lifestyle and lifestyle advice provision. Crosstabulation tables were created to check the frequencies of predictor variables in each group, each group was checked for independence and frequency. Where the frequency was less than one and more than 20% were less than five, this has been indicated in the text.

Open-response answers were transferred into qualitative data analysis software (NVivo, Version 11) and coded line-by-line. The process of content analysis as outlined by ELo and Kyngas (2008) was followed. A deductive approach to analysis was taken wherein open responses to each question were grouped together and the content was analysed for patterns or themes. The final coding was analysed and emerging themes were categorised and enumerated. In total, 79 individual open response comments were analysed.
8.4 Results

8.4.1 Response Rate

The exact reach of the survey is unknown as the link to the survey was posted online or cascaded independently via various professional organisations and individuals. As a guide on the reach of the survey, at the time of recruitment TYAC had approximately 372 members and CLIC Sargent currently employ ~90 services staff. 132 health professionals followed the survey link and consented to participating and 114 (86%) of these completed at least one question. Of these 114, 95 (83%) completed all of the questions relevant to the current study. There were no significant differences in background demographics between full and partial responders.

8.4.2 Sample characteristics

Sample characteristics are shown in Table 8.1 and 8.2. 44% (n=42) of respondents were nurses. 73% (n=69) identified themselves as working with young people aged 13-24 years of age and 63% (n=60) had been working with young people with cancer for more than 5 years. Most respondents (69%, n=66) worked with patients across all cancer sites and were based within a principal treatment centre (68%, n=65). The survey had a response from at least one health professional from each of the home nations (England, Scotland, Wales, and Northern Ireland) within the UK, however a large proportion of respondents worked in London (33%, n=31) and the South of England (26%, n=25).
Table 8.1 Participant Characteristics

<table>
<thead>
<tr>
<th>Professional Group</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>17 (16)</td>
</tr>
<tr>
<td>Nurse</td>
<td>44 (42)</td>
</tr>
<tr>
<td>Allied Health Professional</td>
<td>28 (27)</td>
</tr>
<tr>
<td>Other</td>
<td>11 (10)</td>
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</table>

<table>
<thead>
<tr>
<th>Length of time working with young people with cancer</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2 years</td>
<td>21 (20)</td>
</tr>
<tr>
<td>3-4 years</td>
<td>16 (15)</td>
</tr>
<tr>
<td>5-10 years</td>
<td>30 (29)</td>
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<tr>
<td>10+ years</td>
<td>33 (31)</td>
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</table>

<table>
<thead>
<tr>
<th>Best fit description of patient group</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>13-24 years of age</td>
<td>73 (69)</td>
</tr>
<tr>
<td>18-39 years of age</td>
<td>27 (26)</td>
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</table>

<table>
<thead>
<tr>
<th>Patient cancer group*</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All cancer sites</td>
<td>69 (66)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>13 (12)</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>15 (14)</td>
</tr>
<tr>
<td>Germ Cell Tumours</td>
<td>12 (11)</td>
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<tr>
<td>Central Nervous System</td>
<td>8 (8)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>7 (7)</td>
</tr>
<tr>
<td>Bone Tumour</td>
<td>12 (11)</td>
</tr>
<tr>
<td>Soft Tissue Sarcoma</td>
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<tr>
<td>Carcinoma</td>
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<td>Other</td>
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<table>
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<tr>
<th>Hospital affiliation</th>
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<td>Principal Treatment Centre</td>
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<td>TYA Designated Hospital</td>
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</table>

<table>
<thead>
<tr>
<th>Regional affiliation*</th>
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<tr>
<td>North West England</td>
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<td>London</td>
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<td>Scotland</td>
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<td>Northern Ireland</td>
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*respondents were instructed to tick all that applied from the list
Table 8.2 Participant Characteristics: Professional Role

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<th>Professional Role</th>
<th>Number</th>
<th>Percentage</th>
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<td><strong>Physician</strong></td>
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<td></td>
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<tr>
<td>Consultant Oncologist</td>
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<td>Consultant Haematologist</td>
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<tr>
<td>Consultant in Palliative Medicine</td>
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<td></td>
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<td><strong>Nurse</strong></td>
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<td>Clinical Nurse Specialist</td>
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<td>Deputy Sister</td>
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<td>Lead Nurse</td>
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</tr>
<tr>
<td>Oncology Trials Nurse</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Head of Nursing</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Allied Health Professional</strong></td>
<td>28 (27)</td>
<td></td>
</tr>
<tr>
<td>Social Workers</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Dietician</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Psychologist/ Psychotherapist</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Radiographer</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Music Therapist</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Youth Support Co-Ordinator</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>11 (10)</td>
<td></td>
</tr>
</tbody>
</table>
8.4.3 Awareness of lifestyle guidance

Table 8.3 shows the proportion of health professionals who reported being aware of lifestyle guidelines for each health behaviour. More health professionals were aware of guidance relating to physical activity and diet (62% and 60% respectively) than weight management, smoking, or alcohol consumption (40-59%). 72% (n=68) of health professionals were aware of guidance on one or more health behaviour. Of these, 54% (n=37) could not recall the specific details of the guidance, and most cited charitable bodies such as the Teenage Cancer Trust, Childrens’ Cancer and Leukaemia Group (CCLG) and Macmillan Cancer Support as the source. 24% (n=23) of respondents reported being unaware of any lifestyle guidance for TYA cancer patients. There were no significant differences in the awareness of lifestyle guidance between professional groups.

8.4.4 Levels of enquiry about and provision of lifestyle advice

Table 8.3 shows the proportion of respondents who reported enquiring about lifestyle and providing lifestyle advice to the majority (>75%) of patients within their care. Overall, approximately half (45-55%) of professionals surveyed reported enquiring about physical activity, diet, smoking and drinking alcohol with more than three-quarters of their patients. A larger proportion of health professionals asked about and provided advice on diet and physical activity than any of the other health behaviours. Many health professionals surveyed reported that they provide advice on smoking (54%, n=51) or alcohol consumption (48%, n=46) to less than a quarter of their patients. Similarly 43% (n=41) and 44% (n=42) of health professionals reported starting conversation with very few (0-25%) of their patients about weight management and sun safety.

As shown in Table 8.3, group differences were not observed between physicians and nurses for enquiry or advice provision on any health behaviour. There were no significant differences in the proportion of groups of health professionals who reported enquiring about weight management, or enquiring and providing advice on physical activity. Group differences for enquiry and provision of advice on diet, smoking, alcohol consumption and sun safety were observed between professionals who were physicians/nurses and those who were allied health professionals, or reported their profession as ‘other’. There were no significant difference between professional groups who identified themselves working with TYA cancer survivors aged 13-24, versus those who reported working with young people in the older age range (18-39 years) for level of enquiry or provision of advice.
Table 8.3 Percentage of health professionals overall and within each professional group aware of lifestyle guidance, enquiring about lifestyle and providing lifestyle advice to >75% of patients within their care (n=95)

<table>
<thead>
<tr>
<th></th>
<th>Physical Activity</th>
<th>Diet</th>
<th>Weight Management</th>
<th>Smoking</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% (95% CI)</td>
<td>%</td>
<td>% (95% CI)</td>
<td>% (95% CI)</td>
</tr>
<tr>
<td>Aware of lifestyle guidance</td>
<td>62(52.34-71.86)</td>
<td>56</td>
<td>47(37.36-57.44)</td>
<td>46(36.2-56.33)**</td>
</tr>
<tr>
<td>Enquiring about patients lifestyle</td>
<td>56(45.81-65.79)</td>
<td>44(34.21-54.19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing advice</td>
<td>44(34.21-54.19)</td>
<td>47(37.36-57.44) **</td>
<td>46(36.2-56.33)**</td>
<td>27(18.43-36.37)*</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>60(50.15-69.85)</td>
<td>56(45.81-65.79)</td>
<td>44(34.21-54.19)</td>
<td>47(37.36-57.44) **</td>
</tr>
<tr>
<td>Physicians</td>
<td>63(38.78-86.22)</td>
<td>56(45.81-65.79)</td>
<td>44(34.21-54.19)</td>
<td>47(37.36-57.44) **</td>
</tr>
<tr>
<td>Nurses</td>
<td>57(42.13-72.07)</td>
<td>67(52.45-80.95)</td>
<td>48(32.5-62.7)</td>
<td>41(22.17-59.23)</td>
</tr>
<tr>
<td>Allied Health Professionals</td>
<td>78(62.1-93.46)</td>
<td>52(32.9-70.67)</td>
<td>41(22.17-59.23)</td>
<td>41(22.17-59.23)</td>
</tr>
<tr>
<td>Other</td>
<td>40(9.64-70.36)</td>
<td>20(0-44.79)</td>
<td>20(0-44.79)</td>
<td>20(0-44.79)</td>
</tr>
<tr>
<td>Diet</td>
<td>60(50.15-69.85)</td>
<td>47(37.36-57.44) **</td>
<td>46(36.2-56.33)**</td>
<td>27(18.43-36.37)*</td>
</tr>
<tr>
<td>Physicians</td>
<td>50(25.50-74.5)</td>
<td>44(19.49-68.11)</td>
<td>38(13.78-61.22)</td>
<td>37(27.1-46.5)*</td>
</tr>
<tr>
<td>Nurses</td>
<td>64(49.81-78.79)</td>
<td>69(55.01-82.99)</td>
<td>52(37.3-67.5)</td>
<td>38(13.78-61.22)</td>
</tr>
<tr>
<td>Allied Health Professionals</td>
<td>67(48.88-84.44)</td>
<td>26(9.39-42.45)</td>
<td>19(3.85-33.15)</td>
<td>19(3.85-33.15)</td>
</tr>
<tr>
<td>Other</td>
<td>40(9.64-70.36)</td>
<td>20(0-44.79)</td>
<td>20(0-44.79)</td>
<td>20(0-44.79)</td>
</tr>
<tr>
<td>Weight Management</td>
<td>40(30.15-49.85)</td>
<td>33(23.1-42.03) *</td>
<td>11(4.78-17.42)</td>
<td></td>
</tr>
<tr>
<td>Physicians</td>
<td>38(13.78-61.22)</td>
<td>31(8.58-54.02)</td>
<td>31(8.58-54.0)</td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>38(23.41-52.79)</td>
<td>50(34.88-65.12)</td>
<td>33(19.05-47.55)</td>
<td></td>
</tr>
<tr>
<td>Allied Health Professionals</td>
<td>52(33-70.7)</td>
<td>15(1.41-28.19)</td>
<td>7(0-17.27)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>20(0-44.79)</td>
<td>10(0-28.59)</td>
<td>10(0-28.59)</td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td>47(37.36-57.44)</td>
<td>46(36.2-56.33)**</td>
<td>27(18.43-36.37)*</td>
<td></td>
</tr>
<tr>
<td>Physicians</td>
<td>50(25.50-74.50)</td>
<td>62(38.78-86.22)</td>
<td>50(25.5-74.5)</td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>55(39.75-69.85)</td>
<td>64(49.81-78.79)</td>
<td>36(21.21-50.19)</td>
<td></td>
</tr>
<tr>
<td>Allied Health Professionals</td>
<td>41(22.17-59.23)</td>
<td>19(3.85-33.15)</td>
<td>7(0-17.27)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>30(1.6-58.4)</td>
<td>20(0-44.79)</td>
<td>10(0-28.59)</td>
<td></td>
</tr>
</tbody>
</table>
Table 8.3 Continued

### Drinking Alcohol

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Physicians</th>
<th>Nurses</th>
<th>Allied Health Professionals</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Drinking Alcohol</strong></td>
<td>46 (36.2-56.33)</td>
<td>50 (25.5-74.5)</td>
<td>50 (34.88-65.12)</td>
<td>44 (25.66-63.14)</td>
<td>30 (1.6-58.4)</td>
</tr>
<tr>
<td></td>
<td>45 (35.29-55.31) **</td>
<td>56 (32-80.6)</td>
<td>64 (49.81-78.79)</td>
<td>19 (3.85-33.15)</td>
<td>20 (0-44.79)</td>
</tr>
<tr>
<td></td>
<td>26 (17.45-35.15) *</td>
<td>38 (13.78-61.22)</td>
<td>38 (23.41-52.79)</td>
<td>7 (0-17.27)</td>
<td>10 (0-28.59)</td>
</tr>
</tbody>
</table>

### Sun Safety

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Physicians</th>
<th>Nurses</th>
<th>Allied Health Professionals</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sun Safety</strong></td>
<td>59 (49.01-68.79)</td>
<td>50 (25.5-74.5)</td>
<td>67 (52.45-80.95)</td>
<td>59 (40.66-77.74)</td>
<td>40 (9.64-70.36)</td>
</tr>
<tr>
<td></td>
<td>35 (25.1-44.27) **</td>
<td>38 (13.78-61.22)</td>
<td>55 (39.75-69.85)</td>
<td>11 (0-25.63)</td>
<td>10 (0-28.59)</td>
</tr>
<tr>
<td></td>
<td>26 (17.45-35.15) **</td>
<td>50 (25.5-74.5)</td>
<td>38 (23.41-52.79)</td>
<td>4 (0-10.82)</td>
<td>0 (0-0.2)</td>
</tr>
</tbody>
</table>

Between-group differences indicated by *p<0.05**p<0.005
8.4.5 Reported patient interest in advice

Most (68%-87%) of respondents reported that very few (<25%) of their patients asked them directly for information about weight management, smoking, alcohol consumption or sun safety. Only 27% (n=28) of respondents reported that more than half of their patients ask for information about physical activity: and only 35% (n=36) reported that more than half of their patients asked for information about diet. The percentage of respondents who reported that no young people in their care asked for specific advice about smoking, drinking and sun safety was 42% (n=43), 40% (n=41), and 36% (n=36), respectively.

8.4.6 Delivery of lifestyle advice

As shown in Figure 8.1, health professionals most commonly opted to provide advice either verbally or by referring their patients to another health professional. Although very few respondents reported actually signposting patients in the direction of information online, open responses suggested electronic resources (such as websites or mobile apps) were considered to be acceptable formats of lifestyle information delivery. In the open response sections of the survey, health professionals reported that the format of information delivery was dependent upon on the needs of the patient and that information should be available in a range of formats to reflect differences in patient preferences. 43% (n=41) of health professionals surveyed believed young people with cancer should first be offered lifestyle advice during treatment, 33% (n=31) believed lifestyle advice should be first offered before treatment and 22% (n=21) believed lifestyle advice should be first offered up to 6 months post treatment. Encouragingly, 95% (n=91) said they would be interested in a resource containing relevant lifestyle information which they could give to their patients, and 76% (n=72) perceived no problems in providing such information to young people with cancer.
Figure 8.1 Format of advice delivery

- **Physical Activity**: 45% verbal, 30% written, 15% refer to website, 10% refer to another health professional
- **Diet**: 40% verbal, 20% written, 15% refer to website, 25% refer to another health professional
- **Weight**: 40% verbal, 20% written, 15% refer to website, 25% refer to another health professional
- **Smoking**: 40% verbal, 20% written, 15% refer to website, 25% refer to another health professional
- **Alcohol**: 40% verbal, 20% written, 15% refer to website, 25% refer to another health professional
- **Sun Safety**: 40% verbal, 20% written, 15% refer to website, 25% refer to another health professional

Legend:
- **verbal advice**
- **written advice**
- **refer to website**
- **refer to another health professional**
8.4.7 Barriers to providing lifestyle advice

The most common barrier was ‘not being the right person to give advice’ 38% (n=36); followed by perception of ‘patient feeling too frail or unwell’ 36% (n=34), and perceived lack of patient interest 29% (n=28). 20% (n=19) of the health professionals surveyed felt that ‘lack of clear guidance’ was a barrier to providing lifestyle advice and 17% (n=16) felt that ‘lack of time’ was a barrier. No respondents cited ‘seeming to blame the patient’ as a barrier to providing lifestyle advice and only 12% (n=11) cited the feeling of ‘being judgemental of their choices’ as a barrier. Within open responses (Table 8.4) the lack of specific information and guidance about lifestyle for TYA cancer health professionals and the need to be sensitive towards patients’ needs and sustain good relationships with patients was emphasised. Lack of knowledge or professional support was also highlighted alongside perceived low levels of patient interest in lifestyle information.
Table 8.4 Barriers and problems associated with the delivery of lifestyle information and advice to young people with cancer

<table>
<thead>
<tr>
<th>Lack of patient interest or engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Not receptive. Don’t want to be ‘lectured’’ (Doctor, 2 years working with TYA cancer survivors)</td>
</tr>
<tr>
<td>‘Lack of interest (from patient)…. Lack of perceived relevance. A sense that the worst has already happened to them (i.e. diagnosed with cancer) so will live their life the way they want to.’ (Allied health professional, TYA social worker, 4 years working with TYA cancer survivors)</td>
</tr>
<tr>
<td>‘Engagement from patient (in terms of having so much else going on in cancer diagnosis/treatment)’ (Allied health professional, Wellbeing Co-Ordinator, 1 year working with TYA cancer survivors)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The need to be sensitive to patients’ individual needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Providing information based on patient need/experience that at a time and using an approach that is relevant to each individual's circumstances.’ (Lead Nurse, 7 years working with TYA cancer survivors)</td>
</tr>
<tr>
<td>‘Patient not being at the right stage to accept advice’ (Physiotherapist, 1 year working with TYA cancer survivors)</td>
</tr>
<tr>
<td>‘Has to be done taking into account social situation, access to resources, psychological state…’ (Allied health professional, TYA social worker, 4 years working with TYA cancer survivors)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Maintaining good relationships with patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘It's a case of building up a rapport prior to advice’ (Specialist oncology and haematology physiotherapist, 1 year working with TYA cancer survivors)</td>
</tr>
<tr>
<td>‘Have a duty to discuss this [lifestyle advice] but would do it more sensitively in some cases if appropriate’ (Nurse specialist, 6 years working with TYA cancer survivors)</td>
</tr>
<tr>
<td>‘It [lifestyle advice] would need to be in the context of the therapy or I would lose the relationship with the patient’ (Psychotherapist, 6 years working with TYA cancer survivors)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lack of resources and information</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Written advice is difficult to obtain for young people focuses on paediatrics or adults’ (Clinical nurse specialist, 4 years working with TYA cancer survivors)</td>
</tr>
<tr>
<td>‘Quite often generic advice and written information is not specific enough for the patient.’ (Senior dietitian, 2 years working with TYA cancer survivors)</td>
</tr>
<tr>
<td>‘There is a lack of information for non-medical staff to give out, this information should be bale to be given by all MDT staff so that we can maximise the opportunities for young people to be offered it.’ (Allied health professional, TYA social worker, 2 years working with TYA cancer survivors)</td>
</tr>
</tbody>
</table>
### Lack of knowledge or professional support

- ‘Not feeling confident in giving advice due to lack of knowledge’ (Community worker, 1 year working with TYA cancer survivors)

- ‘Lack of clear and consistent guidelines from the wider MDT’ (Physiotherapist, 3 years working with TYA cancer survivors)

- ‘Time, level of expertise/knowledge depending on topic’ (Allied health professional, Wellbeing Co-Ordinator, 1 year working with TYA cancer survivors)
8.5 Discussion

This is the first detailed study to investigate health professionals' knowledge of health behaviour guidance and provision of lifestyle advice to TYA cancer survivors. Awareness and familiarity of health behaviour guidance and enquiry about health behaviour was generally modest among health professionals working with TYA cancer patients, and few TYA health professionals provided health behaviour advice to the majority of patients within their care. The complexity of providing health behaviour advice to young people with cancer, and the need for specially designed tailored resources for TYA cancer survivors was highlighted.

Although the majority (72%) of survey respondents reported awareness of some health behaviour guidelines, over half (54%) of these professionals could not recall the source of this guidance, suggesting limited knowledge and familiarity with the guideline content. These findings are similar to studies of health professionals working with adult cancer patients (Williams et al., 2015). Low to moderate levels of familiarity with health behaviour guidance among health professionals working with TYA cancer patients is perhaps unsurprising, as although some charitable bodies and medical groups have produced information and guidance about health behaviour, these resources often contain a wide array of information on a variety of topics, with only small sections dedicated to health behaviour and non-specific guidance (such as ‘should remain active’). In addition, although guidance relating to lifestyle and cancer survivorship has been produced by bodies such as the World Cancer Research Fund and American Institute for Cancer Research, the focus of this guidance is aimed at adults and contains little specific reference to TYA cancer patients or their needs. The lack of specific health behaviour guidance for TYA cancer is likely in part due to a lack of trials indicating health behaviour has a positive effect on cancer outcomes among the TYA age group: further research in this area is very warranted (Armenian et al., 2015).

Less than half of the health professionals surveyed reported giving advice on physical activity or diet to the majority (>75%) of patients in their care. Even fewer (less than a third) reported providing specific advice about weight management, smoking, drinking or sun safety to the majority of their patients. These findings suggest that health professionals working with TYA cancer patients do not routinely initiate conversations about health behaviour or health behaviour advice to young people within their care. With regard to physical activity, the relatively low level of advice provision may relate to previously debated confusion regarding the safety of encouraging young people with cancer to be active (Spreafico et al., 2014, Kumar et al., 2015). This notion could also apply to weight management and diet where ‘best practice’ recommendations for TYA cancer patients are yet to be devised due to lack of clear evidence. However, for behaviours such as smoking, drinking, and tanning which have well acknowledged negative associations with health (Klosky et al., 2007), the finding that very few health professionals enquire about or provide advice on these topics was surprising. Nevertheless, previous studies have found similar patterns and rates of lifestyle advice provision in surveys of health professionals working with adult cancer patients (Williams et al.,
2015, Daley et al., 2008, Spellman et al., 2013, Karvinen et al., 2012). For example, a survey commissioned by Macmillan Cancer Support found only 41.5% of UK nurses are aware of recommended guidelines for physical activity and less than 10% talk to their patients about the benefits of physical activity (Macmillan Cancer Support, 2011). Lack of confidence and lack of support may account for the gap between the proportion of health professionals who report being aware of the health behaviour guidelines and the proportion inquiring about and providing advice on health behaviour.

The low level of enquiry about lifestyle and provision of lifestyle advice from TYA health professionals may in part be explained by professionals’ report that very few of their patients ask directly for information about individual health behaviours. The majority of health professionals surveyed (68% -86%) reported that less than half of young people within their care asked them directly for lifestyle information. The finding that very few young people with cancer ask directly for information about lifestyle was unexpected given the findings from Study 2 that there is a level of patient interest in receiving advice on health behaviour (Murnane et al., 2015, Rabin et al., 2013b). TYA health professionals may perceive low levels of patient enquiry about lifestyle as a lack of interest. Previous research conducted among oncologist and cancer nurses indicate that the perception that cancer patients are not interested in physical activity is a barrier to health professionals providing advice (Karvinen et al., 2012). Efforts should be made to ensure health professionals are aware that young people with cancer are interested in receiving advice and support on their health behaviour.

A large proportion of health professionals selected at least one barrier from the formulated list or cited their own barrier to initiating discussion about or providing advice on lifestyle behaviours. Barriers were most commonly centred on patient-related factors such as lack of interest, being sensitive to their emotional needs and maintaining good patient relationships. Consistent with previous studies of health professionals working in adult oncology (Spellman et al., 2013) one of the most commonly endorsed barriers to providing lifestyle advice was perception of ‘not being the right person to provide advice’. This could suggest TYA health professionals believe that addressing lifestyle behaviours and providing lifestyle advice is outside of their professional duty. The need for specifically tailored lifestyle guidance to be made available to all health professionals working with TYA cancer patients was highlighted within open responses. This is encouraging as findings from a survey of oncology nurses (n=274) indicate that those who were uncertain about physical activity recommendations or the safety of physical activity among cancer patients were more reluctant to advise their patients to be active (Karvinen et al., 2012). Clear and comprehensive guidance written specifically for TYA health professionals could improve professionals’ confidence in addressing and providing advice on lifestyle behaviour whilst remaining sensitive to patient needs and maintaining patient relationships.

Findings from this study suggest that professionals were more likely to address (enquire to patients about) and provide advice on physical activity and diet than weight management,
smoking, drinking alcohol, or sun safety. The discrepancies between health behaviours suggest that TYA health professionals may be reluctant to engage in conversation about sensitive issues (such as weight) and ‘risky’ health behaviours (such as smoking, drinking and unsafe sun practices) and may need additional support and guidance on how best to address these issues, or access evidence-based referral pathways.

Nevertheless, despite the numerous perceived barriers and problems to providing lifestyle advice, over 90% of health professionals surveyed were interested in a resource containing relevant lifestyle information they could give to their patients. Although the most commonly reported method of advice delivery was verbal, those surveyed acknowledged the need to provide young people with advice in a range of formats, and at a suitable time for the individual patient. The finding that TYA health professionals seldom refer young people within their care to websites may be explained by the current limited availability of health behaviour information specific to young people with cancer. With regard to the timing of delivery, the largest proportion of respondents believed lifestyle advice should first be provided to TYA cancer patients during treatment. This finding is consistent with emerging evidence that healthy lifestyle behaviours during treatment have a positive impact on quality of life and could influence cancer outcomes among young people (Dubnov-Raz et al., 2015, Siegel et al., 2015).

Although this is the first study to explore TYA health professionals’ knowledge of lifestyle guidance, provision of lifestyle advice and barriers to providing lifestyle advice, a number of limitations must be addressed. Firstly, data on the proportion of respondents who specifically work in long-term follow up or with specific out-patient groups was not collected. In particular, as demonstrated by the wide confidence intervals, the small sample size among some professional groups (specifically physicians) limited the ability to establish precise estimates of between group differences in lifestyle guidance familiarity, enquiry or provision of advice. Moreover, given the broad expertise and clinical roles carried out by allied health professionals it is likely the group differences which were found in the chi-square analyses are arbitrary. However, cancer is relatively uncommon in young people, and the number of health professionals who responded to the survey can be considered as quite large within the TYA health profession. Although the majority of respondents were nurses and were based within London or South East England, survey respondents typically worked with patients with a range of cancer diagnoses and had been working with young people with cancer for more than five years. Health professionals who have been working with TYA cancer patients for longer may have greater appreciation of the importance of promoting health lifestyle choices to young people with cancer and therefore may have been more motivated to participate within the survey. This could suggest that, in general, TYA health professionals who did not complete the survey have poorer knowledge about lifestyle and are less likely to give lifestyle advice than those who completed the survey.
The findings from this study demonstrate a need for further education among TYA health professionals about health behaviour. However, a 'one-size-fits-all' approach to lifestyle information delivery to TYA cancer patients is unlikely to be appropriate given the range of health needs and information comprehension abilities existing within this patient group. Future work should aim to explore how health behaviour interventions could be applied practically in a TYA cancer setting. The development of clear and succinct guidance on lifestyle for health professionals working with TYA cancer patients is vital as supporting young people with cancer to adopt healthy lifestyle choices may prevent some of the short-term, and long-term, consequences of cancer treatment experienced by this unique age group (Carretier et al., 2015). Such information resources should also outline strategies to engage both TYA health professionals and TYA cancer patients in health behaviour promotion initiatives. Such resources have the potential to support professionals to successfully integrate health behaviour promotion into usual care routines. As previously highlighted, the inclusion of specific information about lifestyle and health behaviour within long-term follow-up guidelines for TYA cancer survivors would be a positive first step (Brown et al., 2015).

8.6 Chapter summary

Although the majority of respondents thought lifestyle advice should first be provided to TYA cancer patients during treatment a range of barriers and problems to addressing lifestyle behaviour during conversation and providing advice on some specific behaviours were raised. TYA health professionals' high level of interest in receiving resources containing relevant lifestyle information which could be given to patients was encouraging and supports the growing body of evidence that health behaviour promotion among TYA cancer survivors is a critical topic to address both in research and clinical practice. Efforts are required to ensure professionals working with TYA cancer survivors have the confidence and skills to address lifestyle during consultations and provide sound advice on individual health behaviours.
Chapter 9
Study 5

The Development and User Evaluation of Health Behaviour Change Resources for Teenage and Young Adult Cancer Survivors

9.1 Introduction

Evidence presented within this thesis demonstrates a clear need for the development of a health behaviour intervention specifically for TYA cancer survivors. As shown in Study 1 (Chapter 5) the health behaviours of TYA cancer survivors are sub-optimal. However, encouragingly, as found in Study 2 (Chapter 6) and Study 3 (Chapter 7), a large proportion of young people with cancer are interested in receiving information and support to make positive changes to their lifestyle; over 80% of those surveyed were interested in receiving advice on physical activity, diet and weight management with most reporting they seek information on these behaviours from health professionals or websites. As demonstrated in Study 3, social support and self-efficacy were found to be facilitators of behaviour change among TYA cancer survivors, with many young people reporting that they were interested in resources which could support them to break the unhealthy habits they had formed during treatment. The combined results of Study 2 and Study 3 indicate TYA cancer survivors are most interested in easily accessible health behaviour information, which accounts for the individual needs of young people with cancer, and is available from reliable trustworthy sources. These findings were reflected within Study 4 (Chapter 8) where over 90% of health professionals were interested in resources to support their patients to lead a healthier lifestyle. Similar to TYA cancer survivors, health professionals indicated that information for TYA cancer survivors should be tailored and specific to the needs of young people with cancer. However, within Study 3 (Chapter 7), young people revealed they were often left confused by the lack of clear health behaviour information available to them and within Study 4 (Chapter 8) health professionals cited lack of clear guidance and available resources as one of the many barriers to providing behaviour change support to young people with cancer. Based on these findings a collection of health behaviour change intervention resources containing comprehensive health behaviour information and behaviour change support tools were developed specifically for TYA cancer survivors. The design and purpose of this study (Study 5) reflects Step 5 of the 6SquID framework and incorporates Yardleys and colleagues (2015) person based approach to the development and evaluation of the acceptability and feasibility of the intervention functions (Yardley et al., 2015b).

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20 A poster outlining the development of the health behaviour intervention resources was presented at the Public Health England, Cancer Data and Outcomes Conference, Manchester, 2017
9.2 Aims & Objectives

This study outlines the development and preliminary evaluation of health behaviour intervention resources designed specifically for teenage and young adult cancer survivors. Overall this study aims to:

i) Determine if the health behaviour information developed as part of the proposed intervention meets the needs of TYA cancer survivors and health professionals.

ii) Establish TYA cancer survivor and health professionals receptivity to proposed health behaviour information resources (i.e. paper based materials/ website/ app)

iii) Examine TYA cancer survivor and health professionals receptivity to the inclusion of discrete behaviour change techniques within the intervention resources

9.3 Methods

9.3.1 Study Design

As highlighted in Chapter 4 feasibility and piloting testing is a core step of the intervention development process (Campbell et al., 2007). Carrying out a formative evaluation can provide insight into key issues which may affect the efficacy of a larger scale pilot trials such as: acceptability of the intervention to the target group; acceptability of the intervention to stakeholders and delivery organisations; if the content of the intervention is satisfactory to meet the needs of the target population; and if intervention format and delivery methods are appropriate. Such findings can help identify how best to maximise the uptake and adherence to the intervention and determine if training is required for target groups, stakeholders, and delivery organisations before they use the intervention (Wight et al., 2015). The informal testing and user evaluation stages of intervention development is often not reported or are ‘hurried’ due to lack of time or resources but formative evaluation studies can improve the overall uptake and effectiveness of an intervention (Czajkowski et al., 2015).

9.3.2. Health Behaviour Change Intervention Resources for TYA cancer survivors

Given the time and budget constraints of this PhD, and that feedback from the user evaluation would be used to further refine the intervention materials ahead of a future planned pilot study, the decision was taken to not produce hard copies of the intervention resources. Instead creative illustrations of the intervention resources were developed. Examples of these creative illustrations are shown in Figure 9.1. Written health behaviour information on physical activity, diet, smoking, alcohol consumption and sun safety was developed based upon the health behaviour recommendations contained within Childrens Oncology Group (COG) long term follow up guidance. The health behaviour information developed during this PhD is contained within Appendix 9.1. Dr Helen Crocker and Dr Dimitrios Koutoukidis reviewed and provided feedback on the diet and nutrition sections and Joanne Land (a specialist physiotherapist in cancer rehabilitation) provided feedback on the physical activity sections. Although within
Study 1 a large proportion of TYA cancer survivors were found to be overweight or obese and in Study 2 and 3 many young people expressed an interest in receiving advice on weight management, during consultation with specialist TYA physiotherapists and dieticians valid concerns on how information on weight loss or weight gain may be interpreted by young people with cancer were raised. The decision was made to not include specific information on weight management within the resources as it was agreed that such information should be tailored specifically to the individual, their cancer diagnosis and stage of treatment. Experts in information development for young people with cancer (Cassie Davies, Information Development Manager, CLIC Sargent: Steph Jury-Dale, Information Officer, CLIC Sargent) also reviewed the information and provided feedback on the contents.
Figure 9.1 Creative illustrations of the intervention resources
Figure 9.1 continued

GET STARTED NOW

1. Choose the behaviour you would like to work on
2. Fill in the step-by-step chart (in the back of the booklet)

Active everyday - for 30 minutes correct
Getting stronger and fitter - for those way can do a bit more
Up your fruit and veg - 5 portions or more a day
Has your friend go for wholegrain choices
Watch out for high calorie foods and drinks - reduce your fat and sugar
Reduce red meat - cut your portion sizes and leave it less often
Cut out processed meat - go for fish or nuts instead
Quit smoking - it's the best thing you can do
Cut back on alcohol - a couple of small drinks a day max, and some days alcohol free

HEALTHY LIFE ACTION PLAN

Your goal: ____________________ New everyday habit: ____________________

Steps to support your new habit:

Step 1: ____________________ Step 2: ____________________ Step 3: ____________________

Your progress
Tick for every time you do your new behaviour. 60 times makes it a habit

Don't worry if you slip up

1 2 3 4 5 6 7 8 9 10 Well done! 10 completed!

2 3 4 5 6 7 8 9 10 Good on you! 20 completed!

3 4 5 6 7 8 9 10 That's way! 30 completed!

Great start reward:

1st reward: ____________________ 2nd reward: ____________________ 3rd reward: ____________________

How do you feel?

1st reward: ____________________ 2nd reward: ____________________ 3rd reward: ____________________

How do you feel?

1st reward: ____________________ 2nd reward: ____________________ 3rd reward: ____________________

How do you feel?

1st reward: ____________________ 2nd reward: ____________________ 3rd reward: ____________________

Congratulations!
The health behaviour information and tips on behaviour change were designed to help TYA cancer survivors to make healthy lifestyle choices habitual. The health behaviour information contains reference to the importance and benefits of healthy lifestyle behaviours, how to make sustainable lifestyle behaviour changes, and information on the health consequences of not meeting current Children’s Oncology Group recommendations. Specifically, the information materials highlight TYA cancer survivors increased risk of chronic disease and secondary primary neoplasms. This is in line with the long-term follow up guidance set by the Children’s Oncology Group which states, childhood and TYA cancer survivors (particularly those with metabolic syndrome or cardiovascular disease) should be provided with comprehensive and detailed information on the importance of health behaviours and be fully informed of the benefits of physical activity and healthy dietary behaviours and the risks of smoking, heavy alcohol consumption and sun exposure. Based on findings from Study 3 (Chapter 7), it was important that the information developed addressed issues specific to the needs of TYA cancer survivors such as the impact of physical side-effects of cancer treatment, changes in taste preferences, and limitations in physical activity capability. Similarly, young people within Study 3 talked about the importance of knowing how other TYA cancer survivors had overcome these barriers to leading a healthy lifestyle. Data from research exploring how best to communicate cancer prevention among the general adolescent population suggest health promotion programmes and interventions not only focus on the ‘Dos’ and ‘Don’ts’ of leading a healthy lifestyle but challenge how young people process the benefits and risks of certain health behaviours (Woodgate et al., 2015). Case scenarios have been proposed as useful means to effectively communicate risk information to adolescents and young adults (Woodgate et al., 2015, Kyle et al., 2013). Examples of TYA cancer survivors deliberating the benefits and risks of health behaviour and dealing with a variety of barriers to leading a healthy lifestyle were therefore included within the resources. These case scenarios were designed to be self-reflective and educative tools to empower young people to be more aware of their beliefs and behaviours.

The TYA health behaviour change resources contain behaviour change techniques disguised as ‘support tools’ which are designed to prompt young people to change their behaviour. Table 9.1 outlines the behaviour change techniques selected for inclusion within the behaviour change intervention resources. The illustrations of the goal setting, action planning, prompts/reminders, rewards, self-monitoring and social support health behaviour change ‘support tools’ developed during this PhD are contained within Appendix 9.2. It was important that the behaviour change techniques included could be used flexibly and adapted to young people with differing needs and behaviour change goals. ‘Healthy Life Action Plan’ sheets are included within the resources and are designed to encourage TYA cancer survivors to set goals for their recommended behaviour, to plan strategies to fit their new behaviour goal into their daily routine, and track their progress towards their desired goal overtime. The TYA resources also include prompts encouraging TYA cancer survivors to self-reward themselves for progress made towards their desired behavioural goal and space for TYA cancer survivors
to brain-storm ideas to overcome barriers to behaviour change. The proposed online and app based intervention resources contained features to allow young people to support one another and share information on health behaviour change. The proposed app also contains a function to receive prompts to sustain positive health behaviour changes.
<table>
<thead>
<tr>
<th>Behaviour Change Technique (BCT)</th>
<th>BCT Definition (Abraham and Michie, 2008)</th>
<th>Intervention Feature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal Setting (behaviour &amp; outcome)</td>
<td>Set or agree a goal defined in terms of the behaviour to be achieved and the positive outcomes of the behaviour change.</td>
<td>The paper based, online and app based intervention materials will encourage TYA cancer survivors to identify a target behaviour and a set goals to change.</td>
</tr>
<tr>
<td>Problem Solving</td>
<td>Analyse, or prompt the person to analyse, factors influencing the behaviour and generate or select strategies that include overcoming barriers and/or increasing facilitators.</td>
<td>The paper based, online and app based intervention materials encourage TYA cancer survivors to think creatively of strategies to change their behaviour by writing down ideas which might work for them.</td>
</tr>
<tr>
<td>Action Planning</td>
<td>Prompt detailed planning of performance of the behaviour (must include at least one of context, frequency, duration and intensity).</td>
<td>The paper based, online and app based intervention materials will contain ‘Healthy Life Action Plan’ sheets which are designed to encourage participants to plan how they will fit the new action into their existing routines.</td>
</tr>
<tr>
<td>Behaviour Substitution</td>
<td>Prompt substitution of the unwanted behaviour with a wanted or neutral behaviour.</td>
<td>The paper based online and app based intervention materials contain information and tips ‘ideas for everyday change’ on new actions which could be incorporated into a daily routine to help TYA cancer survivors meet their daily goals.</td>
</tr>
<tr>
<td>Habit Formation</td>
<td>Prompt rehearsal and repetition of the behaviour in the same context repeatedly so that the context elicits the behaviour.</td>
<td>The paper based online and app based intervention materials will contain advice about forming habits and specifically repeating the same actions in similar contexts.</td>
</tr>
<tr>
<td>Habit Reversal/Substitution</td>
<td>Prompt rehearsal and repetition of an alternative behaviour to replace an unwanted habitual behaviour.</td>
<td>The paper based online and app based intervention materials will contain information on the importance of repeating new actions.</td>
</tr>
<tr>
<td>Feedback on behaviour</td>
<td>Monitor and provide information or evaluative feedback on performance of the behaviour.</td>
<td>The online and app based interventions will contain features where young people receive a score or result based upon their health behaviour.</td>
</tr>
<tr>
<td>Self-monitoring of behaviour</td>
<td>Establish a method for the person to monitor and record their behaviour as part of a behaviour change strategy.</td>
<td>The paper based, online and app based intervention materials will contain ‘Healthy Life Action Plan’ sheets which are designed to encourage participants to monitor the change in their behaviour over time.</td>
</tr>
</tbody>
</table>
Table 9.1 Continued

<table>
<thead>
<tr>
<th>Behaviour Change Technique (BCT)</th>
<th>BCT Definition (Abraham and Michie, 2008)</th>
<th>Intervention Feature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information about health consequences</td>
<td>Provide information about health consequences of performing the behaviour.</td>
<td>The paper based online and app based intervention materials will contain information about the potential benefits and costs of either having a healthy lifestyle or not having a healthy lifestyle.</td>
</tr>
<tr>
<td>Prompts/ Cues</td>
<td>Introduce or define environmental or social stimulus with the purpose of prompting or cueing the behaviour. The prompt or cue would normally occur at the time or place of the performance.</td>
<td>The intervention app will contain a feature to send automated reminders to TYA cancer survivors phones prompting healthy lifestyle behaviours.</td>
</tr>
<tr>
<td>Social Support (un-specified)</td>
<td>Advise on, arrange or provide social support (e.g. from friends, relatives, colleagues, buddies and staff) or non-contingent praise or reward for performance of the behaviour. It includes encouragement and counselling, but only when it is directed at the behaviour.</td>
<td>The paper based, online and app based intervention materials will advise participants to find a close friend or family member to encourage continuation with the behaviour change programme.</td>
</tr>
<tr>
<td>Social Comparison</td>
<td>Draw attentions to others’ performance to allow comparison with the persons’ own performance</td>
<td>The online intervention will include a message forum encouraging young people to communicate and praise one another for their achievements. The message forum will also encourage young people to share how they have changed their behaviours, the barriers they came across and how they addressed these challenges.</td>
</tr>
</tbody>
</table>

The online intervention will include a message forum where TYA cancer survivors will be able to share and compare their behaviours with other young people.
9.3.3 Format and modes of delivery

In the past, leaflets and websites have been successfully used as platforms for intervention delivery among TYA cancer survivors (Literature review, Chapter 2). As outlined within Study 2 and 3 (Chapters 6 and 7) TYA cancer survivors have a preference for brief lifestyle information available in digital formats. However within Study 3 and Study 4 (Chapter 7 and 8) both young people and health professionals stressed the importance of lifestyle behaviour available in multiple formats to suit individual needs. Encouragingly, this was reflected by data from Study 2 (Chapter 6) wherein a roughly equal proportion of young people indicated they would be interested in health behaviour information available online, in the form of an app or in the form of a short leaflet.

As mentioned earlier given the time and budget constraints of this PhD the decision was taken to not produce hard copies of the intervention resources. Instead creative illustrations (Figure 9.2) of the possible formats the intervention resources could take (booklet, smartphone app and website) were developed.
Figure 9.2 Intervention Formats
9.3.4 Measures
As outlined within Chapter 4, the written health behaviour information and illustrations of the health behaviour change support tools were incorporated into an online survey evaluation survey. The online survey comprised of two parts. In Part 1 participants (both TYA cancer survivors and health professionals) were asked to review and evaluate the written information on physical activity, diet, smoking, alcohol consumption and sun safety for standard, quality and relevance. Within Part 2 of the evaluation survey, participants were asked to review and evaluate the illustrations of the proposed behaviour change support tools for appeal and usability. Two versions of the survey were created; one for young people with cancer and one for health professionals. The contents of both surveys are displayed in Appendix 4.18.

9.3.5 Population
Recruitment and data collection methods are outlined within Chapter 4, Section 4.9

9.3.6 Statistical analysis
Data from the user evaluation survey was analysed using SPSS version 22. As all response variables are categorical, descriptive statistics were produced to examine the proportion of participants who rate the intervention materials highly for quality, relevance, appeal and usability. Median scores of quality, relevance and utility are presented. Written qualitative data from the open response questions was coded and analysed line-by-line for themes following the process of content analysis outlined by Elo and Kyngas (2008). Where data was missing due to survey drop-out this has been indicated.

9.4 Results

9.4.1 Response rate
A total of 18 TYA cancer survivors and 19 TYA health professionals took part in the online survey.

9.4.2 Participant characteristics
The characteristics of TYA cancer survivors are displayed in Table 9.2; the characteristics of TYA health professionals are displayed in Table 9.3. TYA Cancer Survivors had an average age of 20 years (SD = 3.12), were predominantly female (n=11, 64.7%), and had finished their main cancer treatment more than 12 months ago (n=10, 55.6%). The majority of health professionals were nurses (n=13, 68.4%), who identified themselves as working with young people aged 13-24 years of age (n=17, 81%) and had been working with young people with cancer for more than 5 years (n=13, 62%). Most health professionals (n=14, 66.7%) reported that they worked with patients across all cancer sites and were based within a principal treatment centre (47.6%, n=15). A large proportion of health professionals worked in London (n=12, 57.1%) and the South of England (n=3, 14.3%).
### Table 9.2 Participant characteristics (TYA Cancer Survivors)

<table>
<thead>
<tr>
<th>Category</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (Mean±SD)</strong></td>
<td>20 ± 3.12</td>
</tr>
<tr>
<td><strong>Age Range</strong></td>
<td></td>
</tr>
<tr>
<td>13-18 years</td>
<td>22.2 (4)</td>
</tr>
<tr>
<td>19-25 years</td>
<td>77.8 (14)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>64.7 (11)</td>
</tr>
<tr>
<td>Males</td>
<td>35.3 (6)</td>
</tr>
<tr>
<td>Missing data</td>
<td>5.6 (1)</td>
</tr>
<tr>
<td><strong>Cancer Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Lymphoma</td>
<td>22.2 (4)</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>33.3 (6)</td>
</tr>
<tr>
<td>Bone Tumour</td>
<td>5.6 (1)</td>
</tr>
<tr>
<td>Soft Tissue Sarcoma</td>
<td>11.1 (2)</td>
</tr>
<tr>
<td>CNS Tumour</td>
<td>-</td>
</tr>
<tr>
<td>Germ Cell Tumour</td>
<td>-</td>
</tr>
<tr>
<td>Carcinoma</td>
<td>-</td>
</tr>
<tr>
<td>Melanoma</td>
<td>5.6 (1)</td>
</tr>
<tr>
<td>Other</td>
<td>16.7 (3)</td>
</tr>
<tr>
<td>Missing data</td>
<td>5.6 (1)</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>33.3 (6)</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>27.8 (5)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>77.8 (14)</td>
</tr>
<tr>
<td>Stem Cell Transplant</td>
<td>11.1 (2)</td>
</tr>
<tr>
<td>Other</td>
<td>5.6 (1)</td>
</tr>
<tr>
<td><strong>Time Since Treatment</strong></td>
<td></td>
</tr>
<tr>
<td>Still receiving cancer treatment</td>
<td>5.6 (1)</td>
</tr>
<tr>
<td>&lt;3 months from finishing treatment</td>
<td>-</td>
</tr>
<tr>
<td>4-11 months since finishing treatment</td>
<td>27.8 (5)</td>
</tr>
<tr>
<td>1-5 years since finishing treatment</td>
<td>55.6 (10)</td>
</tr>
<tr>
<td>&gt;5 years since finishing treatment</td>
<td>-</td>
</tr>
<tr>
<td>Missing data</td>
<td>11.1 (2)</td>
</tr>
<tr>
<td>Professional Group</td>
<td>% (n)</td>
</tr>
<tr>
<td>----------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Physician</td>
<td>4.8 (1)</td>
</tr>
<tr>
<td>Nurse</td>
<td>61.9 (13)</td>
</tr>
<tr>
<td>Allied Health Professional</td>
<td>4.8 (1)</td>
</tr>
<tr>
<td>Social Worker</td>
<td>19.0 (4)</td>
</tr>
<tr>
<td>Missing data</td>
<td>9.5 (2)</td>
</tr>
<tr>
<td>Length of time working with young people with cancer</td>
<td></td>
</tr>
<tr>
<td>1-2 years</td>
<td>19 (4)</td>
</tr>
<tr>
<td>3-4 years</td>
<td>19 (4)</td>
</tr>
<tr>
<td>5-10 years</td>
<td>38 (8)</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>24 (5)</td>
</tr>
<tr>
<td>Best fit description of patient group</td>
<td></td>
</tr>
<tr>
<td>13-24 years of age</td>
<td>81 (17)</td>
</tr>
<tr>
<td>18-39 years of age</td>
<td>19 (4)</td>
</tr>
<tr>
<td>Patient cancer group*</td>
<td></td>
</tr>
<tr>
<td>All cancer sites</td>
<td>66.7 (14)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>19 (4)</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>19 (4)</td>
</tr>
<tr>
<td>Germ Cell Tumours</td>
<td>9.5 (2)</td>
</tr>
<tr>
<td>Central Nervous System</td>
<td>14.3 (3)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>-</td>
</tr>
<tr>
<td>Bone Tumour</td>
<td>14.3 (3)</td>
</tr>
<tr>
<td>Soft Tissue Sarcoma</td>
<td>14.3 (3)</td>
</tr>
<tr>
<td>Carcinoma</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>4.8 (1)</td>
</tr>
<tr>
<td>Hospital affiliation</td>
<td></td>
</tr>
<tr>
<td>Principal Treatment Centre</td>
<td>47.6 (10)</td>
</tr>
<tr>
<td>TYA Designated Hospital</td>
<td>23.8 (5)</td>
</tr>
<tr>
<td>Other</td>
<td>28.6 (6)</td>
</tr>
<tr>
<td>Regional affiliation*</td>
<td></td>
</tr>
<tr>
<td>North East England</td>
<td>-</td>
</tr>
<tr>
<td>North West England</td>
<td>-</td>
</tr>
<tr>
<td>Yorkshire and the Humber</td>
<td>4.8 (1)</td>
</tr>
<tr>
<td>East Midlands</td>
<td>4.8 (1)</td>
</tr>
<tr>
<td>West Midlands</td>
<td>4.8 (1)</td>
</tr>
<tr>
<td>East of England</td>
<td>-</td>
</tr>
<tr>
<td>London</td>
<td>57.1 (12)</td>
</tr>
<tr>
<td>South East England</td>
<td>9.5 (2)</td>
</tr>
<tr>
<td>South West England</td>
<td>4.8 (1)</td>
</tr>
<tr>
<td>Wales</td>
<td>9.5 (2)</td>
</tr>
<tr>
<td>Scotland</td>
<td>-</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>4.8 (1)</td>
</tr>
</tbody>
</table>

*respondents were instructed to tick all that applied from the list
9.4.3 Health behaviour information evaluation

TYA cancer survivors and health professionals views on the quality, utility and relevance of the information on each health behaviour topic are displayed in Figures 9.3, 9.4 and 9.5 respectively. Very few TYA cancer survivors or health professionals regarded the information as low quality, unhelpful or irrelevant with most reporting that the information was of either ‘very good’ or ‘good’ quality and ‘very useful’ or ‘quite useful’ to young people with cancer. Specifically, the majority (54.5% - 72.7%) of young people thought the information on smoking and sun safety was of ‘very good’ quality and ‘very useful’ to young people with cancer. Most TYA health professionals held the view that young people with cancer ‘very much’ needed this kind of health behaviour information whereas TYA cancer survivors reported being more unsure if the information was needed selecting ‘neither yes or no’. Encouragingly, no health professionals or TYA cancer survivors thought the information was irrelevant to young people with cancer.

Table 9.4 displays participants’ views on the standard of the written information. All of the TYA cancer survivors surveyed reported that the information was clear and that the language and tone used was appropriate for young people with cancer. However, only 36.4% (n=4) of TYA cancer survivors and 29.4% (n=5) of health professionals felt the information was engaging for young people. As displayed in Figures 9.6 - 9.9 feedback on specific aspects of the information was positive with more than 80% of TYA cancer survivors and over 60% of health professionals indicating they ‘liked’ or ‘loved’ the information on the benefits of a healthy lifestyle, information on the risks of an unhealthy lifestyle or the ‘ideas for everyday change’ sections. Only one TYA cancer survivor indicated that they disliked the information about forming new habits.
Figure 9.3 Quality ratings of the TYA health behaviour change information

Question: How would you rate the quality of the information on [health behaviour topic]?

21 Question: How would you rate the quality of the information on [health behaviour topic]?
Figure 9.4 Utility ratings of the TYA health behaviour change information

Question: ‘How helpful do you think the information on [health behaviour topic] is to young people who have had a cancer diagnosis?’

22 Question: ‘How helpful do you think the information on [health behaviour topic] is to young people who have had a cancer diagnosis?’
Figure 9.5 Relevance ratings of the TYA health behaviour change information\textsuperscript{23}

\begin{figure}
\centering
\includegraphics[width=\textwidth]{figure95.png}
\caption{Relevance ratings of the TYA health behaviour change information.}
\end{figure}

\textsuperscript{23} Question: Do you think young people with cancer need this kind of information about [health behaviour topic]?
Table 9.4 TYA cancer survivors and TYA health professionals’ views on the standard of the health behaviour information

<table>
<thead>
<tr>
<th></th>
<th>TYA Cancer Survivors</th>
<th></th>
<th>TYA Health Professionals</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% (n) (n=11)*</td>
<td></td>
<td>% (n) (n=17)*</td>
<td></td>
</tr>
<tr>
<td><em>Missing data due to survey drop-out: TYA cancer survivors (n=7); TYA health professionals (n=2)</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is it clear what the information is about?</td>
<td>100 (11)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>82.4 (14)</td>
</tr>
<tr>
<td>Do you understand the language used?</td>
<td>100 (11)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>70.6 (12)</td>
</tr>
<tr>
<td>Is the information written at the right level?</td>
<td>100 (11)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>64.7 (11)</td>
</tr>
<tr>
<td>Does the information engage you as a reader?</td>
<td>36.4 (4)</td>
<td>63.6 (7)</td>
<td>0 (0)</td>
<td>29.4 (5)</td>
</tr>
<tr>
<td>Is the information written in the right tone?</td>
<td>81.8 (9)</td>
<td>11.1 (2)</td>
<td>0 (0)</td>
<td>52.9 (9)</td>
</tr>
</tbody>
</table>

*Missing data due to survey drop-out: TYA cancer survivors (n=7); TYA health professionals (n=2)*
Figure 9.6 TYA cancer survivors and TYA health professionals’ views on the information on the benefits of a healthy lifestyle

Figure 9.7 TYA cancer survivors and TYA health professionals’ views on the information on the risks of an unhealthy lifestyle
Figure 9.8 TYA cancer survivors and TYA health professionals’ views on the ‘ideas for everyday change’

Figure 9.9 TYA cancer survivors and TYA health professionals’ views on the information about forming new habits
9.4.4 Suggested improvements

With regard to the information about making health behaviour changes habitual, TYA cancer survivors were generally positive and suggested the information be expanded to include more detailed information addressing specific barriers which young people with cancer face both during and after cancer treatment (e.g. fatigue and constipation). Health professionals were more sceptical about the feasibility of young people with cancer making healthy lifestyle choices habitual and suggested the information should include more detail about staff and services available to support TYA cancer survivors. One health professional suggested the information should include guidance to help young people phrase questions they might want to ask to members of their treating team.

‘Most points are covered but one thing that could be improved on is the fact that it states the side effects can make it difficult to make positive changes. Maybe suggest ways that someone can deal with lack of motivation that doesn’t equate to buy yourself something’

(Male, Age 20 years, Lymphoma)

‘For teenagers with cancer, healthy habits are the last things on their minds, if their calorie intake is poor then our advice is different and does not meet the criteria for a healthy habit. I do think however that they do need something which gets them out of bed and stops them playing ‘sick patient’. They need information about making the best choices available at the time. (Nurse, 4 years TYA cancer experience)

In relation to the information on physical activity; TYA cancer survivors’ predominantly thought more examples would be beneficial and were interested in additional information about specific exercises they could do during treatment, especially when in isolation. Young people also indicated that the information was very generic with one TYA cancer survivor highlighting that the information doesn’t reflect the diversity of cancer patients’ needs. Health professionals expressed concern about the safety of the information contents and felt that physical activity and exercise recommendations for young people with cancer should be individually tailored, especially if a young person is receiving treatment.

‘I feel you could maybe do a section on exercise and cancer with light exercise ideas. I was in an isolated room and could only walk around my bed, I was given a small pedal bike exercising machine to use that really helped so you could include something about exercising in hospital’ (Gender missing, Age 23 years, Leukaemia)

‘Some good information but doesn’t really take into consideration the diversity of cancer patients. Needs some better information encompassing different capabilities. For example, nearly the whole article is useless to a patient in a wheelchair (Female, Age 14, Carcinoma)

‘I think it is important that they if they are having treatment in hospital seek advice from a physiotherapist or the therapy team regarding physical activity, as they can tailor their current function with personalized exercise programme etc. I wouldn’t advise a patient to go
off and independently use an exercise bike unless they have had a discussion with the physiotherapist as they may have low platelets (therefore will not be able to do exercise with very high resistance). If they have a very low Hb this can cause adverse effects etc. (Allied Health Professional, 6 months in current role)

TYA cancer survivors feedback on the diet and nutrition information was minimal with only one request for the information to be made simpler and for example recipes to be included as part of the information resources. One young person suggested the information should include information about ‘positive swaps’ i.e. what healthy foods could be swapped for unhealthy foods.

‘The content is great… I love the idea of the top tips’ (Gender missing, Age 23 years, Leukaemia)

‘It could be simpler… My concentration was bad during treatment so quick short punchy information is better’ (Female, Age 23 years, Leukaemia)

Health professionals were also generally positive about the diet and nutrition information; two professionals suggested the information include more detail on the effects of cancer treatment upon appetite.

‘Does not take into account lower appetite and altered tastes from chemo effects. Also we actually teach them to eat high calorie unhealthy foods just to get the calories in. The challenge is to change once treatment finishes…’ (Nurse, 17 years TYA cancer experience)

TYA cancer survivors provided very little feedback on the alcohol information. One young person suggested the information on alcohol consumption include more detail about the effect of drinking on psychological well-being and specifically how alcohol affects anxiety and depression and another indicated the information might not have an effect on TYA cancer survivors drinking patterns.

‘A little more information on psychological effects would be good. E.g how alcohol can work with anxiety and depression’ (Male, Age 22 years, Leukaemia)

‘The information could be less detailed. I also think that people will drink whether they have cancer or not’ (Gender missing, Age 23 years, Leukaemia)

Health professionals recognized the need to educate TYA cancer survivors on the risks of alcohol consumption but were sceptical that young people would engage with such information. One health professional thought the alcohol information had a ‘telling off feel to it’ and another suggested the section should be more cancer focused and include specific reference to the impact of cancer on a young persons’ lifestyle:

‘Starting with the hard info on the law and units etc may put people off, so suggest this comes later to build up to that. As with previous section relate it to young people with cancer first. So something about “Yeah, you’re young, alcohol is a big part of your social life and when you’ve
been through the kind of life experiences you have, who wouldn’t want to go out and have a
good time with your friends, or drown your sorrows with a big drinking session with your mates.
We get that, but we also think you should take a bit of time to learn about what this could be
doing to you and spend some time thinking about it in relation to your cancer diagnosis. You’ve
come through so much, why risk that by not paying attention to alcohol consumption?’ (Nurse,
4 years TYA cancer experience)

TYA cancer survivors again had very minimal feedback to provide on the smoking information
with one young person suggesting the information include pictures of lungs before and after
smoking. Two health professionals suggested the resources should include information about
vaping.

‘I think there is no need for improvement for information, I think the right amount
of information is included. I like the diagram used. (Gender missing, Age 23 years, Leukaemia)

‘Love this page. Maybe needs something about vaping and CRUK have info. Some of the
approaches to deciding to quit smoking and be confident in the decision could be applied to
the alcohol pages too ((Nurse, 4 years TYA cancer experience)

TYA cancer survivors appeared genuinely interested in the information on sun safety, with one
young person highlighting that they weren’t given any information like this whilst on treatment.
Two young people suggested including information on the risks of sun-burn and how to check
for the signs of skin cancer. Two health professionals suggested the sun safety information
emphasize that TYA cancer survivors are more susceptible to skin cancer later in life.

‘It’s presented well, I wasn’t given any information like this when I was receiving treatment and
I suffered quite bad sunburn that scarred me for about 2 years’ (Female, Age 19 years, Soft
Tissue Sarcoma)

‘Add more tips on how to be safe outdoors and check for skin cancer. Also talk about the
health risks of sun-burn’ (Female, Age 14, Soft Tissue Sarcoma)

‘In sun safety (1st box) say why people treated for cancer are at more risk of skin cancer,
something about the chemo and radiotherapy affects. Block the blaze – add reapply after
swimming as well. Nice design and pictures on this page’ (Nurse, 4 years TYA cancer
experience)

Table 9.5 contains TYA cancer survivors and TYA health professionals’ views on the design
and visual layout of the information resources. Young people indicated that the information
resources were too bright and they would prefer a set colour; one health professional
commented that the colour scheme was too feminine and this may put boys off engaging with
the resources. Both TYA cancer survivors and health professionals suggested some of the
information could be made into infographics and pictures could help link the information
together. One young person highlighted that the information and page layout should be
compatible to screen reading software.
Table 9.5 Feedback on the design and visual layout

<table>
<thead>
<tr>
<th>TYA Cancer Survivors</th>
<th>TYA Health Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am blind and was unable to access it as it is an image and not a body of text which could be read out to me by my screen reading software. (Female, Age 22, Melanoma)</td>
<td>change the pink - for boys we don’t like to see pink automatically, in the past we have found that information sheets that contain age appropriate characters - like a man or woman in gym gear - had better response from young people. An example of how this would be useful could be that they appear standing, hanging or jumping between each step. Young people like parkor, crossfit, MMA and Yoga, so it might be useful to bring these elements in through characters. (Social Worker, 5.5 years TYA cancer experience)</td>
</tr>
<tr>
<td>To be more attractive, the colours could be more coordinated. I feel that there’s too much colour, maybe sticking to one or two colours would be more attractive but the quantity and quality of the information is brilliant. (Female, Age 23, Leukaemia)</td>
<td>I think it is okay as it is...not too wordy and the layout makes it easy to read. (Youth Support Co-Ordinator, 6 months)</td>
</tr>
<tr>
<td>Images to break up large quantities of text. (Female, Age 22, Melanoma)</td>
<td>. Largely female messages. The picture and the ‘rewards’ are female focussed. (Nurse, 14 years TYA cancer experience)</td>
</tr>
<tr>
<td>I feel there could be more photos and less writing. If I’m honest from previous experience, people aren’t going to sit and read a lot of information and would rather visualise the information with less writing and more straight to the point information. Also less mixed colours, maybe have a set of colours rather than a variety of colours if that makes sense. (Age 23, Leukaemia)</td>
<td>Seems small, but the picture maybe could change to something less difficult looking….it would put me off especially if I was not able to face even getting out of bed! (Social worker, 6 years TYA cancer experience)</td>
</tr>
<tr>
<td>I feel there is too much writing that wouldn’t be as attractive. The content is great, also maybe make it less colourful and have each section a different colour. I love the idea of the top tips. (Age 23, Leukaemia)</td>
<td>It’s a little text heavy - perhaps could be broken down into smaller chunks for YP who might be put-off by large elements of text. (Teacher, 8 years TYA cancer experience)</td>
</tr>
</tbody>
</table>

Again, this information page has just the right amount of writing. The photos could both be cartoon to improve the post just to make it look more appealing rather than having a mixture of cartoon and real photography. (Age 23, Leukaemia)
Chapter 9

9.4.5 Intervention resource evaluation

As displayed in Table 9.6 the majority (>80%) of TYA cancer survivors and health professionals viewed the behaviour change support tools as ‘very appealing’ or ‘quite appealing’. Only one TYA cancer survivor reported that they did not find any of the behaviour change support tools interesting.

Table 9.6 TYA cancer survivors and TYA health professionals’ views on the appeal of discreet behaviour change techniques

<table>
<thead>
<tr>
<th></th>
<th>TYA Cancer Survivors (n=6)</th>
<th>TYA Health Professionals (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal Setting</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Appealing/ Quite Appealing</td>
<td>85.7 (6)</td>
<td>66.7 (10)</td>
</tr>
<tr>
<td>Not appealing/ Not at all appealing</td>
<td>14.3 (1)</td>
<td>33.3 (5)</td>
</tr>
<tr>
<td><strong>Action Planning</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Appealing/ Quite Appealing</td>
<td>83.3 (5)</td>
<td>73.3 (11)</td>
</tr>
<tr>
<td>Not appealing/ Not at all appealing</td>
<td>16.7 (1)</td>
<td>26.7 (4)</td>
</tr>
<tr>
<td><strong>Prompts/ Reminders</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Appealing/ Quite Appealing</td>
<td>83.3 (5)</td>
<td>86.7 (13)</td>
</tr>
<tr>
<td>Not appealing/ Not at all appealing</td>
<td>16.7 (1)</td>
<td>13.3 (2)</td>
</tr>
<tr>
<td><strong>Self-Monitoring</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Appealing/ Quite Appealing</td>
<td>83.3 (5)</td>
<td>85.7 (12)</td>
</tr>
<tr>
<td>Not appealing/ Not at all appealing</td>
<td>16.7 (1)</td>
<td>14.3 (2)</td>
</tr>
<tr>
<td><strong>Rewards</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Appealing/ Quite Appealing</td>
<td>83.3 (5)</td>
<td>93.3 (14)</td>
</tr>
<tr>
<td>Not appealing/ Not at all appealing</td>
<td>16.7 (1)</td>
<td>6.7 (1)</td>
</tr>
<tr>
<td><strong>Social Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Appealing/ Quite Appealing</td>
<td>83.3 (5)</td>
<td>80 (12)</td>
</tr>
<tr>
<td>Not appealing/ Not at all appealing</td>
<td>16.7 (1)</td>
<td>20 (3)</td>
</tr>
<tr>
<td><strong>Social Comparison/ Modelling</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Appealing/ Quite Appealing</td>
<td>83.3 (5)</td>
<td>100 (15)</td>
</tr>
<tr>
<td>Not appealing/ Not at all appealing</td>
<td>16.7 (1)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

*Missing data due to survey drop-out: TYA cancer survivors (n=7); TYA health professionals (n=4)
9.4.6 Acceptability and delivery

If these health behaviour change resources were available today, 92.9% (n=13) of health professionals reported that they would be extremely likely to signpost young people towards the resources. Sixty percent of TYA cancer survivors said they would be either ‘extremely likely’ or ‘very likely’ to use the resources and 80% (n=4) said they would definitely recommend the resources to other young people with cancer.

TYA cancer survivors reported that they would be most likely to use the resources if available as paper leaflets or booklets (n=3, 60%) or as an app (n=2, 40%). Health professionals on the other hand reported they were most likely to signpost young people towards a mobile app (n=9, 64.3%) containing the resources. No health professional said they would signpost a young person in their care towards paper based resources.

Figure 9.10 displays TYA cancer survivors’ and health professionals views on when the best time to first offer these resources to young people would be. Most young people (n=2, 40%) felt the resources would be best introduced immediately after treatment whereas most health professionals (n=6, 43%) felt the resources should be delivered 3-5 months after treatment.
Figure 9.10 Timing of health behaviour change intervention delivery

- TYA Cancer Survivors
- TYA Health Professionals
9.5 Discussion

The objective of this study was to design and evaluate health behaviour change intervention resources for TYA cancer survivors. Specifically, this study aimed to assess whether the health behaviour information developed as part of the proposed intervention meet the needs of TYA cancer survivors and TYA health professionals, and if TYA cancer survivors would engage with and use the behaviour change support tools embedded within the intervention resources. Based on the findings from studies 1 to 4, the health behaviour information contains reference to the importance of a healthy lifestyle; how to make sustainable lifestyle changes; and information on the health consequences of not leading a healthy lifestyle. Behaviour change ‘support tools’ included within the intervention resources were: goal setting, action planning, prompts and reminders; rewards; self-monitoring; and social support. Collectively, these resources have the potential to meet TYA cancer survivors’ currently unmet need for information and support to change their health behaviour.

Overall, the development of the intervention resources was guided by the behaviour change intervention development process (Michie et al., 2014); the 6 steps in quality intervention development (Wight et al., 2015) and the Person Based Approach to intervention development (Yardley et al., 2015b). Often behaviour change interventions are developed with minimal understanding of the behavioural needs of the target population and minimal understanding of what functions the intervention should contain and how the intervention should be delivered (Hoddinott, 2015). Studies 1-4 of this thesis have provided thorough insight into these issues. This evaluation study of intervention acceptability is novel and provides important insight into TYA cancer survivors and TYA health professionals’ receptivity to the intervention resources. Such data is important in refining the intervention for future use. Moreover, it is hoped that by developing the health behaviour change intervention resources to be reflective of the needs and preferences of young people, the ensuing intervention is more likely to be effective at prompting sustainable behaviour change (Brett et al., 2014b).

Findings from this study indicate that the written health behaviour change information was generally well received with the majority of TYA cancer survivors and TYA health professionals rating the information as high quality, helpful and relevant. Feedback on the written standard of the information was also high with 100% of TYA cancer survivors reporting the information was clear, understandable and written at the right level. Over 80% of young people ‘liked’ or ‘loved’ information on the benefits of a healthy lifestyle; information on the risks of an unhealthy lifestyle; the ‘ideas for everyday change’ and the information about forming new habits. Health professionals on the other hand were more critical of the information contents with most rating that they ‘liked it’ or ‘thought it was okay’. However, in comparison to young people, health professionals were more likely to view the information as relevant and needed by TYA cancer survivors. TYA cancer survivors may be apathetic towards their needs for health information. Apathy is defined as a lack of motivation relative to one’s level of functioning (Ishizaki and Mimura, 2011). Apathy manifests in the form of diminished goal-directed cognition and...
behaviour (e.g. lack of effort to do things and lack of interest in new experiences) and diminished emotional responsivity to both positive and negative events. Apathy often co-occurs alongside neurological disorders such as depression, schizophrenia and Alzheimer’s disease. The literature regarding apathy and health among adolescents is scant however, one study of adult survivors of childhood posterior fossa brain tumours (n=117, Mean age 32 years: Age range: 18 -53) found 35% of survivors reached or exceed the Marin Apathy Evaluation Scale score for diagnosis of apathy (Carroll et al., 2012). Meeting or exceeding the criteria for ‘apathy’ was associated with decreased likelihood of being employed or in education. Psychological interventions which stimulate care and interest in health behaviour among TYA cancer survivors may increase young peoples’ engagement with health behaviour information and behaviour change resources.

Many TYA cancer survivors and health professionals commented that more specific personalized or tailored health behaviour information would be beneficial. The intervention materials in the current format are ‘targeted’ towards TYA cancer survivors in that they provide a specific message to a specific population (Noar et al., 2007). Future work should explore how the information and behaviour change support components of the intervention could be made personal to the user. In the past, receiving personalized feedback on health behaviour data entered into the intervention has previously been used as an effective means of providing tailored personal health behaviour change support to TYA cancer survivors (Berg et al., 2014). Other methods may include allowing TYA cancer survivors to pick behaviour change modules or information content that they deem most relevant to them. Within one review of digital health interventions for children and young people with mental health problems (depression, anxiety, eating disorders, attention deficit hyperactivity disorder (ADHD), and psychosis) it was suggested that the ability of young people to personalize even small features (e.g. background colour, gender or the appearance of the homepage) influences how users engage with the intervention (Hollis et al., 2017). Further research is required to explore if health behaviour change interventions for TYA cancer survivors should be personalized by the individual, by cancer type, or by age and determine how this may influence intervention uptake and engagement.

TYA cancer survivors and health professionals’ feedback on the behaviour change support tools was also positive. Over 80% of young people who were surveyed reported that they would find the support tools ‘very appealing’ or ‘quite appealing’. Health professionals held similar views and thought rewards and social comparison/ modelling would be most appealing to TYA cancer survivors. These findings strengthen the hypothesis that behaviour change resources designed specifically for TYA cancer survivors might have a widespread use. Moreover, the finding that young people with cancer find such behaviour change techniques appealing is consistent with previous research conducted among the general population. For example, within one study exploring the user requirements of a lifestyle behaviour change app, young people (n=16, Mean age: 24 years) reported that such an app designed to promote
healthy lifestyle choices should include four main features: behaviour tracking, health goal setting, reminders and tailored information (Ribeiro et al., 2016). Participants within this study by Ribeiro and colleagues implied that the behaviour tracking element was an important feature as it was likely to be a ‘call to action’ for behaviour change. This is consistent with evidence which indicates experiential feedback is a key component of successful behaviour change interventions (Michie et al., 2008). Additional research is needed to determine the extent to which TYA cancer survivors would voluntarily engage with such behaviour change techniques embedded within the intervention resources.

Positive feedback from both young people and health professionals on the content and delivery of the resources provide assurance that these behaviour change intervention resources will be useful to young people with cancer. However it is important not to place too much emphasis on the positive feedback from TYA cancer survivors and health professionals as there is a possibility of social desirability bias. The information sheets outlining the study included reference to the fact that researchers from the Department of Behavioural Science and Health at UCL developed the information materials and behaviour change support tools in partnership with CLIC Sargent; there is possibility that young people and health professionals were less likely to criticise the intervention resources as they may have known it would be researchers from UCL looking at their feedback. Similarly, participants may have noted CLIC Sargent’s input and assumed the information materials to be credible and reliable and therefore not been as critical as perhaps they could have been. Moreover, it is unlikely that the views of young people and health professionals within this study reflect the views of the entire TYA cancer survivor population as levels of health literacy and age may affect a young persons’ ability to comprehend or engage with the information and behaviour change resources. A number of TYA cancer survivors also experienced a high-level of survey fatigue and dropped out of the survey after Part 1. This is unsurprising as reading and reviewing the resources was a time consuming task. Future work should therefore explore TYA cancer survivors’ thoughts on behaviour change support tools in a larger sample. Future work should also include ‘think-aloud’ studies to understand how young people of different ages and cancer types may view and engage with the intervention resources, which parts of the intervention could be made redundant, and how the intervention could be made more persuasive to behaviour change. Such approaches to intervention refinement have been adopted before in asthma, weight management, alcohol and smoking research (Yardley et al., 2015b, Bradbury et al., 2015, Crane et al., 2017).

9.6 Chapter Summary

This study provides an important insight into the utility of health behaviour change intervention resources designed specifically for TYA cancer survivors. It confirmed that young people are interested in receiving health behaviour information and are receptive to the idea of engaging with behaviour change intervention resources. Moreover, this study allowed the identification of several features of the information which could be improved upon and highlighted some key
issues which should be considered in the further development and implementation of the resources. The next step in evaluating the health behaviour change intervention resources is to pilot the mode of delivery tested in this study, and carry out a formal randomized controlled trial exploring uptake and effect of the resources on behaviour change among young people with cancer.
Chapter 10

General Discussion & Conclusions

10.1 Thesis Aims
The primary aim of this thesis was to conduct a series of studies culminating in the development of a health behaviour change intervention designed specifically for TYA cancer survivors. In accordance with frameworks and guidance on intervention development a behaviour change intervention developed specifically for young people with cancer should be grounded in a thorough understanding of the needs and preferences of TYA cancer survivors. The novel work in this thesis comprised a narrative review of health behaviour and TYA cancer survivorship; a systematic review of existing health behaviour change interventions piloted among TYA cancer survivors (Pugh et al., 2016) and additional studies assessing the current health behaviours status of TYA cancer survivors; TYA cancer survivors interest in health behaviour intervention and preference regarding the content, format and timing of delivery. This thesis also included a study investigating TYA cancer specialists views on how best to promote a healthy lifestyle among young people with cancer (Pugh et al., 2017c, Pugh et al., 2017b, Pugh et al., 2017a). The following section summarises the research findings from each of these studies and the implications this research has in informing the further development of health behaviour interventions for young people with cancer.

10.2 Summary of main findings and their implications

10.2.1 Review of existing interventions for TYA cancer survivors
The systematic review presented in Chapter 2 is the first comprehensive examination of existing interventions designed to prompt positive change in physical activity, dietary intake, alcohol consumption, smoking and sun exposure among TYA cancer survivors. A total of 14 articles detailing the outcomes from 13 individual interventions were found. The majority were pre-post design intervention trials with no control group. The health behaviour most frequently target within these interventions was physical activity. Overall, the results of the systematic review suggest behaviour change among TYA cancer survivors is feasible. However, due to the heterogeneity of the intervention contents and the outcome measures used it was not possible to conclude which format of intervention, mode of delivery or behaviour change techniques are most efficacious at prompting behaviour change among TYA cancer survivors.

Nevertheless, some promising intervention features were brought to attention. It was evident within the literature that there has been a shift from interpersonal counselling and mass communication towards interventions being delivered remotely in digital formats. Technology based approaches to intervention delivery have the potential to overcome typical geographical, human resource and financial barriers which often hinder intervention uptake and engagement (Demark-Wahnefried et al., 2005b, Stull et al., 2007). Among TYA cancer survivors, behaviour
change interventions delivered remotely using technology demonstrated high feasibility and acceptability indicating that the use of technology to support young people with cancer is suitable (Kopp et al., 2016). However, as outlined within Chapter 2 the way in which technology had been applied was diverse, ranging from interventions with fixed content and limited interactivity to interventions which offer the possibility of interactive and tailored content. For example, within the intervention conducted by Hollen and colleagues (2013) DVDs containing videos on decision making, the health consequences of smoking, and the health consequences of drinking were delivered to participants alongside CD-ROMs containing interactive materials on decision making. In contrast within the website intervention conducted by Berg and colleagues (2014) young people were routed to tailored graphical depictions of their daily physical activity, alcohol consumption and smoking behaviours after recording their health behaviour in an online log. No systematic review to date has attempted to synthesize and review exiting electronic patient platforms for young people with cancer and as such little is known regarding the true benefit of delivering supportive-care or health interventions via technology to TYAs living with and beyond a cancer diagnosis (Pugh and McCann, 2017).

Among adults (n=7974, mean age: 43.5 years) low levels of health literacy are significantly associated with lower use and engagement with health information technology (defined in this study as fitness and nutrition apps, activity trackers and patient portals) (Mackert et al., 2016). This observed disparity in health literacy and health behaviour intervention engagement is concerning. Behaviour change interventions available solely online or delivered only in digital formats are dependent upon pro-active information seeking and access to technology: factors which should not be taken for granted and may not be possible for young people in some social and financial circumstances. Thus, at present, some caution should be given to the overall reach and uptake of digital intervention platforms (Michie et al., 2017).

Despite the use of technology to deliver interventions remotely, social support was another key feature of many of the interventions. However, due to the variation in social support formats between interventions it was not possible attribute social support with intervention efficacy or outcome. Nevertheless, it was evident that emotional and instrumental support from healthcare professionals, friends, and family are important in promoting behaviour change among young people with cancer. For example, within the FIT-NET intervention conducted by Valle and colleagues (2013) young people within both the intervention group (wherein participants received regular prompts from a moderator to facilitate group discussion) and the control group (where participants received no discussion prompts) posted and shared messages of encouragement and support on the private Facebook page. The finding that the unmoderated group posted more frequently than the moderated group (188 comments vs 153 comments) suggests TYA cancer survivors are interested in receiving support offered from peers who have been through cancer themselves (Valle et al., 2013). This is to be expected as it is well known that as a young person transitions from childhood, through adolescence and into adulthood the role of direct and indirect support from close friends and peers takes increasing precedence (Draper et al., 2015). Behaviour change interventions which include an
aspect of social support have proven efficacious among other TYA populations suffering from chronic health conditions such as asthma and diabetes (Sawyer et al., 2007). Efforts to target health behaviour change among TYAs with cancer should therefore address, and account for, social influences on health behaviour.

Another notable feature of many of the interventions was the inclusion of personalized risk counselling and tailored education. As discussed in Chapter 4, according to the COM-B model of behaviour change, behavioural interventions must enhance an individuals’ capability to regulate their behaviour, maximise opportunities for an individual to support self-regulation and increase individuals motivation to engage in the desired target behaviour (Michie et al., 2011b). Incorporating risk-based counselling into health behaviour interventions for young people with cancer may motivate young people to make positive behaviour changes, as young people who are unaware of their heightened risk of chronic health problems are likely to be passive towards health information and unable commit to specific health goals (Tyc et al., 1999, Ford et al., 2014b). Given the variation in the intensity and form of risk counselling and tailored education within the included studies it was not possible to conclude specifically what type of counselling and information provision is most effective at prompting behaviour change. However, although no statistically significant effects were found on health behaviour outcome Hollen and colleagues (2013) RCT of a substance use decision-aid intervention had promising results as risk motivation (the motivation an individual has to engage in a risk behaviour) was significantly decreased after 6 months of follow-up. It was concluded that whilst behaviour change was not immediately observed personalized risk counselling and tailored education may exert ‘a dampening effect on the upward trajectory’ for poor health behaviour among adolescents and young adults (Hollen et al., 2013). It is likely that such interventions which foster autonomous motivation, build self-regulatory skills, and encourage positive decision making will be more effective than intervention which solely rely on education alone (D’Agostino et al., 2011).

Overall, the findings from the systematic review suggested that very little was known on how best to promote healthy lifestyle choices among TYA cancer survivors. Results from the systematic review suggested health behaviour interventions delivered in digital formats which included tailored risk counselling and an aspect of peer support were promising strategies to prompt behaviour change among TYA cancer survivors. However, none of the studies had been conducted in the United Kingdom among young people with cancer aged between 13 and 24 years and very few interventions had been developed in consultation with young people with cancer or TYA health professionals. It was also evident that very little was known regarding the health behaviour needs of TYA cancer survivors and their preferences on health behaviour intervention delivery. Together these data demonstrate the pressing need for and importance of the work contained within this thesis.

10.2.2 The health behaviour status of TYA cancer survivors and general population controls (Study 1)
Although previous research (Chapter 2) conducted among long-term survivors of childhood cancer indicate the health behaviours of young people who have had a cancer diagnosis are suboptimal, there was no up-to-date data on the health behaviour status of TYA cancer survivors in the UK and it was unknown whether their health behaviours of young people with cancer differed to general population controls. To address this gap, Study 1 (Chapter 5) aimed to determine group differences in health behaviour and perception of health behaviour on current and future health between TYA cancer survivors on treatment, TYA cancer survivors off treatment, and general population TYAs. Results suggested that despite the importance of health behaviour in cancer survivorship, TYA cancer survivors have a similar health behaviour status to TYAs within the general population in that they are mostly inactive; consume diets low in fibre, lean meat, and fruit and vegetables; and regularly binge on alcohol. These findings are not dissimilar to previous research exploring the health behaviour status of young people with cancer in other countries (Kaul et al., 2016, Zhang et al., 2015c, Levy-Shraga et al., 2015) and further emphasize the need to promote healthy lifestyle choices among both cancer survivors and general population TYAs (Nass et al., 2015).

The key differences between TYA cancer survivors and general population TYAs health behaviour were in physical activity and dietary intake. TYA cancer patients on treatment were significantly less active than both general population TYAs and TYA cancer survivors’ who had completed treatment. Although the low levels of physical activity observed among TYA cancer patients on-treatment are most likely due to the impact of cancer diagnosis and treatment upon physical health and function; 44.5% of TYA cancer survivors who had finished cancer treatment reported that their physical activity levels were lower than before their cancer treatment. This suggests young people with cancer often struggle to return to the same level of activity they had prior to their cancer diagnosis. Data from Study 1 also indicate TYA cancer survivors consume diets higher in fat, sugar and processed meat than general population TYAs. These data confirm anecdotal evidence that TYA cancer survivors establish unhealthy dietary patterns (consumption of high energy, sweet, fast food) during treatment and often find it difficult to break these habits once treatment had finished. Combined these data suggests that efforts should be made to address physical activity and dietary intake among TYA cancer survivors during treatment. As discussed in Chapter 2, it is feasible and safe to deliver physical activity interventions to young people with cancer during the intense treatment phase (Grimshaw et al., 2016); whether it is feasible to also deliver dietary interventions during treatment remains to be explored. Nevertheless, introducing physical activity and dietary interventions early in the cancer pathway may be a means of preventing unhealthy behaviours becoming habitual and extending beyond treatment (Barnes et al., 2016).

In relation to risk behaviours (smoking, alcohol consumption and sun exposure) data indicated that very few TYA cancer survivors and general population TYAs were smoker. However, binge drinking and intentional sun-exposure to get a tan were common in both groups. The high prevalence of alcohol use and excess sun exposure among TYA cancer survivors is
concerning given TYA cancer survivors heightened risk of chronic disease and second primary skin cancer (Perkins et al., 2005, Oeffinger et al., 2006). As per the Theory of Planned Behaviour (Ajzen, 1991) and Health Belief Model (Rosenstock, 1974) health beliefs and attitude predict behaviour. Particularly, affective attitude and instrumental attitude24 have been found to significantly affect TYA cancer survivors intention to be physically activity (Beta = 0.32, p=0.016 and Beta = 0.31, p=0.037, respectively) (Keats et al., 2007). However, within Study 1 despite recognizing alcohol consumption and skin protection as important to current and future health a substantial proportion of TYA cancer survivors report binge drinking and very few reported looking after their skin in the sun. Among TYAs the social norms and interpersonal influences underpinning alcohol consumption and tanning are similar: both are behaviours which are often actively endorsed by peers and are valued as socially normative. In the past it has been suggested that TYA cancer survivors engage in alcohol consumption due to peer pressure or in an attempt to bring a sense of normalcy to their lives (Morgan et al., 2010). It is therefore highly likely that the same psychosocial factors which influence the health behaviours of general population adolescents influence the health behaviours of TYA cancer survivors (Murphy, 2013). Thus, addressing social and environmental factors which influence alcohol consumption and sun exposure among TYA cancer survivors may encourage them to drink less and protect their skin in the sun (Cox, 2003).

However, very few young people perceived a need to change their alcohol consumption and only half of TYA cancer survivors who were smokers had tried to quit since their cancer diagnosis. TYA cancer survivors’ indifference to changing these risk health behaviours could be partially explained by variation in development of executive function. The prefrontal cortex of the brain (the area of the brain responsible for weighing the consequences of behaviour, controlling impulses, and decision making) has been found to be still maturing for up to a decade after puberty (Viner et al., 2015). Self-control and self-regulation is dependent upon executive function and involves self-conscious appraisal of motives (feelings of want and need) and health beliefs (i.e. what is good or bad). Therefore, efforts to encourage young people to abstain from alcohol consumption, smoking and tanning may possibly be thwarted by their incompletely developed prefrontal cortex which directs executive function and self-control. Similarly, the PRIME theory of addictive behaviour proposes that addictive substances (e.g. alcohol and nicotine) create stimulus-impulses (West, 2008). These feelings of pleasure inhibit motivation to disengage in the addictive behaviour. TYA cancer survivors’ engagement in risk behaviour (drinking, tanning and smoking) and lack of interest in support to make changes to these behaviours may partially be explained by the pleasurable nature of these behaviours. Stopping or reducing alcohol consumption, intentional tanning and smoking would require young people to exert a high level of self-control, something they may not yet have the developmental capacity to do.

24 Affective attitude refers to the emotional approach to a behaviour (e.g. pleasant or unpleasant, enjoyable or unenjoyable) whilst instrumental attitude refers to the perception of favourableness and relates to the benefits and costs associated with the behaviour (e.g healthy or unhealthy, sensible or silly) (Azjen, 1991).
As outlined in Chapter 2, in the interest of intervention timing and delivery, researchers and practitioners concerned with cancer survivorship and health behaviour change have become increasingly interested in the concept of a ‘teachable moment’ (McBride et al., 2013). Some have suggested that a cancer diagnosis and its’ subsequent treatment may be a ‘teachable moment’ for TYA cancer survivors and prompt spontaneous behaviour change (George and Smith, 2012). To further investigate this notion Study 1 included questions about how young people thought their lifestyle compared to before their cancer diagnosis and if they had made any attempt to change their health behaviour since their diagnosis. Findings from Study 1 indicate that 28% of young people who had finished cancer treatment were more active than before their diagnosis and 42% had a healthier diet. These findings support the notion of a cancer diagnosis during adolescence or young adulthood being a ‘teachable moment’ wherein diagnosis and treatment trigger an affective re-evaluation of health status and prime individuals towards leading a healthy lifestyle. However, as discussed earlier, although a small proportion of TYA cancer survivors are changing their health behaviour in response to a cancer diagnosis, the majority do not meet current health behaviour guidelines and are largely inactive, consume poor diets and regularly binge drink. These results suggest overall that a cancer diagnosis during childhood, adolescence or young adulthood does not significantly reduce risk taking or improve health behaviour demonstrating a need for best practice interventions which target health promotion among young people who have had a cancer diagnosis.

10.2.3 TYA cancer survivors health behaviour change intervention needs and preferences (Study 2 & Study 3)

Prior to this thesis very little was understood regarding how best to deliver health behaviour information and support to TYA cancer survivors as most of the quantitative and qualitative research investigating the information needs and preferences of young people with cancer had focused on late effects management and psychosocial issues such as fertility, education and relationships (Nass et al., 2015, Barakat et al., 2016, Zebrack, 2008). Given that understanding and incorporating users’ needs and perspectives is central in intervention design and development, Study 2 and Study 3 aimed to establish TYA cancer survivors’ interest in receiving health behaviour information and their views on health behaviour intervention design and delivery.

TYA cancer survivors demonstrated a high level of interest in receiving health behaviour change intervention with 71% reporting that they would take up the offer of health behaviour information, advice and support if given the opportunity. In Study 3, participants specifically discussed their beliefs about health behaviour in relation to their well-being; many young people talked about the role of health behaviour in boosting their self-efficacy and taking back control over their health. In Study 3, young people also disclosed that their motivation behind seeking health behaviour information predominantly stemmed from a heightened perception of risk and desire to look after their own health. This reflected findings from Study 1 that TYA
cancer survivors perceived some health behaviours as more important to their current and future health than general population TYAs. The heightened interest and awareness of TYA cancer survivors on the importance of leading a healthy lifestyle suggests young people with cancer may be more engaged than general population TYAs in health and lifestyle advice.

The most commonly desired topic of advice was physical activity, closely followed by weight, and diet. This high level of interest is encouraging and confirms that a health behaviour intervention designed specifically for young people with cancer is warranted. However, very few TYA cancer survivors (<20%) reported an interest in advice on smoking and alcohol consumption which is particularly concerning given the well-established risks these behaviours have on current and future health (Wilson et al., 2016). Combined with the findings from Study 1 that TYA cancer survivors, despite acknowledging that alcohol consumption is important to current and future health, drink heavily and do not perceive a need to change their alcohol intake suggest that health protective and health risk behaviours are separate behavioural categories. Possible explanations underpinning TYA cancer survivors disinterest in support on health risk behaviours are discussed in Section 10.2.1.

Despite the high level of interest expressed by TYA cancer survivors in receiving health behaviour change advice many young people had not received health behaviour information or support since their diagnosis. Approximately 40% reported they received no advice on diet and physical activity and fewer than 30% reported receiving advice on smoking or alcohol consumption. These findings are concerning as there is evidence that unmet information needs contribute to poor health related quality of life among young people with cancer (Gupta et al., 2013, Smith et al., 2013). These findings highlight a need for TYA cancer survivors to be provided with, or signposted towards, health behaviour information. However many TYA cancer survivors did not have a positive past experience of searching for or receiving health behaviour information.

As found in Study 2, TYA cancer survivors predominantly seek health behaviour information from websites or health professionals. However, within Study 3 TYA cancer survivors disclosed that often health professionals were not forthcoming with advice and that they were often left confused a lack of clear information available online. This likely reflects the current lack of health behaviour information resources available to both health professionals and young people with cancer. When surveyed in Study 2, TYA cancer survivors demonstrated a preference for health behaviour information to be delivered online, in the form of an app, or in the form of a short booklet. These findings were reflected in Study 3 by young people discussing the importance of information being made accessible and available in multiple formats. Young people emphasized that a 'one-size-fits-all' intervention delivery strategy is unlikely to suit the range of individual preferences TYA cancer survivors have. These data indicate that the delivery of health behaviour information for TYA cancer survivors should include physical resources (e.g. leaflets and booklets); online resources (e.g. websites and social media platforms) and face-to-face communication (e.g. health professionals). Such data
challenge the increasingly prevalent narrative that information resources and behaviour change interventions for young people should be made available solely in digital formats. As highlighted by Gray and colleagues although the internet is an important source of information for young people it often is superseded by information and advice received from family, peers and trusted health professionals (Gray et al., 2005). Moreover, information and interventions only available in digital formats require young people to pro-actively seek information which is linked to greater levels of health engagement and higher levels of health literacy (Strekalova, 2016). In addition, web-based interventions are notorious for having poor intervention uptake and adherence: it has even been suggested that young people with cancer may view the internet, and particularly social media sites, as a personal space where interventions are not welcome (Bradford and Chan, 2017).

In terms of content, findings from both Study 2 and Study 3 indicate that TYA cancer survivors have a preference for health behaviour information which is tailored to the needs of young people with cancer. Young people were particularly interested in information which addressed health behaviour issues specific to TYA cancer survivors including physical activity limitations, dietary intake advice whilst on treatment, and whether they could join in drinking with their friends. TYA cancer survivors also emphasized the need for health behaviour change information and intervention resources to be non-judgemental and recognize that young people of differing cancer types, ages and stages on the cancer journey have differing needs. These findings are reflective of existing studies conducted among TYA Type 1 diabetes patients which indicate young people value social comparison and knowing how other young people in similar situations to them have coped (Hood and Nansel, 2007). Akin to the intention behind including explicit risk information in interventions for TYA cancer survivors; health behaviour information for young people with cancer should include case scenarios and examples of how other young people have dealt with barriers to behaviour change. These forms of self-reflective and educative tools could improve decision making and aid young people to make positive health behaviour choices.

In terms of timing, from the perspective of TYA cancer survivors there was no clear consensus on the optimal time to receive health behaviour change information and support. TYA cancer survivors who were undergoing treatment at the time of the study indicated a greater interest in receiving health behaviour information during treatment. However, as a collective sample a roughly equal proportion of participants indicated health behaviour change support would be best provided before treatment, during treatment and immediately after cancer treatment. Combined with data on TYA cancer survivors’ preferences regarding intervention content and format, these findings on timing suggest young people with cancer are most interested in health behaviour information resources available in multiple formats throughout the cancer pathway.

10.2.4 Health professionals’ perspectives on the delivery of health behaviour information to TYA cancer survivors (Study 4)
Results from the systematic review, Study 2, and Study 3 indicate clearly that health professionals are central to the delivery of health behaviour information to TYA cancer survivors. However, prior to this thesis no research had specifically examined the delivery of health behaviour information to TYA cancer survivors from the perspective of TYA cancer specialists. Therefore, Study 4 aimed to investigate TYA health professionals’ knowledge and understanding of health behaviour guidance for TYA cancer survivors and level of advice provision to young people within their care.

Results indicate that TYA health professionals were generally unaware of guidance on health behaviour and very few enquired or provided advice about lifestyle to the majority of the patients under their care. The finding that TYA health professionals were not familiar with health behaviour guidance was foreseeable as the majority of information and training resources created for health professionals contain only small sections on health behaviour with non-specific guidance such as ‘should remain active’. Similarly, the finding that very few health professionals initiate discussion about or provide advice on health behaviour could be explained by the fact most health professionals report that very few (<25%) of their patients ask directly for lifestyle information. This finding somewhat contradicts the findings from Study 2 and Study 3 that young people are highly interested in talking to health professionals about their lifestyle. Perceived lack of patient interest and lack of engagement are known barriers to oncology professionals providing advice (Williams et al., 2015). Efforts should be made to ensure health professionals working with TYA cancer patients are aware of the findings from Study 2 and Study 3 that young people with cancer are interested in receiving advice and support to make positive health changes.

TYA health professionals reported a variety of barriers to providing health behaviour advice to young people. Perceived barriers were most commonly patient-related factors such as lack of interest, being sensitive to emotional needs and maintaining good clinician-patient relationships. These findings indicate a need for resources for health professionals to improve confidence and skills in addressing health behaviour with TYA cancer patients. Specifically, given that health professionals were reluctant to address risk behaviours education and training resources for TYA health professionals should include advice and tips on how to initiate difficult conversations with young people and reference to evidence based referral pathways (for example to quit smoking). Health professionals should feel enabled to discuss health behaviour with young people without feeling uneasy and, fearing they may jeopardize their relationship with their patient. Very brief advice (VBA), which takes 30 seconds to 2 minutes to provide has emerged as a promising strategy to health behaviour intervention delivery (Webb et al., 2016, NICE, 2014). For example, among newly diagnosed breast cancer patients (n=329; mean age: 56 years) women who received a simple recommendation from their oncologist to exercise were significantly more active than those who did not (mean difference: 3.4 MET hr per week, p=0.011) (Jones et al., 2004). Health professionals should also be encouraged to identify local support services available within their hospital or
community (e.g. GP exercise referral, quit smoking) to signpost or refer young people towards when needed or desired.

Despite the numerous barriers to providing advice, the majority of health professionals surveyed were interested in health behaviour change resources which they could give to young people with cancer. Most health professionals provided health behaviour advice written or verbally and the majority felt health behaviour advice and support should be provided during cancer treatment. These results differ somewhat to TYA cancer survivors perspectives, who indicated a preference for information delivered throughout the cancer pathway from the point of diagnosis. However, within open responses TYA health professionals, like young people in Study 3, acknowledged the importance of providing advice in a range of formats to reflect differences in patients’ preferences. This reflects TYA health professionals’ commitment to patient-centred age-appropriate care.

10.2.5 The development of health behaviour intervention resources for TYA cancer survivors

The results of the systematic literature review and studies 1 to 4 informed the development of the health behaviour change intervention resources outlined within Chapter 9. The intervention resources were designed to encourage TYA cancer survivors to make healthy lifestyle choices habitual and included health behaviour information containing reference to the importance of a healthy lifestyle; how to make sustainable lifestyle changes; and information on the health consequences of not leading a healthy lifestyle. The intervention resources also contained formal behaviour change techniques (goal setting, action planning, prompts and reminders; rewards; self-monitoring; and social support) in the form of behaviour change ‘support tools’.

The process undertaken in the development of these resources reflects intervention development frameworks (Wight et al., 2015, Campbell et al., 2007, Yardley et al., 2015a) which advocate that intervention development should be carried out in a logically ordered sequential fashion, be grounded in solid understanding of the target behaviour, and reflective of the needs and preferences of the user group. Such an approach to intervention development contributes significantly to ensuring the ensuing intervention may be widely distributed and used.

Results of the preliminary evaluation showed the health behaviour intervention resources were well received by both TYA cancer survivors and TYA health professionals with both groups indicating that if these resources were made available they would use them. Encouragingly the majority of young people ‘liked’ or ‘loved’ the information on the benefits of a healthy lifestyle; the information on the risks of an unhealthy lifestyle; the ‘ideas for everyday change’ and the information about forming new habits. Both TYA cancer survivors and health professionals reported that the information was clear; the language used was appropriate and the information was written at the right level. TYA cancer survivors and health professionals’ feedback on the behaviour change support tools was also positive with the majority reporting that they would find the support tools ‘very’ or ‘quite’ appealing. Health professionals held
similar views and thought rewards and social comparison/ modelling would be most appealing to TYA cancer survivors. Such positive feedback from health professionals and young people strengthen the hypothesis that health behaviour change resources designed specifically for TYA cancer survivors could have wide-spread use. However, health information is not static and continual updates should occur to ensure the intervention resources remain relevant and appealing to young people with cancer over time (Moult et al., 2004).

Suggested improvements to the health behaviour information included: more detailed information addressing health behaviour issues specific to TYA cancer survivors; information about the safety of exercising during treatment; recipes and meal ideas for young people feeling un-well during treatment; and more information on the risks of alcohol consumption and sun exposure. These suggestions for improvement indicate the resources should include more specific and tailored information for young people with cancer. At present the health behaviour change resources developed within this thesis for TYA cancer survivors are ‘targeted communication’ materials in that they were developed specifically for a certain segment of the population (Noar et al., 2007). However, tailored health behaviour information (information specific to one persons’ characteristics based an individual assessments of their information needs (Kreuter and Skinner, 2000)) has been found to have a greater effect on behaviour change than generic messages (r=0.058; OR: 1.21) (Noar et al., 2007). From the patient perspective, tailored health messages have been found to be more likely to be rated highly, perceived as credible, and recalled successfully (Brug et al., 2011, Kreuter et al., 1999). Whilst the targeted information materials developed within this thesis may be beneficial for young people with cancer, it is likely that tailored information may increase the probability of individual TYA cancer survivors’ changing their health behaviour. Tailored information is highly individualized and developments in digital health and technology now mean information could be easily tailored to individuals on a large scale (Majeed-Aris et al., 2015).

Findings from Study 5 indicate most health professionals would signpost young people towards the intervention resources in the form of a website whilst young people were most interested in accessing the intervention resources in paper format or through a mobile app. These results reinforce findings from Studies 2-4 that intervention resources for TYA cancer survivors should be available in multiple formats for young people to access in a medium they find most preferable. Similar to findings within this thesis, other studies have shown that TYA cancer survivors have multiple preferences for the delivery of information which is dependent upon their circumstance (Playdon et al., 2016). As described in Chapter 9, traditional paper based resources containing general targeted information could be useful as a ‘first line’ of intervention for young people to pick up on their own volition or for health professionals to easily hand-out or discuss with young people during consultations. Intervention resources available online or in the form of an app could be the ‘second level’ to the intervention designed to include tailored information and support.
As demonstrated in Study 1, most TYA cancer survivors engage in multiple unhealthy behaviours. Given the presence of multiple risk behaviours is known to have an additive and synergistic effect on health outcomes (i.e. the presence of two or more poor health behaviours is greater than sum one poor health behaviour) the intervention resources developed within this thesis were designed to target multiple health behaviour change among TYA cancer survivors. Multiple behaviour change interventions capitalize on an individuals’ self-efficacy and confidence as success in changing one health behaviour is likely to prompt behaviour change in other behaviours (Prochaska and Prochaska, 2011). For example, an intervention targeting physical activity could increase an individuals’ motivation and confidence to stop smoking or drink less. This concept of is often referred to as ‘gateway behaviour change’ where one behaviour change prompts another behaviour change (Prochaska et al., 2010). Among young people with cancer there is a high potential that multiple behaviour change may be an effective and cost-efficient means of prompting several positive behaviour changes. However, there is also a potential risk that multiple behaviour change interventions may be too demanding and burdensome to TYA cancer survivors, especially those undergoing treatment. Single health behaviour interventions focus on only one behaviour and are highly targeted and specific. Although there is no definitive evidence to suggest multiple health behaviour change interventions are better or worse than single interventions (Prochaska and Prochaska, 2011): there is potential given the complex needs of some TYA cancer survivors highly tailored individualized interventions focusing on a single health behaviour may have a greater effect than interventions which focus on multiple behaviour change. More research is required to establish if multiple health behaviour change is an effective approach to behaviour change among TYA cancer survivors or if single behaviour change interventions may be more achievable.

Equally further work is required to establish if health risk behaviours (smoking, alcohol consumption and sun safety) should be addressed separately to health protective behaviours (physical activity and diet). Within studies 2, 3 and 4 it was evident that young people and health professionals view smoking, alcohol consumption and tanning as different to physical activity and diet. TYA cancer survivors were not as interested in information on these topics whilst health professionals expressed they were sometimes reluctant to bring them up with patients for fear of jeopardizing the relationship they had with the patient or appearing judgemental about their lifestyle choice. However, data from Study 5 indicate both TYA cancer survivors and health professionals deem information on these topics as useful and needed by young people with cancer. It is clear that despite TYA cancer survivors apathy towards information on smoking and alcohol consumption, efforts to provide young people with cancer with information on these topics should be continued.

The use of psychological theory is widely recognized as a key component of behaviour change interventions (Glanz and Bishop, 2010). Theoretical frameworks are useful as they explain predictors of behaviour and factors which may influence behaviour change; therefore
interventions which clearly articulate how theory has been used to prompt behaviour change provide insight into not only what works but why the intervention may work (Michie et al., 2008). Existing health behaviour change interventions conducted among TYA cancer survivors (Chapter 2) have predominantly been based upon theoretical frameworks which target young peoples’ reflective motivation to initiate health behaviour change. However, factors which prompt initiation of behaviour change (i.e. reflective factors such as intentions and beliefs) do not explain long-term behavioural engagement (Gardner, 2015). In light of this evidence, the contents of the intervention materials developed within this thesis were based upon the theoretical constructs of habit theory (Gardner et al., 2012). Habits do not require reflective motivation and are triggered automatically by conditioned contextual cues. Habit strength is a measure of the automaticity of behavioural repetition and has been used as a proxy for behavioural maintenance in several domains including dietary behaviour (Wiedemann et al., 2014); physical activity (Gardner et al., 2012) and medication adherence (Phillips et al., 2016). In particular the contents of the health behaviour information and behaviour change support tools developed during this PhD were written and designed to support young people to make lasting changes to their lifestyle. Data from studies conducted among Type 2 diabetes patients indicate such interventions which focus on the routinization of behaviour and the removal of structural barriers to long-term behaviour change may be more beneficial than interventions which focus on beliefs or experiential feedback (Phillips et al., 2016). Although the current intervention resources target lifestyle behaviour change it would be possible to adapt the resources to target other behavioural issues among TYA cancer survivors such as non-adherence to medication or poor self-management.

However, critical to health behaviour change intervention outcomes among TYA cancer survivors is further understanding of which BCTs work in what context. Within existing interventions designed for TYA cancer survivors the level of human support and interaction is often poorly defined leading there to be question as to whether factors such as: who is delivering the intervention (e.g. clinician, nurse, researcher, layperson); the purpose of the support (e.g. to provide technical support or to augment the intervention) and what kind of support is being delivered (tailored and individualised or general) affect intervention outcomes. This is important, as TYA cancer survivors motivation and continued engagement with the intervention resources are often heavily mediated by human interactions with the person delivering the intervention (Hollis et al., 2017). This issue is particularly relevant with the increase in remotely delivered digital health interventions for TYA cancer survivors (Pugh and McCann, 2017). Digital health interventions are often promoted as low-cost, sustainable alternatives to standard face-to-face health interventions. However, as discussed within Chapter 7 (Study 3) TYA cancer survivors recognize their need for support from health professionals, parents and friends in making healthy lifestyle choices. With increasing advances in technology (particularly machine learning and artificial intelligence) there is a question as to whether such human support could be delivered via virtual reality where virtual ‘coaches’ ‘mentors’ and ‘agents’ provide personalized and interactive support. Although the
information and behaviour change tools for TYA cancer survivors developed during this PhD are a positive step in improving the support available to young people with cancer, if such resources are to be made available in digital formats harnessing new technologies greater understanding of factors affecting health behaviour intervention engagement and uptake among TYA cancer survivors is needed.

10.3 Limitations

Although the research contained within this thesis has important implications for young people with cancer, there are a number of limitations which should be considered when interpreting the results. The specific limitations of each study have been outlined within the relevant chapter, this section describes some of the common limitations which apply to multiple studies.

10.3.1 Recruitment

Adolescents and young adults are notoriously difficult to recruit to research studies. As TYA cancer survivors account for less than 2% of the total cancer survivor population, the number of young people living with and beyond cancer eligible to participate in TYA specific cancer research is limited. Furthermore, TYA cancer survivors are often juggling multiple demands with school or work, are highly mobile, and geographically dispersed. These factors make recruiting young people with cancer particularly challenging (Cantrell et al., 2012). Moreover, there is evidence that poor research recruitment may be due to ‘professional gatekeeping’ and ‘paternalism’ among health professionals responsible for recruiting participants to research studies (Borschmann et al., 2014) For example, analysis of screening logs from the BRIGHTLIGHT study found 42% of potentially eligible patients had not been approached regarding the study (Taylor et al., 2016).

In an attempt to overcome these factors several recruitment strategies were employed within this thesis. The Health and Lifestyle Questionnaire which was used to gather data for studies 1 and 2 was professionally designed by the visual marketing team at CLIC Sargent and made available in multiple formats which were advertised through several channels. Young people with cancer were offered the opportunity to participate online via the CLIC Sargent website, twitter page and Facebook page. Young people who were members of CLIC Sargents’ young peoples’ reference group and online community page were also invited to take part. CLIC Sargent social workers were given paper copies of the survey to distribute to young people within their care, and were encouraged to sign-post young people towards the online version. Young people receiving care at UCLH were invited to complete either the paper version of the survey or were signposted towards the online version. A prize draw incentive was introduced to encourage participation. Over the course of 15 months in which the survey was open to recruitment a total of 299 young people with cancer took part in the survey. Whilst this sample size is larger than most cross-sectional studies conducted among TYA cancer survivors, a number of factors may have stopped young people from taking part. For example, as described in Chapter 5, the sample of TYA cancer survivors who participated had
predominantly finished cancer treatment and were over the age of 20 years suggesting an individual’s age and stage on the cancer pathway may have impacted their decision to participate. Moreover, it is possible that some young people who were offered the opportunity to participate may have felt that some of the questions were sensitive (particularly those regarding alcohol consumption and smoking) and therefore declined the opportunity to take part. Other barriers to participation may have included cultural factors, lack of time, or mistrust of how the research team would use the results.

Similar factors may have also prevented general population TYAs from filling in the Health and Lifestyle Questionnaire. A similar recruitment strategy to that employed among TYA cancer survivors was used for the general TYA population; the health and lifestyle questionnaire was advertised through multiple channels and available both online or in paper format. The Health and Lifestyle questionnaire was made available online via the UCL research participation pages and was advertised through social media and websites aimed at young people. Several schools were approached regarding handing out paper copies of the survey to young people. Recruitment was incredibly challenging and numerous request to schools went unanswered. This may reflect the increasing demands being placed upon teachers or, akin to the problem with gatekeeping observed among TYA cancer survivors, paternalism among teachers might have led to hesitancy in engaging with research out-with the immediate school environment.

Following the Health and Lifestyle Questionnaire a total number of 93 young people left their contact details expressing an interest in taking part in Study 3. However, very few young people responded to the initial recruitment email. An ethics amendment was made, incentives were introduced, and young people were offered the opportunity of taking part over the phone instead. This improved the recruitment rate marginally. Akin, to the Health and Lifestyle questionnaire, there is potential that not wanting to discuss sensitive issues surrounding their cancer and the health behaviour advice they had received since their diagnosis prevented young people taking part in the qualitative study despite indicating an interest.

TYA cancer care is a distinct professional specialism comprising of a mixture of health professionals from a variety of backgrounds and disciplines. Within Study 4, health professionals who work directly with TYA cancer survivors were recruited via the mailing lists of several UK based professional and charitable bodies specialising in the care of young people with cancer. However, the majority of respondents were nurses. This may be due to the large number of nursing posts funded by Teenage Cancer Trust and CLIC Sargent or could be an indication that TYA cancer nurses have a greater appreciation of the importance of promoting health behaviour among young people with cancer.

10.3.2 Sample Size

The results of this thesis must also be interpreted with a degree of caution due to sample sizes. It is well known the smaller the sample size the narrower the 95% CI and therefore the more imprecise the results (Hackshaw, 2008). Within studies with a small sample the imprecise
estimate of effect makes it harder to distinguish between a real effect and random variation, meaning no firm conclusions can be drawn as the likelihood of Type II statistical errors (incorrect retention of a null hypothesis i.e. a false negative) is increased due to lack of statistical power. Although Study 1 is the largest population based sample of TYA cancer survivors health behaviour, sample size prohibited exploring variation in behaviour by cancer site, time since diagnosis, and treatment received. Similarly, in Study 4 sample size also limited analysis of attributions between profession, length of time caring for TYA cancer survivors and knowledge of health behaviour guidance or the provision of advice. In order to increase the accuracy of the estimates of prevalence the main results of Study 1 and Study 4 include 95% CI.

Chi-square tests were used to establish group differences in studies 1, 2 and 4. The Chi-square statistic is a robust non-parametric test which allows evaluation of dichotomous independent variables and multiple groups (McHugh, 2013). However, the sampling distribution of a chi-square test is an approximate (Field, 2009) as a result within studies where the sample size is small there is chance that the significance tests of chi-square distributions may be inaccurate. Fishers exact test overcomes this limitation by computing the exact probability of the chi-square statistic. In instances where the expected frequency of each cell in a 2x2 chi-square contingency table was less than 5, Fishers Exact Test was reported (Field, 2009). Where the expected frequency of each cell in a 2x3 chi-square contingency table was less than 5, maximum likelihood ratio Chi-square test were reported (McHugh, 2013).

10.3.3 Study Design

As discussed within Chapter 4, it is well recognized that poor intervention design can impede the overall uptake and effect of an intervention. As also outlined within Chapter 4, the development of the health behaviour intervention for TYA cancer survivors within this thesis has been guided by the Behaviour Change Intervention Design Process (Michie et al., 2014) and the 6 Steps to Quality Intervention Design (6SQuiD) (Wight et al., 2015). These frameworks are not dissimilar to one another and place emphasis upon firstly identifying and understanding key behavioural issues (Study 1 of this thesis) and secondly identifying how the behaviour change intervention should be delivered (Studies 2-4 of this thesis). These steps in intervention development are important as they articulate the need for the intervention in the first instance and when and how such an intervention would be best delivered to the target population. Such data ensures the ensuing intervention is not redundant and will be engaging for target users.

However, aside from Study 3 (Chapter 6) which was purely qualitative, much of the data in this thesis were cross-sectional. Ideally, within a cross-sectional study the sample should be representative of the whole population. Although, efforts were made to ensure that TYA cancer survivors of a variety of ages and cancer types could take part, it is somewhat possible that not all were accurately reflected in the sample. Moreover, although associations between variables were explored it is not possible to infer causation. Chapters 7, 8 and 9 of this thesis...
also involved qualitative analysis. Qualitative methodologies are used as a means to gather an in-depth understanding of the populations’ behaviour and viewpoints on certain phenomena. Whilst findings from qualitative research do not represent the whole population of interest given that health behaviour research among TYA cancer survivors is a relatively new field of research with very little existing evidence, it was necessary to gather data on the experiences, thoughts and preferences of young people with cancer and health professionals. Specifically, within Chapters 7, 8 and 9 content analysis of the open responses provided by young people and health professionals enhance the quantitative findings. Although steps (acknowledging bias in sampling, keeping a clear decision trail, and second-coding) were taken to ensure the reliability and validity of these findings, the interpretation of qualitative data is inherently subjective.

10.3.4 Methodology

Although the majority of the survey tools used within this thesis were validated and had been used in previous research, the use of self-report measures is a limitation. The self-reported measures used in this thesis may have resulted in participants providing socially desirable responses. Social desirability bias refers to the phenomenon wherein participants provide answers which they feel are socially desirable rather than accurate responses. Social desirability bias is a particularly relevant within studies exploring sensitive topics such as health behaviour where individuals may feel they are being judged for their lifestyle choices. Moreover, within Study 4, there is possibility that TYA health professionals may also have given socially desirable responses when answering questions on their familiarity with health behaviour guidelines and frequency of health behaviour advice provision. Similarly, within Study 5 there is a possibility that young people and health professionals may ranked their liking as higher as they may have been consciously aware that the results of the survey would be analysed by the same research team who developed the resources.

In addition, the internal validity of Study 1 may also be compromised by response bias. Response bias (sometimes referred to as recall bias or reporting bias) refers to the systematic error caused by participants inaccurately or incompletely recalling events or experiences. As accurate recall is dependent on memory care was taken throughout this thesis to include measures which only included recent recall periods such as ‘over the past week’ or ‘in the past month’. However, in Study 2, participants were asked to recall the advice they had received since their cancer diagnosis, this may have involved recalling an event from over 5 years ago. Similarly, for those undergoing treatment where each day or month is often vastly different from the previous, recall of behaviour over the past week or month may be inaccurate. Objective measures of health behaviour would overcome this issue, however objective measures are expensive and funding was not available.

A major strength of this thesis is the gathering of data from a diverse range of cancer survivors rather than limiting to samples of selected TYA cancer survivors of a specific cancer type, age at diagnosis or cancer stage. However, the external validity of the results from this thesis must
also be given careful consideration. The external validity of a study relies on the assumption that participants who took part are wholly representative of the population from which they were drawn. However, bias can be introduced by selective participation. It is likely that TYA cancer survivors who took part in the research studies contained within this thesis were on average healthier and more engaged in leading a healthy lifestyle than those who did not. Unfortunately, no information is available on non-responders to confirm that they led an unhealthy lifestyle or were less interested in health behaviour advice. Similarly, the findings from Study 4 may have been over-estimated as it is possible that the health professionals who did not take part may have been less interested in health behaviour and therefore less likely to be familiar with health behaviour guidelines for TYA cancer survivors or provide advice on health behaviour to young people within their care.

10.4 Further Research

The high level of interest demonstrated by TYA cancer survivors within this thesis towards health behaviour change support is strongly supportive of proceeding with further work developing the intervention resources and testing their effect. A two-arm pilot randomised controlled trial is planned. However, the efficacy of existing health behaviour interventions conducted among TYA cancer survivors have been undermined by inadequate delivery of the intervention, poor study recruitment, and low participant retention (Pugh et al., 2016). In accordance with the MRC Guide to Complex Intervention Development a series of feasibility and piloting work should be carried out prior to any large scale studies investigating the efficacy and cost-effectiveness of an intervention (Craig et al., 2008). Piloting intervention procedures and estimating recruitment and participant retention ahead of further developments will ensure the overall efficacy of the intervention (and the end results of the larger evaluation study) are not affected by these factors. The outcomes of the proposed pilot trial will therefore include assessing: i) the acceptability of the main trial components (e.g. recruitment procedures, randomization procedures) to TYA cancer survivors ii) TYA cancer survivors engagement with the intervention materials and iii) the feasibility of collecting data high quality data on proposed trial outcomes measures (including objective measures of health behaviour and well-being) among TYA cancer survivors. The results of this pilot trial will be used to refine and modify the intervention materials and study methods ahead of a definitive, large-scale, national, cluster-randomised controlled trial to examine the effects of the intervention on health outcomes and the use of the programme in routine TYA cancer care.

Moreover, as TYA health professionals have demonstrated a lack of confidence and skill in discussing health behaviour change with their patients, there is clear need to develop education and training resources for TYA health professionals. These resources should focus on, and be designed to improve, health professionals understanding of the importance of providing health behaviour information to TYA cancer survivors; knowledge of what advice to

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25 This work will be funded by a 12-month Pan-London research fellowship awarded by The Cancer Vanguard. An overview of the Fellowship proposal is contained in Appendix 10.1
say, how to say it and when to say it; and knowledge of where to signpost patients for more support. As discussed in Chapter 8, education and training resources which encompass the principles of the COM-B model of behaviour change have proven successful at increasing the frequency of delivery of very brief advice (VBA) on physical activity from nurses to adult cancer patients (Webb et al., 2016). However, it is imperative that health behaviour education and training for TYA health professionals is based upon and refers to succinct clinical guidance on the safety and efficacy of health behaviour promotion among young people with cancer. As increasingly recognised clear practical health behaviour guidance for professionals working with TYA cancer patients, (specifically professionals working with patients undergoing treatment and/or experiencing late-effects) is very much needed (Brown et al., 2015).

However, the development of such guidance is reliant upon a robust evidence base indicating health behaviour to play a role in TYA cancer outcomes. Within the UK there are two existing TYA cancer cohorts, the Teenage and Young Adult Cancer Survivor Cohort (TYACSS) and the BRIGHTLIGHT study cohort. Whilst these cohorts are extremely valuable; neither of these cohorts are designed to explore the role of potentially modifiable factors (like health behaviours) in the development or management of toxicities of TYA cancer and treatment. TYACSS provides insight into the incidence of treatment related toxicities and chronic health conditions among TYA cancer survivors and BRIGHTLIGHT is providing insight into the value of specialist TYA cancer services. No studies have identified or investigated the longitudinal relationship between health behaviour and biomarkers of chronic disease or indicators of treatment toxicity following a TYA cancer diagnosis. Prospective cohort studies of newly diagnosed TYA cancer patients are required to investigate the cross-sectional and longitudinal associations between both positive and negative health behaviours and the incidence of negative side-effects of cancer treatment. Such data will provide crucial insight as to whether behaviours such as physical activity, diet, smoking and alcohol consumption are possible intervention targets to prevent or ameliorate the onset of treatment related toxicities and long-term health conditions identified by the TYACSS.

10.5 Final Conclusions

Prior to this thesis, little was known about the lifestyle behaviours of TYA cancer survivors and how best to promote health behaviour change among young people with cancer. This thesis demonstrates inactivity, poor dietary intake, sun exposure and alcohol consumption are prevalent among TYA cancer survivors signifying that health behaviour change interventions are very much necessary. Encouragingly, TYA cancer survivors and TYA health professionals had a high level of interest and support for health behaviour change resources. TYA cancer survivors displayed an interest in health behaviour change interventions which covered multiple topics, addressed issues specific to young people with cancer, and were available and accessible in multiple formats throughout the cancer pathway. These findings have resulted in the development of a set of health behaviour change intervention resources for young people with cancer. Results from the preliminary evaluation indicate both TYA cancer
survivors and health professionals found the intervention resources relevant, appealing and usable. Future planned research aims to evaluate the effect of the intervention resources on health behaviour and the use of the programme in routine clinical care. If the health behaviour change intervention resources are proven to be effective; the health behaviour information and behaviour change support tools developed within this thesis could make a huge contribution to improving the health and well-being of young people with cancer.
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References


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References


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Appendix 4.1 Intervention development frameworks

Medical Research Council Complex Intervention Framework

**Feasibility and Piloting**
- Testing procedures
- Estimating recruitment and retention
- Determining sample size

**Development**
- Identifying the evidence base
- Identifying or developing theory
- Modelling process and outcomes

**Evaluation**
- Assessing effectiveness
- Understanding change process
- Assessing cost effectiveness

**Implementation**
- Dissemination
- Surveillance and monitoring
- Long term follow up

**Identifying the evidence base**
‘You should begin by identifying the relevant, existing evidence base, ideally by carrying out a systematic review’

**Identifying or developing theory**
‘Develop a theoretical understanding of the likely process of change, by drawing on existing evidence and theory, supplemented if necessary by new primary research, for example interviews with ‘stakeholders’, i.e. those targeted by the intervention, or involved in its development or delivery.’

**Modelling process and outcomes**
‘Modelling a complex intervention prior to a full scale evaluation can provide important information about the design of both the intervention and the evaluation.’
### Intervention Mapping Framework (Batholomew et al., 1985)

| Step 1. Logic model of the problem | • Establish and work with a planning group  
• Conduct a needs assessment to create a logic model of the problem  
• Describe the context for the intervention including the population, setting and community  
• State program goals |
|-----------------------------------|------------------------------------------------|
| Step 2. Programs outcomes and objectives: logic model of change | • State expected outcomes for behaviour and environment  
• Specify performance objectives for behavioural and environmental outcomes  
• Select determinants for behavioural and environmental outcomes  
• Construct matrices of change objectives  
• Create a logic model of change |
| Step 3. Program design | • Generate program themes, components, scope and sequence  
• Choose theory- and evidence-based change methods  
• Select or design and practical applications to deliver change methods |
| Step 4. Program Production | • Refine program structure and organization  
• Prepare plans for program materials  
• Draft messages, materials and protocols  
• Pretest, refine, and produce materials |
| Step 5. Program Implementation Plan | • Identify potential program users (implementers, adopters and maintainers)  
• State outcomes and performance objectives for program use  
• Construct matrices of change objectives for program use  
• Design implementation interventions |
| Step 6. Evaluation Plan | • Write effect and process evaluation questions  
• Develop indicators and measures assessment  
• Specify the evaluation design  
• Complete the evaluation plan |

<table>
<thead>
<tr>
<th>PRECEDE phases</th>
<th>PROCEED phases</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 1. Social Diagnosis</strong></td>
<td><strong>Phase 5. Implementation</strong></td>
</tr>
<tr>
<td>Identify and evaluate social problems affecting the quality of life of the target population.</td>
<td>Design and implement the intervention programme.</td>
</tr>
<tr>
<td><strong>Phase 2. Epidemiological, Behavioural &amp; Environmental Diagnosis</strong></td>
<td><strong>Phase 6. Process Evaluation</strong></td>
</tr>
<tr>
<td>Determine specific health issues affecting the community and behavioural factors influencing the social problems identified in phase 1. Analyse wider social and environmental factors influencing the target behaviour.</td>
<td>Determine if the intervention programme has been implemented according to protocol.</td>
</tr>
<tr>
<td><strong>Phase 3. Educational &amp; Ecological Diagnosis</strong></td>
<td><strong>Phase 7. Impact Evaluation</strong></td>
</tr>
<tr>
<td>Identify factors which predispose, enable and reinforce the target behaviour.</td>
<td>Measure the effect of the intervention programme on the intermediate outcomes.</td>
</tr>
<tr>
<td><strong>Phase 4. Administrative &amp; Policy Diagnosis</strong></td>
<td><strong>Phase 8. Outcome Evaluation</strong></td>
</tr>
<tr>
<td>Identify and address policies, resources, and organizational circumstances which could affect the implementation of the intervention programme.</td>
<td>Determine the effect of the intervention programme on the health and health related quality of life of the target population.</td>
</tr>
</tbody>
</table>
**Six Steps in quality intervention development (6SquiD) (Wight et al., 2015)**

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Define and understand the problem and its causes</td>
</tr>
<tr>
<td>2.</td>
<td>Clarify which causal or contextual factors are malleable and have the greatest scope for change</td>
</tr>
<tr>
<td>3.</td>
<td>Identify how to bring about the change: the change mechanism</td>
</tr>
<tr>
<td>4.</td>
<td>Identify how to deliver the change mechanism</td>
</tr>
<tr>
<td>5.</td>
<td>Test and refine on a small scale</td>
</tr>
<tr>
<td>6.</td>
<td>Collect sufficient evidence of effectiveness to justify rigorous evaluation/ implementation</td>
</tr>
</tbody>
</table>
### Behaviour Change Intervention Design Process (Michie et al., 2014)

#### Stage 1. Understand the behaviour

1. Define the problem in behavioural terms
2. Select target behaviour
3. Specify the target behaviours
4. Identify what needs to change

#### Stage 2. Identify intervention options

5. Intervention functions
6. Mode of delivery

#### Stage 3. Identify content & implementation options

7. Behaviour change techniques
8. Policy categories
Appendix 4.2 Study approval letter – UCL ethics 6206/001

UCL RESEARCH ETHICS COMMITTEE
ACADEMIC SERVICES

Dr Abigail Fisher
HBRC
Department of Epidemiology and Public Health
UCL

24 February 2015

Dear Dr Fisher

Notification of Ethical Approval
Project ID: 6206/001: Health behaviour change in teenage and young adult cancer survivors

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been approved by the UCL REC for the duration of the project i.e. until February 2018.

Approval is subject to the following conditions:

1. You must seek Chair’s approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the Amendment Approval Request Form.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events
For non-serious adverse events you will need to inform Helen Dougall, Ethics Committee Administrator (ethics@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Reporting Serious Adverse Events
The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/consolidated comments to the Committee, which includes in particular issues relating to the ethical implications of the research.
With best wishes for the research.

Yours sincerely

Professor John Foreman
Chair of the UCL Research Ethics Committee

Cc:
Gemma Pugh, Applicant
Professor Jane Wardle
Appendix 4.3 Study approval letter – NHS ethics 15/LO/0764

22 May 2015
Dr Abigail Fisher
Health Behaviour Research Centre
1-19 Torrington Place
WC1E 0BT

Dear Dr Fisher

Study title: Health Behaviour Change in Teenage and Young Adult Cancer Survivors
REC reference: 15/LO/0764
IRAS project ID: 178800

Thank you for your letter of 22nd May 2015, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Dr Ashley Totenhöfer, nrescommittee.london-hampstead@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.
Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [http://www.refnum.nhs.uk](http://www.refnum.nhs.uk).

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database. This should be before the first participant is recruited but no later than 8 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@hra.net](mailto:hra.studyregistration@hra.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/RSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites
Appendix 4.3

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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</thead>
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<tr>
<td>Evidence of Sponsor insurance or indemnity (non NHS Sponsorship) [Arthur J Malaguti International]</td>
<td>2.0</td>
<td>14 July 2014</td>
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<tr>
<td>Interview schedules or topic guides for participants [Focus Group Schedule]</td>
<td>2.0</td>
<td>04 March 2015</td>
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<tr>
<td>Letter from funder [Funding Award Letter]</td>
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<td>28 September 2014</td>
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<tr>
<td>Non-validated questionnaire [Health and Lifestyle Questionnaire]</td>
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<tr>
<td>Other [Ethics Response]</td>
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<tr>
<td>Participant consent form [Focus Groups]</td>
<td>2.0</td>
<td>04 March 2015</td>
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<tr>
<td>Participant consent form [Parent and Guardian Assent Form]</td>
<td>2.0</td>
<td>04 March 2015</td>
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<tr>
<td>Participant information sheet (PIS) [Participant Information Sheet, Health and Lifestyle Questionnaire]</td>
<td>3.0</td>
<td>10 May 2015</td>
</tr>
<tr>
<td>Participant information sheet (PIS) [Participant Information Sheet, Focus Groups]</td>
<td>3.0</td>
<td>18 May 2015</td>
</tr>
<tr>
<td>REC Application Form</td>
<td>3.5</td>
<td>19 March 2016</td>
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<tr>
<td>Referee’s report or other scientific critique report [CLIC Sargent Letter]</td>
<td></td>
<td>09 March 2015</td>
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<tr>
<td>Referee’s report or other scientific critique report [NCRI Clinical Studies Sub Group]</td>
<td></td>
<td>09 March 2015</td>
</tr>
<tr>
<td>Research protocol or project proposal</td>
<td>2.0</td>
<td>04 March 2015</td>
</tr>
<tr>
<td>Summary CV for Chief Investigator (CI) [Abigail Fisher]</td>
<td></td>
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<tr>
<td>Summary CV for student [Gemma Pugh]</td>
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<tr>
<td>Summary CV for supervisor (student research) [Jana Warte]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Summary, synopsis or diagram (flowchart) of protocol in non-technical language</td>
<td>1.0</td>
<td>10 February 2015</td>
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</table>

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hr-training/

15/LO/0704 Please quote this number on all correspondence

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

Yours sincerely

Signed on behalf of
Miss Stephanie Ellis
Chair

Email: nrescommittee.london-hampstead@nhs.net

Enclosures: “After ethical review – guidance for researchers”

Copy to: Ms Suzanne Emerton, Joint Research Office
Appendix 4.4 Health and lifestyle questionnaire

HEALTH AND LIFESTYLE QUESTIONNAIRE

CLIC Sargent and, in partnership with University College London, want to increase the support we can provide to all young people with cancer. Our vision includes providing lifestyle advice to teenagers and young adults between the age of 13-24.

This survey includes questions about your health behaviour and how you would like to receive information, support and advice relating to your lifestyle. This study is funded by CLIC Sargent and University College London.

Remember there are no right or wrong answers to any of the questions. Please be as honest as possible when answering. Your answers will be confidential and will not be shared with anyone other than the research team.

If you are struggling to answer any questions please ask for help from a family member, friend or trusted nurse or clinician.

By completing this questionnaire you are consenting to your anonymous information being used for research on lifestyle in young people diagnosed with cancer.

If you have any questions about the study, or need further information, please contact Gemma Pugh on 020 7679 1736 or at gemma.pugh.14@ucl.ac.uk

www.clicsargent.org.uk
### SECTION 1: ABOUT YOU

1. **How old are you?**
   - [ ] Years

2. **What is your gender?**
   - [ ] Female  [ ] Male

3. **What educational or professional qualifications do you currently have? (Please tick all that apply to you)**
   - [ ] GCSE/School certificate
   - [ ] Vocational qualifications (e.g. NVQ1+2)
   - [ ] A-level/Higher school certificate or equivalent (e.g. NVQ3)
   - [ ] Bachelor Degree or equivalent (e.g. NVQ4)
   - [ ] Masters/PhD/PGCE or equivalent
   - [ ] I am still studying
   - [ ] I have no formal qualifications
   - [ ] Other (please specify)

4. **What is your current employment situation?**
   - [ ] Employed full-time
   - [ ] Employed part-time
   - [ ] Self-employed
   - [ ] Unemployed and looking for work
   - [ ] Full-time education
   - [ ] Part-time education
   - [ ] Unable or too ill to work
   - [ ] Voluntary work
   - [ ] Other

5. **What is your current marital status**
   - [ ] I am married/living with partner
   - [ ] I have a girlfriend/boyfriend
   - [ ] I am single
   - [ ] I am divorced
   - [ ] I am separated/widowed
   - [ ] Prefer not to say

6. **Describe your living arrangement**
   - [ ] I live alone
   - [ ] I live with my partner
   - [ ] I live with immediate family (mum/dad/siblings)
   - [ ] I live with other family
   - [ ] I live with friends
   - [ ] I live in residential care
### SECTION 2: YOUR HEALTH

1. Which type of cancer have you been diagnosed with? (Please tick all that apply)
   - Leukaemia
   - Melanoma
   - Lymphoma
   - Bone tumour
   - Carcinoma
   - Soft tissue sarcoma
   - Germ cell tumours
   - Other cancers (please specify)
   - CNS tumours

2. When did you receive your diagnosis? (MM/YY)
   - [ ] Date
   - [ ] Don’t know
   - [ ] I don’t want to answer this

3. At the time of diagnosis what stage was your cancer?
   - [ ] Stage 0
   - [ ] Stage III
   - [ ] Don’t know
   - [ ] Stage I
   - [ ] Stage IV
   - [ ] I don’t want to answer this

4. What treatment(s) have you had for your cancer? (tick all that apply)
   - [ ] Surgery
   - [ ] Hormone therapy
   - [ ] Radiotherapy
   - [ ] Active surveillance
   - [ ] Chemotherapy
   - [ ] None
   - [ ] Other (please give details)
   - [ ] Don’t know
   - [ ] I don’t want to answer this

5. What is your treatment status?
   - [ ] I have not yet started treatment
   - [ ] I am having active cancer treatment (e.g. chemotherapy/radiotherapy/surgery)
   - [ ] I have finished all active cancer treatment (e.g. no longer receiving chemotherapy/radiotherapy/surgery)
   - [ ] I have relapsed - having further active cancer treatment (e.g. further chemotherapy/radiotherapy/surgery)
   - [ ] I am receiving palliative care
   - [ ] Don’t know
   - [ ] I don’t want to answer this
6 Please tick which of the following applies
   □ I am still having active cancer treatment
   □ It is less than 3 months since I finished receiving active cancer treatment
   □ It is between 4 and 11 months since I finished receiving active cancer treatment
   □ It is between 1 and 5 years since I finished receiving active cancer treatment
   □ On active surveillance
   □ Don’t know/can’t remember
   □ I don’t want to answer this

7 Have you had any of the following health problems? (Please tick all that apply)
   □ Osteoporosis
   □ Diabetes
   □ Asthma
   □ Irregular heart rhythm
   □ Extreme fatigue
   □ Mental health problems
   □ Lung disease
   □ Arthritis
   □ Any other heart trouble
   □ Another cancer
   □ Sensory impairment
   □ Other

8 What is your current height?
   _______ inches or _______ cm

9 What is your current weight?
   _______ lbs or _______ kg

10 Is your weight today.....
   □ More than when you were diagnosed with cancer
   □ About the same as when you were diagnosed with cancer
   □ Less than before you were diagnosed with cancer

11 Which of these best describes you at the current time
   □ I think I should be trying to lose weight
   □ I think I should be trying to gain weight
   □ I don’t think I need to change my weight
   □ Don’t know
SECTION 3: HOW ACTIVE ARE YOU?

These questions are about how active you are and how this might have changed since you were diagnosed with cancer.

Here's a few definitions to bear in mind...

- Strenuous exercise is when your heart beats rapidly e.g running, jogging, vigorous swimming, cycling
- Moderate exercise gets your heart rate going but is not exhausting e.g fast walking, easy cycling, easy swimming
- Mild exercise requires minimal effort e.g easy walking, fishing, bowling

1. On average how many times a week do you do the following kinds of exercise for more than 15 minutes during your free time?
   a. Strenuous exercise (hearts beats rapidly) e.g running, jogging, vigorous swimming, cycling
      - Times per week: 
      - Duration of each session: 
      - Hours: 
      - Mins: 
   b. Moderate exercise (not exhausting) e.g fast walking, easy cycling, easy swimming
      - Times per week: 
      - Duration of each session: 
      - Hours: 
      - Mins: 
   c. Mild exercise (minimal effort) e.g easy walking, fishing, bowling
      - Times per week: 
      - Duration of each session: 
      - Hours: 
      - Mins: 

2. During a typical week in your leisure time how often do you engage in any regular activity long enough to work up a sweat (e.g. heart beats rapidly)
   - Often
   - Sometimes
   - Rarely/Never

3. During a typical week in your leisure time how often did you engage in any regular activity long enough to work up a sweat (heart beats rapidly)
   - Before Diagnosis
     - Often
     - Sometimes
     - Rarely/Never
   - During Treatment
     - Often
     - Sometimes
     - Rarely/Never
   - Post Treatment
     - Often
     - Sometimes
     - Rarely/Never
4 Which of these statements do you agree with

☐ I do more physical activity than before I was diagnosed with cancer
☐ I do about the same physical activity as when I was first diagnosed with cancer
☐ I do less physical activity than before I was diagnosed with cancer

5 Which of the following describes you right now

☐ I think I should do more physical activity
☐ I think I should do less physical activity
☐ I don’t need to change my physical activity
☐ Don’t know

These questions are about the time you spend sitting on weekdays while at school or work, at home, and during leisure time. This includes time spent sitting at a desk, visiting friends, reading, traveling on a bus or sitting or lying down to watch television.

6 During the past week how much time did you usually spend sitting on a week day?

☐ Hours per week day
☐ Minutes per week day
☐ Don’t know

7 Over the past month, on average how many hours per day did you sit and watch TV or DVD’s?

☐ Less than 1 hour
☐ 1 hour
☐ 2 hours
☐ 3 hours
☐ 4 hours
☐ 5+ hours
☐ I do not watch TV or video’s

8 Over the past month, on average how many hours per day did you use a computer or play a computer games outside of work or school? Include time spent working at a computer and using playstations, X-box, Nintendo DS, and other portable video games….

☐ Less than 1 hour
☐ 1 hour
☐ 2 hours
☐ 3 hours
☐ 4 hours
☐ 5+ hours
☐ I do not use the computer or play computer games
## SECTION 4: YOUR DIET

These questions are about your diet. They do not cover everything you eat, just a few of the types of foods we are interested in. We know some of these questions are difficult but we would be grateful if you could answer them as best you can.

1. About how many times a week do you eat a serving of the following foods?

<table>
<thead>
<tr>
<th>Food Description</th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pasta, rice, noodles, or cous cous</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potatoes, sweet potatoes, yams, or plantains</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peas</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beans (including kidney), lentils, chickpeas or other pulses</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any other vegetables</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fruit (fresh, frozen, canned, dried)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cheese (any except cottage cheese)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beef (excluding burgers), pork, lamb, or goat</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beef burgers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bacon, ham, salami, hot dogs, or sausages</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chicken or turkey (including nuggets/burgers but not fried versions of these)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fish or shell fish (including tinned and breaded fish but excluding fried/battered fish)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meat alternatives (e.g. eggs, soya, tofu, Quorn but excluding nuts, hummus)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nuts eaten in a meal as an alternative to meat (e.g. nut roast)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fried food (e.g. fried/battered fish or chicken, chips, fried breakfast, samosas, fried rice, bhajis, pilus, fritters)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cakes, pies, puddings, pastries, or Indian sweets</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biscuits, chocolate or savoury snacks (e.g. crisps, sav, Bombay mix, nuts)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coconut milk or coconut cream</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yoghurts, rice puddings, or any other desserts (but not low fat versions)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low fat versions of yoghurts, rice puddings or desserts</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 2. How often do you drink the following?

<table>
<thead>
<tr>
<th></th>
<th>Never/rarely</th>
<th>Once a week</th>
<th>2-3 times a week</th>
<th>4-6 times a week</th>
<th>Once a day</th>
<th>Twice a day</th>
<th>3 or more times a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular squash, cordials, fizzy drinks and juice drinks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sugar-free squash and diet fizzy drinks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pure fruit juice (including from concentrate)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 3. About how many times a week do you have breakfast cereal or porridge?

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than 1 per week</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sugary, Chocolate, Rice or Corn cereals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. Frosted, Fudge, Sugar Puffs, Corn flakes, Nice Crisps, Special K</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Porridge, Ready Brek, Muesli, Multigrain/wheat cereals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. Shredded Wheat, Weetabix, Kivett Wheat, Fruit n Fibre, Just Right, Shreddies, Start, Cheerios, Nutri-Grain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bran cereals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. All-bran, Branflakes, Sultana Bran</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 4. About how many rounded teaspoons of margarine, butter or other spread do you usually use in a day (e.g. on bread, sandwiches, toast, potatoes, vegetables)? NB: One rounded teaspoon is roughly the amount used to cover a slice of bread

<table>
<thead>
<tr>
<th></th>
<th>Total teaspoons per day</th>
<th>Total teaspoons per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Butter (including ‘Lighter’, ‘Spreadable’ and half fat), Ghee or Margarine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. Stocks, Bertolli, Clover, Clover Lighter, I Can’t Believe It’s Not Butter, Flora, Flora Buttery, Flora Pro-activ, Benecol, Vitalite, supermarket own brand olive/sunflower spread</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low fat spread</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. Flora Light, Flora Lighter Than Light, Flora Pro-activ Olive, Flora Pro-activ Light, I Can’t Believe It’s Not Butter Light, own brand olive/sunflower light spread, Bertolli Light, Benecol Light, Clover Lighter Than Light</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5 About how many rounded teaspoons of sugar, honey, or syrup do you usually use in a day (e.g. on coffee, tea, milk, bread, cereals, fruit)?

Total teaspoons per day

6 About how much milk do you yourself use in a day e.g. on cereal or in tea or coffee?

<table>
<thead>
<tr>
<th>None</th>
<th>Less than a quarter-pint per day</th>
<th>About a quarter-pint per day</th>
<th>About a half pint per day</th>
<th>At least 1 pint per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-fat (whole)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Semi-skimmed</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>1% fat</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Skimmed</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Non-dairy (e.g. rice or soya milk)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

7 About how many pieces of bread, rolls, chapatis etc. do you eat on a usual day?

<table>
<thead>
<tr>
<th>None</th>
<th>Less than 1 per day</th>
<th>1-2 per day</th>
<th>3-4 per day</th>
<th>5 or more per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Brown, granary, half and half, seeded, wheatgerm, or oat</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Wholemeal (including wholemeal seeded and wholemeal granary) or whole grain</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

8 Over the past month, how many portions of fruit did you usually eat?

Include fruit eaten at meal times or as a snack. Examples of a serving are 1 apple or banana, a large slice of melon, 2 plums or satsumas, a small bowl of grapes, 2 tablespoons of strained fruit or ½ tablespoon of dried fruit.

- ☐ Less than 1 per week
- ☐ 1 per week
- ☐ 2-3 per week
- ☐ 4-6 per week
- ☐ 2 per day
- ☐ 3 or more per day

9 Over the past month, how many portions of vegetables did you usually eat?

Include vegetables eaten at meal times or as a snack. Examples of a serving are 2 heaped tablespoons of broccoli or carrots, 3 tablespoons of sweetcorn or peas or a bowl of salad. Please do not include potatoes, sweet potatoes or plantains as a vegetable serving.

- ☐ Less than 1 per week
- ☐ 1 per week
- ☐ 2-3 per week
- ☐ 4-6 per week
- ☐ 2 per day
- ☐ 3 or more per day
- ☐ 1 per day
10 Would you say your diet now is...
- [ ] Healthier than before you were diagnosed with cancer
- [ ] About the same as before you were diagnosed with cancer
- [ ] Less healthy than before you were diagnosed with cancer

11 Which of the following best describes you at the present time:
- [ ] I think I should have a healthier diet
- [ ] I don’t think I need to change my diet
- [ ] Don’t know

12 On a typical weekday how often do you have the following meals:

<table>
<thead>
<tr>
<th></th>
<th>1-2 days a week</th>
<th>3-4 days a week</th>
<th>5-6 days a week</th>
<th>Everyday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breakfast</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Lunch</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Dinner</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>
SECTION 5: SUN SAFETY

1. Did you sunbathe regularly last summer to try to get a suntan?
   (By sunbathe, we mean that you stayed out in the sun because you
   wanted your skin to go browner or more golden in colour.)
   □ No
   □ Yes

2. Last summer, did you sunburnt after being in the sun?
   (By sunburnt, we mean that your skin went red or pink due to being out in the sun.)
   □ No, never
   □ Yes, only on one occasion
   □ Yes, on more than one occasion
   □ Don’t know, can’t remember

3. Have you used a sunbed or tanning bed on the
   high street in the last 12 months?
   □ No
   □ Yes, daily
   □ Yes, twice a week
   □ Yes, once a week
   □ Yes, once a fortnight
   □ Yes, monthly
   □ Yes, every 2 or 3 months
   □ Yes, less often than
     every 2 or 3 months
SECTION 6: HOW MUCH DO YOU DRINK?

These questions are about how much alcohol you drink and how this might have changed since you were diagnosed with cancer.

1a How often do you have a drink containing alcohol?

- Never
- Monthly or less
- 2 - 4 times per month
- 2 - 3 times per week
- Every day

This is one unit of alcohol...

...and each of these is more than one unit

<table>
<thead>
<tr>
<th>Unit of Alcohol</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Half pint of regular beer/lager or cider</td>
<td>1.5</td>
</tr>
<tr>
<td>1 small glass of wine</td>
<td>1.5</td>
</tr>
<tr>
<td>1 single measure of spirits</td>
<td>1.5</td>
</tr>
<tr>
<td>1 small glass of sherry</td>
<td>1.5</td>
</tr>
<tr>
<td>1 single measure of spirits</td>
<td>1.5</td>
</tr>
</tbody>
</table>

1b How many units of alcohol do you drink on a typical day when you are drinking?

- I never drink alcohol
- 1-2
- 3-4
- 5-6
- 7-9
- 10+

1c How often have you had 6 or more units (for women), or 8 or more (for men), on a single occasion in the last year?

- Never
- Less than monthly
- Monthly
- Daily or almost daily
- Weekly

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

- More than before you were diagnosed with cancer
- About the same as before you were diagnosed with cancer
- Less than before you were diagnosed with cancer

3 Which of the following best describes you at the present time:

- I think I should drink less alcohol
- I don't think I need to change my alcohol consumption
- Don't know

Health and Lifestyle Questionnaire | Page 13
SECTION 7: HOW MUCH DO YOU SMOKE?

1. Do you currently smoke cigarettes?  
   [ ] Yes   [ ] No

2. If yes, how many cigarettes do you smoke a day?  
   [ ] a day

3. If yes, have you ever tried to quit since you were diagnosed with cancer?  
   [ ] Yes   [ ] No

4. If yes, did you ever try to quit smoking before you were diagnosed with cancer?  
   [ ] Yes   [ ] No

5. If no, in the past did you ever smoke cigarettes regularly? (at least 1 cigarette a day)  
   [ ] Yes   [ ] No

6. Are you currently trying to quit smoking?  
   [ ] Yes   [ ] No
Appendix 4.4

SECTION 8: HOW WELL DO YOU FEEL?

The following questions ask about your energy and sleep patterns.

1. Please circle or mark at least one number to indicate your response as it applies to the past 7 days.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel fatigued</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel weak all over</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel listless (‘washed out’)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel tired</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have trouble starting things because I am tired</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have trouble finishing things because I am tired</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to do my usual activities</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I need to sleep during the day</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am too tired to eat</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I need help doing my usual activities</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am frustrated by being too tired to do the things I want to do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have to limit my social activity because I am tired</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

2. During the past month, what time have you usually gone to bed?

   [ ] : [ ] (HH:MM) [ ] am/pm

3. During the past month, how long (in minutes) has it taken you to fall asleep each night?

   [ ] number of minutes

4. During the past month, when time have you usually gotten up in the morning?

   [ ] : [ ] (HH:MM)

5. During the past month, how many hours of actual sleep did you get a night (This may be different than the number of hours you spent in bed).

   [ ] hours of sleep per night
### Appendix 4.4

6. During the past month, how often have you had trouble sleeping because you....

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannot get to sleep within 30 minutes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wake up in the middle of the night or early morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have to get up to use the bathroom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cough or snore loudly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel too cold</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel too hot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have bad dreams</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other reason(s), please describe, including how often you have had trouble sleeping because of this reason(s):

7. During the past month, how often have you taken medicine (prescribed or over the counter) to help you sleep?

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

8. During the past month, how often have you had trouble staying awake while eating meals, engaging in social activity or while driving?

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

9. During the past month, how much of a problem has it been for you to keep up enthusiasm to get things done?

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

10. During the past month how would you rate your sleep quality overall?

- Very good
- Fairly good
- Fairly bad
- Very bad
11 Under each heading, please tick the one box that best describes your health today.

a Mobility
- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

b Self care
- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

c Usual Activities
- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

d Pain/Discomfort
- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

e Anxiety/Depression
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed
SECTION 9: YOUR THOUGHTS ABOUT LIFESTYLE ADVICE

These questions are about lifestyle advice you received since you were diagnosed with cancer.

Lifestyle is defined as the way in which a person lives. Health behaviours such as exercise, healthy eating, smoking, and alcohol consumption form your lifestyle.

We are not able to ask about all aspects of your life so we have just focused on a few areas. These questions will help us see what support you are getting and whether you feel anything is missing.

1. In the time since you were diagnosed did a health professional (e.g. doctor, nurse, physiotherapist, or dietitian) ever give you any advice about the following topics?
   - Physical activity & exercise  □ Yes □ No
   - Your diet  □ Yes □ No
   - Your weight  □ Yes □ No
   - Your alcohol intake  □ Yes □ No
   - Your smoking habits  □ Yes □ No

   If you answered yes to question 1, please answer questions 2 to 4 and continue with the survey. If you did not receive any lifestyle advice please skip to question 5.

2. If yes, what did they tell you about the following?
   a. Physical activity and exercise

   b. Diet

   c. Your weight

   d. Alcohol intake

   e. Smoking

   [Space for answers]
3. Do you remember who gave you the information about the following? (Please tick all that apply)

<table>
<thead>
<tr>
<th></th>
<th>GP</th>
<th>Oncologist</th>
<th>Surgeon</th>
<th>Dentist</th>
<th>Physiotherapist</th>
<th>Support Worker</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Activity and Exercise</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your Weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol Intake</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. Which of the following best describes the amount of information you received

- [ ] Too much
- [ ] About right
- [ ] Not enough

5. If you were given the opportunity to have more information, advice and support on making lifestyle changes now, would you take up the offer?

- [ ] Yes definitely
- [ ] Probably not
- [ ] Not sure
- [ ] Yes probably
- [ ] Definitely not

6. If you had been given the opportunity to have more information, advice and support on making lifestyle changes at the end of your main treatment, would you have taken up the offer?

- [ ] Yes definitely
- [ ] Probably not
- [ ] Not sure
- [ ] Yes probably
- [ ] Definitely not

7. When do you think would be the best time to offer information about lifestyle (e.g. physical activity) to people diagnosed with cancer?

- [ ] Before treatment starts
- [ ] Immediately after treatment
- [ ] 6-12 months after treatment
- [ ] During treatment
- [ ] 3-5 months after treatment
- [ ] More than 1 year after treatment
- [ ] More than 1 year after treatment
- [ ] 6-12 months after treatment
- [ ] Immediately after treatment
- [ ] Before treatment starts
8. How interested would you be in any information/advice/support to...

<table>
<thead>
<tr>
<th>Options</th>
<th>Not at all interested</th>
<th>A little interested</th>
<th>Somewhat interested</th>
<th>Very interested</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help you to have a healthy diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you to maintain a healthy weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you increase your physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you stop smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you reduce your alcohol consumption</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you adopt an overall healthy lifestyle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

9. Which of the following sources would you most likely turn to for information, advice, and support about the topics below?

<table>
<thead>
<tr>
<th>Sources</th>
<th>Friends</th>
<th>Parents</th>
<th>Printed materials/leaflets</th>
<th>YouTube</th>
<th>Websites online</th>
<th>Telephone helpline</th>
<th>Doctors, nurses, support workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet and nutrition advice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight management advice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information about physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help to stop smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you reduce your alcohol consumption</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you adopt an overall healthy lifestyle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
10 Would you be interested in any of the following formats of information/advice/support about making lifestyle changes?

<table>
<thead>
<tr>
<th>Format</th>
<th>Not at all interested</th>
<th>A little interested</th>
<th>Somewhat interested</th>
<th>Very interested</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short leaflet (up to 5 pages)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Longer leaflet/booklet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>An App for a mobile or tablet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DVD/Video information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telephone call from a health professional</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One individual counselling session</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple individual counselling sessions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One group counselling session</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple group counselling sessions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SECTION 10: YOUR THOUGHTS ABOUT LIFESTYLE AND HEALTH

These questions are about your views on the relationship between lifestyle and health.

1. How important do you think the following are to your health right now

<table>
<thead>
<tr>
<th></th>
<th>Not at all important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Eating a balanced diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not smoking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doing exercise regularly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding alcohol</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating plenty of fruit and vegetables</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding red or processed meat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trying to maintain a healthy weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Looking after my skin in the sun (e.g. wearing sun-screen, and/or wearing a hat, covering up with clothes, or sitting in the shade).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. How important do you think each of the following are to your future health

<table>
<thead>
<tr>
<th></th>
<th>Not at all important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Eating a balanced diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not smoking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doing exercise regularly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding alcohol</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating plenty of fruit and vegetables</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding red or processed meat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trying to maintain a healthy weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Looking after my skin in the sun (e.g. wearing sun-screen, and/or wearing a hat, covering up with clothes, or sitting in the shade).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SECTION 11: A FINAL FEW DETAILS...

Are you currently enrolled in a formal lifestyle programme or trial?

☐ Yes  ☐ No

We are aiming to explore ways of providing health behaviour information and advice to teenagers and young people with cancer. In order to make services as successful as possible we are recruiting teenagers and young people to take part in focus groups and further surveys to help us identify the format, setting, timing and mode of delivery health behaviour information would be most preferred in.

If you think you might be interested in taking part in this next stage of investigation, please leave your contact details below and we will send you further information.

You do not need to commit to taking part at this stage. All information you provide is confidential and will not be shared.

Name

Email

Address

Phone Number

Thank you for taking time to complete this survey, we really appreciate your input.
Appendix 4.5 Participant information sheet (health and lifestyle questionnaire)

University College London Hospitals NHS
NHS Foundation Trust

Health Behaviour Change in Teenage and Young Adult Cancer Survivors
(Student Study)

Health and Lifestyle Questionnaire
PARTICIPANT INFORMATION SHEET

We would like to invite you to participate in some voluntary research on the current lifestyles and health behaviours of teenagers and young adults who have been diagnosed with cancer. This research is being funded by CLIC Sargent and University College London. Before you decide whether to take part it is important for you to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?
The aim of this study is to gather information about the health behaviours of teenage and young adults who have had a diagnosis of cancer.

Why have I been invited?
We would like to design some advice on lifestyle (for example exercise and diet) that can be given to young people who have had cancer. You have been invited to join our study as you are between the age of 13 and 24 years and have been diagnosed with cancer. We would like to gather information on your views about lifestyle advice, for example what you received, or would like to have liked to receive, when, from who and in what format.

What will taking part involve?
You are invited to complete the ‘Health and Lifestyle Questionnaire’. It asks questions about your current health and lifestyle and about the advice you received when you were diagnosed with cancer, as well as what else you might have liked. The survey should take around 15-20 minutes to complete.

At the end of the Health and Lifestyle Questionnaire you will be asked if you’d like to be contacted about taking part in future focus groups aiming to discuss some of the topics contained within the questionnaire. You can also complete the survey without leaving your contact details.

Are there any risks in taking part?

Participant Information Sheet, Health and Lifestyle Questionnaire, Version 3.0
Page 1 of 4
There are no risks associated with completing the survey. The survey can be completed at any time you choose and you can stop at any point.

What will the benefits of value of the research be?
This information is very important to us as it will help us improve the care of young people diagnosed with cancer.

Do I have to take part?
It is up to you to decide if you take part. If you choose not to do so it will not affect your medical care in anyway. You are free to withdraw from the study at any time and do not need to give any reason.

Confidentiality
All information we obtain about you will remain confidential. All the data collected from this study will be locked at by authorised persons from UCL. As participation is anonymous it will not be possible for us to withdraw your data once you have completed and submitted your questionnaire.
Should there be an incident where you or another participant discloses information that would lead a member of the research team to think you were at harm, confidentiality will be broken and concerns will be discussed with Dr Rachael Hough and Wendy King. An appropriate safeguarding action will be subsequently be identified and followed.

What will happen to the results of the study?
Results from the study will be published in peer reviewed journal articles aimed towards clinical academics and health care professionals. Confidentiality and anonymity will be maintained and it will not be possible to identify you from any publications.

All data will be collected and stored in accordance with the Data Protection Act 1998.

Who has reviewed this study?
The trial has been reviewed by the Hampstead Research Ethics Committee

What if there is a problem? or What happens if something goes wrong?
If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your
participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor’s (University College London) or the hospital’s negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Dr Abigail Fisher, who is the Chief Investigator for the research and is based at University College London, Department of Epidemiology and Public Health, Health Behaviour Research Centre. The Chief Investigator will then pass the claim to the Sponsor’s Insurers, via the Sponsor’s office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

**Insurance**

University College London holds insurance against claims from participants for harm caused by their participation in this clinical study. Participants may be able to claim compensation if they can prove that UCL has been negligent. However, if this clinical study is being carried out in a hospital, the hospital continues to have a duty of care to the participant of the clinical study. University College London does not accept liability for any breach in the hospital’s duty of care, or any negligence on the part of hospital employees. This applies whether the hospital is an NHS Trust or otherwise.

Neither the chief investigator of any of the other investigators/ collaborators have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest.

**Whom should I contact about further information?**

If you have any questions about the study or require further information please do not hesitate to contact Gemma Pugh on 020 7679 41736 or at gemma.pugh.14@ucl.ac.uk

**Comments or Concerns**

If you have any comments or concerns you may discuss these with the investigator Dr Abigail Fisher at abigail.fisher@ucl.ac.uk

Thank you for taking the time to read this information sheet. Please keep it for future reference.
What will this study involve?

**Study 1. Health Behaviour Survey**

You receive your survey during your usual visit to clinic. The survey will be available both in paper format or online.

Once you have completed the survey, at the end you will be given the option to leave your contact details.

- If you don’t leave your contact details your anonymous survey answers will be kept for analysis and we will thank you for your time.
- If you choose to leave your contact details you will be invited to take part in our focus groups.

**Study 2. Lifestyle advice for young survivors: focus groups.**

If you indicate that you are interested in participating in focus groups you will be sent an information letter and consent forms. If you are under the age of 16 your parent or guardian will have to provide consent that they are willing for you to take part in these focus groups.

Once you have read through the information we send you about the groups we will then send an invitation for you to attend a focus group.

Focus groups will be organized at a time convenient to you. As a group we will discuss the topics relating to lifestyle and health such as physical activity, diet, smoking and alcohol consumption. We will explore questions such as when the best time to receive information about lifestyle would be and in what format would you like to receive this kind of information.
Appendix 4.6 Ethics amendment 6206/001

### Amendment Approval Request Form

<table>
<thead>
<tr>
<th>1</th>
<th>Project ID Number: 6206/001</th>
<th>Name and Address of Principal Investigator: Dr Abigail Fisher</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Project Title: Health behaviour change in teenage and young adult cancer survivors</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Type of Amendments (tick as appropriate)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☑ Research procedure/protocol (including research instruments)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Participant group</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Sponsorship/collaborators</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Extension to approval needed (extensions are given for one year)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☑ Information Sheets</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Consent forms</td>
<td></td>
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<tr>
<td></td>
<td>☐ Other recruitment documents</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☑ Principal researcher/medical supervisor</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Other *</td>
<td></td>
</tr>
</tbody>
</table>

*Additional to the research team other than the principal researcher, student supervisor and medical supervisor do not need to be submitted as amendments but a complete list should be available upon request.*

### Justification (give the reasons why the amendments are needed)

Since our original submission (which focussed on young cancer survivors) we have become aware that in general little is understood about the health behaviours and lifestyle advice preferences of teenagers and young adults (TYA) aged between 13 and 24 within the UK. Many health promotion efforts have made attempts to engage this hard to reach population. However knowledge regarding the preferences and interest of this age group in health and lifestyle advice is limited, and no studies have compared interest in and preference for, lifestyle advice between TYAs who have had cancer, and their age-matched peers. Therefore, we are interested in replicating the Health and Lifestyle Survey we are conducting in TYA cancer survivors in TYAs within the general population. Our preliminary qualitative work has begun to highlight that TYA survivors may not view themselves as very different from their peers in terms of current lifestyle and we would like to explore this quantitatively.

### Details of Amendments (provide full details of each amendment requested, state where the changes have been made and attach all amended and new documentation)

Minor changes have been made to the health and lifestyle questionnaire (see attached Appendix A, all changes have been highlighted in yellow). We have removed all questions relating to cancer diagnosis and experience of treatment that featured within the original survey but have included a question relating to family history of cancer and other chronic health conditions. Minor amendments have also been made to the participant information sheets to exclude all references to previous cancer diagnosis. The recruitment strategy has also been extended and we will now extend the reach of the questionnaire to
all TYA’s in the UK. The survey will be made available online through social media, online youth networks, and websites directed towards young people. The survey will also be made available to young people through schools, health professionals and community organisations.

Ethical Considerations (insert details of any ethical issues raised by the proposed amendments)
It is not anticipated that any ethical, legal or management issues will arise from the inclusion of additional questions in the proposed study. The amendments made to the health and lifestyle survey were carefully considered by all members of the research team. Due to the nature of the questions it is unlikely that participation in the survey will cause distress. However, to avoid any unnecessary distress, participants will be informed at the beginning of the survey and at the beginning of the subsequent focus groups that they may discontinue their participation in the survey or focus group at any time they wish.

Other Information (provide any other information which you believe should be taken into account during ethical review of the proposed changes)

Declaration (to be signed by the Principal Researcher)
- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendments to be implemented.
- For student projects I confirm that my supervisor has approved my proposed modifications.

Signature: [Name]
Date: 07/07/15

FOR OFFICE USE ONLY:
Amendments to the proposed protocol have been approved by the Research Ethics Committee.

Signature of the REC Chair: [Name]
Date: 13/07/2015
Appendix 4.7 General population TYA survey

TEENAGE AND YOUNG ADULT
HEALTH AND LIFESTYLE QUESTIONNAIRE
TEENAGE AND YOUNG ADULT HEALTH AND LIFESTYLE QUESTIONNAIRE

This survey includes questions about your health behaviour and how you would like to receive information, support and advice relating to your lifestyle.

Remember there are no right or wrong answers to any of the questions. Please be as honest as possible when answering. Your answers will be confidential and will not be shared with anyone other than the research team.

By completing this questionnaire you are consenting to your anonymous information being used for research about the health and lifestyle of young people aged between 13 and 24 years.
### SECTION 1: ABOUT YOU
First of all we would like to know a bit about you?

1. **How old are you?** ______ years

2. **What is your gender?**
   - [ ] Female
   - [ ] Male

3. **What educational or professional qualifications do you currently have?**
   (Please tick all that apply to you)
   - [ ] GCSE/School certificate
   - [ ] Vocational qualifications (e.g. NVQ1+2)
   - [ ] A-level/Higher school certificate or equivalent (e.g. NVQ3)
   - [ ] Bachelor Degree or equivalent (e.g. NVQ4)
   - [ ] Masters/PhD/PGCE or equivalent
   - [ ] I am still studying
   - [ ] I have no formal qualifications

4. **What is your current employment situation?**
   - [ ] Employed full-time
   - [ ] Employed part-time
   - [ ] Self-employed
   - [ ] Unemployed and looking for work
   - [ ] Full-time education
   - [ ] Part-time education
   - [ ] Unable or too ill to work
   - [ ] Voluntary work

5. **What is your current marital status?**
   - [ ] I am married/living with partner
   - [ ] I have a girlfriend/boyfriend
   - [ ] I am single
   - [ ] I am divorced
   - [ ] I am separated/widowed
   - [ ] Prefer not to say

6. **Describe your living arrangement**
   - [ ] I live alone
   - [ ] I live with my partner
   - [ ] I live with immediate family (mum/dad/siblings)
   - [ ] I live with other family
   - [ ] I live with friends
   - [ ] I live in residential care

7. **Which of these best describes your ethnic group?**
   - [ ] White British
   - [ ] White Irish
   - [ ] Any other White (please specify)
   - [ ] Indian
   - [ ] Bangladeshi
   - [ ] Pakistani
   - [ ] Chinese
   - [ ] Any other Asian (please specify)
   - [ ] Mixed White and Black African
   - [ ] Mixed White and Black Caribbean
   - [ ] Mixed White and Asian
   - [ ] Any other mixed (please specify)
   - [ ] Black African
   - [ ] Black Caribbean
   - [ ] Any other Black (please specify)
**SECTION 2: YOUR HEALTH**

1. **Have you ever had any of the following health problems?** (Please tick all that apply)
   - Osteoporosis
   - Diabetes
   - Asthma
   - Irregular heart rhythm
   - Extreme Fatigue
   - Mental Health Problems
   - Lung disease
   - Arthritis
   - Any other heart trouble
   - Cancer
   - Sensory impairment
   - Other
   - I don’t want to answer this question

2. **Do you have a family history of any of the following health problems?**
   - Heart Disease
   - Stroke
   - Diabetes
   - Mental Health Problems
   - Blood Clots
   - Arthritis
   - High Blood Pressure
   - High Cholesterol
   - Any Cancers
   - Yes
   - No
   - If Yes, please give details (e.g. family relation and health problem)

3. **What is your current height?**
   - ft
   - inches
   - cm

4. **What is your current weight?**
   - St
   - lbs
   - kg

5. **Which of the following best describes you at the present time?**
   - I think I should be trying to lose weight
   - I think I should be trying to gain weight
   - I don’t think I need to change my weight
   - Don’t know
SECTION 3: PHYSICAL ACTIVITY

These questions are about how active you are and types of activities you usually carry out.

Here’s a few definitions to bear in mind...
- Strenuous exercise is when your heart beats rapidly e.g running, jogging, vigorous swimming, cycling
- Moderate exercise gets your heart rate going but is not exhausting e.g fast walking, easy cycling, easy swimming
- Mild Exercise requires minimal effort e.g easy walking, fishing, bowling

<table>
<thead>
<tr>
<th>1</th>
<th>On average how many times a week do you do the following kinds of exercise for more than 15 minutes during your free time?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time per week</td>
<td>Duration</td>
</tr>
<tr>
<td>Strenuous exercise (hearts beats rapidly) e.g running, jogging, vigorous swimming, cycling</td>
<td>Hours</td>
</tr>
<tr>
<td>Moderate exercise (not exhausting) e.g fast walking, easy cycling, easy swimming</td>
<td>Hours</td>
</tr>
<tr>
<td>Mild Exercise (minimal effort) e.g easy walking, fishing, bowling</td>
<td>Hours</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2</th>
<th>During a typical week in your leisure time how often do you engage in any regular activity long enough to work up a sweat (e.g. heart beats rapidly)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Often</td>
<td>Sometimes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3</th>
<th>Which of the following describes you right now</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think I should do more physical activity</td>
<td></td>
</tr>
<tr>
<td>I think I should do less physical activity</td>
<td></td>
</tr>
<tr>
<td>I don’t need to change my physical activity</td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
</tr>
</tbody>
</table>

These questions are about the time you spend sitting on weekdays while at school or work, at home, and during leisure time. This includes time spent sitting at a desk, visiting friends, reading traveling on a bus or sitting or lying down to watch television.

<table>
<thead>
<tr>
<th>4</th>
<th>During the past week how much time did you usually spend sitting on a week day?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hours per weekday</td>
<td>Minutes per weekday</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5</th>
<th>Over the past month, on average how many hours per day did you sit and watch TV or DVD's?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 hour</td>
<td>2 hours</td>
</tr>
<tr>
<td>1 hour</td>
<td>3 hours</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6</th>
<th>Over the past month, on average how many hours per day did you use a computer or play a computer games outside of work or school? Include time spent working at a computer and using tablets, iPads, playstations, X-box, Nintendo DS, and other portable video games...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 hour</td>
<td>2 hours</td>
</tr>
<tr>
<td>1 hour</td>
<td>3 hours</td>
</tr>
</tbody>
</table>
## SECTION 4. YOUR DIET

These questions are about your diet. They do not cover everything you eat, just a few of the types of foods we are interested in. We know some of these questions are difficult but we would be grateful if you could answer them as best you can.

1. **About how many times a week do you eat a serving of the following foods?**

<table>
<thead>
<tr>
<th>Food</th>
<th>Less than once a week or never</th>
<th>1–2 per week</th>
<th>3–5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pasta, rice, noodles, or cous cous</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potatoes, sweet potatoes, yams, or plantains</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peas</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beans (including baked, lentils, chickpeas, or other pulses)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any other vegetables</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fruit (fresh, frozen, canned, dried)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cheese (any except cottage cheese)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beef (excluding burgers), pork, lamb, or goat</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beef burgers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bacon, ham, salami, hot dogs, or sausages</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chicken or turkey (including nuggets/burgers but not fried versions of these)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fish or shell fish (including tinned and breaded fish but excluding fried/battered fish)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meat alternatives (e.g. eggs, soya, tofu, Quorn but excluding nuts, hummus)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nuts eaten in a meal as an alternative to meat (e.g. nut roast)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fried food (e.g. fried/battered fish, chips, fried breakfast, samosas, fried rice, bhejies, puris, fritters)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cakes, pies, puddings, pastries, or Indian sweets</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biscuits, chocolate or savoury snacks (e.g. chips, sev, Bombay mix, nuts)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coconut milk or coconut cream</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yoghurts, rice puddings, or any other desserts (but not low fat versions)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low fat versions of yoghurts, rice puddings or desserts</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2 How often do you drink the following?

<table>
<thead>
<tr>
<th></th>
<th>Never/rarely</th>
<th>Once a week</th>
<th>2–3 times a week</th>
<th>4–6 times a week</th>
<th>Once a day</th>
<th>Twice a day</th>
<th>3 or more times a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular squash, cordials, fizzy drinks and juice drinks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sugar-free squash and diet fizzy drinks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pure fruit juice (including from concentrate)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3 About how many times a week do you have the following breakfast cereals or porridge?

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than 1 per week</th>
<th>1–2 per week</th>
<th>3–5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sugary, Chocolate, Rice or Corn cereals (e.g. Frosties, Coco Pops, Sugar Puffs, Corn Flakes, Rice Crispies, Special K)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Porridge, Ready Brek, Muesli, Multigrain/Wheat cereals (e.g. Shredded Wheat, Weetabix, Puffed Wheat, Fruit n Fibre, JustRight, Shreddies, Start, Cheerios, Nutri Grain)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bran cereals (e.g. All-bran, Branflakes, Sultana Bran)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4 About how many rounded teaspoons of margarine, butter or other spread do you usually use in a day (e.g. on bread, sandwiches, toast, potatoes, vegetables)? NB: One rounded teaspoon is roughly the amount used to cover a slice of bread thinly.

<table>
<thead>
<tr>
<th></th>
<th>Total teaspoons per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Butter (including ‘Lighter’, ‘Spreadable’ and half-fat), Ghee or Margarine (e.g. Stork, Bertolli, Clover, Clover Lighter, I Can’t Believe It’s Not Butter, Flora, Flora Buttery, Flora Pro-activ, Benecol, Vitalite, supermarket own brand olive/sunflower spread)</td>
<td></td>
</tr>
<tr>
<td>Low fat spread (e.g. Flora Light, Flora Lighter Than Light, Flora Pro-activ Olive, Flora Pro-activ Light, I Can’t Believe It’s Not Butter Light, own brand olive/sunflower light spread, Bertolli Light, Benecol Light, Clover Lighter Than Light)</td>
<td></td>
</tr>
</tbody>
</table>

5 About how many rounded teaspoons of sugar, honey, or syrup do you usually use in a day (e.g. in coffee, tea, milk, bread, cereals, fruit)?

Total teaspoons per day

---

**TEENAGE AND YOUNG ADULT HEALTH AND LIFESTYLE QUESTIONNAIRE**
### Appendix 4.7

6. **About how much milk do you use in a day (e.g., on cereal and in tea or coffee)?**

<table>
<thead>
<tr>
<th>Option</th>
<th>None</th>
<th>Less than a quarter-pint per day</th>
<th>About a quarter-pint per day</th>
<th>About a half-pint per day</th>
<th>At least 1 pint per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-fat (whole)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Semi-skimmed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1% fat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skimmed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-dairy (e.g., rice or soya milk)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

7. **About how many pieces of bread, rolls, chapatis etc. do you eat on a usual day?**

<table>
<thead>
<tr>
<th>Option</th>
<th>None</th>
<th>Less than 1 per day</th>
<th>1–2 per day</th>
<th>3–4 per day</th>
<th>5 or more per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brown, granary, half and half, seeded, wheatgerm, or oat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wholemeal (including wholemeal seeded and wholemeal granary) or wholegrain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

8. **Over the past month, how many portions of fruit did you usually eat?** Include fruit eaten at meal times or as a snack. Examples of a serving are 1 apple or banana, a large slice of melon, 2 plums or satsumas, a small bowl of grapes, 2 tablespoons of tinned fruit or ½ tablespoon of dried fruit.

<table>
<thead>
<tr>
<th>Option</th>
<th>Less than 1 per week</th>
<th>1 per week</th>
<th>2–3 per week</th>
<th>4–6 per week</th>
<th>1 per day</th>
<th>2 per day</th>
<th>3 or more per day</th>
</tr>
</thead>
</table>

9. **Over the past month, how many portions of vegetables did you usually eat?** Include vegetables eaten at meal times or as a snack. Examples of a serving are 2 heaped tablespoons of broccoli or carrots, 3 tablespoons of sweetcorn or peas or a bowl of salad. Please do not include potatoes, sweet potatoes or plantains as a vegetable serving.

<table>
<thead>
<tr>
<th>Option</th>
<th>Less than 1 per week</th>
<th>1 per week</th>
<th>2–3 per week</th>
<th>4–6 per week</th>
<th>1 per day</th>
<th>2 per day</th>
<th>3 or more per day</th>
</tr>
</thead>
</table>

10. **Which of the following best describes you at the present time?**

- [ ] I think I should have a healthier diet
- [ ] I don’t think I need to change my diet
- [ ] Don’t know

11. **During a typical week how often do you have the following meals?**

<table>
<thead>
<tr>
<th>Meal</th>
<th>1–2 days a week</th>
<th>3–4 days a week</th>
<th>5–6 days a week</th>
<th>Everyday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breakfast</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lunch</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dinner</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### SECTION 5. SUN SAFETY

1. Did you sunbathe regularly last summer to try to get a suntan? (By sunbathe, we mean that you stayed out in the sun because you wanted your skin to go brown or more golden in colour.) (circle only one number)
   - No
   - Yes

2. Last summer, did you get sunburnt after being in the sun? By sunburnt, we mean that your skin went red or pink due to being out in the sun. (circle only one number)
   - No, never
   - Yes, only on one occasion
   - Yes, on more than one occasion
   - Don’t know, can’t remember

3. Have you used a sunbed or tanning bed on the high street in the last 12 months? (circle only one number)
   - No
   - Yes, daily
   - Yes, twice a week
   - Yes, once a week
   - Yes, once a fortnight
   - Yes, monthly
   - Yes, every 2 or 3 months
   - Yes, less often than every 2 or 3 months
SECTION 6. HOW MUCH DO YOU DRINK?
These questions are about how much alcohol you drink and how this might have changed since you were diagnosed with cancer.

1a How often do you have a drink containing alcohol?
- Never
- Monthly or less
- 2–4 times per month
- 2–3 times per week
- 4–5 times per week
- Every day

This is one unit of alcohol...

Half pint of regular beer, lager or cider
1 small glass of wine
1 single measure of spirits
1 small glass of sherry
1 single measure of aperitifs

…and each of these is more than one unit

Pint of regular beer/lager/cider
Pint of premium beer/lager/cider
Alcopop or can/bottle of regular lager
Can of premium lager or strong beer
Can of super strength lager
Glass of wine (175ml)
Bottle of wine

1b How many units of alcohol do you drink on a typical day when you are drinking?
- I never drink alcohol
- 1–2
- 3–4
- 5–6
- 7–9
- 10+

1c How often have you had 6 or more units (for women), or 8 or more (for men), on a single occasion in the last year?
- Never
- Less than monthly
- Monthly
- Weekly
- Daily or almost daily

2 Which of the following best describes you at the present time?
- I think I should drink less alcohol
- I don’t think I need to change my alcohol consumption
- Don’t know

SECTION 7. HOW MUCH DO YOU SMOKE?

1 Do you currently smoke cigarettes? □ Yes □ No

2 If yes, how many cigarettes do you smoke a day? __________ a day

3 If no, in the past did you ever smoke cigarettes regularly? □ Yes □ No

4 Are you currently trying to quit smoking? □ Yes □ No
### SECTION 8. HOW WELL DO YOU FEEL?

The following questions ask about your energy and sleep patterns.

<table>
<thead>
<tr>
<th>1</th>
<th>Please circle or mark at least one number to indicate your response as it applies to the past 7 days.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
</tr>
<tr>
<td>I feel fatigued</td>
<td>0</td>
</tr>
<tr>
<td>I feel weak all over</td>
<td>0</td>
</tr>
<tr>
<td>I feel listless (&quot;washed out&quot;)</td>
<td>0</td>
</tr>
<tr>
<td>I feel tired</td>
<td>0</td>
</tr>
<tr>
<td>I have trouble starting things because I am tired</td>
<td>0</td>
</tr>
<tr>
<td>I have trouble finishing things because I am tired</td>
<td>0</td>
</tr>
<tr>
<td>I have energy</td>
<td>0</td>
</tr>
<tr>
<td>I am able to do my usual activities</td>
<td>0</td>
</tr>
<tr>
<td>I need to sleep during the day</td>
<td>0</td>
</tr>
<tr>
<td>I am too tired to eat</td>
<td>0</td>
</tr>
<tr>
<td>I need help doing my usual activities</td>
<td>0</td>
</tr>
<tr>
<td>I am frustrated by being too tired to do the things I want to do</td>
<td>0</td>
</tr>
<tr>
<td>I have to limit my social activity because I am tired</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2</th>
<th>During the past month, what time have you usually gone to bed?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HH/MM am/pm</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3</th>
<th>During the past month, how long (in minutes) has it taken you to fall asleep each night?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of minutes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4</th>
<th>During the past month, when time have you usually gotten up in the morning?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HH/MM am/pm</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5</th>
<th>During the past month, how many hours of actual sleep did you get a night (This may be different than the number of hours you spent in bed).</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hours of sleep per night</td>
</tr>
</tbody>
</table>

---

**TEENAGE AND YOUNG ADULT HEALTH AND LIFESTYLE QUESTIONNAIRE**
### Appendix 4.7

#### 6 During the past month, how often have you had trouble sleeping because you...

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannot get to sleep within 30 minutes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wake up in the middle of the night or early morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have to get up to use the bathroom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cough or snore loudly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel too cold</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel too hot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have bad dreams</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other reason(s), please describe, including how often you have had trouble sleeping because of this reason(s)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 7 During the past month, how often have you taken medicine (prescribed or over the counter) to help you sleep?

- [ ] Not during the past month
- [ ] Less than once a week
- [ ] Once or twice a week
- [ ] Three or more times a week

#### 8 During the past month, how often have you had trouble staying awake while eating meals, engaging in social activity or while driving?

- [ ] Not during the past month
- [ ] Less than once a week
- [ ] Once or twice a week
- [ ] Three or more times a week

#### 9 During the past month, how much of a problem has it been for you to keep up enthusiasm to get things done?

- [ ] Not during the past month
- [ ] Less than once a week
- [ ] Once or twice a week
- [ ] Three or more times a week

#### 10 During the past month how would you rate your sleep quality overall?

- [ ] Very good
- [ ] Fairly good
- [ ] Fairly bad
- [ ] Very bad
11 Under each heading, please tick the one box that best describes your health today.

a MOBILITY
- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

b SELF CARE
- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

c USUAL ACTIVITIES
- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

d PAIN/DISCOMFORT
- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

e ANXIETY/DEPRESSION
- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed
SECTION 9. YOUR THOUGHTS ABOUT LIFESTYLE ADVICE

Lifestyle is defined as the way in which a person lives. Health behaviours such as exercise, healthy eating, smoking, and alcohol consumption form your lifestyle.

We are not able to ask about all aspects of your life so we have just focused on a few areas. These questions will help us see what support you are getting and whether you feel anything is missing.

1. If you were given the opportunity to have more information and support on making lifestyle changes (such as eating a better diet or being more active) would you take up the offer?
   - Yes definitely
   - Yes probably
   - Probably not
   - Definitely not
   - Not Sure

2. How interested would you be in any information/ advice/ support to...

<table>
<thead>
<tr>
<th>Support Provided</th>
<th>Not at all interested</th>
<th>A little interested</th>
<th>Somewhat interested</th>
<th>Very interested</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help you to have a healthy diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you to maintain a healthy weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you increase your physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you stop smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you reduce your alcohol consumption</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you adopt an overall healthy lifestyle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 4.7

#### 3 Which of the following sources would you most likely turn to for information, advice, and support about the topics below?

<table>
<thead>
<tr>
<th>Sources</th>
<th>Friends</th>
<th>Parents</th>
<th>Printed Materials eg leaflets</th>
<th>YouTube</th>
<th>Websites Online</th>
<th>Telephone Helpline</th>
<th>Doctors, nurses or support workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet and Nutrition advice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight Management advice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information about physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help to stop smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you reduce your alcohol consumption</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you adopt an overall healthy lifestyle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 4 Would you be interested in any of the following formats of information/advice/support about making lifestyle changes?

<table>
<thead>
<tr>
<th>Formats</th>
<th>Not at all interested</th>
<th>A little interested</th>
<th>Somewhat interested</th>
<th>Very interested</th>
<th>Very interested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short leaflet (up to 5 pages)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Longer leaflet/booklet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internet information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>An App for a mobile or tablet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DVD/Video information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telephone call from a health professional</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One individual counselling session</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple individual counselling sessions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One group counselling session</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple group counselling sessions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## SECTION 10. YOUR THOUGHTS ABOUT LIFESTYLE AND HEALTH

These questions are about your views on the relationship between lifestyle and health.

### 1 How important do you think the following are to your health right now.

<table>
<thead>
<tr>
<th>Not at all important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Eating a balanced diet</td>
<td></td>
</tr>
<tr>
<td>Not smoking</td>
<td></td>
</tr>
<tr>
<td>Doing exercise regularly</td>
<td></td>
</tr>
<tr>
<td>Avoiding alcohol</td>
<td></td>
</tr>
<tr>
<td>Eating plenty of fruit and vegetables</td>
<td></td>
</tr>
<tr>
<td>Avoiding red or processed meat</td>
<td></td>
</tr>
<tr>
<td>Trying to maintain a healthy weight</td>
<td></td>
</tr>
<tr>
<td>Looking after my skin in the sun (e.g. wearing sun-screen, and/or wearing a hat, covering up with clothes, or sitting in the shade).</td>
<td></td>
</tr>
</tbody>
</table>

### 2 How important do you think each of the following are to your future health.

<table>
<thead>
<tr>
<th>Not at all important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Eating a balanced diet</td>
<td></td>
</tr>
<tr>
<td>Medical check-ups/screening</td>
<td></td>
</tr>
<tr>
<td>Not smoking</td>
<td></td>
</tr>
<tr>
<td>Taking dietary supplements (e.g., vitamins)</td>
<td></td>
</tr>
<tr>
<td>Doing exercise regularly</td>
<td></td>
</tr>
<tr>
<td>Avoiding alcohol</td>
<td></td>
</tr>
<tr>
<td>Eating plenty of fruit and vegetables</td>
<td></td>
</tr>
<tr>
<td>Trying to maintain a healthy weight</td>
<td></td>
</tr>
<tr>
<td>Avoiding red or processed meat</td>
<td></td>
</tr>
<tr>
<td>Looking after my skin in the sun (e.g. wearing sun-screen, and/or wearing a hat, covering up with clothes, or sitting in the shade).</td>
<td></td>
</tr>
</tbody>
</table>
## SECTION 11. TECHNOLOGY QUESTIONS

1. Which of the following devices do you own? (Please tick all that apply)
   - [ ] Smartphone
   - [ ] iPod
   - [ ] Smart watch
   - [ ] MP3 Players
   - [ ] Television
   - [ ] Tablet (iPad, Nexus, Amazon Fire)
   - [ ] Other (Please specify):

2. On average, how many hours per day do you use one or more of the technology devices that you own? _______ hours

3. What device(s) would you most commonly use to carry out the following activities?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Device(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Networking Sites</td>
<td>e.g. Laptop, smartphone</td>
</tr>
<tr>
<td>e.g. Facebook, Bebo, MySpace</td>
<td></td>
</tr>
<tr>
<td>Social Media</td>
<td></td>
</tr>
<tr>
<td>e.g. Instagram, Twitter, Snapchat</td>
<td></td>
</tr>
<tr>
<td>Periscope</td>
<td></td>
</tr>
<tr>
<td>Instant messaging</td>
<td></td>
</tr>
<tr>
<td>e.g. Whatsapp, Skype, Facetime</td>
<td></td>
</tr>
<tr>
<td>News Websites</td>
<td></td>
</tr>
<tr>
<td>e.g. BBC News, Buzzfeed</td>
<td></td>
</tr>
<tr>
<td>Blogs</td>
<td></td>
</tr>
<tr>
<td>e.g. Bloglovin’, Imgur</td>
<td></td>
</tr>
<tr>
<td>Short video websites</td>
<td></td>
</tr>
<tr>
<td>e.g. Youtube, Vine</td>
<td></td>
</tr>
<tr>
<td>Watch TV Online</td>
<td></td>
</tr>
<tr>
<td>e.g. Netflix, i-Player, 4OD</td>
<td></td>
</tr>
<tr>
<td>Music Websites</td>
<td></td>
</tr>
<tr>
<td>e.g. i-Tunes, google play, soundcloud, spotify</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td></td>
</tr>
<tr>
<td>e.g. Hotmail, Gmail, Yahoo, Outlook</td>
<td></td>
</tr>
</tbody>
</table>
4 List the top 5 Apps on your phone that you use most often. Put number 1 as the app you use most.

1
2
3
4
5

5 Which social networks do you use? (Tick all that apply)

☐ Facebook  ☐ Twitter  ☐ Pinterest  ☐ Tumblr
☐ Google+  ☐ Instagram  ☐ Flickr  ☐ Vine
☐ Other (Please specify) ____________________________________________________________

6 Do you use technology to track your health behaviour? (step counter, calorie counter, diet planner)

☐ Yes  ☐ No  If yes, what app or device do you use to track your health behaviour? ________________

7 Number each of the following in order of how important it is to you. (Put number 1 next to the most important, number 2 next to the second most important, and so on…)

Rank
Looking physically attractive
Learning a new skill
Doing well at school
Staying fit and healthy
Making new friends
Having fun and enjoying yourself
Saving money
Getting the latest technology

8a If you were looking for information about the following topics online which website would you go to?

Health Behaviour  Website
Physical Activity
Diet
Weight Loss
Smoking
Drinking Alcohol
Sun Safety

Page 18
Appendix 4.7

8b When looking for health information online what technology device do you use to search? e.g. I-Pad, Computer, Smartphone

---

9 We are aiming to develop an app to support young people to lead a healthier lifestyle. The app will be designed to motivate and support you to achieve healthy lifestyle goals such as being more active or eating a healthier diet. Please indicate your level of interest in the following app features:

<table>
<thead>
<tr>
<th>Feature</th>
<th>1 Not at all interested</th>
<th>2 A little interested</th>
<th>3 Neutral</th>
<th>4 Somewhat interested</th>
<th>5 Very interested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on the benefits of a healthy lifestyle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information on the risks of an unhealthy lifestyle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Goal setting feature e.g. a feature which allows you to make up your own lifestyle goal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behaviour tracking e.g. a feature which tracks the number of steps taken per day or number of calories burned.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personalised feedback on your lifestyle choices e.g. feedback on the health benefits of a specific amount of physical activity or the consequences of drinking a certain amount of alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Photo feedback feature e.g. Feature providing progress photos of weight loss</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reminders to reach a selected goal e.g. Daily pop up reminders to eat your 5 a day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rewards for effort or achievements e.g. Earning points for achieving a certain goal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instructions on how to perform specific behaviours e.g. Instructions on certain exercises or recipes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BMI calculator</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short videos</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network forums e.g. opportunity to post messages and talk to other young people about healthy lifestyles</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Please turn over to the final page >>
SECTION 11. A FINAL FEW DETAILS...

Thank you for completing the health and lifestyle survey. If you would like to be entered into a prize draw to win online shopping vouchers please enter your contact details below. There will be three prize draws, 1st draw winning £50, 2nd draw winning £30, and 3rd draw winning £15.

Name

Email

Address

Phone number
Appendix 4.8 Participant information sheet (General population TYAs)

Exploring the Lifestyle and Technology Use Behaviours of Teenagers and Young Adults
Student Study

I would like to invite you to participate in some voluntary research about the lifestyle of teenagers and young adults. This research is being funded by CLIC Sargent and University College London. Before you decide whether to take part it is important for you to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

The aim of this study is to gather information about the health behaviours of teenage and young adults and to gather information about how lifestyle information should be given to young people. We would like to gather information on your views views about lifestyle advice, for example what information you would like on topics like physical activity, healthy diets and sun-safety and how you would like to be given this information. We would also like to know whether you would like any information on the health benefits of not smoking or drinking alcohol.

Why have I been invited?

We would like to design some advice on lifestyle (for example exercise and diet) that can be given to young people. You have been invited to join our study as you are between the age of 13 and 24 years of age and we are interested in your opinions.

What will taking part involve?

You are invited to complete the ‘Health and Lifestyle Questionnaire’ online. It asks questions about your current health and lifestyle and how you would like to receive information about these topics. The survey should take around 15-20 minutes to complete.

At the end of the Health and Lifestyle Questionnaire you will be asked if you’d like to be contacted about taking part in future focus groups aiming to discuss some of the topics contained within the questionnaire. You can also complete the survey without leaving your contact details.
Appendix 4.8

Are there any risks in taking part?
There are no risks associated with completing the survey online, the survey can be completed at any time you choose and you can stop at any point.

What will the benefits of value of the research be?
This information is very important to us as it will help us design a lifestyle intervention for teenagers and young adults aged between 13 and 24 years old. You will also have the option of entering a prize draw for Amazon vouchers if you choose to participate.

Do I have to take part?
It is up to you to decide if you take part. You are free to withdraw from the study at any time and do not need to give reason.

Confidentiality
All information we obtain about you will remain confidential. All the data collected from this study will be looked at by authorised persons from UCL. As participation is anonymous it will not be possible for us to withdraw your data once you have completed and submitted your questionnaire.

What will happen to the results of the study?
Results from the study will be published in peer reviewed journal articles aimed at academics and health researchers. Confidentiality and anonymity will be maintained and it will not be possible to identify you from any publications.

All data will be collected and stored in accordance with the Data Protection Act 1998.

Whom should I contact about further information?
If you have any questions about the study or require further information please do not hesitate to contact Gemma Pugh on 020 7679 41736 or at gemma.pugh.14@ucl.ac.uk

Comments or Concerns
If you have any comments or concerns you may discuss these with Dr Abigail Fisher at abigail.fisher@ucl.ac.uk
Thank you for taking the time to read this information sheet. Please keep it for future reference.
Appendix 4.9 Parent information sheet and consent form

Parent Information Sheet

Exploring The Lifestyle and Technology Use Behaviours of Teenagers and Young Adults
Student Study

Your child will soon be invited to participate in some voluntary research about the health behaviours of teenagers and young adults. This research is being funded by CLIC Sargent and University College London. Before you and your child decide whether to take part it is important for you to read the following information carefully and discuss it with others if you wish. Please get in contact with your child’s school or a member of the research team if there is anything that is not clear or if you would like more information.

What is the purpose of this study?
The aim of this study is to gather information about the health behaviours of teenagers and young adults aged between 13 – 24 years. We would like to gather information on your child’s views about lifestyle advice, for example what information they would like on topics like physical activity, healthy diets and sun-safety and how they would like to be given this information. We would also like to know whether they’d like any information on the health benefits of not smoking or drinking alcohol.

Why have has my child been invited to take part?
Your child has been invited to join our study as they are teenager or young adult aged between 13 and 24 years.

What will taking part involve?
Your child will be invited to complete the ‘Health and Lifestyle Questionnaire’ during school hours. The survey will ask questions about their current health and lifestyle and how they would like to receive information about these topics. The survey should take around 15-20 minutes to complete during allocated school time.

Are there any risks in taking part?
There are no risks associated with completing the survey. the survey will be completed during allocated school time. Your child will be given the opportunity to choose to take part or not and can also choose to stop at any point.

What will the benefits of value of the research be?
This information is very important to us as it will help us design a healthy lifestyle programme for teenagers and young adults aged between 13 and 24 years old.

Does my child have to take part?
It is up to you and your child to decide to take part in the study. Your child is free to withdraw from the study at any time and they do not need to give reason.

Confidentiality
All information we obtain about your child will remain confidential. All the data collected from this study will be looked at by authorised persons from UCL. As participation is anonymous it will not be possible for us to withdraw your child’s data once they have completed and submitted their questionnaire.

University College London, Gower Street, London WC1E 6BT
Tel: +44 (0)20 7679 2000
email@ucl.ac.uk
www.ucl.ac.uk
What will happen to the results of the study?
Results from the study will be published in peer reviewed journal articles aimed towards clinical academics and health care professionals. Confidentiality and anonymity will be maintained and it will not be possible to identify you from any publications.

All data will be collected and stored in accordance with the Data Protection Act 1998.

Whom should I contact about further information?
If you have any questions about the study or require further information please do not hesitate to contact Gemma Pugh on 020 7679 1736 or at gemma.pugh.14@ucl.ac.uk

Comments or Concerns: If you have any comments or concerns you may discuss these with the principal investigator Dr Abigail Fisher at abigail.fisher@ucl.ac.uk. Thank you for taking the time to read this information sheet. Please keep it for future reference.
PARENTAL CONSENT FORM

Exploring the lifestyle and technology use behaviours of teenagers and young adults study

To be completed by a parent or guardian who DOES NOT AGREE to their child taking part in the lifestyle and technology use survey at their child's school. By not submitting this form you are consenting to your child taking part in the study named above.

Name of Researchers:

Please tick boxes if you agree with the following:

1. I confirm that I have read and understand the information sheet dated…………………… for the above study and have had the opportunity to ask questions.

2. I DO NOT wish my child to take part in the above study

Please use BLOCK CAPITALS

Your Name ........................................................................................................................................

Child's full name................................................................................................................................

Child's school .........................................................................................................................................

..............................................................................................................................................................

Signature of Parent/Guardian Date of signature
Appendix 4.10 Participant information sheet (Interviews and focus groups)

DEPARTMENT OF EPIDEMIOLOGY
& PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE

INFORMATION SHEET

Health Behaviour Change in Teenage and Young Adult Cancer Survivors (Student Study)

Lifestyle Advice for Teenage and Young Adult Cancer Survivors: Focus Groups and Interviews

We would like to invite you to participate in some voluntary research aiming to explore how lifestyle advice should be delivered to young people who have had a cancer diagnosis. This research is being funded by CLIC Sargent and involves researchers from University College London. Before you decide whether to take part it is important for you to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

The purpose of this study is to identify the type of lifestyle advice young people would like and how best to provide this kind of advice. We are interested to know your experience of asking for or receiving advice about physical activity, diet, smoking and alcohol and how you think this advice should be given out. We hope that this will guide the design and development of a 'best practice' health behaviour intervention for teenage and young adult cancer survivors. We hope that this will enable us to improve the long-term health of teenagers and young people between the age of 13 and 24 who have been diagnosed with cancer.

Why have I been invited?

You have been invited to join our study as you are between 13 and 24 years old and have received a cancer diagnosis.

What will taking part involve?

You will be invited to attend a group meeting of other people your age who are also cancer survivors or if you would prefer you also have the option to schedule a one-to-one interview.

Participant Information Sheet, Focus Groups. Version 4.0 (26/08/15)
Page 1 of 5
with a member of the research team. The interview can either be face-to-face or over the phone. The purpose of the focus group/interview is to try and understand how best to design a lifestyle intervention for teenage and young adult cancer survivors. You will be asked questions about the kind of information about physical activity, diet, smoking and drinking you have received in the past and the kind of advice you would like in the future. The information learned in the focus group/interview will be used to develop interventions designed to encourage a healthy lifestyle amongst teenagers and young adults. Focus groups will typically comprise of around 4-6 people of similar age to yourself; you will be also be asked open ended questions about lifestyle intervention format, timing and delivery. Your responses to questions will be kept anonymous.

Are there any disadvantages in taking part?
A possible disadvantage of taking part is the inconvenience of having to travel to participate in the focus group or face-to-face interview. However all your travel expenses for this journey will be fully reimbursed upon the presentation of appropriate receipts. A potential disadvantage of participating in the telephone interview will be the time spent speaking on the phone, however interviews can be scheduled to take place at a time that suits your schedule.

What will the benefits of value of the research be?
This information is very important to us as it will help us improve the care of young people diagnosed with cancer.

Do I have to take part?
It is up to you to decide if you take part. If you choose not to do so it will not affect your medical care in anyway. You are free to withdraw from the study at any time and do not need to give reason.

Confidentiality
All information we obtain about you will remain confidential. All the data collected from this study will be looked at by authorised persons from UCL. Should there be an incident where you or another participant discloses information that would lead a member of the research team to think you were at harm, confidentiality will be broken and concerns will be discussed with Dr Rachael Hough and Wendy King. An appropriate safeguarding action will be subsequently be identified and followed.

What will happen to the results of the study?
Participant Information Sheet. Focus Groups. Version 4.0 (28/08/15)
Page 2 of 5
Results from the study will be published in peer reviewed journal articles aimed towards clinical academics and health care professionals. Confidentiality and anonymity will be maintained and it will not be possible to identify you from any publications.

All data will be collected and stored in accordance with the Data Protection Act 1998.

What if there is a problem? or What happens if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor’s (University College London) or the hospital’s negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Dr Abigail Fisher, who is the Chief Investigator for the research and is based at University College London, Department of Epidemiology and Public Health, Health Behaviour Research Centre. The Chief Investigator will then pass the claim to the Sponsor’s Insurers, via the Sponsor’s office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Insurance

University College London holds insurance against claims from participants for harm caused by their participation in this clinical study. Participants may be able to claim compensation if they can prove that UCL has been negligent. However, if this clinical study is being carried out in a hospital, the hospital continues to have a duty of care to the participant of the clinical study. University College London does not accept liability for any breach in the hospital’s duty of care, or any negligence on the part of hospital employees. This applies whether the hospital is an NHS Trust or otherwise.

Neither the chief investigator of any of the other investigators’ collaborators have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest.

Participant Information Sheet. Focus Groups. Version 4.0 (26/08/15)
Page 3 of 5
Whom should I contact about further information?
If you have any questions about the study or require further information please do not hesitate to contact Gemma Pugh on 020 7679 1736 or at gemma.pugh.14@ucl.ac.uk.

Comments or Concerns
If you have any comments or concerns you may discuss these with the investigator Dr Abigail Fisher at abigail.fisher@ucl.ac.uk.
Thank you for taking the time to read this information sheet. Please keep it for future reference.
What will this study involve?

**Study 2. Lifestyle advice for young survivors: focus groups/ interviews**

Once you have read through the information and confirmed that you are interested in taking part we will send you an invitation for you to attend a focus group or you will be invited to schedule an interview with a member of the research team.

Focus groups and interviews will be organized at a time and/or location convenient to you.

**Focus Groups**

The focus group will be made up of 4-6 other young people who have also had a cancer diagnosis.

As a group we will discuss the topics relating to lifestyle and health such as physical activity, diet, smoking and alcohol consumption. We will explore questions such as when the best time to receive information about lifestyle would be and in what format would you like to receive this kind of information.

**Interviews**

The interview will be conducted over the telephone or face to face.

One to one with a member of the research team you will be invited to share your opinion and experiences about topics relating to lifestyle and health such as physical activity, diet, smoking and alcohol consumption. We will explore questions such as when the best time to receive information about lifestyle would be and in what format would you like to receive this kind of information.

Information gathered in the group discussion and interviews will help guide the development of information resources to encourage a healthy lifestyle among teenage and young adult cancer survivors.

*Please note. That if you are under the age of 16 your parent or guardian will have to provide consent that they are willing for you to take part in a focus group.*
Appendix 4.11 Consent form: interview and focus group study

DEPARTMENT OF EPIDEMIOLOGY
& PUBLIC HEALTH
HEALTH BEHAVIOUR RESEARCH CENTRE

Participant ID number:

Study title: Health Behaviour Change in Teenage and Young Adult Cancer Survivors
(Student Study)
Lifestyle Advice for Teenage and Young Adult Cancer Survivors: Focus Groups/Interview

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 6206/001 and Hampstead Research Ethics Committee Ref. 15LO/0764
Thank you for your interest in taking part in this research. Before you agree to take part, the
person organising the research must explain the project to you. If you have any questions
arising from the Information Sheet or explanation already given to you, please ask the
researcher before you to decide whether to join in.

You will be given a copy of this Consent Form to keep and refer to at any time.

1. I confirm that I have read and understood the information sheet
dated 26/08/15 Version 4.0 for the above study and have had the
opportunity to ask questions. I have the opportunity to consider the
information, ask questions and have had these questions answered
satisfactorily.

2. I understand that my participation in this study is voluntary and that I
am free to withdraw at any time and without giving any reason and
without my medical care or legal rights being affected.

3. I understand that such information will be treated as strictly
confidential and handled in accordance with the provisions of the

4. I agree that the research project named above has been explained
to me to my satisfaction and I agree to take part in this study.

Name of Participant __________________________ Date __________ Signature __________________________

Name of Person taking consent __________________________ Date __________ Signature __________________________

Contact details of researcher:
Dr. Abigail Fisher
Health Behaviour Research Centre
Department of Epidemiology and Public Health
University College London
3-19 Torrington Place

Consent Form, Focus Groups/Interview, Version 3.0. (26/08/15)
Page 1 of 2
Appendix 4.12 Focus group and interview schedule

**Aim:** To explore Teenage and Young Adult Cancer Survivors views about lifestyle and how they would like to receive such advice.

**Introductions & House-keeping**

- Introduce self and the aim of the group meeting.
- Check the length of the session is okay for everyone.
- Highlight fire exits and where the bathrooms are.
- Remind participants that discussion is confidential and that views shared within the group should not be discussed outside the room.
- Remind participants to say their name before they speak so we can identify who is talking and when.
- Remind participants that if they wish to leave at any time they are free to do so.
- Check everyone is okay and comfortable.

<table>
<thead>
<tr>
<th>Participant Introductions</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>'Can you please tell us your name, age, your cancer diagnosis and what treatments you are currently or have previously received'</td>
<td>- When diagnosed&lt;br&gt;- Type of cancer&lt;br&gt;- Treatment&lt;br&gt;- Recovery</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lifestyle</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>'What is a healthy lifestyle to you?'</td>
<td>- Healthy eating&lt;br&gt;- Physical Activity&lt;br&gt;- Alcohol &amp; Smoking&lt;br&gt;- Sun Safety</td>
</tr>
<tr>
<td>'Have any of you ever tried to change your health behaviour since your diagnosis with cancer - What changes did you make?'</td>
<td>- Where you successful?&lt;br&gt;- Did you feel supported to make these changes?</td>
</tr>
<tr>
<td>What challenges have you faced when you have tried to change your lifestyle?</td>
<td>- Barriers&lt;br&gt;- Lack of support?&lt;br&gt;- Time?&lt;br&gt;- Health?</td>
</tr>
<tr>
<td>'Have any of you ever been given advice about lifestyle from a health professional, what did they tell you?'</td>
<td>- Healthy eating&lt;br&gt;- Physical Activity&lt;br&gt;- Alcohol &amp; Smoking&lt;br&gt;- Sun Safety</td>
</tr>
<tr>
<td>'What kind of information would you like to receive about lifestyle?'</td>
<td>- Healthy eating&lt;br&gt;- Physical Activity&lt;br&gt;- Alcohol &amp; Smoking&lt;br&gt;- Sun Safety</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sources of information</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>'Has anyone ever tried to go and find information out for themselves - Where did you look, what did you find?'</td>
<td>- Online&lt;br&gt;- Social workers&lt;br&gt;- App&lt;br&gt;- Good experience/ bad experience</td>
</tr>
<tr>
<td>Did anyone assist you in finding out this information?</td>
<td>- Parent&lt;br&gt;- Sibling/ Friend&lt;br&gt;- Social Worker</td>
</tr>
<tr>
<td>Delivery</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>‘When do you think lifestyle advice should be given to young people who have had a cancer diagnosis’</td>
<td>Before treatment, post treatment, at late effects clinic</td>
</tr>
<tr>
<td>‘Who would you want to talk to about this kind of information?’</td>
<td>Social Worker, Doctor, Nurse, Parent, Trusted Friend</td>
</tr>
<tr>
<td>How do you think information should be given out?</td>
<td>Online, Internet, Leaflet, Group counselling, App</td>
</tr>
<tr>
<td>Where should this information be made available?</td>
<td>Internet (home), in clinics (hospital), by social workers (in the community)</td>
</tr>
<tr>
<td>What do you think about setting goals or keeping a log?</td>
<td>Suggest other BCT, Self-help manual?</td>
</tr>
<tr>
<td>How should information look?</td>
<td>Small bitesize pieces of information, Lists, Facts, Instructions, Pictures</td>
</tr>
<tr>
<td>How would you feel about participating in a group programme?</td>
<td></td>
</tr>
<tr>
<td>What are your thoughts about an app to support behaviour change?</td>
<td>Good/ Bad, Explore why</td>
</tr>
<tr>
<td>Do you have any advice for us as we develop and design a lifestyle intervention for young people who have had a cancer diagnosis.</td>
<td></td>
</tr>
</tbody>
</table>

**Conclusion**
- Anything else?
Appendix 4.13 Ethics amendment – UCL ethics 4556/001

UCL RESEARCH ETHICS COMMITTEE

Amendment Approval Request Form

1. Project ID Number: 4455/001

2. Project Title: Health behaviour advice to cancer survivors: the perspective of health professionals

3. Type of Amendment(s) (tick as appropriate)
   - Research procedure/protocol (including research instruments)
   - Participant group
   - Sponsorship/In-kind assistance
   - Extension to approval needed (extensions are given for one year)
   - Information Sheets
   - Consent forms
   - Other recruitment documents
   - Principal researcher/medical supervisor
   - Other

4. Justification (give the reasons why the amendments are needed)
   Teenage and young adult (TYA) cancer nursing and care has emerged as a distinct specialism. Thirteen designated age-appropriate facilities, an identified TYA workforce, and a specialist TYA multidisciplinary team. Young people who had had a cancer diagnosis have expressed a desire for lifestyle advice from health professionals. However, it is understood that TYA health professionals current practice with CLIC Sargent, a young peoples cancer charity in the UK and have identified a gap in the provision of lifestyle advice to young people who have had a cancer diagnosis and will help highlight issues of concern. We wish to expand the reach of this survey to UK based oncology professionals (including medical and surgical oncologists and cancer nurse specialists) who specifically work with TYA cancer patients. To be eligible to participate health professionals must now be in a position where they work directly with cancer patients who are between 13 and 24 years of age. CLIC Sargent have expressed an interest in disseminating the survey to health professionals affiliated with and working for the charity. We have also made the decision to include two extra questions at the end of the survey. In addition we have also included these responses will identify gaps in the provision of lifestyle advice to young people who have had a cancer diagnosis and will help highlight issues of concern. A question asking if the health professional works in a TYA principal treatment centre or a TYA designated hospital will feature a question asking participants how they have been in their current role as a TYA specialist. These questions will be asked to highlight issues of concern. It is not anticipated that any ethical, legal or management issues will arise from the inclusion of additional questions in the proposed study. The addition of the extra questions by the proposed amendments was carefully considered by all members of the research team. Due to the nature of the questions it is unlikely that participation in the survey will cause distress.
### Appendix 4.13

<table>
<thead>
<tr>
<th>7</th>
<th>Other Information (provide any other information which you believe should be taken into account during ethical review of the proposed changes)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Declaration (to be signed by the Principal Researcher)</td>
</tr>
<tr>
<td></td>
<td>- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.</td>
</tr>
<tr>
<td></td>
<td>- I consider that it would be reasonable for the proposed amendments to be implemented.</td>
</tr>
<tr>
<td></td>
<td>- For student projects I confirm that my supervisor has approved any proposed modifications.</td>
</tr>
<tr>
<td></td>
<td>Signature:</td>
</tr>
<tr>
<td></td>
<td>Date: 15/04/15</td>
</tr>
</tbody>
</table>

**FOR OFFICE USE ONLY:**

Amendments to the proposed protocol have been **approved** by the Research Ethics Committee.

Signature of the REC Chair, Professor John Foreman

Date: 16/4/2015
Appendix 4.14 Health professionals survey

TYA Health Professionals Survey

We would like to invite you to complete this brief survey about your views on lifestyle advice (e.g. on physical activity, diet, smoking) for young people diagnosed with cancer. Your responses will help inform the development of an intervention to improve the lifestyle behaviour of teenage and young adult cancer survivors.

This survey contains a maximum of 24 questions and should take no longer than 10 minutes to complete. All questions will require a response but if the question is not relevant to you, please type N/A.

To be eligible to take part you must meet the following criteria:

- Be a cancer specialist or work with cancer patients (e.g. haematologist, oncologist, nurse or allied health professional)
- Currently be in a position where you are working directly with cancer patients who are between 13 and 39 years of age.
- Work in the UK

If you would like to take part please continue to the next page. You are free to withdraw at any time without giving reason.

All data will be collected and stored in accordance with the Data Protection Act 1998 and will not be shared or used for any purpose. This study has been approved by the UCL Research Ethics Committee.

If you would like more information please contact the research team using the contact details below. We can provide you with a summary of our findings on request.

Research Team
Gemma Pugh
Professor Jane Wardle
Dr Abigail Fisher
Helen Gravestock (CLIC Sargent)
Wendy King
Dr Rachael Hough

Research Team Contact
Gemma Pugh
Department of Epidemiology and Public Health
University College London
1-19 Torrington Place
TYA Health Professionals Survey

Thank you for your interest in taking part in this research. If you have any questions arising from the information on the previous page, please contact Gemma Pugh at gemma.pugh.14@ucf.ac.uk

We need to request formal consent so please read the following statements and check the box below if you agree to take part

1. I have read the study information on the previous page and understand what it involves

2. I understand that if I decide at anytime that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately

3. I consent to the processing of my personal information for the purposes of this research study

4. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998

5. I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

* 1. I have read the above statements and I agree to complete the survey
   ○ I agree
**TYA Health Professionals Survey**

* 2. What age range best describes the young people you care for?
   - [ ] 13-24
   - [ ] 18-39

* 3. What percentage of your patients are within each age range?

<table>
<thead>
<tr>
<th>Age Range</th>
<th>&lt;10%</th>
<th>10-25%</th>
<th>26-50%</th>
<th>51-75%</th>
<th>&gt;75%</th>
</tr>
</thead>
<tbody>
<tr>
<td>13-18 years</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>19-24 years</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>25-30 years</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>30+ years</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

I don’t care for young people in this age range

* 4. How long have you been working with young people with cancer?

[ ]
TYA Health Professionals Survey

5. What is your profession?
   - Physician
   - Surgeon
   - Nurse
   - Social Worker
   - Allied Health Professional
   - Other (please specify)

6. What is your job title? (E.g. Consultant Medical Oncologist, Clinical Nurse Specialist)

7. How long have you been in your current role for?

8. Which group of cancer patients do you work with? Please select all that apply
   - All cancer sites
   - Lymphoma
   - Leukaemia
   - Germ Cell Tumours
   - Central Nervous System Tumours
   - Melanoma
   - Bone Tumour
   - Soft Tissue Sarcoma
   - Carcinoma
   - Other (please specify)
### TYA Health Professionals Survey

**9. Are you familiar with any guidelines specifically for cancer patients for any of the following lifestyle topics? Please select all that apply.**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical activity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight Management</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drinking Alcohol</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sun Safety</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**10. Do you remember the name of the guidelines (or who produced them)? Please give details if you can.**


<table>
<thead>
<tr>
<th>Topic</th>
<th>None</th>
<th>0-25%</th>
<th>25-50%</th>
<th>51-75%</th>
<th>&gt;75%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Activity</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Diet</td>
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<tr>
<td>Weight Management</td>
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<tr>
<td>Smoking</td>
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<tr>
<td>Drinking Alcohol</td>
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<tr>
<td>Sun Safety</td>
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</tbody>
</table>
Appendix 4.14

TYA Health Professionals Survey

12. Thinking of all your patients who have completed primary treatment for cancer, with what percentage do you enquire about the following lifestyle topics?

*By enquire we mean asking patients directly about their lifestyle e.g asking 'Do you smoke?' or 'Are you regularly active?*

<table>
<thead>
<tr>
<th>Topic</th>
<th>None</th>
<th>0-25%</th>
<th>26-50%</th>
<th>51-75%</th>
<th>&gt;75%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td></td>
<td></td>
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<tr>
<td>Weight Management</td>
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<tr>
<td>Smoking</td>
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<tr>
<td>Drinking Alcohol</td>
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<td></td>
</tr>
<tr>
<td>Sun Safety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
13. Again thinking of all your patients who have completed primary treatment for cancer, with what percentage do you give specific advice about the following lifestyle topics? e.g referring them to someone else or giving them specific information?

<table>
<thead>
<tr>
<th>Topic</th>
<th>None</th>
<th>0-25%</th>
<th>26-50%</th>
<th>51-75%</th>
<th>&gt;75%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Activity</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Diet</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Weight Management</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Smoking</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Drinking Alcohol</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Sun Safety</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
### TYA Health Professionals Survey

**14. If you do give advice on the following lifestyle topics, what form does this advice take?**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Verbal Advice</th>
<th>Written advice (leaflet/pamphlet)</th>
<th>Refer to website</th>
<th>Refer to another health professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating a healthy diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintaining a healthy weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quitting smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reducing alcohol consumption</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sun Safety</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other (please specify)

---

**15. Can you remember which resources (e.g. the name or brand of website/leaflet) you use when giving young people specific advice about their lifestyle?**
TYA Health Professionals Survey

16. Would any of the following factors put you off giving your patients advice about their lifestyle?
   Please tick all that apply

- [ ] Lack of time
- [ ] Lack of patient interest
- [ ] Not being the right person to give advice
- [ ] Patient to frail/unwell
- [ ] Felt I was being judgmental of their choice
- [ ] Lack of clear guidelines
- [ ] Not convinced it would affect cancer outcomes
- [ ] Don't think advice would change their behaviour
- [ ] None of the above
- [ ] Other (please specify):
## TYA Health Professionals Survey

**17. Would you be interested in a resource containing relevant lifestyle information that you could give to your patients?**
- [ ] Yes
- [ ] No

**18. From your experience which format do you think patients would like lifestyle information to be in? Please tick all that apply**
- [ ] Leaflet/ pamphlet
- [ ] Website
- [ ] Mobile App
- [ ] Other (please specify) [ ]

**19. From your experience at which time point during the cancer care pathway do you think young people should first be offered lifestyle advice?**
- [ ] Before treatment
- [ ] During treatment
- [ ] 0-6 months post treatment
- [ ] 6-12 months post treatment
- [ ] 12+ months post treatment
26. Would you perceive any problems in providing any of these resources or information about lifestyle to your patients?

☐ Yes
☐ No
* 21. Please give details of any problems you perceive.
### TYA Health Professionals Survey

**22. Do you work in**
- [ ] Principal treatment centre
- [ ] TYA designated hospital
- [ ] Other (please specify)

**23. Which region of the UK do you work in?**
- [ ] North East England
- [ ] North West England
- [ ] Yorkshire and the Humber
- [ ] East Midlands
- [ ] West Midlands
- [ ] East of England
- [ ] London
- [ ] South East England
- [ ] South West England
- [ ] Wales
- [ ] Scotland
- [ ] Northern Ireland
- [ ] Channel Islands
* 24. We are planning on developing a lifestyle intervention that could be given to cancer patients at the end of primary treatment. Would you be willing for us to contact you in the future about the possibility of being involved with this? For example short interviews regarding topics discussed in this survey, or the design and piloting of such an intervention?

☐ Yes
☐ No
## TYA Health Professionals Survey

25. Please provide your contact details:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td></td>
</tr>
<tr>
<td>Email Address</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 4.15 Study approval letter – UCL ethics 6206/003

30th November 2016

Dr Abigail Fisher
HBRC, UCL Department of Epidemiology and Public Health

Dear Dr Fisher

Notification of Ethical Approval
Re: Ethics Application 6206/003: Development and user evaluation of lifestyle intervention resources for teenage and young adult cancer survivors

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the REC until 30th November 2017.

Approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair’s approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the ‘Amendment Approval Request Form’:
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

Yours sincerely

Professor John Foreman
Chair, UCL Research Ethics Committee

Cc: Gemma Pugh & Dr Sarah Jackson

Academic Services, 1-19 Torrington Place (9th Floor),
University College London
Tel: +44 (0)20 3109 8216
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/
Appendix 4.16 TYA cancer survivor participant information sheet (Study 5)

Development and User Evaluation of Lifestyle Intervention
Resources for Teenage and Young Adult Cancer Survivors

PARTICIPANT INFORMATION SHEET
TYA Cancer Survivors

Researchers from the Health Behaviour Research Centre, University College London, in partnership with CLIC Sargent, want to increase the support available to young people with cancer. Together we have developed a collection of resources about physical activity, diet, drinking, smoking, alcohol consumption and sun safety for young people with cancer.

We would like to invite you to evaluate these resources ahead of any further developments. We want to know how useful you would find these resources and if you have any suggestions for how they could be improved.

You are invited to complete the ‘user-evaluation’ survey. There are two parts to this evaluation survey: Part A, Lifestyle Information Evaluation and Part B, Lifestyle Intervention Materials Evaluation. We would like to know how useful and appealing you find the lifestyle information and whether you would use the intervention resources.

At the end of the survey you will be invited to leave your contact details to participate in a short telephone interview to discuss how you think the intervention resources could be shaped for further use. The telephone interview will be arranged for a date and time that suit you best.

If you choose to participate, you will also have the option of entering a prize draw for Amazon vouchers.

If there is anything that is not clear or you have any questions about the study please contact Gemma Pugh on 020 7679 1736 or at gemma.pugh.14@ucl.ac.uk. It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

All information we obtain about you will remain confidential. All the data collected from this study will be looked at by authorised persons from UCL. As participation is anonymous, it will not be possible for us to withdraw your data once you have completed and submitted your questionnaire.

Results from the study will be published in peer-reviewed journal articles aimed at academics and health researchers. Confidentiality and anonymity will be maintained and it will not be possible to identify you from any publications.

All data will be collected and stored in accordance with the Data Protection Act 1998.

If you have any comments or concerns you may discuss these with Dr Abigail Fisher at abigail.fisher@ucl.ac.uk
Appendix 4.17 TYA health professionals participant information sheet (Study 5)

Development and User Evaluation of Health Behaviour Change
Intervention Resources for Teenage and Young Adult Cancer Survivors

PARTICIPANT INFORMATION SHEET
TYA Health Professionals

Researchers from the Health Behaviour Research Centre, University College London, with support from CLIC Sargent, want to increase the health behaviour support available to young people with cancer. Together we have started to develop some information on physical activity, diet, drinking, smoking, alcohol consumption and sun safety for young people who have had cancer diagnosis.

We would like to invite you to tell us what you think about this information before we go any further.

You are invited to complete a ‘user-evaluation’ survey. There are two parts to this evaluation survey: Part A. Lifestyle Information Evaluation and Part B. Intervention Resources Evaluation. We would like to know how useful and appealing you find the lifestyle information and whether you would use the intervention resources. The survey will take about 20 minutes to complete.

At the end of the survey you will be given the choice to submit your answers without leaving any of your personal details or you can choose to leave your contact details to participate in a short telephone interview to discuss how you think the intervention resources could be changed and what you liked or didn’t like about the intervention resources. The telephone interview will be arranged for a date and time that suit you best.

Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information.

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

If you have any questions about the study, or need further information, please contact Gemma Pugh on 020 7679 1736 or at gemma.pugh.14@ucl.ac.uk
All information we obtain about you will remain confidential. All the data collected from this study will be looked at by authorised persons from UCL. As participation is anonymous it will not be possible for us to withdraw your data once you have completed and submitted your questionnaire.

Results from the study will be published in peer reviewed journal articles aimed at academics and health researchers. Confidentiality and anonymity will be maintained and it will not be possible to identify you from any publications.

All data will be collected and stored in accordance with the Data Protection Act 1998.

If you have any comments or concerns you may discuss these with Dr Abigail Fisher at abigail.fisher@ucl.ac.uk

Thank you for taking the time to read this information sheet. Please keep it for future reference.
Appendix 4.18 User evaluation of lifestyle intervention resources for teenage and young adult cancer survivors questionnaire

TYA Cancer Survivors Survey

**Section 1. About You**

First of all we would like to know a bit about you.

1. How old are you?
2. What is your gender? Female ☐ Male ☐
3. What educational or professional qualifications do you currently have? (Please tick all that apply to you?)
   - GCSE/School certificate ☐
   - Vocational qualifications (e.g. NVQ1+2) ☐
   - A-level/Higher school certificate or equivalent (e.g. NVQ3) ☐
   - Bachelor Degree or equivalent (e.g. NVQ4) ☐
   - Masters/PhD/PGCE or equivalent ☐
   - I am still studying ☐
   - I have no formal qualifications ☐
   - Other (please specify) ☐

4. What is your current employment situation?
   - Employed full-time ☐
   - Employed part-time ☐
   - Self-employed ☐
   - Unemployed and looking for work ☐
   - Full-time education ☐
   - Part-time education ☐
   - Unable or too ill to work ☐
   - Voluntary work ☐
   - Other ☐

5. Describe your living arrangement
   - I live alone ☐
   - I live with my partner ☐
   - I live with immediate family (mum/dad/siblings) ☐
   - I live with other family ☐
   - I live with friends ☐
   - I live in residential care ☐
6. Which best describes your ethnic group?

<table>
<thead>
<tr>
<th></th>
<th>White British</th>
<th>Indian</th>
<th>Mixed White and Black African</th>
<th>White Irish</th>
<th>Bangladeshi</th>
<th>Mixed White and Black Caribbean</th>
<th>Any other White (please specify)</th>
<th>Pakistani</th>
<th>Mixed White and Asian</th>
<th>Black African</th>
<th>Chinese</th>
<th>Any other mixed (please specify)</th>
<th>Black Caribbean</th>
<th>Any other Asian (please specify)</th>
<th>Black Caribbean</th>
<th>Any other black (please specify)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>


Section 2. Your Health

Next, we’d like to know a little about the cancer you have been diagnosed with and the treatment you have received...

1. Which type of cancer have you been diagnosed with? (Please tick all that apply)
   - Lymphoma
   - Carcinoma
   - Germ Cell tumours
   - CNS tumours
   - Leukaemia
   - Melanoma
   - Bone Tumour
   - Soft Tissue Sarcoma
   - Other Cancers
   - If other (Please Specify) __________
   - I don’t know
   - I don’t want to answer this question

2. When did you receive your diagnosis?
   ______/_______ (month/year)  I don’t know

3. At the time of diagnosis what stage was your cancer?
<table>
<thead>
<tr>
<th>Stage 0</th>
<th>Stage I</th>
<th>Stage II</th>
<th>Stage III</th>
<th>Stage IV</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>❑</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. What treatment(s) have you had for your cancer? (tick all that apply)
   - Surgery
   - Radiotherapy
   - Chemotherapy
   - Hormone therapy
   - Active surveillance
   - None
   - I’m not sure
   - Other (please give details) __________
   - I don’t want to answer this question

5. What is your treatment status?
   - I have not yet started treatment
   - I am having active cancer treatment (e.g. chemotherapy/ radiotherapy/ surgery)
   - I have finished all active cancer treatment (e.g. no longer receiving chemotherapy/ radiotherapy/ surgery)
   - I have relapsed – having further active cancer treatment (e.g. further chemotherapy/ radiotherapy/ surgery)
   - I am receiving palliative care
   - I don’t want to answer this question

6. Please tick which of the following applies
I am still having active cancer treatment
It is less than 3 months since I finished receiving active cancer treatment
It is between 4 and 11 months since I finished receiving active cancer treatment
It is between 1 and 5 years since I finished receiving active cancer treatment
On active surveillance
I don’t want to answer this question
Don’t know/ can’t remember

7. Have you had any of the following health problems? (Please tick all that apply)

<table>
<thead>
<tr>
<th>Osteoporosis</th>
<th>Lung Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>Arthritis</td>
</tr>
<tr>
<td>Asthma</td>
<td>Any other heart trouble</td>
</tr>
<tr>
<td>Irregular Heart Rhythm</td>
<td>Another Cancer</td>
</tr>
<tr>
<td>Extreme Fatigue</td>
<td>Sensory impairment</td>
</tr>
<tr>
<td>Mental Health Problems</td>
<td>Other</td>
</tr>
<tr>
<td>I don’t know</td>
<td>I don’t want to answer this question</td>
</tr>
</tbody>
</table>
Section 3a. Your thoughts on the written information

[Health Behaviour Information Pages (PART A)]

1. Please rate the quality of the information on [insert topic]
   a) Very good quality
   b) Good quality
   c) Neither high or low quality
   d) Low quality
   e) Very low quality

2. How useful is this information on [insert topic] to you?
   a) Very useful
   b) Quite useful
   c) Neither useful or unhelpful
   d) Unhelpful
   e) Very unhelpful

3. Do you think young people with cancer need this kind of information?
   a) Yes, very much
   b) Yes
   c) Neither yes or no
   d) No
   e) No, this information is irrelevant

4. How do you think the information on [insert topic] could be improved? (Open response)
### Section 3b. Your thoughts on the written information

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Partly</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is it clear what the information is about?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Do you understand the language used?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Is the information the right level for you?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Does the information engage you as a reader?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Is the information written in a tone which you think is respectful (i.e. non-judgemental)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. To what extent do the resources cover all of the information that you require about each of the following topics?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Not at all</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Physical Activity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol Consumption</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Habit Formation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Rate how much you liked each of the following aspects of the information

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Dislike 1</th>
<th>Thought it was okay 3</th>
<th>Liked Aloat 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on the benefits of a healthy lifestyle</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information on the risks of an unhealthy lifestyle</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The 'ideas for everyday change' sections</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information about forming new habits</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. What further information would you like to see included about each of the following topics?

<table>
<thead>
<tr>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Activity</td>
</tr>
<tr>
<td>Diet</td>
</tr>
<tr>
<td>Weight Management</td>
</tr>
<tr>
<td>Smoking</td>
</tr>
<tr>
<td>Alcohol Consumption</td>
</tr>
<tr>
<td>Sun Safety</td>
</tr>
</tbody>
</table>
Section 4. Intervention Resources
[Intervention Resource Pages, PART B]

1. How appealing do you find the idea of [insert behaviour change technique]?
   a) Very appealing
   b) Quite appealing
   c) Not appealing
   d) Not at all appealing

2. For each health behaviour listed below, how likely are you to [insert behaviour change technique]?

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Not at all likely</th>
<th>Maybe</th>
<th>Very Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Activity &amp; Exercise</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol Consumption</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sun Safety</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section 5. The Intervention as a whole

1. Number each of the following intervention features in order of how much you liked it.
   (Put number 1 next to the feature you liked the most, number 2 next to the one you like second best, and so on....)

<table>
<thead>
<tr>
<th>Feature</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>The goal-setting tools</td>
<td></td>
</tr>
<tr>
<td>The Healthy Life Action Plan</td>
<td></td>
</tr>
<tr>
<td>The self-monitoring tools</td>
<td></td>
</tr>
<tr>
<td>The automated prompt messages</td>
<td></td>
</tr>
<tr>
<td>The feedback on your behaviour feature</td>
<td></td>
</tr>
<tr>
<td>The Peer-support forum</td>
<td></td>
</tr>
</tbody>
</table>

2. Would you recommend these intervention resources to other young people with cancer?
   No, Not at all | Maybe | Definitely, Yes
   1             | 3     | 5

3. If the intervention resources were available for you to use today, how likely would you be to use them?
   a. Extremely likely
   b. Very likely
   c. Somewhat likely
   d. Not so likely
   e. Not at all likely

4. When do you think would be the best time to offer these resources on leading a healthy lifestyle to young people diagnosed with cancer.
   a. Before treatment starts
   b. During treatment
   c. Immediately after treatment
   d. 3-5 months after treatment
   e. 6-12 months after treatment
   f. More than 1 year after treatment

5. Do you think the intervention resources would be effective at helping you to...

<table>
<thead>
<tr>
<th>Activity</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be more active</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have a healthier diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quit smoking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limit your alcohol consumption</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve you sun safe behaviours</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6. Which of information resources would you be most likely to use? (Please only select one)

<table>
<thead>
<tr>
<th>Leaflets</th>
<th>Website</th>
<th>App</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

7. What did you like most about the intervention resources?

8. What did you dislike most about the intervention resources?

9. What improvements would you make to the intervention resources?

10. Would you be interested in taking part in a study looking at the effects of the intervention resources on young peoples’ health behaviour?

   f. Yes, very interested
   g. Maybe
   h. No, not interested
Section 1. About You

First, before you review the intervention resources, we would like to know a bit about you.

1) What is your gender?
2) What is your age?
3) What is your profession?
   a. Physician
   b. Surgeon
   c. Nurse
   d. Allied Health Professional (Please Specify)
   e. Social Worker
   f. Other
4) What age range best describes the young people you care for?
   a. 13-24
   b. 18-39
5) In general what is the average age of your patients?
6) Do you work in
   a. Principal Treatment Centre
   b. TYA Designated Hospital
   c. Other
7) What region of the UK do you work in?
   a. North East England
   b. North West England
   c. Yorkshire and the Humber
   d. East Midlands
   e. West Midlands
   f. East of England
   g. London
   h. South East England
   i. South West England
   j. Wales
   k. Scotland
   l. Northern Ireland
   m. Channel Islands
8) What group of cancer patients do you work with? Please select all that apply.
   a. All cancer sites
   b. Lymphoma
c. Leukaemia
d. Germ Cell Tumours
e. Central Nervous System Tumours
f. Melanoma
g. Bone Tumour
h. Soft Tissue Sarcoma
i. Carcinoma
j. Other

9) How long have you been in your current role for?

10) From your experience at which time point during the care pathway do you think patients should be offered lifestyle advice?
   a. Before Treatment
   b. During treatment
   c. 0-6 months post treatment
   d. 6-12 months post treatment
   e. 12+ months post treatment
   f. Throughout treatment

11) Which best describes your ethnic group?

<table>
<thead>
<tr>
<th></th>
<th>White British</th>
<th>Indian</th>
<th>Mixed White and Black African</th>
<th>White Irish</th>
<th>Bangladeshi</th>
<th>Mixed White and Black Caribbean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any other white (please specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black African</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Any other mixed (please specify)</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Any other Asian (please specify)</td>
</tr>
<tr>
<td>Any other black (please specify)</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
**Section 2a. Your thoughts on the written information**

**[Health Behaviour Information Pages –PART A]**

*At the bottom of each information section:*

1. Please rate the quality of the information on [insert topic]
   - a) Very good quality
   - b) Good quality
   - c) Neither high or low quality
   - d) Low quality
   - e) Very low quality

2. How useful do you think the information on [insert topic] is to young people who have had cancer?
   - a) Very useful
   - b) Quite useful
   - c) Neither useful or unhelpful
   - d) Unhelpful
   - e) Very unhelpful

3. Do you think young people with cancer need this kind of information?
   - a) Yes, very much
   - b) Yes
   - c) Neither yes or no
   - d) No
   - e) No, this information is not relevant

4. How do you think the information about [insert topic] could be improved? (Open response)

**Section 2b. Your thoughts on the written information**

<table>
<thead>
<tr>
<th>Yes</th>
<th>Partly</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is it clear what the information is about?</td>
<td>☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>2. Do you think the language used is appropriate for young people with cancer?</td>
<td>☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>3. Is the information short and concise?</td>
<td>☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>4. Will the information be engaging for young people?</td>
<td>☐ ☐ ☐</td>
<td></td>
</tr>
<tr>
<td>5. Is the information written in a tone which you think is appropriate for young people?</td>
<td>☐ ☐ ☐</td>
<td></td>
</tr>
</tbody>
</table>
1. For each health behaviour topic, rate the extent to which the resources cover all of the information young people with cancer require.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol Consumption</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Habit Formation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Rate how much you liked each of the following aspects of the information

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Dislike 1</th>
<th>Thought it was okay 3</th>
<th>Liked A lot 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on the benefits of a healthy lifestyle</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information on the risks of an unhealthy lifestyle</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The ‘ideas for everyday change’ sections</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Space to write down ideas which might work for you</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information about forming new habits</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. What further information would you like to see included about each of the following topics?

- Physical Activity
- Diet
- Weight Management
- Smoking
- Alcohol Consumption
- Sun Safety

**Section 4. Intervention Resources**

[Intervention Resource Pages – PART B]

1. How appealing do you think young people with cancer will find the idea of [insert behaviour change technique]?
   a) Very appealing
   b) Quite appealing
   c) Not appealing
   d) Not at all appealing
Appendix 4.18

Section 5. The Intervention as a whole

1. How much did you like each of the following features?

<table>
<thead>
<tr>
<th></th>
<th>Dislike</th>
<th>Thought it was okay</th>
<th>Liked A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>The goal-setting tools</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The Healthy Life Action Plan</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The self-monitoring tools</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The automated prompt messages</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The feedback on your behaviour feature</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The peer-support forum</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. How likely are young people with cancer to use each of the following features of the intervention resources?

<table>
<thead>
<tr>
<th></th>
<th>Not at all likely</th>
<th>Maybe</th>
<th>Very likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>The goal-setting tools</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The Healthy Life Action Plan</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The self-monitoring tools</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The automated prompt messages</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The feedback on your behaviour feature</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The peer-support forum</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. Would you recommend these intervention resources to young people with cancer?

- No, Not at all
- Maybe
- Definitely, Yes

4. If the intervention resources were available for you to provide to young people with cancer today, how likely would you be to use them?
   a. Extremely likely
   b. Very likely
   c. Somewhat likely
   d. Not so likely
e. Not at all likely

5. Which of information resource would you be most likely to signpost young people towards? (Please only select one)

<table>
<thead>
<tr>
<th>Leaflets</th>
<th>Website</th>
<th>App</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. When do you think would be the best time to offer these resources on leading a healthy lifestyle to young people diagnosed with cancer.
   a. Before treatment starts
   b. During treatment
   c. Immediately after treatment
   d. 3-5 months after treatment
   e. 6-12 months after treatment
   f. More than 1 year after treatment

6. What did you like most about the intervention resources?

7. What did you dislike most about the intervention resources?

8. What improvements would you make to the resources?
Appendix 4.19 Study 5 online survey screenshot
Appendix 5.1 Health behaviour data cleaning

Physical Activity Godin LTEQ

Within the Godin LTEQ young people were asked three questions about the frequency and duration of mild, moderate and strenuous exercise. Many participants only answered one of these questions. Where this was the case it was assumed that young people did not engage in the other types of exercise and missing values were imputed as zero times per week for zero minutes. If a participant had not answered any of the three questions then missing values remained missing.

DINE Food Frequency Questionnaire

Within the DINE FFQ all question items regarding fibre and fat intake had the response option ‘never’ or ‘none’. The format of these questions involved young people answering how often they consumed different types of the same food or drink; for example cereal options included sugary, oat/ wheat and bran, and milk options included full fat, semi-skimmed, 1% fat, skimmed and non-dairy. If a participant reported that they consumed one item from this list for example semi-skimmed milk but left all other FFQ items blank it was assumed that they did not consume this food or drink item and the missing value was imputed as none.

Such an approach to missing data handling, defined as imputation based upon logical reasoning (STAT Columbia Edu, Accessed 2016), is a simple and effective approach to data handling based upon the assumption that the underlying reason behind missing data is known.
Appendix 5.2 Health behaviour scoring & cut-offs

**Body Fatness**

All weights were converted to kilos and heights converted to metres.

The standard BMI equation \(BMi = \frac{weight}{height^2}\) was used to classify body fatness.

- \(\leq 18.5\) kg/m\(^2\) = underweight
- 18.5kg/m\(^2\) to 25 kg/m\(^2\) = healthy weight
- \(>25\) kg/m\(^2\) = overweight
- \(>30\) kg/m\(^2\) = obese

**Physical Activity**

The duration of each physical activity session was converted to minutes only (e.g 1 hour 20 mins = 80)

Total number of minutes per week of each physical activity intensity were calculated from the following equations:

\[N_{\text{moderate}} = T_{\text{moderate}} \times D_{\text{moderate}}\]
\[N_{\text{vigorous}} = T_{\text{vigorous}} \times D_{\text{vigorous}}\]

Total number of minutes of physical activity per week was calculated.

Total number of minutes per week = \(N_{\text{moderate}} + (N_{\text{vigorous}} \times 2)\)

T: Times per week
D: Duration of each session
N: Number of minutes per week

Young people ≥18 years = meeting recommendation if total number of minutes per week ≥150 minutes

Young people ≤17 years of age = meeting recommendation if total number of minutes per week ≥300 minutes
### Fibre

**About how many times a week do you eat a serving of the following foods?**

<table>
<thead>
<tr>
<th></th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fb1. Pasta, rice, noodles, or cous cous</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Fb2. Potatoes, sweet potatoes, yams, or plantains</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Fb3. Peas</td>
<td>1</td>
<td>3</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>Fb4. Beans (including baked), lentils, chickpeas, or other pulses</td>
<td>1</td>
<td>4</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td>Fb5. Any other vegetables</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Fb6. Fruit (fresh, frozen, canned, dried)</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

**How many times a week do you have breakfast cereal or porridge?**

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than 1 per week</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fb7. Sugary, Chocolate, Rice or Corn cereals</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Fb8. Porridge, Ready Brek, Muesli, Multigrain/ wheat cereals</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Fb9. Bran cereals</td>
<td>0</td>
<td>2</td>
<td>5</td>
<td>12</td>
<td>18</td>
</tr>
</tbody>
</table>

**About how many times a week do you have the following breakfast cereals or porridge?**

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than 1 per day</th>
<th>1-2 per day</th>
<th>3-4 per day</th>
<th>5 or more per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fb10. White</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>9</td>
<td>13</td>
</tr>
<tr>
<td>Fb11. Brown, granary, half and half, seeded, wheatgerm, or oat</td>
<td>0</td>
<td>2</td>
<td>7</td>
<td>15</td>
<td>22</td>
</tr>
<tr>
<td>Fb12. Wholemeal (including wholemeal seeded and wholemeal granary) or wholegrain</td>
<td>0</td>
<td>3</td>
<td>8</td>
<td>18</td>
<td>26</td>
</tr>
</tbody>
</table>
Fat

About how many times a week do you eat a serving of the following foods?

<table>
<thead>
<tr>
<th>Food Description</th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ft1. Cheese (any except cottage cheese)</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Ft2. Beef (excluding burgers), pork, lamb, or goat</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Ft3. Beef burgers</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Ft4. Bacon, ham, salami, hot dogs, or sausages</td>
<td>1</td>
<td>2</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Ft5. Chicken or turkey (including nuggets/burgers but not fried versions of these)</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Ft6. Fish or shell fish (including tinned and breaded fish but excluding fried/battered fish)</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Ft7. Meat alternatives (e.g. eggs, soya, tofu, Quorn but excluding nuts, hummus)</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Ft8. Nuts eaten in a meal as an alternative to meat (e.g. nut roast)</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Ft9. Fried food (e.g. fried/battered fish or chicken, chips, fried breakfast, samosas, fried rice, bhajis, puris, fritters)</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Ft10. Cakes, pies, puddings, pastries, or Indian sweets</td>
<td>1</td>
<td>2</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Ft11. Biscuits, chocolate or savoury snacks (e.g. crisps, sev, Bombay mix, nuts)</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Ft12. Coconut milk or coconut cream</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Ft13. Yoghurts, rice puddings, or any other desserts (but not low fat versions).</td>
<td>0.5</td>
<td>1</td>
<td>3</td>
<td>4.5</td>
</tr>
<tr>
<td>Ft14. Low fat versions of yoghurts, rice puddings or desserts</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ft 15. Butter (including ‘Lighter’ ‘Spreadable’ and half-fat), Ghee or Margarine</th>
<th>E.g. Stork, Bertolli, Clover, Clover Lighter, I Can’t Believe It’s Not Butter, Flora, Flora Buttery, Flora Pro-activ, Benecol, Vitalite, supermarket own brand olive/ sunflower spread</th>
<th>Total teaspoons per day Score = No. tsp x 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ft 16. Low fat spread</td>
<td>E.g. Flora Light, Flora Lighter Than Light, Flora Pro-activ Olive, Flora Pro-activ Light, I Can’t Believe It’s Not Butter Light, own brand olive/sunflower light spread, Bertolli Light, Benecol Light, Clover Lighter Than Light</td>
<td>Total teaspoons per day Score = No. tsp x 4</td>
</tr>
</tbody>
</table>
### Appendix 5.2

**Fat**

About how much milk do you yourself use in a day e.g. on cereal or in tea or coffee?

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than a quarter-pint per day</th>
<th>About a quarter-pint per day</th>
<th>About a half-pint per day</th>
<th>At least 1 pint per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ft 17. Full-fat (whole)</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Ft 18. Semi-skimmed</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Ft 19. 1% fat</td>
<td>0</td>
<td>0</td>
<td>0.5</td>
<td>1.5</td>
<td>3</td>
</tr>
<tr>
<td>Ft 20. Skimmed</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Ft 21. Non-dairy (e.g. rice or soya milk)</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>
## Red Meat Scoring

About how many times a week do you eat a serving of the following foods?

<table>
<thead>
<tr>
<th></th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rm1. Beef (excluding burgers), pork, lamb, or goat</td>
<td>0</td>
<td>1.5</td>
<td>4</td>
<td>6.5</td>
</tr>
<tr>
<td>Rm2. Beef burgers</td>
<td>0</td>
<td>1.5</td>
<td>4</td>
<td>6.5</td>
</tr>
</tbody>
</table>

## Processed meat scoring

<table>
<thead>
<tr>
<th></th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pm 1. Bacon, ham, salami, hot dogs, or sausages</td>
<td>0</td>
<td>1.5</td>
<td>4</td>
<td>6.5</td>
</tr>
</tbody>
</table>
### Sugar

**About how many times a week do you eat a serving of the following foods?**

<table>
<thead>
<tr>
<th></th>
<th>Less than once a week or never</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1. Biscuits, chocolate or savoury snacks (e.g. crisps, sev, Bombay mix, nuts)</td>
<td>0.066**</td>
<td>0.214</td>
<td>0.571</td>
<td>0.857</td>
</tr>
</tbody>
</table>

**How many times a week do you have breakfast cereal or porridge?**

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Less than 1 per week</th>
<th>1-2 per week</th>
<th>3-5 per week</th>
<th>6 or more per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>S2. Sugary, Chocolate, Rice or Corn cereals</td>
<td>0</td>
<td>0.066**</td>
<td>0.214</td>
<td>0.571</td>
<td>0.857</td>
</tr>
<tr>
<td>S3. Porridge, Ready Brek, Muesli, Multigrain/ wheat cereals</td>
<td>0</td>
<td>0.066**</td>
<td>0.214</td>
<td>0.571</td>
<td>0.857</td>
</tr>
<tr>
<td>S4. Bran cereals</td>
<td>0</td>
<td>0.066**</td>
<td>0.214</td>
<td>0.571</td>
<td>0.857</td>
</tr>
</tbody>
</table>

**How often do you drink the following?**

<table>
<thead>
<tr>
<th></th>
<th>Never/ rarely</th>
<th>Once a week</th>
<th>2-3 times a week</th>
<th>4-6 times a week</th>
<th>Onc e a day</th>
<th>Twic e a day</th>
<th>3 or more times a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>S5. Regular squash, cordials, fizzy drinks and juice drinks</td>
<td>0</td>
<td>0.143</td>
<td>0.357</td>
<td>0.714</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>S6. Pure fruit juice (including from concentrate)</td>
<td>0</td>
<td>0.143</td>
<td>0.357</td>
<td>0.714</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

S7. About how many rounded teaspoons of sugar, honey, or syrup do you usually use in a day (e.g. on coffee, tea, milk, bread, cereals, fruit)?

Total teaspoons per day ____________
<table>
<thead>
<tr>
<th></th>
<th>Estimated average portion size</th>
<th>Estimated average portion size</th>
<th>Total sugars (g) per portion size (N)</th>
<th>Mean total sugars (g) per 100g</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1. Biscuits</td>
<td>50g</td>
<td>One small bar of chocolate/a biscuit</td>
<td>15g (N1)</td>
<td>30g*</td>
</tr>
<tr>
<td>S2. Regular squash</td>
<td>330ml</td>
<td>One can</td>
<td>33g (N2)</td>
<td>10g</td>
</tr>
<tr>
<td>S3. Pure fruit juice</td>
<td>250ml</td>
<td>One glass</td>
<td>25g (N3)</td>
<td>10g</td>
</tr>
<tr>
<td>S4. Sugary cereals</td>
<td>60g</td>
<td>One bowl</td>
<td>18g (N4)</td>
<td>30g</td>
</tr>
<tr>
<td>S5. Porridge etc</td>
<td>60g</td>
<td>One bowl</td>
<td>4.8g (N5)</td>
<td>8g</td>
</tr>
<tr>
<td>S6. Bran cereals</td>
<td>60g</td>
<td>One bowl</td>
<td>12g (N6)</td>
<td>20g</td>
</tr>
<tr>
<td>S7. Total teaspoons</td>
<td>As reported (S8)</td>
<td></td>
<td>5g (N7)</td>
<td>100g</td>
</tr>
</tbody>
</table>

*Given 50g sugar / 100g chocolate, 20g sugar 100g biscuit, <10g sugar/ 100g savoury snacks
DINE FFQ Scoring

**Fibre Scoring**
Total fibre score = sum of all scores on 19 items
Score of ≥30 = meeting recommendation (equivalent to more than 20g per day).
Score of <30 = not meeting recommendation

**Total Fat Scoring**
Total fat score = \( F_{t1} + F_{t2} + F_{t3} + F_{t4} + F_{t5} + F_{t6} + F_{t7} + F_{t8} + F_{t9} + F_{t10} + F_{t11} + F_{t12} + F_{t13} + F_{t14} + F_{t15} + F_{t16} + F_{t17} + F_{t18} + F_{t19} + F_{t20} + F_{t21} \)
Score of ≤30 = Meeting recommendation (equivalent to 35% total energy intake)
Score of >30 = not meeting recommendation

**Red meat scoring**
Total number of portions per week = sum of scores on 2 items
One portion = 100g (O'Brien et al., 2015)
Number of grams per week = No. portions * 100
Less than 500g per week = Meeting recommendation
500G or more per week = Not meeting recommendation

**Processed meat scoring**
Score of 0 = Meeting recommendation
Any other score = not meeting recommendation

**Sugar Scoring**
Total daily intake of sugar grams = \( S_{1}*N_{1} + S_{2}*N_{2} + S_{3}*N_{3} + S_{4}*N_{4} + S_{5}*N_{5} + S_{6}*N_{6} + S_{7}*N_{7} \)
Score of ≤30 = Meeting recommendation (equivalent to 5% of total energy intake)
Score of >30 = not meeting recommendation

**Fruit and vegetable scoring:**
Total number of portions per day = sum of scores on 2 items
Score of >5 = Meeting recommendation
Score of <5 = Not meeting recommendation
**Appendix 5.2**

**Smoke**: Do you currently smoke cigarettes? Yes/ No

If yes to Smoke = not meeting recommendations

### Binge Drinking

**Alcohol1**: How often do you have a drink containing alcohol?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Monthly or less</th>
<th>2 - 4 times per month</th>
<th>2 - 3 times per week</th>
<th>4-5 times per week</th>
<th>Every day</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

**Alcohol2**: How many units of alcohol do you drink on a typical day when you are drinking?

<table>
<thead>
<tr>
<th>I never drink alcohol</th>
<th>1-2</th>
<th>3-4</th>
<th>5-6</th>
<th>7-9</th>
<th>10+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

**Alcohol3**: How often have you had 6 or more units (for women) or 8 or more (for men), on a single occasion within the past year?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Less than monthly</th>
<th>Monthly</th>
<th>Weekly</th>
<th>Daily or almost daily</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### Alcohol Number of units per day scoring

**Alcohol1**: How often do you have a drink containing alcohol?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Monthly or less</th>
<th>2 - 4 times per month</th>
<th>2 - 3 times per week</th>
<th>4-5 times per week</th>
<th>Every day</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>0.04</td>
<td>0.11</td>
<td>0.36</td>
<td>0.64</td>
<td>1</td>
</tr>
</tbody>
</table>

**Alcohol2**: How many units of alcohol do you drink on a typical day when you are drinking?

<table>
<thead>
<tr>
<th>I never drink alcohol</th>
<th>1-2</th>
<th>3-4</th>
<th>5-6</th>
<th>7-9</th>
<th>10+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1.5</td>
<td>3.5</td>
<td>5.5</td>
<td>8</td>
</tr>
</tbody>
</table>

Binge drinking score/ Alcohol misuse score = Alcohol1 + Alcohol2 + Alcohol3

Binge drinking score ≥3 = classed as binge drinker (Cortes-Tomas et al. 2016)

Alcohol misuse score ≥5 = Alcohol misuse (Bradley et al., 2007)

Number of units per week = Alcohol1 x Alcohol2 x 7

Number of units per week > 14 = Not meeting recommendations

If any young person below the age of 18 reported any alcohol consumption they were classed as an underage drinker.
### Sun Health Behaviour

<table>
<thead>
<tr>
<th>Sun</th>
<th>Did you sunbathe regularly last summer to try and get a tan?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Response Option</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sun</th>
<th>Last summer, did you get sunburnt after being in the sun?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Response Option</td>
</tr>
<tr>
<td></td>
<td>No, never</td>
</tr>
<tr>
<td></td>
<td>Yes, only on one occasion</td>
</tr>
<tr>
<td></td>
<td>Yes, on more than one occasion</td>
</tr>
<tr>
<td></td>
<td>Don’t know, can’t remember</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sun</th>
<th>Have you used a sunbed or tanning bed on the high street in last 12 months?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Response Option</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Yes, daily</td>
</tr>
<tr>
<td></td>
<td>Yes, twice a week</td>
</tr>
<tr>
<td></td>
<td>Yes, once a week</td>
</tr>
<tr>
<td></td>
<td>Yes, once a fortnight</td>
</tr>
<tr>
<td></td>
<td>Yes, monthly</td>
</tr>
<tr>
<td></td>
<td>Yes, every 2 or 3 months</td>
</tr>
<tr>
<td></td>
<td>Yes, less often than every 2 or 3 months</td>
</tr>
</tbody>
</table>

Total sun behaviour score = Sun1 + Sun2 + Sun3

Total sun behaviour score ≥1 = not meeting recommendation

*Arbitrary variable weightings to score sun health behaviour index were based upon values previously reported by Larcombe and colleagues used to calculate a health behaviour index among 178 young adult aged childhood cancer survivors.*
Appendix 7.1. Published paper *Cancer Nursing*

The Lifestyle Information and Intervention Preferences of Teenage and Young Adult Cancer Survivors

A Qualitative Study

**Background:** Little is currently known about how best to promote healthy lifestyle choices among teenage and young adult (TYA) cancer survivors. Such data gathered from a patient-centered perspective are instrumental for the development of health behavior change interventions for young people with cancer. **Objective:** This study aimed to explore the lifestyle information needs of TYA cancer survivors and their preferences regarding lifestyle information and intervention delivery. Lifestyle behaviors of interest were physical activity, diet, smoking, alcohol consumption, and sun safety. **Methods:** A total of 13 TYA cancer survivors (mean age, 22.9 years) participated in 10 individual interviews and 1 focus group (n = 3). Each interview and focus group followed the same semistructured interview guide, which was designed to explore young peoples’ motivation behind leading a healthy lifestyle, their past experience of searching for lifestyle information, and their preferences relating to lifestyle information delivery. **Results:** Three core themes emerged: cancer as a catalyst to lifestyle behavior change, factors influencing health behavior change, and health behavior information preferences. Social support emerged as facilitator of both health behavior change and self-efficacy. **Conclusion:** Young people with cancer want age-appropriate lifestyle information on a range of topics.

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The author affiliations are as follows:

- Gemma Pugh, BSc, Raeloch Hough, MD, Helen Grovesock, MA, Jessica B. Hadlow, MSc, Rebecca J. Beeken, PhD, and Abigail Fisher, PhD

**Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal’s Web site (www.cancer.org.au).**

[Address of Correspondence: Gemma Pugh, BSc, Department of Behavioural Science and Health, University College London, 9-19 Torrington Pl, Fitzrovia, London WC1E 7LE, UK (gemma.pugh.l43@ucl.ac.uk). This is an open-access article distributed under the Creative Commons Attribution License 4.0 (CCBY), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. Accepted for publication: March 9, 2017. DOI: 10.1177/0269880616670508]
delivered in multiple formats at various time points. **Implications for Practice:** Health professionals working with TYA cancer survivors should address young peoples’ lifestyle information needs throughout the cancer care pathway and support young people to foster the confidence to make, and sustain, positive lifestyle behavior changes.

The improvements in teenage and young adult (TYA) cancer survival rates over the past 20 years has resulted in a growing number of young people living with and beyond the disease. However, estimated age-specific cumulative prevalence data indicate that by the age of 45 years, 95.5% of young people who have had a cancer diagnosis will have a chronic health condition of some kind, and 80.9% will have a chronic health condition defined as life-threatening. Many of the long-term consequences of cancer (e.g., cardiovascular disease, metabolic syndrome, chronic fatigue, and psychosocial difficulties) experienced by TYA cancer survivors manifest as direct results of treatment or indirectly through treatment-related adverse effects such as weight gain. Healthy lifestyle choices such as being active, eating a balanced diet, abstaining from smoking, avoiding excessive alcohol consumption, and being “sun smart” have the potential to partially ameliorate TYA survivors’ risk of chronic disease, cancer recurrence, and poor health-related quality of life. Conversely, low levels of physical activity and high levels of alcohol consumption and smoking have been associated with adverse health outcomes among TYA cancer survivors.

As a result, the promotion of a healthy lifestyle is increasingly being recognized as an important aspect of care for young people affected by cancer. Moreover, previous studies have found high levels of patient-reported interest in receiving lifestyle information. One survey exploring the follow-up care preferences of childhood cancer survivors in the United Kingdom (N=112, aged 18–45 years) found that more than half had a desire to discuss current health behaviors during a late-effect clinic appointment. Moreover, survey data from 74 TYA cancer survivors (mean age, 23 years) in the United States indicated that 85% of young people would have liked information about exercise at some point after their cancer treatment. However, despite the high level of expressed patient interest in receiving lifestyle information, TYA cancer survivors’ lifestyle behaviors are generally poor. Very few young people with cancer meet diet or physical activity recommendations, and rates of binge drinking among young people with cancer have been found to be comparable to age-matched peers. Specifically, a study exploring changes in TYA cancer patients (N=98, mean age=17.3 years) physical activity across the cancer continuum (pre-treatment, during treatment, and post-treatment) found physical activity levels decline significantly during treatment and nearly a quarter of young people remain inactive post-treatment despite being active pre-treatment. Efforts are required to support TYA cancer survivors to make, and sustain, healthy lifestyle choices both during and after treatment.

At present, very little is understood about how best to deliver lifestyle information and behavior change support to TYA cancer survivors as much of the qualitative and quantitative evidence concerning the information needs and preferences of TYA cancer survivors has focused on late-effect management and psychosocial issues such as fertility, education, and relationships.

Assessing TYA cancer survivors’ specific needs and preferences regarding lifestyle information delivery is an important step in the development and design of health behavior interventions for young people with cancer. Such data gathered from a patient-centred perspective and used in the development of lifestyle intervention programs increases the likelihood that young people with cancer will engage with the lifestyle information being provided.

However, lifestyle information provision is passive and unlikely to prompt behavior change without the incorporation of behavior change techniques or an understanding of the underlying motives behind lifestyle change.

**Method**

Participants, Recruitment, and Ethical Approval

The participants were TYA cancer survivors aged 13 to 25 years. Consistent with the National Cancer Institute definition of cancer survivor, any young person who received a diagnosis of cancer at any point within their lifetime was eligible to participate. The participants were recruited as part of a large-scale health and lifestyle survey being delivered to young people with cancer through University College Hospital, London, and CLIC Sargent (a UK-based cancer charity supporting young people and their families). Surveys were anonymous, but the participants who completed them had the option to express interest in being involved in a qualitative study focusing on the development of a lifestyle intervention for TYA cancer survivors. Young people had the option to choose the method of participation most convenient to them (a focus group or telephone interview). It was hoped that by proposing a combination of participation methods there would be increased interest. If a young person indicated interest in taking part in either a focus group or interview, they were sent an information sheet and consent form for the current study. All interviews and focus groups were conducted by the same person (C.P.) between July 2016 and May 2017.

2 Cancer Nursing, Vol. 00, No. 0, 2017

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Appendix 8.1

2015 and January 2016. All participants provided informed written consent before the commencement of interview or focus group. Young people received a £15 online shopping voucher for their participation. Ethical approval for this study was provided by University College London Research Ethics Committee (reference, 6266/003) and London Hampstead Research Ethics Committee (reference, 15/LO/0764).

Interview Topic Guide
The interviews and focus group followed the same semi-structured interview guide (provided as Document: Supplement Digital Content 1, http://links.lww.com/CNA111), which focused on 3 main themes: (i) what a healthy lifestyle means; (ii) past experiences of receiving, asking, and searching for lifestyle advice; and (iii) preferences relating to lifestyle information delivery with regard to content, format, and delivery. The participants were prompted when necessary and encouraged to share their thoughts and experiences openly.

Analysis
The qualitative data were transcribed verbatim and checked for accuracy during the familiarization phase of the 6-phase process of thematic analysis as outlined by Braun and Clarke. After the generation of the initial list of emerging themes, several meetings between the study team (G.P., A.F., and R.B.) were held until a single list of codes and themes was agreed upon. Each core theme and any unrelated subthemes were then discussed with a TTY cancer expert (R.H.) for affirmation and identification of missing themes. An independent researcher (J.H.) then coded 3 of the interview transcripts to ensure that each theme worked in relation to each coded extract. Any disagreements were resolved through discussion. All qualitative data analyses were carried out in NVivo. Qualitative data analysis software, version 11 (QRS International Pty Ltd, Melbourne, Australia). To ensure transparency, the final report and generation of results were guided by the consolidated criteria for reporting qualitative research. Percentage agreement and Cohen’s kappa were calculated to determine the interrater reliability of the analysis.

Results
From the original survey study (N = 294), 93 young people left their contact details, indicating interest in participating within this subsequent study. Of these, 13 young people responded to 1 of the 3 recruitment emails sent inviting them to take part in this study. In total, 10 young people took part in a telephone interview. Interviews typically lasted 30 minutes in duration (range, 19 minutes and 41 seconds to 43 minutes and 16 seconds). A single focus group (n = 5) was conducted in partnership with CLIC Sargent (project funders) with members of the charities’ young people’s reference group using existing nonclinical meeting facilities within the charities’ head office in London. The focus group lasted approximately 1.5 hours and was arranged at a time convenient to the group members.

The mean age of the sample was 22.5 years (range, 17–25 years), and most participants were female (n = 9, 79%). The mean age at diagnosis was 18.6 years. One participant was a TTY cancer survivor of a cancer diagnosed during childhood. Most participants (n = 6, 60%) had received a diagnosis of a hematological malignancy such as leukemia or lymphoma (Table 1).

Three core themes emerged from the interviews and the single focus group: cancer as a catalyst to behavior change, factors influencing health behavior change, and health behavior information preferences. The figure provides an overview of the thematic map generated within this study. The internet agreement on emerging themes was high (mean weighted percentage agreement, 99.14%; mean weighted K, 0.89).

Cancer as a Catalyst to Lifestyle Behavior Change
Young people indicated that their cancer diagnosis was often the underlying reason behind interest in lifestyle information and the catalyst behind any attempts to lead a healthier lifestyle. Leading a healthy lifestyle was seen by participants as a positive way of feeling better within themselves, regaining normality, regaining control of their health, and managing treatment-related adverse effects of cancer treatment including cancer recurrence. The participants also voiced an increased awareness of the importance of lifestyle for long-term health. This heightened awareness of health was often attributed to the effect of their cancer diagnosis on life outlook.

I think being diagnosed with cancer, you tend to be a bit more aware afterwards because you sort of don’t take your health for granted as much. I think (Female, 17 years, age at diagnosis, 17 years. Wilms tumor)

With reference to smoking and drinking, young people often indicated aversion to smoking “since obviously it causes cancer” and increased awareness of the risks of smoking and sun exposure. Often, young people indicated that their cancer and their treatment led them to be more conscious of their alcohol

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Participant Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participant Demographics</strong></td>
<td>n (%)</td>
</tr>
<tr>
<td>Age at diagnosis, y</td>
<td>1 (1)</td>
</tr>
<tr>
<td>&lt;15</td>
<td>4 (23)</td>
</tr>
<tr>
<td>15–17</td>
<td>6 (61)</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
</tr>
<tr>
<td>Leukemia</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>4 (31)</td>
</tr>
<tr>
<td>Cancers</td>
<td>4 (31)</td>
</tr>
<tr>
<td>Central nervous system tumour</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Treatment status</td>
<td></td>
</tr>
<tr>
<td>Still receiving cancer treatment</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Less than 3 mos since treatment</td>
<td>1 (8)</td>
</tr>
<tr>
<td>4–11 mos since treatment</td>
<td>1 (8)</td>
</tr>
<tr>
<td>1–5 y since treatment</td>
<td>5 (38)</td>
</tr>
<tr>
<td>On active surveillance</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Missing data</td>
<td>3 (23)</td>
</tr>
</tbody>
</table>

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Appendix 8.1

Factors Influencing Health Behavior Change

Cognitive Factors
- Self-efficacy
- Confidence
- Knowledge & Skills

Social Factors
- Perceived family influence
- Peer support

Cancer-related physical changes
- Treatment-related side effects
- Physical changes following cancer treatment (nursing, body composition, hair loss)

Practical Factors
- Resource availability
  - Internet (website information/health
  - Confusion/uncertainty from unclear or toxic advice

Information Content
- Range of lifestyle topics
- Information about late effects
- Specific TNM cancer therapy
- Information
- Recognition of individual needs
- Nonjudgmental information

Presentation/Format
- Range of formats
  - Accessible: (optional to stop in and just to read/phone)
  - Appropriate
  - Visual features (attractive/compelling)
- Concise information

Timing & Delivery
- When
  - Pre-diagnosis/treatment
- Where
  - Inpatient/Outpatient/Community Resources

Figure: Thematic map of the lifestyle information and intervention preferences of teenage and young adult cancer survivors.

Consumption, but some admitted being "probably what you'd call a binge drinker." Two participants specifically indicated that they drink less now after their cancer diagnosis because they considered "more important things in life" and "life too short to be unhealthy." Young people typically did not bring risk behaviors (smoking, drinking, or tanning) up within discussion unless prompted.

Factors Influencing Health Behavior Change

It was evident that cognitive factors such as health beliefs, self-efficacy, and confidence often contributed to young people's lifestyle behavior and engagement with health and lifestyle information.

Sometimes, you have low self-esteem and you don’t want to... It's not that the information isn't engaging, it's more how you feel yourself. (Female; 24 years, age at diagnosis, 21 years; Hodgkin lymphoma)

Peer and social support were found to be the main facilitators of confidence and self-efficacy among young people. Young people often talked about the influence that their immediate family and social network had on their lifestyle both during and after treatment and emphasized the need for peer support to come from other young people of a similar age and position to them. Many young people looked to identify with other TYN cancer survivors and described wanting to know more about their lifestyles and what was "normal" for them.

You just kind of think, well, they understand, and I think it's a lot easier to get the information into your head when it's another person's story. Like, talking is rather than just someone whose job is it to write the information, it's coming from someone who's been through a similar situation. (Male; 23 years, age at diagnosis, 21 years; Hodgkin lymphoma)

All participants viewed education on the benefits of a healthy lifestyle and guidance on making lifestyle changes as important. Young people often reported that goals and progress monitoring would be useful motivational tools to encourage young people to sustain positive health behavior changes. The participants generally supported the notion that any changes should be made gradually to sustain health behavior change over time, and young people often acknowledged that a healthy lifestyle could be of benefit to everyone.

I think a lot of people, yeah, they're disillusioned and think they can't exercise as well. But even a little bit is good for you. So it's just kind of making the best of what you've got, and being able to make a bit of time to keep active. (Male; 23 years, age at diagnosis, 21 years; Hodgkin lymphoma)
Appendix 8.1

Despite the high level of interest in leading a healthy lifestyle, many young people described challenges that they had faced in attempts to change their health behavior. Young people talked about the difficulty of having to navigate a "new body" posttreatment that is "not the same as it was pre-treatment." Often, treatment-related adverse effects or late effects were the main barrier to improving lifestyle behaviors, specifically diet- or exercise-related behavior. Young people were often frustrated by treatment-related fluctuations in weight and failed attempts to maintain or reach a healthy body weight. Dietary habits and food preferences formed during treatment were often named as one of the biggest challenges to changing diet-related behaviors.

I ate so much junk when I was on steroids that I just... it just became a habit, and I never broke it. Really. So it's taken, like, 6 years for me to break the unhealthy eating. I was doing for 2.5 years. (Female; 25 years; age at diagnosis, 15 years; acute lymphoblastic leukemia)

Specifically regarding physical activity, many participants shared that cancer and its associated treatment had led to a loss of confidence in their ability to exercise. One participant explained feeling self-conscious around other young people in public places such as local gyms because of cancer-related physical changes in his appearance such as "hair loss" and "a faster face" and "steroids." In addition, young people often viewed themselves as different to other young people who had not had cancer.

I'd never dream of going to the gym with... I don't mean to say ordinary people, but people of good health because I would have felt like such an outsider. (Female; 24 years; age at diagnosis, 17 years; Hodgkin lymphoma)

Geographical, financial, and time-related barriers to leading a healthy lifestyle were also mentioned by young people who indicated that traveling to support groups, paying for gyms, and preparing or cooking healthy meals were barriers to being active and eating healthfully. Barriers to reducing alcohol consumption, quitting or abstaining from smoking, or being safe in the sun were often not discussed unless prompted. When prompted, young people were typically uncertain about the need to change these aspects of their lifestyle and cited lack of clear information as the primary barrier to change.

Although some young people did have a positive experience, most participants within this study reported a high level of dissatisfaction with the practical support and lifestyle information that they had received in the past. Young people typically reported previously receiving very brief information about lifestyle from health professionals: often, this advice was given within the context of treatment or during discussions about management of late effects. The participants often reported that health professionals were not forthcoming with information about lifestyle and that either no information was given or that the information they were given was vague and out of context. One young person described an incident where a health professional was caught off guard by their request for specific information about can. 

I did ask the doctor about you know, "Was it okay to be in the sun?" I think it was a question that they weren't really... I don't know if the'd done that any, you know, prepared for it as a kind of a responsibility. He kind of was like, [...] Oh, you'll be okay [you] without sun cream if you're outside for just a little while, which didn't really kind of answer... I'd quite like to have known, you know, what I... How... You know, can I go... Can I sit in the sun on the summer, for instance? (Female; 22 years; age at diagnosis, 21 years; L1H chronic active B virus)

Lack of information from health professionals often prompted young people to search elsewhere for information, most commonly online.

So the first thing I did was went on the Internet, Googling it. (Female; 28 years; age at diagnosis, 17 years; Hodgkin lymphoma)

Young people's level of satisfaction with the information that they had found themselves varied. Some reported finding useful recipes and blogs from other cancer survivors, whereas others reported struggling to find any age-appropriate resources or any information relevant to their needs. Young people had mixed views that there was not enough practical support available for young people with cancer that focused on TVA-specific issues, specifically alcohol consumption.

When you finished treatment you sort of feel a bit... not abandoned, but you are sort of on your own dealing with it yourself, trying to manage. You know, you feel like you're in charge of your own health again, which can be a bit of a responsibility, it would nice to be able to have someone... giving you a bit of guidance. (Female; 24 years; age at diagnosis, 23 years; breast cancer)

Yeah, because um, I would like to know, you know, can I drink? Will it affect me? You know, does it relate to, like, what kind of cancer I had? Too much... having too much bad for me? Probably anyway. But just, just in general like, if if I wanted to go out with my friends, would I have a drink, because I don't, I don't know, I don't know, if that makes sense, I don't really know if I'm allowed or not. (Female; 23 years; age at diagnosis, 18 years; central nervous system tumor)

### Health Behavior Information Preferences

#### INFORMATION CONTENT

Young people were interested in lifestyle information on a range of topics and suggested such information should be integrated with other information topics such as late-effect management and maintaining normalcy. Interest in specific information on weight maintenance was also common. Many participants expressed a specific interest in information about socializing, particularly drinking. The participants highlighted strongly that the content of lifestyle information for TVA cancer survivors should be relevant to the needs of young people with cancer and reflect the individual needs of survivors of specific cancers (Table 2).

#### RESOURCE FORMAT

Overall, young people were interested in information presented in a variety of formats that could be accessed depending on their needs at any given time. Information delivered online or via

---

**TVA Cancer Survivors' Lifestyle Intervention Preferences**

*Cancer Nursing™, Vol. 00, No. 0, 2017*
Table 2 • Lifestyle Intervention Preferences: Content

<table>
<thead>
<tr>
<th>Subthemes and Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range of Lifestyle Topics</td>
</tr>
<tr>
<td>“Like, um, healthy food, and what maybe we should be eating now, like something to do with alcohol and smoking, um, if it’s relevant to them. Um, you know, just about like why is it not good for you and, you know, this is why we should stop...” (Female; 22y; age at diagnosis, 22y; thyroid cancer)</td>
</tr>
<tr>
<td>“Um, just stuff like diet, kind of how to deal with changes in appearance, and like, how your lifestyle’s going to change, physical activity, stuff on nutrition, if you’re going to be going back into education, or if you’re thinking of going into it. Just kind of, a bit of everything, across all areas.” (Male; 23y; age at diagnosis, 21y; Hodgkin lymphoma)</td>
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<tr>
<td>“Maybe a bit more about sort of drinking and smoking and going out stuff.” (Male; 23y; age at diagnosis, 21y; Hodgkin lymphoma)</td>
</tr>
<tr>
<td>Lifestyle information specific to the impact and effects of TVA cancer survivors</td>
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<tr>
<td>“I don’t think that would help your weight not fluctuate as much when you are not able to be as active as you used to be. That might be quite helpful.” (Male; 26y; age at diagnosis, 19y; acute lymphoblastic leukemia)</td>
</tr>
<tr>
<td>“And I suppose you’d have different sections. I think a neuroendocrine section would be really useful. Even and then, um, maybe, like, a trying to gain weight section and also like a trying to lose weight section because if you’ve been on steroids.” (Female; 22y; age at diagnosis, 21y; Hodgkin lymphoma)</td>
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<tr>
<td>“Like, more about um, what the impact of my lifestyle now might have in the future.” (Female; 22y; age at diagnosis, 20y; Hodgkin lymphoma)</td>
</tr>
<tr>
<td>“I think there needs to be more information, because some people might want information about a healthier lifestyle, on chemotherapy, what foods are good, and what foods are bad.” (Male; 25y; age at diagnosis 21y; testicular cancer)</td>
</tr>
<tr>
<td>“I don’t know, things relevant to the different kind of cancer that young people often have. I know hormonal cancer isn’t very common, so it probably wouldn’t be on there, but there are some that are really common to young people, so specialized information on how they should exercise and what they should do, especially if they had restrictions and stuff like that.” (Female; 26y; age at diagnosis, 21y; bowel cancer)</td>
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<tr>
<td>Recognition of individual needs</td>
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<tr>
<td>“It’s quite hard when your body, kind of, changes without... When you... And you have no control over it. It’s... It’s... You’re just the per... You don’t look like the person you used to look like. Even and I think sort of just kind of acknowledging that when you talk about, ‘Oh, if you need to lose weight, or if you need to gain weight,...’ even, I just... I think maybe acknowledging that at the beginning of the section. Just saying, you know, ‘Yeah, we...’ This is really hard, but, you know, don’t worry, you could lose the weight again,’ or you’ll put on the weight again. Here’s some helpful tips of how to do that,’ kind of thing.” (Female; 22y; age at diagnosis, 21y; Hodgkin lymphoma)</td>
</tr>
<tr>
<td>“I think the general how to look after myself. I mean, I know how to look after myself, obviously, but recommendations for specific types of cancer. I mean, I’ve got a brain tumor, so I’ll say I wasn’t affected. But things that would be specific to me. Whereas someone who... say, had Hodgkin lymphoma might be completely different. You can’t just give everyone the same information and just hope it works out.” (Female; 25y; age at diagnosis, 18y; brain meningiomas)</td>
</tr>
<tr>
<td>“I think the thing as well, because all cancers are different and so are treatments, and also the way that you respond is different. I feel like sometimes, the information in the booklet can be quite generic and might not apply to all situations.” (Female; 26y; age at diagnosis, 21y; Hodgkin lymphoma)</td>
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<tr>
<td>“Like... I know this sounds weird, but sometimes when you’re reading, like, a general leaflet, you’re kind of like... Yeah, this is all well and good, but what about someone who’s been through treatment or diagnosis and stuff?” (Female; 25y; age at diagnosis, 15y; acute lymphoblastic leukemia)</td>
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</table>

Mobile applications appealed to TVA cancer survivors because these formats were perceived as more accessible and appealing to young people (Table 3). However, several young people acknowledged that online information is only seen if it is being actively searched for. In such instances, young people highlighted the need for information to be available in multiple formats including in the form of counseling from health professionals.

“I think online it tends to be... you only see it when you go looking for it... Like, when I was diagnosed, my CLIC support social worker came in, and she just gave me loads of leaflets and just said, ‘Look through these,’ and then I looked through them, whereas I wouldn’t have gone onto a Web site and looked at it myself. Really.” (Male; 20y; age at diagnosis, 19y; acute lymphoblastic leukemia)

The participants during discussions regarding the design and presentation of lifestyle information indicated that information should be concise, accessible, attractive, and age-appropriate. Young people wanted lifestyle information that was easy to find and easy to navigate. Specific features such as designated topic sections, links, and interactive online features such as hyperlinked content and the ability to “pin” or “like” favorites appealed.

Young people expressed frustration at having to sift through “endless” information resources in the past. Short articles or information presented in “chunks that you can read one by one” were preferred. The participants also emphasized the need for lifestyle information resources to be designed specifically for “young people rather than children.” Many of the participants emphasized the need for making sure both the context and format of health and lifestyle information were neither patronizing nor “tagged-out”.

Visual features such as use of colour, infographics, and imaginative page layouts were suggested by young people as being key aspects of lifestyle information design and format.
Table 3: Lifestyle Intervention Preferences. Format

Subthemes and Quotes

Range Format
"Or even if you just have the little business cards with the address on, just say, 'Oh hear you go, it's all on there if you want it,' or 'We've got an app.' Because, I mean, that's the thing, isn't it? This generation, you don't need to do this. (Female; 24y; age at diagnosis: 18y; benign meningioma)
"Um, nothing too long. Like, it's got to be, like, easy to read. Like, concise, um... I'm trying to think what else. Like, accessible as well. I suppose. Not just like a leaflet, but if you can get it online or... available in different ways.” (Female; 25y; age at diagnosis: 21y; Hodgkin lymphoma)
"I think having a leaflet with the Web site on will kill 2 birds with 1 stone, so then they've got the leaflet rather than printing out loads and loads of leaflets. Because I remember getting information when I was having radiotherapy, I was saying, 'What am I going to do with all these leaflets? I don't need all these.' Because they had the Web site on the bottom, I was like, 'Well I can just go online and look at it. I don't need it all kind of printed out.'” (Female; 24y; age at diagnosis: 18y; benign meningioma)
"I prefer to have a communication where you can talk openly, answer questions, because you can't really ask anybody a question when you read a leaflet.” (Female; 22y; age at diagnosis: 19y; thyroid cancer)
"I do use mobile apps pretty, quite a lot, so I think that would be pretty useful because you can just go on your phone and have a little leaflet instead of like looking at a book or something, because some people like things to read and then some people like looking on their phone for information.” (Female; 22y; age at diagnosis: 19y; thyroid cancer)
"Just because, you know, everyone is glued to their phones, and especially if you're in hospital having treatment, or you've had treatment, or whatever, it can just be quite good to kind of pick up your phone and just scroll through stuff to kill some time. I think an app would be really good.” (Female; 23y; age at diagnosis: 21y; Hodgkin lymphoma)

Accessible, easy to digest, and concise
"I'd like the thought of looking at a little... like looking at a little book and just like looking at little facts and stuff about what you can eat and, do you know? (Female; 22y; age at diagnosis: 19y; thyroid cancer)
"A bit like a section in the little handbook, maybe, and then you just jump to the bit like... you know, that's ideal... what you... what, what you do, so you.” (Female; 22y; age at diagnosis: 19y; thyroid cancer)
"Almost like an interactive Web site, almost like a Pinterest, with all different tabs, just because I think it would help to target the audience.” (Female; 24y; age at diagnosis: 17y; Hodgkin lymphoma)
"I liked the fact that I just had something to read and quickly access.” (Female; 24y; age at diagnosis: 23y; Hodgkin lymphoma)
"I think probably like a little bit of a nice little guide and then kind of an option to go into more detailed bit if you'd like to kind of read into it yourself a bit more than, would be best in general.” (Male; 23y; age at diagnosis: 21y; Hodgkin lymphoma)
"Um, I like the idea of infographics. I find them, just, they're always, like, quite a good thing to have, like, kind of giving in to the nice, concise bits of information.” (Female; 23y; age at diagnosis: 21y; Hodgkin lymphoma)
"If I don't want to read it all, but I just want to read a certain section, then I'd just want it to be easily found. I like the use of headings, so I'd just think, 'Ok, right, that's the bit I want to read right now,' quite small. Easy to take in, especially when you are going through treatment and stuff, you don't want to read a massive article.” (Female; 24y; age at diagnosis: 21y; bowel cancer)
"Not so you feel like it's going to be a bunch of things for you to read through, and it won't like really sitting in. So maybe something that's quite punchy, I guess.” (Male; 22y; age at diagnosis: 20y; acute lymphoblastic leukemia)

Timing and delivery
No consensus of when the best time to provide lifestyle information to young people with cancer was reached. Often, young people felt that the correct time for lifestyle information delivery was dependent on an individual's frame of mind concerning the diagnosis, treatment status, and prognosis and that such information may be best delivered as and when a person is "ready.” Young people were often acutely aware of the risk-taking mind-set of young people and acknowledged that information delivered at the wrong time can sometimes fall on deaf ears. The participants stressed the importance of not being overwhelmed with information and that they were more receptive to information if advice was offered in a supportive and open manner. Young people also indicated that access to the information resources should be voluntary and that young people should have the opportunity to be sign-posted to relevant information to take in during their own time.

If somebody's kind of lectured you about it, and if you're kind of being told, 'Oh yeah, go check this out, go check this out, go check this out,' sometimes you just kind of think, 'Oh, well, I don't really want to look at that.' So I think, if they could be given a resource pack, maybe, to go and look into themselves. (Male; 22y; age at diagnosis: 21y; Hodgkin lymphoma)

Throughout all interviews and focus groups, young people indicated a strong preference for information that was "sensible" and "legitimate" from reliable and trustworthy sources. Young people commonly cited well-known YCA cancer charities in the United Kingdom as the best sources of information and that they would prefer information endorsed by health professionals specializing in YCA care who "know what they are talking about.”

Discussion
There is a need to provide young people who have had cancer with lifestyle information and health behavior change interventions to ameliorate their risks of chronic disease and cancer
Appendix 8.1

Our findings highlight the need for readily available age-appropriate lifestyle information covering a wide range of health topics for TYA cancer survivors. Such information should be incorporated into health behavior change interventions that support young people with cancer to make and sustain positive lifestyle changes.

In this study, young people often described their cancer diagnosis as the primary reason behind their interest in lifestyle information and engagement in health behavior change. Many young people reported an increased perception of personal health risk after their cancer diagnosis and viewed adapting healthy lifestyle behaviors as a positive strategy to improve their health and well-being. There is potential that a cancer diagnosis may trigger an effective re-evaluation of health status among TYA cancer survivors and may potentially prime young people toward making healthier lifestyle choices. However, as with adult cancer survivors, it is unlikely that such spontaneous behavior change will occur, or be sustained over time, without intervention.14,15 Lifestyle information and behavior change delivery strategies should capitalize on the potential “teachable moment” when young people’s motivation to receive and act on information or behavior change support is high.

Despite the high level of engagement with lifestyle-related topics, young people in this study often described numerous barriers to health behavior change. Specifically, many young people reported that cancer-related physical changes had negatively affected their confidence and self-efficacy toward being active. This is consistent with previous reports indicating that the greatest psychosocial challenge faced by young people who have had cancer is the adjustment to physical and mental limitations resulting from their diagnosis and treatment.14 Consent analysis of messages posted on an online forum for TYA cancer survivors confirm our findings that treatment-related physical changes or physiological problems (such as gastrointestinal issues) promote anxiety and diminish self-efficacy among young people with cancer.14 Conversely, social support emerged as a facilitator of both health behavior change and self-efficacy. Specifically, young people discussed the importance of social comparisons and the value of knowing about the challenges that other young people with cancer faced when making lifestyle changes. Such findings support the overwhelming evidence concerning TYA cancer survivors’ need for social support both during and after treatment and reflect the importance of behavioral modeling among adolescents and young adults.

Within this study, young people’s account of their experience and satisfaction of receiving and searching for information on physical activity, diet, drinking, smoking, and sun safety was often negative, perhaps reflecting the lack of lifestyle information or behavior change resources available for TYA cancer survivors. This is concerning given the strong correlation between unmet information needs and poor health-related quality of life among TYA cancer survivors.14 Young people with cancer have previously reported lifestyle information as being “overlooked” and specifically raised concerns about the effect of health professionals failing to address the consequences of alcohol consumption during treatment.28 A recent survey of TYA cancer survivors (N = 216; mean age, 29 years) in the United Kingdom found that the proportion of young people expressing interest in receiving advice on physical activity, diet, and weight management was greater than the proportion of young people who reported that they had actually received advice on these topics suggesting some TYA cancer survivors have unmet information needs in these areas.30 Addressing specific lifestyle information needs of young people with cancer is important because information provision is a core aspect of supportive cancer care.31 Young people in this study were interested in age-appropriate lifestyle information specific to their needs as TYA cancer survivors. A desire for lifestyle information that includes reference to adverse-effect or late-effect management was also common. This is reflective of previous reports detailing young people’s high level of interest in discussing health behavior during late-effect consultations.31 In addition, consistent with previous research exploring intervention design and delivery preferences, TYA cancer survivors within this study specified that lifestyle information and health behavior change interventions should be readily available and continually accessible.32,33 Young people in this study also specified that lifestyle information should be available in multiple formats to suit individual preferences. The participants discussed the explicit advantages of lifestyle information available online, highlighting the accessibility of this format of information and intervention delivery. However, despite young people indicating a strong preference for lifestyle information and health behavior interventions to be made available and delivered online, young people acknowledged that information delivered via such mediums lack the personal support from health professionals, immediate family, and social networks, which they like. This is reflective of parent and professional opinion expressed within previous research exploring the user requirements and considerations of Web-based self-management for TYA cancer survivors; parents and health professionals both stressed the importance of online information resources not replacing face-to-face consultations and interactions with either peers or health professionals.24

No consensus as to when the most appropriate time to introduce lifestyle information to young people with cancer was reached. Consistent with the thoughts of TYA cancer specialists, the participants within this study typically felt that the timing and delivery of lifestyle information should take into account the individual needs of the young person being given advice. However, it was generally agreed that although health behavior change may not occur immediately it would be beneficial to introduce TYA cancer survivors to the concept of lifestyle change as early as possible in the cancer care pathway. Such early introductions to lifestyle and health behavior change information may prevent the accumulation of bad habits, trigger behavior change among some young people, and prime those who are not yet ready for lifestyle change to at least be thinking about this issue.

This study has a number of strengths and limitations. A major strength of this study is the inclusion of young people’s perspectives on drinking, smoking, and sun safety. The relevance of these behaviors to TYA cancer survivors is often overlooked within studies, which typically address diet and physical...
activity. Moreover, this study provides qualitative insight into some of the previously reported correlates of health behavior among TYA cancer survivors. Such information is invaluable to the development and design of health behavior interventions for TYA cancer survivors. We aimed to obtain a breadth of opinions from a wide range of TYA cancer survivors; however, very few young people answered our call for participants despite having indicated an interest in taking part during a previous study. A mixed method qualitative approach was taken, and incentives were introduced to this study to overcome recruitment barriers; these decisions were based on previous reports detailing the difficulties typically faced within TYA cancer survivorship research. Although there were no differences between the qualitative data generated from the interviews and focus group, social barriers during the focus group may have reduced the likelihood of an individual sharing an experience or idea. It would also be important to suggest that the young people who took part within this study were engaged with health and lifestyle information, and as a result, the possibility of response bias is high. Further research to clarify the lifestyle information needs and health behavior interventions preferences of TYA cancer survivors with low levels of engagement is required.

### Implications for Practice

Our findings highlight the need for readily available age-appropriate lifestyle information for young people with cancer covering a wide range of health topics. This is supported by recent quantitative data indicating that 71% of TYA cancer survivors would take up the offer of lifestyle behavior information and support if given the opportunity. Given the correlation between health beliefs and behavioral intentions among TYA cancer survivors, health behavior change interventions developed and designed specifically for TYA cancer survivors should facilitate self-efficacy through social support, goal setting, and behavior tracking. Nurses and health professionals working with TYA cancer survivors should address young people's lifestyle information needs throughout the cancer care pathway and support young people to foster the confidence to make, and sustain, positive lifestyle behavior changes. Within this context, peer-to-peer support from another young person with cancer may be particularly helpful to TYA cancer survivors during the diagnosis and treatment process. Greater insight into specific correlates of health behavior and the differences between health protective behaviors such as physical activity and diet and risk behaviors such as drinking, smoking, and tanning are required. The development and design of health behavior interventions for TYA cancer survivors must also consider the perspective of health professionals working within this field.

### Conclusion

The findings from this study demonstrate that lifestyle information needs of TYA cancer survivors are currently unmet and that tailored approaches to health behavior change among this group of cancer survivors are desired. It is evident that health behavior promotion among TYA cancer survivors is complex and requires integration of physical activity, diet, alcohol consumption, smoking, and sun safety as well as the disease-specific barriers that young people with cancer encounter when making lifestyle-related changes.

### References

Appendix 9.1 Health behaviour information and behaviour change support resources

Why is your lifestyle important?
Having a healthy lifestyle can help aid your recovery from cancer. Healthy habits such as being regularly active and eating a balanced diet can reduce treatment side-effects such as fatigue, weight gain, and muscle loss and prevent the development of other health problems like diabetes or heart disease. On the other hand, unhealthy habits such as smoking, drinking and tanning are likely to increase your risk of health difficulties.

Unhealthy habits might not have a huge impact on your health now but over many years bad habits stack up and increase your risk of health problems later in life.

Leading a healthy lifestyle whilst you are young is the best way to stay healthy both now and when you are older.

Making the right choice
Evidence suggests that you will find it easier to make permanent healthy lifestyle choices if you turn the healthy actions into habits.

Introduce small changes to your day and repeat them often and your actions will soon become habits.

Why make changes to your lifestyle now?
As a teenager or young adult you will be making choices about the kind of lifestyle you lead. For example how often you are active, if you smoke, or how much you drink. Evidence indicates that young people who have unhealthy habits often grow up to become adults with unhealthy habits. For example a teenager who smokes is likely to become an adult who regularly smokes.
Healthy Habits: How to make them?
The easiest way of making new behaviours a habit is to make the action part of your normal daily routine.

Step 1: Choose your goal
Think about how and when you'll make your changes—it's easier to link an action to a situation than a specific time.

Step 2: Create an action plan
Once you've decided which lifestyle changes you'd like to make, start taking small steps that will get you there.

Step 3: Think it through
Think about how and when you'll make your changes—it's easier to link an action to a situation than a specific time. Having a quick walk before breakfast or eating a salad with lunch for example.

Step 4: Plan in advance
Think about what you need to do in advance, whether that's buying new ingredients to cook with, booking an exercise class, or downloading a stop smoking app.

Reward Ideas!
- Spend some quality time with your friends
- Take a relaxing bath
- Plan a day trip to somewhere you've never been before
- Have a pamper session

Step 5: Reward yourself
Treat yourself with rewards that make you feel good.

Step 6: Keep at it!
Repeating the same actions each day helps make them second nature.
Physical Activity & Exercise

Staying active during and after your cancer treatment will help with your recovery. Being active will help increase your strength and help combat feelings of muscle weakness and fatigue. Sitting or staying in bed for a long time has the opposite effect.

Regular exercise has lots of health benefits for young people who have had cancer, such as:
- improving fitness
- providing an opportunity to socialise
- building a stronger heart, bones and healthier muscles
- improving self-esteem
- improving posture and balance
- lowering stress
- encouraging a better night's sleep

It's important to remember that any amount of physical activity is better than none. Try to do as much as you can but don't be down on yourself if you can't. Try to gradually build up the amount of exercise you do at a pace that is comfortable for you.

Experts recommend 10,000 steps a day. This might be too many for you at the moment so try to do as many as feels right for you.

It's good to avoid sitting or staying in bed for long periods of time. Move around for 2 minutes out of every 20 minutes spent sitting down. If possible set reminders on your phone to get up at regular intervals.

How much activity is recommended?

Experts recommend you aim to do 150-300 minutes of at least moderate activity a week. Moderate physical activity is any activity which makes you feel warm or breathe a little faster for example a brisk walk or cycling.

This might sound like a lot of exercise but 300 minutes over a whole week is equivalent to 60 minutes of walking a day on 5 days of the week.

This could be broken up into 20 minutes of activity three times a day!

Ideas for everyday change

Small changes can be an easy way to increase the amount of activity in your day. Take a moment to think about your regular day? How might you increase the amount of activity you do?
- Do you need to travel to work or school? Try walking all or part of the way.
- Get a pedometer to measure your daily steps. Or if you use a smartphone, download an app with a step counter.
- Swap the lift for a couple of flights of stairs.
- Try standing on public transport.
- Try a short bike ride or a walk at lunchtime.
- Use TV ad breaks to walk around or do some light chores.
- If you are currently on treatment in hospital ask the staff on the ward if there are any exercise bikes you could use. Ask if you could find a space to do some simple stretching exercises.
- How about signing up to join a class?
- Your GP may provide exercise on prescription so you can use a gym for free.

Getting fitter and stronger

If you feel you can do a bit more, building up to more energetic exercise and adding in some strength training will increase your fitness and with it the benefits to health.

A cancer diagnosis and treatment can make people less active and cause muscle fitness to decline. By being active and doing strength exercises, you can reverse some of this weakness, keep your muscles and bones strong, and you will be able to go about your daily activities more easily.

Experts recommend you do exercises that cover strength, balance and stretching at least twice a week.

If you feel able, try to incorporate at least two 30 minute sessions of vigorous exercise into your week (jogging, fast swimming, riding a bike uphill, or playing a team sport). If you're exercising at this level you'll be breathing hard and will struggle to talk without pausing for breath.
Appendix 9.2

Physical activity during treatment

Whilst you are on treatment it is important to remain as active as you can. However, whilst you are on treatment certain things such as the stage of cancer you have, your cancer treatment and your stamina might affect how active you can be. It is important you do a daily exercise which is right for you and seek advice from the medical team looking after you. Exercise specialists, doctors, nurses and physiotherapists are there to guide you and help you find activities which are safe for you to do.

If you exercised a lot before your cancer diagnosis you might find that you need to do less exercise than usual or at a lower intensity whilst you receive your treatment. It might take some time to figure out what is your ‘new normal’ for you but don’t be put off.

If before you were diagnosed with cancer you weren’t really into exercise now is a good time to start trying to be a little more active. Start slowly with low intensity activities such as short walks. If you can, gradually build up the amount of activity you do each week.

Physical Activity & Fatigue

You will probably find that cancer has caused you to have a lot less energy. It’s likely that your body and brain will feel very tired and lethargic. This is very common and is often described by young people as one of the worst side-effects of cancer treatment. The fatigue causes you to normal fatigue and will often get immediately better with rest.

Physical activity can help you manage these symptoms of fatigue and tiredness. Regular exercise has been linked to reduced fatigue. If you remain active and make an effort to do some exercise, even when it’s the last thing you feel like doing, you might find that you have more energy. Physical activity will prevent your muscles from weakening and will help you feel fitter and stronger.

Staying safe when exercising

- Whether you are receiving cancer treatment, or have had cancer treatment in the past, if you experience any of the following problems it is important you stop the activity you are doing and contact your medical team for advice.
  - Heart palpitations
  - Unexplained chest pain
  - Dizziness or have problems balancing
  - Difficulty breathing
- Be careful about your blood and platelet counts. If your haemoglobin (Hb) counts are low, your muscles and organs will not be getting enough oxygen, and exercise may cause you to faint or feel breathless. Low platelet counts can also increase the risk of bruising and bleeding. Your medical team can give you more specific advice about this and whether it is safe for you to exercise.
- Be careful about infection. If you have a central line, catheter, or feeding tube, avoid swimming and other activities that may cause infection. Talk with your cancer team about what’s safe for you. If you have an infection or a temperature take time to recover and come back to exercise when you are better.
Appendix 9.2

**Why is a good diet important?**

Having a healthy diet can help aid your recovery from cancer. Eating the right kinds of food before, during, and after treatment will help you get the nutrients you need. Different foods contain different nutrients which are important for your growth and development and to recover from the cancer you have had.

**What does a healthy diet look like?**

Experts recommend young people with cancer have a healthy balanced diet which contains fruit, vegetables, plenty of fibre, and lean meat, fish, or nuts.

**Getting the right advice about your diet**

Cancer treatment can often cause problems with appetite, taste, and the ability to digest certain food types. Eating the right kind of food can help overcome these difficulties. A dietician is the best source of information about diet and can help you choose the right foods to eat.

Top tip: If you are meeting with a dietician write down any questions you have before you meet so you don’t forget to ask.

Where to find a dietician? If you would like to speak to a registered dietician contact your medical team, local hospital, or speak to your GP.

When developing an eating plan for you, a dietician will consider things such as your age, the kind of cancer you have been diagnosed with, the kind of treatment you are having or have had, your weight, your activity levels and whether you dislike any particular foods.

**Could you add more fruit and veg into your day?**

Experts recommend eating 5 or more portions of fruit and vegetables each day. A portion is equal to one medium sized piece of fruit such as an apple, three tablespoons of veg, or a handful of smaller fruits.

Vegetables should take up at least one third of your plate at meal times.

**Tips for everyday change!**

What do you have for breakfast?
- Try adding banana, berries or dried fruit every time you have cereal
- Try having an apple or something similar with every breakfast

Do you eat snacks?
- Prepare bite-sized fruit and veg (carrots, cucumber, cherry tomatoes) fresh or dried fruit and take them with you.

What do you eat for lunch or dinner?
- Add a side salad or vegetables
- Make fruit your pudding every day
- Sneak extra vegetables into casseroles, curries, soups or pasta dishes. If you are making a chilli-con-carne add in extra vegetables such as peppers, onions and carrots

**What about fibre?**

Eat plenty of high fibre foods, such as wholegrain breads and cereal, and brown rice, and pasta

Limit refined carbohydrates including pastries, sweetened cereals, soft drinks and sugary foods.

**Which white starchy foods could you swap for wholegrain versions?**

- Change your cereal for wholegrain versions like muesli or porridge
- Change your bread (white or brown) for seeded or granary wholemeal
- Pick high fibre fruits such as pears and bananas
- Keep the skins on potatoes and sweet potatoes
- Add a portion of pulses such as beans or peas, to salads, casseroles, stews and soups.
- Choose wholegrain brown pasta and noodles and where possible eat only brown rice
- Keep the skins on potatoes and sweet potatoes
Appendix 9.2

Red Meat: The Recommendations

Limit red meat intake and substitute with beans, pulses, nuts, fish, eggs, and poultry.

Avoid processed meat such as bacon, sausages and meat-based sauces

When eating meat, choose leaner or smaller portions.

How often do you eat red meat? How could you reduce the amount you eat?

- Have red meat no more than once or twice a week
- Replace red meat with chicken or fish
- Substitute half of the meat in casseroles or stews with pulses such as lentils or chickpeas (canned chickpeas, lentils or kidney beans are handy)
- Try meat alternatives such as Quorn, tofu, eggs or nuts
- Go veggie once or twice a week
- Search for new recipes which don't contain meat

Cutting out processed meat

Think about the meals you eat each day and the healthier options you could try. Are processed meats a part of your diet?

If you have bacon or sausages for breakfast swap to vegetarian sausages or mushrooms

Avoid pepperoni or salami meat toppings on pizzas, try spicy chicken instead or chilli for extra punch.

Replace sandwich fillings such as ham and bacon with veggie options, or other fillings such as fish or chicken.

Instead of burgers try veggie burgers, falafels, or fish cakes.

Fats & Fried Foods

Decrease the amount of fat in meals by baking, grilling or boiling foods.

Limit the amount of fried, high fat, high sugar foods in your diet.

Avoid fast food in particular as this is often high in fat and sugar.

Choose low fat milk and dairy products.

Swap butter, ghee and margarine for vegetable oil products.

How can I make the right food choices?

Reading Food Labels

Most pre-packed foods available in supermarkets have a traffic-light nutrition label on the back or side of the packaging. These labels contain information about the number of calories in the food as well as the amount of fat, saturated fat, carbohydrate, sugar, protein and salt. These labels can help you choose healthier options.

If you pick up a food item and the nutrition label is made up of mostly red labels this means that the item is unhealthy and contains a high amount of fat, saturated fat, salt or sugar.

If you pick up a food item and it has all green or mostly green in its nutrition label this means the food is a healthy choice.

What does the label mean?

You can tell if a food is high in fat, saturated fat, salt or sugar based on these guidelines.

- Total fat
  - High: more than 17.5g of fat per 100g
  - Low: 3g of fat or less per 100g
- Saturated fat
  - High: more than 5g of saturated fat per 100g
  - Low: 1.5g of saturated fat or less per 100g
- Sugars
  - High: more than 22.5g of total sugars per 100g
  - Low: 5g of total sugars or less per 100g
- Salt
  - High: more than 1.5g of salt per 100g (or 0.6g sodium)
  - Low: 0.3g of salt or less per 100g (or 0.1g sodium)

If you were trying to cut down on sugar you might limit the amount of food you eat which contains more than 5g per 100g.

The manufacturer's idea of a portion may not be the same as what you think a portion looks like.

The traffic-light colour-coded nutritional information on the front of food is high, medium or low in fat, saturated fat, sugar and salt.
Choosing a healthy diet whilst on treatment

Lots of young people when they are receiving cancer treatment crave sweet, salty or unhealthy foods. This is completely normal and it is okay to eat the foods you like the most when you are having a tough time. However, bad habits are hard to break. When having treatment try to stick as much as you can to having a healthy balanced diet.

What if I am taking steroids?

Young people with cancer are often prescribed steroids as part of their treatment. Often steroids can cause feelings of hunger, cause water retention and may cause weight gain. Often these symptoms will go away when steroid treatment ends.

If you are taking steroids a healthy diet will help minimize weight gain and certain food types can help prevent fluid retention.

A dietician can help you plan meals and snacks which are satisfying but not high in calories which will help keep your weight at a healthy level. You do not need to deprive yourself of your favourite foods but some simple changes in recipe or portion size might be useful. For example if you often eat thick crust pepperoni pizzas with extra cheese swapping to thin crust pizza with a chicken or veggie topping can help cut some calories from your diet.

Be aware of extra un-needed calories in fizzy drinks and fruit juice.

Upset Stomach

Sometimes cancer treatment can cause problems with the way the body digests certain foods. This might cause you to go to the toilet more or less often. If you are constipated or have diarrhoea speak to your medical team. Often if you have constipation they will suggest increasing the amount of fibre in your diet.

Foods such as whole-grain bread, cereals, raw fruits, raw vegetables, dried fruits, beans and nuts contain high amounts of fibre. Being active can also help relieve constipation. If you have diarrhoea avoid high-fat, greasy or fried foods and drinks which contain caffeine.

Foods which are high in potassium and soluble fibre such as bananas can help alleviate the symptoms of diarrhoea.

Treatment has weakened my immune system

How can I prevent an infection?

Cancer treatments often cause the body’s natural defence to germs and bacteria to weaken. This means your immune system often won’t or can’t prevent you from getting infections. While your immune system is recovering from treatment it is important you avoid possible infection-causing germs. Talk to your doctor and dietician about what foods you should avoid and how you can prepare your meals safely.

Tips on what foods to avoid and how to prepare your foods can be found online: http://www.cancer.org/cancer/groups/sid/documents/webcontent/002902-pdf.pdf

I’m on treatment and it’s changed my taste in food

– what can I do?

Sometimes cancer treatment can cause changes in the way food tastes. Young people often report that foods become bitter and metallic tasting whilst on treatment.

• Try serving food cold or at room temperature. This can decrease the foods taste and smell making them easier to eat.

• If you have a metallic taste in your mouth when eating try using plastic plates, bowls, knives, and forks to eat with.

• Avoid eating 1 to 2 hours before chemotherapy and up to 3 hours after chemotherapy. This will help prevent you going off any food or associating that food with nausea and vomiting.
Appendix 9.2

**Alcohol**

It is illegal for someone under the age of 18 to buy alcohol

Young people aged 16 or 17 can drink beer, wine or cider with a meal if it is bought by an adult and they are accompanied by an adult. It is illegal for under 18s to drink spirits in pubs even with a meal. It is illegal for under 18s to buy alcohol in pubs, off-licences, shops or anywhere else.

If you are under 18 and you are caught with alcohol three or more times you could face an anti-social behaviour order (ASBO), a fine or arrest. This could lead to a criminal record which could affect you getting a job and travelling to countries like the USA.

This is one unit of alcohol...

![Units of Alcohol](image)

...and each of these is more than one unit

1. Pint of regular lager
2. Pint of premium beer, larger or cider
3. Alcoholic cider or cider
4. Can of premium lager or stronger lager
5. Can of super strong lager
6. Glass of wine
7. Bottle of wine

**Drinking too much alcohol can affect your health**

Alcohol is addictive and can impact on both your physical and psychological wellbeing. It is important you are aware alcohol can also interfere with cancer treatment, make side-effects worse, and cause weight gain.

**How much is too much?**

Experts recommend you drink no more than 14 units a week. Don’t save up your units to drink in one go, experts recommend that these units are spread over three or more days.

**What are the health risks of drinking too much, too often?**

Drinking excessive amounts as a young adult can cause learning difficulties and memory problems. Drinking at an early age has also been linked to alcohol dependence and depression later in life.

Drinking large amounts of alcohol over a long period of time can cause scar tissue to form around the liver, this is called fibrosis and a liver which has scar tissues is called a fibrotic liver. A build-up of scar tissue can cause blood flow in the liver to be blocked and can cause the liver to stop functioning. When a liver has lots of scar tissue and has problems functioning the liver is now referred to as a cirrhotic liver. Cirrhotic liver damage is irreversible.

Unfortunately, cancer treatments like radiotherapy can often cause fibrosis and liver damage among young people. Drinking too much alcohol could make the fibrosis and liver damage worse which might cause the fibrotic liver damage to become cirrhotic liver damage.

To give your liver the best chance of being healthy and functioning for as long as possible avoid drinking alcohol when you can and when you do drink, limit the amount you consume.
Appendix 9.2

**How many calories?!**

Alcoholic drinks are packed full of calories. Drinking too much, too often, will not only have an effect on your health but might cause unwanted weight gain.

**Reducing the amount you drink**

Try to cut your alcohol consumption by stopping completely, drinking less frequently, or drinking smaller amounts.

**When you are out?**

- Have smaller measures or dilute your drinks.
- If you are in a bar or a pub ask the bartender specifically for a single rather than a double.
- Choose non-alcoholic versions or lower strength options
- Quench your thirst with a large glass of water first and alternate each alcoholic drink with a glass of water

**It’s important you feel confident and happy to make decisions about how much you are drinking without feeling left out.**

- Think about places, situations and people that encourage you to drink most and consider other non-alcoholic drinks.
- Before going out, make a plan for how to avoid drinking more than you mean to, such as offering to be the designated driver
- Drink slowly and at your own pace
- Find a distraction such as getting up and dancing
- Talk to your friends, let them know you are trying to drink less – you might find having an honest conversation with them will allow them to support you better.

**I’m still having cancer treatment, can I drink?**

Whether you can drink whilst you are on treatment will depend on the kind of treatment you are having. Alcohol can interfere with the way some drugs work and could prevent your treatment from being successful. Talk to your medical team to see whether it is safe for you to drink whilst on treatment.
Appendix 9.2

**Smoking & Tobacco**

**It’s no secret - smoking is bad for you!**

Tobacco smoke contains more than 70 different cancer-causing substances.

- These chemicals enter your lungs and spread round the rest of your body damaging cells.
- The younger you are when you start smoking the more time these chemicals have to cause damage as you get older.

Smoking as a teenager or young adult has been shown to double the chances that you will struggle with your overall health and will almost triple the risk of you coughing, wheezing, and experiencing shortness of breath when exercising.

Smoking doesn’t just do damage to your insides, it also has an impact on your appearance. The chemicals in cigarettes can cause problems with blood flow. This is what makes smokers skin look yellow and saggy.

**Did you know?**

1. The average smoker spends £2,000 a year on cigarettes.
2. In developing countries, each year forests and woodlands the size of 243,000 football pitches are cut down in the tobacco farming process!

**Smoking & TYA Cancer**

For young people who have had cancer smoking is even more damaging to health. Often chemotherapy drugs and radiotherapy will weaken the heart and lungs, making young people who have had these treatments much more susceptible to respiratory infections or breathing difficulties. If you’ve had cancer treatment and you smoke you are increasing your risk of organ damage, heart failure, lung disease and problems with your bones such as osteoporosis.

**Want to stop smoking?**

We know it’s tough to stop smoking but there is support available if you’re finding it difficult to quit.

**Make a battle plan**

- Set a definite date and time to stop.
- Avoid having even a puff of a cigarette from that point onwards.

**Avoid the temptation!**

- Try to avoid situations where you would usually smoke.

**Have a comeback!**

If someone is giving you a hard time for quitting or tries to tempt you with a cigarette be prepared to answer back. Be confident in your decision to stop smoking.

**Buddy Up!**

Make a pact with a friend to quit smoking with you. If you’re both quitting together, and you have a deal, then you’re more likely to encourage and support each

**Practise changing the way you think about yourself**

Imagine you are a non-smoker. Repeat to yourself: ‘I do not smoke and smoking is not an option’
Sun Safety

Sunlight is a vital source of vitamin D, which is essential for healthy strong bones. However, ultraviolet (UV) rays from the sun are a major risk factor for most skin cancers. Sun damage to your skin when you are young could lead to skin cancer developing when you are older.

It is important to protect your skin when you are in the sun.

Unfortunately young people who have already had a cancer diagnosis are at increased risk of developing non-melanoma skin cancer. Because of this increased risk it is even more important for you to avoid or minimise your exposure to sunlight.

Sun Safety & TYA Cancer

If you are worried about your risk of skin cancer or cancer recurrence speak to your medical team. They will be able to talk to you about your worries and provide advice about how to reduce your risk of cancer again in the future.

There is no such thing as a safe or healthy tan

Protecting your skin (and eyes) from UV light is essential to prevent damage and reduce your risk of skin cancer.

Block the Blaze!

1. **Apply sunscreen.** Wear at least SPF 15 sunscreen and remember to reapply every two hours.

2. **Seek shade.** Avoid being in direct sunlight as much as possible, stay in the shade between 11am-3pm when the sun is at its strongest.

3. **Wear sunglasses.** Your eyes are also vulnerable to damage by UV rays. Protect your eyesight by wearing sunglasses.

4. **Cover up.** Wear long sleeved tops and shorts or sarongs to protect your skin. Wear a hat to protect your scalp and head from burning.

Do not use sun-beds!

Sunbeds and tanning lamps contain a concentrated source of UV radiation making the rays even more harmful. It is illegal for people under 18 years old to use sunbeds, including in tanning salons, beauty salons, leisure centres, gyms and hotels.
Appendix 9.2  Health behaviour behaviour change support resources

Making Goals!

Many people have a general idea that they would like to lead a healthier lifestyle by, for example, quitting smoking, reducing the amount of alcohol they drink, or increasing the amount of physical activity they do. To want to be successful at changing your health behaviour, setting a goal is the first step.

Without a goal you will probably lack focus and direction. Setting yourself a goal not only allows you to define what part of your behaviour you would like to change but also provides a benchmark for determining if you are actually succeeding in changing your behaviour for the better.

Below is an example of a goal-setting support tool taken from a health behaviour change booklet developed for adult cancer survivors.

Take time to look through the illustration and read the short information card on setting S.M.A.R.T. goals before answering the questions at the bottom of the page.

GET STARTED NOW
1. Choose the behaviour you would like to work on.
   - I do this already
   - I want to change

Making S.M.A.R.T. Goals

S is for Specific
- Target a specific behaviour you would like to improve

M is for Measurable
- This means you need to be able to assess how far you have reached your goal. If you make a goal like ‘I’ll be more active’ you won’t know when you have succeeded. A measurable goal would be “I’m going to spend 30 minutes a day either walking or swimming, at least twice a week.”

A is for Achievable
- Set realistic goals by aiming for small, specific steps and then working gradually towards your main goal.

R is for Relevant
- Don’t try to change something just because everybody else says you should. If the goal you set is not relevant to you, you are unlikely to stick to it.

T is for Time-specific
- Give yourself a realistic time frame for your goal. Changing your lifestyle behaviour will take a while because it means changing long-term daily habits.

Goal setting tools could also be available in app or website formats.
Action Planning! Making the goal happen!

Once you have decided on the lifestyle change you would like to make, and set yourself a goal about that behaviour you will need to make and start taking small steps to help you achieve your goal.

In the illustration below you will see the outline of a Step-by-Step action plan. Take time to look through the action plan before answering the questions at the bottom of the page.

Healthy Life Action Plan – An example

Jess was diagnosed with Lymphoma when she was 15. During treatment she had to really tough time and struggled to stay active. After her treatment had finished she set herself a goal of decided she wanted to re-gain her strength and get fit again. She set herself a goal of competing in a charity 5k race in two months’ time. Jess knew she tried to run this distance straight away she wouldn’t have been able to manage the race. Instead, Jess thought it through and decided to make small steps towards achieving her goal.

She set herself a series of sub-goals and tackled these one at a time, keeping track of her progress along the way and rewarding herself as she went.

1. Fill in the Step-by-Step Chart

Decide on your goal and write it down on the chart.

2. Think it through

Think about how and when you’ll make your changes – it’s easier to link an action to a situation rather than a specific time.

3. Plan in advance

Think about what you need to do in advance. Plan the steps which will help you achieve your goal whether that’s buying in fruit, booking an exercise class or downloading a stop smoking app.

4. Reward Yourself

Treat yourself with rewards that make you feel good – maybe a massage, a new book, or trip to the cinema or theatre.

5. Keep at it!

Repeating the same actions each day helps make them second nature. It can take a while for a new action to become a habit and part of your everyday routine, so stick to it!

HEALTHY LIFE ACTION PLAN

Your goal: 

New everyday habit: 

Steps to support your new habit:

Step 1: Step 2: Step 3: 

Don’t worry if you slip up

WELL DONE! Well done! Well done! 

Great job! Well done! Great job! Well done! 

5 reward 5 reward 5 reward 

How do you feel? How do you feel? How do you feel? 

Congratulations, you’re going well! Congratulations, you’re going well! Congratulations, you’re going well! 

Rewards

Treat yourself with rewards that make you feel good – maybe a massage, a new book, or trip to the cinema or theatre.

Did you know?

It takes an average of 66 days for a new behaviour to become habit.
Making the goal happen! Monitoring your progress!

Research has found that if you keep note and track what you have done you are more likely to successfully achieve your goal.

**Keeping note and tracking your behaviour is called self-monitoring**

Self-monitoring increases your awareness of your behaviour and helps you stay focused on your goal.

For example: If your healthy lifestyle goal was to eat less junk food, keeping notes and tracking your diet would help you be more aware of what you eat, when you eat, and what causes you to eat more than planned.

**Seeing is believing!**

Self-monitoring is also helpful in showing how far you have come. For example, if your healthy lifestyle goal was to increase your strength by upping the amount of physical activity you do. Later on, when you compare your strength now with how strong you were in the past, it will help you see how well you have done.

Did you know? If you suffer from problems such as fatigue or bowel problems, keeping a diary can help you identify what triggers these so you can better manage your symptoms.

What's normal? Should I feel this way?

Understanding the experiences of other young people with cancer is an important part of figuring out your new normal.

Demo videos online are a good way of getting new ideas for exercise routines or recipes.

Testimonials, real-life stories, or vlogs by other young people with cancer can be useful way to hear about someone else's cancer experience.
Rewards! Celebrating Success!

Changing your health behaviour is hard. Often the behaviours you are trying to change are things that used to give you pleasure. That’s why it is important you reward yourself for each small step of progress.

Rewards are a way of recognizing achievement, motivating yourself to continue, and building your self-esteem. These things are vital to keep you moving forward and trying to achieve your goal. Self-esteem can counter low feelings that may accompany a slip back into bad habits.

Reminders & Prompts!

Sometimes even though we have set ourselves a goal and made a plan to change our behaviour we forget. We need prompts and cues to remind us to do what we intended.

Prompts and cues are a stimulus in your environment which reminds you to do something specific.

E.g. If you put your trainers beside the front door you will be prompted to take them with you and go to the gym that day.

Apps and websites can be programmed to send you messages throughout the day to remind you do something specific.
Getting others to help you!

Changing your lifestyle can be hard! Having support from your family, friends, and health care team is important. If you talk to the people in your life about the change you are making to your lifestyle they might be able to help.

For example, if you are trying to quit smoking, talking to your family and friends about cravings might mean they can provide you with encouragement and remind you to stick at your quit attempt.

What can other people do for me?

- Provide encouragement!
- Reinforce the risks of unhealthy behaviour!
- Reinforce the benefits of healthy lifestyle choices!
- Give you a gentle reminder
- Share ideas on how to be healthier
- Join in with you

Family, friends, health professionals, and other young people who have had cancer can provide you with emotional and practical support to help you lead a healthier lifestyle.

Online support forums are a handy way of looking for advice from other young people who have had a cancer diagnosis.
Appendix 10.1 Pan- London research fellowship

Project Title: Feasibility Pilot of a Health Behaviour Change Intervention for TYA Cancer Survivors

Proposal Summary: Teenage and young adult cancer survivors (TYACS) are at an increased risk of cancer recurrence and other chronic health conditions. There is a strong need for this group to adopt a healthy lifestyle in order to reduce the impact a cancer diagnosis has upon growth and development as well as long-term health. However, there are no health behaviour interventions available in the UK to support TYACS after a cancer diagnosis. To meet this need a multi-format, habit theory-based, health behaviour intervention containing formal behaviour change support tools and age-appropriate information on physical activity, diet, smoking, and alcohol consumption has been developed by our group. The aim of this project is to conduct a two-arm pilot randomised controlled trial, exploring the feasibility of delivering the intervention to TYACS. The outcomes of this pilot trial will include i) acceptability of the main trial components (e.g. recruitment procedures, randomization procedures) to TYACS ii) TYACS engagement with the intervention materials and iii) the feasibility of collecting data high quality data on proposed trial outcomes measures (including measures of health behaviour and well-being) among TYACS post-cancer treatment. The results of the pilot trial will inform the design of a future large scale randomised controlled trial.

Background & Rationale: In the UK, there are approximately 16,630 teenage and young adult cancer survivors (TYACS). This figure will increase annually relative to the improvements continually being made in cancer treatment. However, it is estimated that by the age of 45, 95.5% of TYACS will suffer from at least one chronic health condition. Therefore there is a strong impetus to improve the quality of long-term survivorship among young people. Within this context the Cancer Taskforce Strategy advocates that all cancer patients should be receiving health behaviour intervention by 2020.

However, there are currently no health behaviour interventions available in the UK to support TYACS after a cancer diagnosis. Recent qualitative data gathered by our group demonstrate that most TYACS in the UK desire age-appropriate health behaviour information on physical activity, diet, smoking, alcohol consumption, and sun safety; delivered in multiple formats (paper, face-to-face, websites, and apps); at various time-points throughout the cancer pathway. TYACS also noted they would benefit from formal behaviour change support to overcome the multiple psychosocial and practical barriers they face when attempting to lead a healthy lifestyle. When surveyed TYA cancer professionals cite lack of available resources as a barrier to providing health behaviour information to patients within their care. Based upon these findings we developed a health behaviour change intervention specifically for TYACS in the UK.

However, the efficacy of existing health behaviour interventions conducted among TYA cancer survivors have been undermined by inadequate delivery of the intervention, poor study recruitment, and low participant retention. As per the Medical Research Councils’ Guide to Complex Intervention Development a series of feasibility and piloting work should be carried out prior to any large scale evaluation studies investigating the efficacy and cost-effectiveness of an intervention. Piloting intervention procedures and estimating recruitment and participant retention ahead of further developments ensures the overall efficacy of the intervention (and the end results of the larger evaluation study) are not affected by these factors.

The aim of this fellowship is therefore to carry out a two-arm pilot randomised controlled trial of a health behaviour intervention designed specifically for TYACS versus usual care. The results of this feasibility trial will be used to refine and modify the intervention materials and study methods ahead of a definitive, large-scale, national, cluster-randomised controlled trial to examine the effects of the intervention on health outcomes and the use of the programme in routine TYA cancer care.
Appendix 10.1

Project Description:

Aims of project:
The primary aim of this project is to assess the feasibility and acceptability of a health behaviour change intervention designed specifically for TYACS. Specifically this project will i) determine the proportion and demographic characteristics of TYACS interested in participating in a health behaviour intervention and ii) assess TYACS engagement with and adherence to the health behaviour change intervention materials.

The secondary aim of this project is to determine the feasibility and acceptability of the main trial components (e.g. recruitment procedures, randomisation procedures). Specifically the pilot trial will allow insight into the feasibility of collecting data high quality data on proposed trial outcomes measures (including measures of health behaviour and wellbeing) among TYACS post-cancer treatment.

Methodology:

Participants
Any young person between the age of 13 and 24 who had been diagnosed with cancer at any point in their lifetime will be eligible to participate; this includes young people aged 13-25 years of age who were diagnosed with cancer during their childhood (aged 0-12 years). Young people with cancer will be eligible to take part if they have i) stable disease and ii) are off treatment or on maintenance therapy. Patients will be excluded if they i) are unable or unwilling to provide informed consent, ii) have persistent disease unstable disease and/or iii) are receiving active cancer treatment requiring hospital admission.

Design
This is a two-arm pilot randomised controlled trial. The intervention will last 12 weeks. Data will be collected from participants at three time points, baseline (week 0, T0), immediately following delivery of the intervention programme (week 12, T1) and at three month follow up (24 weeks, T2).

Setting
TYACS (n=40) will be recruited from the out-patient clinics of the two TYA principal treatment centres based within London (University College London Hospital and The Royal Marsden). Health professionals who work with young people in these settings will be asked to sign-post their patients towards the intervention study. Advertisements for the study will also be placed upon CLIC Sargents participation pages, twitter page and young peoples’ network page. CLIC Sargent is a UK based cancer charity specialising in providing supportive care to young people, and their families, who have been affected by cancer.

The Intervention
The TYACS health behaviour change intervention consists of an A5 booklet containing self-guided information and behaviour change materials designed to help TYACS make healthy lifestyle choices habitual. The paper based materials, designed to prompt sustained behaviour change, are based upon habit-theory and contain self-monitoring logs, advice on habit-formation and guidance on how to set achievable goals. Information on local resources in the London and Thames area are also included within the intervention. These materials are accompanied by a website containing the same health behaviour information and behaviour change materials in digital format. An online peer-to-peer support group is included within the intervention in the form of a private Facebook group. These intervention materials have been developed following a programme of research in partnership with CLIC Sargent.

Control Group (Usual Care)
Patients randomised to the control group will receive ‘usual care’. Previous research\textsuperscript{3,4} suggests TYA cancer survivors do not receive formal health behaviour change information or support as part of routine care. Participants within the control group will be asked to complete the same outcome measures as the intervention group and specify if they are involved in any other health behaviour change programme and at follow-up will be asked about any changes to their health or treatment.

Outcome Measures

Primary Outcome: Intervention Feasibility

The feasibility of the intervention will be assessed by recording participant recruitment to (% uptake) and compliance with (% drop-out) the intervention across the study period. At the post intervention assessment (T1) TYACS will be asked to complete a questionnaire which will include questions on how useful the intervention contents were, reasons for not complying with the intervention, if participants engaged with the intervention tools (the action plans, goal setting logs, private peer support forum), if they set goals, things that prevented them from setting goals and their overall satisfaction with the intervention. We will also test study attrition post-intervention (T1) and at follow-up (T2) to determine if it is feasible to engage TYACS in an intervention study over a long period of time.

Previous research suggests some health professionals are reluctant to discuss health behaviour with TYACS as they fear jeopardising the young persons’ engagement with the health-care system.\textsuperscript{5} Health professionals who were actively involved in sign-posting or recruiting young people towards the intervention study will be invited to take part in an adjoining qualitative study exploring the barriers they faced when sign-posting TYACS towards health behaviour information resources.

Secondary Outcome: Behaviour change and well-being

The secondary research objective is to test the feasibility of collecting high quality data on proposed trial outcome measures. Participants will be asked to complete a health and lifestyle questionnaire at each measurement time-point. The questionnaire will include validated measures of physical activity, sedentary behaviour, diet, smoking, alcohol consumption and sun-safety. Physical activity will also be assessed using accelerometers which provide a reliable and accurate assessment of step count. In order to assess the impact of the intervention on TYA cancer survivors well-being, measures of psychosocial health (general quality of life, fatigue and sleep quality) will be included in the questionnaire booklet at each assessment.

Covariates

Demographic data including age, sex, employment/education status, marital status, living arrangements, and ethnicity will also be collected via the self-report questionnaire. Participants will also be asked to self-report the type of cancer they were diagnosed with, date of their diagnosis, type of treatments they have received and if they are experiencing any treatment related toxicities or other health problems. These will be checked against medical records.

Milestones:

Ethical approval for the study will be sought from the relevant institutional review boards. Recruitment will take place over a period of 2 months wherein we anticipate to recruit a total of 40 TYA cancer survivors to the intervention (20 participants per intervention arm). This is reflective of the recruitment rate we anticipate we would be able to successfully recruit each week in a larger scale project.