Positive Change for Life

Improving health, wellbeing and quality of life for survivors of blood cancer following stem cell transplantation by promoting a healthy lifestyle through diet and physical activity

Victorian Cancer Survivorship Program
Pilot Projects – Ref: VCSP:PP003

FINAL REPORT
Prepared by: Dr Sharon Avery

March 2014
Updated June 2014
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Authorship

This report was written by Dr Sharon Avery from the Alfred Hospital Malignant Haematology and Stem Cell Transplantation Service, Late Effects Clinic and Project Lead for the Positive Change for Life Survivorship pilot project.

This project was funded and governed by the Victorian Cancer Survivorship Program, Cancer Strategy and Development section of the Victorian Department of Health.
Certifications

Certification by the lead applicant

I certify that to the best of my knowledge, this is an accurate report.

<table>
<thead>
<tr>
<th>Name</th>
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<tr>
<td>Date:</td>
<td>25 March 2014</td>
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Date of final report 31/03/2014
Updated 30/06/2014

Certification by the head of the host organisation

<table>
<thead>
<tr>
<th>Name</th>
<th>Andrew Way</th>
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<tr>
<td>Position</td>
<td>CEO, Alfred Health</td>
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I certify that to the best of my knowledge, information contained in this report is complete and true.
Acknowledgments

The project is a Victorian Cancer Survivorship Pilot Project and is funded by the Victorian Government Department of Health.

I would like to thank the members of the project steering group, for providing expert opinion and/or project oversight. In particular, I would like to acknowledge the following individuals for their invaluable advice, enthusiasm and generosity of time:

- Anne Hodgson
- Beth Viner-Smith
- Patricia Walker
- Daniela Klarica
- Helen McLauchlan
- Sue Liersch
- Audrey Tierney

A number of individuals and organisations also supported the project and provided their expertise including:

- Kia Noble
- Jill Beattie
- Clinicians of the Malignant Haematology and Stem Cell Transplantation Service

Finally, I would like to thank the participants, their families and carers.
Key messages

- Health promotion is an essential component of optimal survivorship care. The completion of cancer treatment can represent an opportunity for lifestyle modification to reduce the effects of treatment, minimise risk for future health problems and promote long term wellness. Regular exercise, good nutrition and maintaining a healthy weight are all strategies that may improve health, wellbeing and quality of life.

- Resulting from their treatment exposures, long term survivors of blood cancer treated with stem cell transplantation have a significantly increased risk of premature mortality, serious morbidity, and adverse health status requiring a continuing focus on risk factor identification and opportunities to modify behaviours to reduce lifestyle related health risks.

- Historically, under-nutrition and cancer-related cachexia were the primary nutritional concerns in regard to cancer. While these issues remain important for some cancer survivors, excess body weight is the main nutritional concern facing most cancer survivors today. Due to the adverse effects of being overweight or obese on cancer survival, general health outcomes and quality of life, weight management is now considered a priority for optimal survivorship care.

- In addition to weight gain, hypertension, dyslipidemia and elevated blood glucose are common problems in long term survivors of blood cancer and increase the risk for future chronic illness including cardiovascular disease. Other late effects experienced by some survivors include psychosocial sequelae and significant fatigue. Importantly, many of these late effects are modifiable through prevention or early detection and lifestyle modification.

- The chosen 12 month lifestyle intervention program integrating the key components of nutritional advice, individually tailored community-based physical activity, group physical activities, educational resources and incentive strategies facilitated consequential and impactful changes in behaviour and lifestyle. Important outcomes relating to increased physical activity levels, improved nutrition, weight loss, reduced fatigue and enhanced health-related quality of life including physical, emotional and functional wellbeing were evident for the majority of participants. A comparator group of long term stem cell transplant survivors receiving general health advice but not engaging in a structured physical activity and dietary intervention did not demonstrate similar favourable changes over a 12 month observation period.

- The current program was acceptable to and highly valued by participants who demonstrated readiness to participate in the program with strong themes emerging of a desire to improve health, increase fitness and lose weight. Participants that wanted a partner or significant other involved found that they both achieved health benefits.

- Dietetic support plays a critical role beyond the acute care phase of the cancer trajectory and into survivorship care. A structured program of telephone-based dietetic consultation based on the ‘Coach for Heart Health’ model initially used for cardiac rehabilitation represents an effective and inexpensive means of improving nutrition and reducing unhealthy eating behaviours. Its further appeal lies in its safety, high-level of acceptance and broad applicability.

- The majority of beneficial outcomes occurred for participants within the first 6 months of the project. These benefits have then been maintained over time including up to 6 months after project completion.

- This project has identified significant barriers to primary care and acute care facility collaboration around cancer survivorship care including the perception that cancer survivorship care needs are ‘cancer-related’ and therefore out of scope and not relevant to general practice rather than as chronic disease management where general practice expertise lies.

- Quality care of cancer survivors must start with shifting from a disease focused approach to a wellness centred approach that provides coordinated, patient-centred, comprehensive care, including detection and treatment of the long term effects of cancer and its treatment. Care should include surveillance for non-cancer health problems and health promotion in order to minimise dysfunction or disability and maximise wellbeing and overall quality of life.

- Our project model highlights the potential of an individualised community-based physical activity program coupled with nutritional advice to improve health behaviours, enhance quality of life and reduce fatigue with much overlap and applicability evident to all cancer survivors.
Executive summary

This report and the accompanying Evaluation Report presents the findings from the Positive Change for Life cancer survivorship pilot. In these documents, we outline the methodology used in the Positive Change for Life project, assess the extent to which project delivery adhered to project procedures and measure the impact and outcomes of the project to date. Recommendations for refining and improving future programs of a similar nature are made based on these findings.

For context, every day, 31 people in Australia are diagnosed with a blood cancer such as leukaemia, lymphoma or multiple myeloma. Haemopoietic stem cell transplantation – also referred to as bone marrow transplantation - has been increasingly used since the late 1960’s as an additional treatment to chemotherapy offering effective control and potential cure of a proportion of these blood cancers. After preparation with high doses of chemotherapy sometimes combined with radiotherapy, healthy stem cells are given to the patient to produce new healthy bone marrow. The Malignant Haematology and Stem Cell Transplantation service at the Alfred Hospital is one of only two adult allogeneic stem cell transplant facilities in Victoria.

More than 60,000 stem cell transplants are currently performed worldwide every year. In Australia in 2012, a total of 1567 transplants were performed. Currently there are 11,847 transplant survivors requiring follow-up care in Australia. 2,854 of these were Victorian residents at the time of transplant and although some will have been treated as children, 92% of survivors are currently adults.

Major progress has been made in improving survival after stem cell transplantation and this treatment is therefore more widely available, even to older populations. Patients free of their blood cancer for 2 years after transplantation have a 89% probability of living another 5 years and most of these people will become very long term survivors. Stem cell transplantation, however, is a highly aggressive and demanding medical intervention. Survivors are therefore at the highest risk for a range of long term or late effects which may be physical, emotional, social or spiritual.

The Alfred Hospital’s Late Effects Clinic is a multidisciplinary clinic dedicated specifically to the long term follow-up of stem cell transplant survivors, their families and carers. Through this clinic, a critical need for this group of survivors to address lifestyle to minimise risk for future chronic illness has been identified. Assessments of modifiable risk factors have revealed high levels of obesity, hypertension, diabetes and dyslipidemia. These rates appear to be higher than that observed in the general Australian population and do not differ depending on the type of transplant that the person has undergone. Lifestyle modification focusing on nutrition and physical activity has the potential to impact substantially on these future health risks.

The current pilot project aimed to empower survivors to develop and maintain lifelong healthy eating and physical activity patterns. The target population was long term survivors of blood cancer in ongoing remission from their blood cancer who had been treated at least two years previously with either autologous or allogeneic stem cell transplantation. Within the setting and work flow of the Alfred Late Effects Clinic, each project participant entered a 12 month program integrating the key components of individually tailored community-based physical activity, group physical activity, general practitioner support, education, motivational strategies and a structured program of dietetic consultation based on the ‘Coach for Heart Health’ model used for rehabilitation after heart attacks.

Patient-reported outcome measures were recorded at baseline and following 6 and 12 months of project participation and included quality of life scales, fatigue assessments, self-efficacy scores, physical activity and nutrition questionnaires. Baseline weight, abdominal and hip circumference, systolic and diastolic blood pressure, fasting glucose and lipid profiles were performed at baseline and repeated at 12 months. A final series of questionnaires were administered at 18 months i.e. 6 months after project completion to assess if any documented changes have been maintained.

Between June 2012 and July 2013, the project enrolled 53 participants (25 male; median age 48 years). The average time since either autologous (32%) or allogeneic (68%) stem cell transplants, the patient is their own stem cell donor. The patient’s blood stem cells are collected in advance while they are in remission and then returned to them after they receive high doses of chemotherapy and/ or radiotherapy. In allogeneic stem cell transplants, the stem cells are donated by another person whose tissue type is compatible with the patient.
transplantation was 6 years. Recruitment of participants was spread across existing Late Effects Clinic patients and external referrals. Recruitment was not limited by interest from the target population, but rather by resources and constraints imposed by the evaluation time frame of the pilot. Participant attrition was low. No adverse events were reported.

Project participants at baseline were representative of Late Effects Clinic attendees in general with 68% of participants being overweight or obese and 85% meeting criteria for central obesity. Assessments of modifiable risk factors revealed a large proportion of participants had hypertension (58%), dyslipidemia (49%) and elevated blood glucose (17%).

At baseline 15% of participants reported severe fatigue. Higher fatigue levels were strongly associated with lower self-reported physical, social, emotional, functional and overall quality of life. Unhealthy eating behaviours – such as skipping breakfast, eating large amounts of take away foods - were commonly reported by participants at baseline coupled with high levels of willingness to make dietary changes to improve their health. Prior to engaging in the Positive Change for Life project, 59% of participants reported insufficient physical activity to make any contribution to health.

6 month data collection is complete with evaluations returned by 41 participants (80% return rate). With rolling recruitment, 12 month evaluations are currently available for 47 participants with 3 participants currently remaining on project. 18 month evaluations have been distributed to the 33 participants who have currently reached that time point and returned by 25 representing a 76% return rate.

The majority of beneficial outcomes appear to have occurred for participants within the first 6 months of project participation. Positive benefits have been subsequently maintained between 6 and 12 months and beyond to 18 months albeit with only small numbers of 18 month evaluations currently available for analysis. 32% of participants report clinically meaningful improvements in fatigue and functional wellbeing at 6 months compared with baseline, increasing to 43% and 40% at 12 months, respectively. 27% also report improvements in their physical and emotional wellbeing and overall quality of life at 6 months with modest additional enhancements reported at 12 months.

Marked improvements in physical activity levels were identified at both 6 and 12 months with striking increases compared with baseline in overall physical activity, moderate and strenuous physical activity and frequency of activity sufficient enough to work up a sweat. Ongoing improvement in the proportion of participants engaging in levels of physical activity sufficient to contribute to health was reported at 12 months (58%) compared with baseline (21%).

Higher physical activity levels were significantly associated with reduced self-reported fatigue, improved overall quality of life in addition to physical and functional wellbeing, and enhanced self-efficacy scores at both 6 and 12 months. At 12 months, higher physical activity levels were significantly correlated with reductions in unhealthy eating behaviours, improved nutrition scores and healthier lipid profiles.

Improvement in nutrition scores occurred progressively throughout the 12 months of project participation. Better absolute nutrition scores were reported by 61% of participants at 6 months and 81% at 12 months with a corresponding reduction in unhealthy eating behaviours in 56% and 66% of participants at 6 and 12 months, respectively. Willingness to make dietary change did not change over time remaining high at all evaluation time points.

75% of participants had documented weight loss at their 12 month face-to-face evaluation with an average weight loss of 4.0 kg or 4.7% change in body weight. Further, 76% had a reduction in their visceral adiposity as measured by abdominal circumference with an average loss of 4.0 cm. This was not seen in a matched group of Late Effects Clinic attendees receiving general health advice but not participating in Positive Change for Life who had a median increase of 1.5 kg in weight and 1.5 cm in abdominal circumference over a 12 month observation period. Favourable changes in HLD cholesterol also differed significantly between Positive Change for Life participants and the comparator group. A reduction in both systolic and diastolic blood pressure by at least 4 mmHg was observed in 47% and 40% of project participants at 12 months, respectively, again not documented in clinic attendees not participating in Positive Change for Life.
A summary of key outcomes is shown in the following table:

<table>
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<th>6 months</th>
<th>12 months</th>
<th>18 months</th>
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<tbody>
<tr>
<td><strong>Fatigue</strong></td>
<td></td>
<td></td>
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<tr>
<td>Clinically meaningful fatigue reduction*</td>
<td>32%</td>
<td>43%</td>
<td>36%</td>
</tr>
<tr>
<td><strong>Nutrition</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Absolute increase in nutrition scores</td>
<td>61%</td>
<td>81%</td>
<td>72%</td>
</tr>
<tr>
<td>Reduced unhealthy eating habits</td>
<td>56%</td>
<td>66%</td>
<td>72%</td>
</tr>
<tr>
<td><strong>Physical activity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased overall physical activity levels</td>
<td>78%</td>
<td>74%</td>
<td>80%</td>
</tr>
<tr>
<td><strong>Quality of Life</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Clinically meaningful increase in physical wellbeing*</td>
<td>27%</td>
<td>19%</td>
<td>28%</td>
</tr>
<tr>
<td>Clinically meaningful increase in emotional wellbeing*</td>
<td>27%</td>
<td>28%</td>
<td>33%</td>
</tr>
<tr>
<td>Clinically meaningful increase in functional wellbeing*</td>
<td>32%</td>
<td>40%</td>
<td>33%</td>
</tr>
<tr>
<td>Clinically meaningful increase in overall quality of life*</td>
<td>25%</td>
<td>30%</td>
<td>46%</td>
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<tr>
<td><strong>Qualitative</strong></td>
<td></td>
<td></td>
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<tr>
<td>Continue nutrition changes after project?</td>
<td>96%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continue exercise program after project?</td>
<td>89%</td>
<td></td>
<td></td>
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<tr>
<td>Carers observed benefit to participant</td>
<td>94%</td>
<td></td>
<td></td>
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<tr>
<td>Carer personally benefited</td>
<td>85%</td>
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<table>
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<th>18 months</th>
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<tr>
<td><strong>Weight</strong></td>
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<td></td>
<td></td>
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<tr>
<td>Weight loss (mean 4.7%)</td>
<td></td>
<td>75%</td>
<td></td>
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<tr>
<td><strong>Measurements</strong></td>
<td></td>
<td></td>
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<tr>
<td>Reduced waist circumference (mean 4 cm)</td>
<td>76%</td>
<td></td>
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<tr>
<td>Reduced hip circumference (mean 2.9 cm)</td>
<td>52%</td>
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<tr>
<td>Absolute reduction in waist:hip ratio</td>
<td>70%</td>
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<tr>
<td><strong>Blood pressure</strong></td>
<td></td>
<td></td>
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<tr>
<td>Systolic blood pressure reduction by ≥4 mmHg</td>
<td>47%</td>
<td></td>
<td></td>
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<tr>
<td>Diastolic blood pressure reduction by ≥4 mmHg</td>
<td>40%</td>
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* by validated published criteria

This project has identified significant barriers to primary care and acute care facility collaboration around cancer survivorship care including the perception that cancer survivorship care needs are ‘cancer-related’ and therefore out of scope and not relevant to general practice rather than as chronic disease management where general practice expertise lies. Successful aspects of general practitioner engagement in the project included favourable feedback from general practitioners regarding the survivorship care plans sent to them as standard Late Effects Clinic practice and communication through newsletters, magazines and conferences.

The current project model was acceptable to and highly valued by participants who demonstrated readiness to participate in the program with strong themes emerging of a desire to improve health, increase fitness and lose weight. Participants that wanted a partner or significant other involved found that they both achieved health benefits.

Lifestyle modification is an increasingly important component of cancer survivorship to ameliorate the effects of treatment, minimise risk of associated co-morbidities and promote long term wellness. Our project demonstrates the potential of an individualised community-based physical activity program coupled with nutritional advice to improve healthy lifestyle behaviours, promote weight loss, enhance quality of life and reduce fatigue levels in long term survivors of stem cell transplantation. In the immediate future, the most successful aspects of the Positive Change for Life project will be integrated into the Leukaemia Foundation’s existing suite of services as their Jump Start Program which will be suitable for a broader range of blood cancer survivors not only those who have undergone stem cell transplantation. For the future, the current Positive Change for Life project pilot with appropriate resource support is perceived to be directly transferrable to most cancer types with the benefits of exercise already well documented in a number of tumour streams, with additional benefits anticipated relating to the inclusion of nutritional support.
Section 1: Background

1.1 Health service
Alfred Health is a leading major metropolitan health service, serving the population in Melbourne's Bayside and Inner Southeast area. As Victoria’s oldest hospital operating on its original site, The Alfred is renowned for its honoured tradition of community service and high-end clinical expertise. Since its inception in 1871, it has been recognised as a pacesetter in the national medical arena and has consistently been linked to progressive developments in acute care, medical research and health care teaching.

The Alfred has a long and esteemed history in the diagnosis and treatment of blood diseases. Several major advances in the understanding of blood diseases have been the direct outcome of work here and this strong history has enabled the hospital to continue to grow its clinical program in blood diseases to its current size, where it is now the largest and most comprehensive haematology service in Australia encompassing clinical, teaching and research activities through the Australian Centre for Blood Diseases. The service has internationally recognized expertise in the treatment of multiple myeloma and acute myeloid leukaemia.

The Malignant Haematology and Stem Cell Transplantation Service at Alfred Health, is an integral part of the Department of Clinical Haematology and a critical component of the hospital's comprehensive cancer program providing high acuity malignant haematology services for an extended catchment of approximately two million Victorians. Haemopoietic stem cell transplantation – also referred to as bone marrow transplantation - has been increasingly used since the late 1960's as a potentially curative treatment for a variety of blood cancers that may be incurable with conventional therapy. Stem cell transplantation can be either autologous (using the patient's own stem cells) or allogeneic (using stem cells from a family member or unrelated donor), with allogeneic being more complex than autologous transplants. The Malignant Haematology and Stem Cell Transplantation service is one of only two adult allogeneic stem cell transplant facilities in the state.

1.2 Needs Assessment
Haemopoietic stem cell transplantation is potentially curative for many people with otherwise incurable blood cancers. For context, every day, 31 people in Australia are diagnosed with a blood cancer such as leukaemia, lymphoma or multiple myeloma. Stem cell transplantation, as an additional treatment to chemotherapy, offers effective control and potential cure of a proportion of these blood cancers. After preparation with high doses of chemotherapy sometimes combined with radiotherapy, healthy stem cells are given to the patient to produce new healthy bone marrow.

More than 60,000 stem cell transplants are performed worldwide every year. In Australia in 2012, 1016 autologous and 551 allogeneic transplants were performed in 40 transplant centres. Of these, 387 were performed in Victoria. Major progress has been made in improving survival after transplants and transplants are therefore more widely available, even to older populations.1-3 Patients who are disease-free 2 years following transplantation for blood cancers have a 89% probability of living another 5 years and most will become very long term survivors.4 At the current time there are 11,847 transplant survivors requiring follow-up care in Australia with an average age of 56 years. 2,854 of these were Victorian residents at the time of transplant and although some people will have had their transplants as children, 92% of survivors are currently of adult age.

Stem cell transplantation, however, is a highly aggressive and demanding medical intervention. Stem cell transplant survivors, therefore, are a particularly high risk group for late effects which can affect a survivor's physical, cognitive, and psychosocial wellbeing.5 Although many long term survivors enjoy good health, for others cure or control of their underlying disease is not accompanied by full restoration of their former health resulting in an overall health status inferior to matched control groups.6

In recognition of this, The Alfred Malignant Haematology and Stem Cell Transplantation Service has established Australia's first Late Effects Clinic dedicated specifically to the long term follow-up of stem cell transplant survivors, their families and carers. Within a clinic-based multidisciplinary comprehensive care model we:

- Assess and manage a wide range of psychological, social and physical late effects
- Promote wellness through preventative strategies, empowerment and patient education
- Raise awareness, provide leadership and promote partnerships within the primary care sector.
Patients greater than two years following transplantation and in ongoing remission from their blood cancer are eligible to attend the clinic. These criteria allow for acute medical issues to have resolved and the focus to be on future health risks. Survivors are reviewed annually to set individualised health goals for the next 12 months. The clinic's risk-based care strategy is proactive including a systematic plan of prevention and surveillance tailored to an individual's prior cancer therapy, lifestyle behaviours, family history, current health status and laboratory tests. Survivors and their general practitioners are engaged to take responsibility for following up recommendations with the provision of a written Survivorship Care plan and clear contact information for ongoing support.

Since its establishment in 2008, the Alfred Late Effects Clinic has provided comprehensive health assessment and Survivorship Care planning for over 150 long term stem cell transplant survivors. Within the particularly complex care needs of this group, a number of areas of critical, yet unmet, need have emerged. Assessments of modifiable risk factors have revealed a large proportion of the transplant survivors attending the Alfred Late Effects Clinic are overweight or obese (73%), have hypertension (54%), elevated triglycerides (46%) or raised blood glucose (25%). The metabolic syndrome is a clustering of risk factors characterised by abdominal obesity, insulin resistance, atherogenic dyslipidemia and hypertension. In men, the metabolic syndrome is associated with a 4 fold increase in risk for fatal coronary heart disease and a 2 fold greater risk of cardiovascular disease, even after adjusting for age, cholesterol, smoking and family history.7, 8 The metabolic syndrome is also associated with increased coronary heart disease risk in women.9 Similar to the international literature10-18, we have previously reported a high prevalence of metabolic syndrome in transplant survivors with 49% of Late Effects Clinic attendees receiving a diagnosis of metabolic syndrome. By comparison, the general prevalence of metabolic syndrome in Australian adults aged more than 18 years is 22.8% (men 26.4%, women 15.7%).19 Lifestyle modification with an emphasis on nutrition and physical activity has the potential to impact substantially on these risk factors.

Of particular concern is the risk of second malignancy following curative therapy for cancer. The incidence of second malignancy continues to rise without a plateau with increasing follow-up of long term stem cell transplant survivors.20 In addition to adherence to appropriate screening recommendations to detect and treat these cancers at an early stage, preventative health measures relating to lifestyle factors, including nutrition and regular exercise, should be encouraged to reduce the risk of developing cancer.21 Many of the lifestyle and health risk factors identified in transplant survivors are remediable with early recognition, education, behaviour modification and appropriate treatment where necessary. Considerable health benefits are to be derived from addressing these issues in a systematic way. Overall, good nutrition and regular exercise are thought to have protective or beneficial effects relating to many health issues identified in this group of blood cancer survivors including obesity and weight management, heart disease, type 2 diabetes, hypertension, high cholesterol, osteoporosis, breast and colon cancer, anxiety and depression, psychosocial functioning, fatigue and quality of life.22 Further, extensive research strongly supports the efficacy and safety of physical activity interventions in cancer survivors both during and following cancer treatment.23-27

Section 2: Project model

2.1 Project Aims and Objectives

This project aims to provide a range of community-based physical activities, support and health education opportunities to enable survivors of stem cell transplantation, at any fitness level, to take an active role in their ongoing physical and emotional healing to benefit health, wellbeing and quality of life. Expected project outcomes are therefore:

1. Implementation of an innovative program to address an area of identified need in stem cell transplant survivors
2. Delivery of quality survivorship care in a community-based accessible program integrated with specialist and peer support
3. Empowerment of survivors to be active participants in their own lifelong care through psychological, social and educational support
4. Promotion of awareness of cancer survivorship needs
5. Engagement of the wider community in survivorship care
6. Development of a program model transferable across tumour streams.
2.2 Pilot Model

2.2.1 Governance and Stakeholders

Collaborators
The project was developed in collaborative partnership with the Leukaemia Foundation and the Southern Melbourne Integrated Cancer Service (SMICS). The Leukaemia Foundation is the only Australian not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemia, lymphoma, myeloma and related blood disorders. The Integrated Cancer Services (ICS) are clusters of hospitals and associated health services that plan and improve services for people with cancer within a geographic area. SMICS is one of eight regionally based integrated cancer services comprising Alfred Health, Cabrini Health, Peninsula Health and Southern Health.

Governance

Project Steering Committee
The role of the project steering committee was to provide expert advice, deliver and action project requirements and provide feedback on all project activities. Members of the steering group were expected to regularly report the project’s purpose, objectives and progress to their organisation / professional group and bring feedback to the steering group meetings. 16 meetings were convened.

Project management
A project manager (HS4 Grade 4, 0.6 EFT) with a qualification in physiotherapy and experience in project management was appointed to develop and manage the project. The Late Effects Clinic team consisting of two haematologists and a nurse coordinator were responsible for the day-to-day management of the project.

2.2.2 Target Population
Long term survivors of blood cancer in ongoing remission from their haematological malignancy who are at least two years following treatment with either autologous or allogeneic stem cell transplantation were offered the opportunity to participate in the Positive Change for Life project. This group of cancer survivors are all considered to be at high risk for late effects and, therefore, the current project was not designed to specifically analyse or test a risk stratification approach.
2.2.3 Project Design

The project design did not require any specific additional workforce training. Within the setting and work flow of the Alfred Late Effects Clinic, each project participant entered a 12 month program integrating the key components of:

a) Professional nutritional advice provided by a dedicated dietitian

A structured program of dietetic consultation based on the COACH (Coaching Patients on Achieving Cardiovascular Health) model used for rehabilitation after heart attacks was adopted.\textsuperscript{30} The COACH program has been validated by two randomised controlled trials.\textsuperscript{31, 32} The first was from a single centre and the second from six Victorian teaching hospitals including the Alfred resulting in high levels of local expertise with the program. In both trials, The COACH Program was found to be a highly effective strategy in reducing coronary risk factors in patients with coronary heart disease with potential effectiveness across the whole spectrum of chronic disease management.\textsuperscript{31-33}

In essence, the COACH intervention is a telephone-delivered program to engage people in pursuing behaviours to assist their health, to achieve risk factor targets and maintain adherence with evidence based treatment. Each participant received a detailed face-to-face dietetic consultation at the time of enrolment to the Positive Change for Life project. One to two weeks following this, and on 2 more occasions (4 months and 8 months following the initial consultation) coaching telephone calls were conducted with the participant by the dietitian as previously described.\textsuperscript{31} A final face-to-face consultation with the dietitian was undertaken following 12 months of project participation with an ongoing referral to a community dietitian made if clinically appropriate.

b) Individually tailored community-based physical activities

More than 70 intervention trials of physical activity for cancer survivors have now been published.\textsuperscript{23} This extensive research strongly supports the efficacy and safety of physical activity interventions in cancer survivors both during and following cancer treatment. The general exercise recommendations for people having completed cancer treatment is low to moderate intensity sessions 3-5 times per week for at least 20 minutes involving aerobic, resistance or mixed exercise types.\textsuperscript{34, 35} This is largely consistent with recommendations for the general adult population. These recommendations formed the basis of a desirable physical activity plan for project participants.

Most studies, however, have found that lifestyle modification counselling in a primary care setting alone is not sufficient to effect behavioural change. More intensive and individualized engagement \textsuperscript{36, 37} and provision of a personalised exercise prescription\textsuperscript{38} is likely to be more effective. Therefore, an individualised physical activity plan was collaboratively developed between the project manager/physiotherapist and the participant and tailored to account for current fitness level, past medical history and personal goals. Activities were community-based and cost neutral to the participant. Appropriate physical activities varied for each participant and included membership to gymnasiums, fitness centres, yoga, personal training, water exercise, Local Council fitness programs, walking schedules, Pilates etc. Community-based physiotherapy or exercise physiology referrals prior to commencing individual physical activity program were offered to all participants. Participants were provided with a physical activity training diary incorporated into their participant handbook at the baseline visit to record and monitor their individual physical activities.

c) Group physical activities to promote peer support

A variety of group activities for all fitness and experience levels were held in various locations throughout Southern Melbourne. These activities were designed to provide a fun, friendly way to begin, or maintain, a regimen of regular physical activity and social interaction. Family members were welcome and encouraged to attend. All activities were cost neutral to participants. At project enrolment, participants were asked to provide feedback via a specific form to facilitate planning of suitable group physical activity events. Notification of upcoming events was sent to all participants several weeks in advance of the event either at the time of monthly newsletter distribution or as a separate mailed flyer. RSVPs were requested.

d) Educational Resources - Participant Handbook and Monthly Newsletter

A comprehensive participant handbook was developed with the intention of supporting self management and survivor empowerment through education. Multiple studies have demonstrated that patients who are involved in their own care have improved health outcomes compared with those who are less engaged.\textsuperscript{39, 40} The handbook was therefore developed collaboratively with consumer engagement, contributions from key stakeholders and a specific nutrition component
developed for transplant survivors. The handbook was distributed to all participants at the time of entry to the Positive Change for Life program. In response to feedback from participants, a second version of the handbook was developed incorporating a 3 day food diary, weekly meal planner and weekly shopping list.

To positively reinforce and encourage participants, newsletters were prepared by the project manager and distributed monthly by mail to all participants (past and present), their general practitioners, and Positive Change for Life Steering Group members in addition to being available on the Late Effects Clinic and Australian Cancer Survivorship Centre websites and Hume Regional Integrated Cancer Service Cancer Survivorship Collaborative workspace. Newsletters typically contained motivational hints and tips, educational articles, photos of recent events, upcoming group activities and healthy living recipes.

e) Incentive strategies
To promote ongoing engagement of participants in the program, in addition to promoting community awareness of survivorship, promotional items were sourced, purchased and distributed to participants at a time relevant to scheduled group physical activities or given to participants at the time of enrolment to the Positive Change for Life program. These included easily recognisable 'branded' promotional items e.g. T-shirts, drink bottles, frisbees, and pedometers.

f) Shared care with community general practitioners
A shared care model for Positive change for Life participants with their community general practitioners including communication and engagement strategies was envisioned. The Alfred Late Effects Clinic team strongly and actively encourages survivors to continue routine and non-cancer related follow-up care with their general practitioners. In line with published recommendations, written survivorship care plans that are updated annually have been embedded as part of routine survivorship care provided by the Alfred Late Effects Clinic since 2008. These are provided to clinic attendees (including Positive Change for Life participants), their general practitioners and other health care providers. The development and implementation of a survivorship care plan, therefore, has not been a specific focus of the Positive Change for Life Project. For participants in the Positive Change for Life project, additional involvement of their general practitioner was invited to regularly guide, supervise and monitor their progress throughout project involvement.

g) Ongoing Annual Late Effects Clinic Attendance
The Late Effects Clinic will continue its role in the delivery of survivorship care plans and transplant specific survivorship care in line with published consensus guidelines. Beyond the life of the project, all participants, regardless of referral pathway, will be invited to continue their long term survivorship care through this established multi-disciplinary clinic.

2.3 Evaluation strategy
Appendix 2 outlines the detailed evaluation strategy. The following key performance indicators were developed to monitor and evaluate each component of the Positive Change for Life program:

- Individual program participants’ outcomes
- Uptake of the program by individuals
- Acceptability to program participants (satisfaction)
- Effectiveness of program for participants (measurements against baseline)
- Acceptability to community and specialist stakeholders
- Cost benefits/limitations for individual participants
- Cost benefits/limitations for specialist and community stakeholders
- Sustainability of the program beyond the life of the project to the broader national haematological cancers services and other tumour streams.

The evaluation framework for the Positive Change for Life project, therefore, included:
1. Process evaluation – relating to each key component of the project in addition to the agreed communication strategy.
2. Impact evaluation – relating to change over time (measured at 6 and 12 months) in the following patient-reported outcome measures compared with pre-participation baseline measurements for individuals and the participating group as a whole.
   - Quality of Life
   - Fatigue
   - Barriers to physical activity
Dietary intake, and
Leisure time physical activity levels.

A final series of questionnaires are administered at 18 months i.e. 6 months after project completion to assess if any documented changes have been maintained.

3. Outcome evaluation – relating to change in the following anthropometric and laboratory measures following 12 months of project participation compared with pre-participation baseline measures for individuals and the participating group as a whole. Comparison to a cohort of long term survivors of stem cell transplantation with 2 or more consecutive annual Late Effects Clinic consultations who received general health advice but did not participate in Positive Change for Life was also performed.

a. Anthropometric measurements
   - Weight and body mass index
   - Abdominal circumference
   - Hip circumference
   - Waist:hip ratio
   - Systolic and diastolic blood pressure

b. Laboratory parameters
   - Fasting lipid profile (total cholesterol, HDL-cholesterol, LDL-cholesterol, triglycerides)
   - Fasting blood glucose.

Qualitative evaluation of the project involved key stakeholder focus groups and in-depth interviews (participants, allied health professionals and gym, fitness and health centre providers) facilitated by a professional moderator and evaluator. To supplement and guide the focus groups, the following surveys were developed collaboratively by the steering committee and distributed electronically (survey monkey) and in paper-based format by mail with reply paid return envelopes supplied:

- Participant satisfaction survey – following 4 months of project participation
- Participant outcome survey – following 9 months of project participation
- Carers’ survey – following 9 months of project participation
- General practitioner survey – following 9 months of project participation (including questions relating to the survivorship care plan).

Section 3: Project Implementation

3.1 Implementation strategy

Approval for the project was obtained from the Alfred Hospital Ethics committee. The target population of long term survivors of either autologous or allogeneic stem cell transplant were recruited by several means including from within the existing Alfred Late Effects clinic by invitation and through external recruitment by information sessions within the Leukaemia Foundation, Late Effects Clinic website, general practitioner e-publications and word of mouth.

Rolling recruitment of participants occurred over a 12 month period within the usual workflow of the Late Effects Clinic. Participants attended separate face-to-face visits at project entry (baseline) and at 12 months. Each face-to-face visit occurred within a standard Late Effects Clinic consultation consisting of a 30 minute nursing review and 60 minute medical consultation. Following informed consent and medical clearance, participants were then assessed by the project dietitian within the same clinic and interviewed by the project manager to discuss physical activity options, set up gym or other service membership and facilitate formal physiotherapy / exercise physiology review. During these face-to-face visits, patient-reported outcome measures were completed, anthropometric measurements recorded and blood testing performed. Additional patient-reported outcome measures were completed at 6 and 18 months via mail with reply paid return envelopes supplied.

A dietitian was employed for one session each week (0.1 EFT) to provide services for the Positive Change for Life project including baseline and 12 month face-to-face consultations with onward referral to a community dietitian as required at project completion, and telephone follow up sessions.

Participant’s nominated general practitioners were mailed an information pack containing a clinic letter, a project information flyer, project newsletter and a copy of the survivorship care plan as per standard Late Effects Clinic practice. Encouragement to implement a GP Management Plan and/or Team Care Arrangement allowing for referral to services recommended in the participant’s care plan.
under current Medicare guidelines was included in the information pack mailed to GPs. At the time of project completion, general practitioners received a summary of their patient’s outcomes resulting from Positive Change for Life participation incorporated into the participant’s survivorship care plan.

**Measurements and Assessments**

The following standardised patient-reported outcome measures were utilised:

1. **Health-related Quality of Life**

   Treatment specific quality of life was evaluated by the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT) scale, a validated self-administered tool used to assess health-related quality of life in patients after stem cell transplantation. It consists of the FACT-General (FACT-G) and a transplant-specific Bone Marrow Transplantation subscale covering additional concerns related to treatment. The FACT-G consists of 27 questions divided into four quality of life domains: physical, social, emotional and functional wellbeing. All scales are scored so that higher scores represent better quality of life (0 – 108 for FACT-G; 0 – 148 for FACT-BMT).

   A minimal important difference (MID) is defined as the “smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate, in the absence of troublesome side effects and excessive cost, a change in patient’s management”. MIDs for scores of scales and subscales from several FACIT instruments have been determined. A score difference at least equal to the MID was considered a clinically meaningful difference.

2. **Fatigue**

   The FACIT-Fatigue scale is a 13 item, symptom-specific subscale of the FACT scales with demonstrated reliability and validity that assesses self-reported fatigue and its impact upon daily activities and function. All FACIT scales are scored so that a high score is good with 0 being the worst possible score and 52 the best. A FACIT-Fatigue Scale of 30 or less, which is 2.0 SD below the average for the US general population is considered to be indicative of severe fatigue.

   The MID of the FACIT-Fatigue Scale has been determined to be 3 points.

3. **Barriers to Physical Activity**

   The Barriers Specific Self-Efficacy Scale (BARSE) is designed to capture participants’ perceived capabilities to exercise three times per week for 40 minutes over the next two months in the face of commonly identified barriers. For each item, participants indicate their confidence to execute the behaviour on a 100-point percentage scale comprised of 10-point increments, ranging from 0% (not at all confident) to 100% (highly confident). A total is then calculated by summing the ratings and dividing by the total number of items, resulting in a maximum possible efficacy score of 100.

4. **Leisure Time Physical Activity**

   The Godin Leisure Time Physical Activity questionnaire is a brief four-item survey assessing self-reported leisure-time physical activity over the previous 7 days. The score is expressed in units. Weekly frequencies of strenuous, moderate and mild activities are multiplied by nine, five, and three respectively with the derived values corresponding to metabolic equivalent of task (MET) values. The final weekly leisure activity score is computed in arbitrary units by summing the products of the separate components. The frequency of strenuous and moderate activities has been used to compute a health contribution score as follows:

   - ≥ 24 units (i.e. approximately ≥ 14 kcal/kg/week): Active with substantial benefits
   - 14-23 units (i.e. 7 - 13.9 kcal/kg/week): Moderately active with some benefits
   - < 14 units (i.e. < 7 kcal/kg/week): Insufficiently active to strongly contribute to health.

5. **Dietary Intake**

   The Rapid Eating Assessment for Patients (REAP) is a short validated questionnaire designed to quickly assess the dietary and eating habits of patients. It can be used to identify which patients would benefit most from further dietary/nutritional counselling. It includes 27 frequency questions answered with usually/often, sometimes, rarely/never, or does not apply to me. It is suggested that physicians consider referral to a dietician if five or more usually/often answers are elicited.
Physical Assessment / Anthropometric Measurements

- Height - measured after shoe removal using a wall-mounted stadiometer and recorded in metres to two decimal points.
- Weight - measured after shoe removal and recorded in kilograms (kg) to the nearest 0.5 kg.
- Body mass index (BMI) - calculated \(\frac{\text{weight in kg}}{\text{(height in metres)}^2}\) and recorded to one decimal point.
- Abdominal circumference\(^f\) - measured at the minimum diameter between the lower rib cage and the top of the iliac crest from the front with the participant erect and at the end of a gentle exhalation and recorded to the nearest centimetre.
- Hip circumference - measured from the side at the maximum protrusion of the buttocks, attempting to maximise the hip measure and recorded to the nearest centimetre.
- Waist:hip ratio\(^g\) - calculated as abdominal circumference in cm / hip circumference in cm and recorded to two decimal points.
- Systolic and diastolic blood pressure - auscultatory cuff systolic and diastolic blood pressure measurements with calibrated instruments were recorded to the nearest mmHg.

Laboratory Assessment

Following an 8 – 12 hour fast, blood samples were drawn for laboratory analysis of triglycerides, total cholesterol, HDL-cholesterol, LDL-cholesterol and blood glucose and recorded in mmol/L to the nearest decimal point.

Statistical Analysis

All analyses were conducted using SPSS statistical software package, Version 21.0. Descriptive statistics were calculated according to standard procedures. For paired group comparisons, a Wilcoxon signed-rank test was used for non-parametric variables, and a paired t-test for symmetric variables. For independent sample comparisons, Kruskal-Wallis testing was used for non-parametric variables, and 2 samples independent t-test for symmetric variables. The Friedman test was employed for analysis of repeated measures over multiple time points. Pearson’s correlation was used for associations between variables with coefficient \(r > 0.3\) regarded as moderate and \(r > 0.5\) regarded as strong. A p value of \(≤ 0.05\) was considered to be statistically significant.

3.2 Modifications made to the model

To allow adequate evaluation of outcomes within the project time frame, recruitment was limited to 53 participants in total rather than the 50 per year of the project initially anticipated. This ensured that all participants had a minimum of 6 months follow up prior to submission of the final report.

3.3 Key learnings from the implementation process

- Strong clinical leadership was integral to all aspects of the project including implementation.
- Clearly identify suitably qualified key staff with backgrounds relevant to the aims of the project.
- Ensure contingency plans to sustain the project if one or more key members of the project team are absent for a period of time e.g. maternity leave.
- The ‘Coach for Heart Health’ model proved a highly effective and inexpensive means of providing dietetic support.
- Individual tailoring of physical activity programs by necessity required negotiation with numerous separate facilities and was unexpectedly resource and labour intense. Where possible, attempt to consolidate individual physical activities with a single provider.
- The implementation of robust assessment and evaluation is essential to clearly document outcomes. A 6 month face-to-face anthropometric evaluation may have been beneficial.
- Incorporation of patient-reported outcome measures as well as health-related quality of life as the standard tools for directly eliciting the patient experience is advocated.
- Quantitative measures of fitness at baseline and following project participation, with formal assessments of body composition at these same time points may have provided additional useful information.
- Attendance at group physical activities was limited by time, location and distance for many participants in spite of incorporating participant feedback into the planning of events.

\(^f\)Abdominal circumference is clinically useful in assessing individual risk for chronic disease (such as diabetes, heart disease and hypertension) and for detecting obesity and where body fat is located. It is also useful in detecting changes in early fat loss. An indication of increased risk of developing chronic disease is an abdominal circumference of > 94 cm for men and > 80 cm for women.

\(^g\)The waist:hip ratio is the best predictor of risk factors for cardiovascular disease and is a better predictor than waist circumference alone, although waist alone is a better predictor than body mass index. A healthy ratio for women is ≤ 0.8, and for men ≤ 0.9.
3.4 Communication strategy
The project communication plan was developed with the aim of addressing the interests and concerns of key stakeholders by providing timely information and relevant updates. The detailed communication strategy is available in Appendix 3. A summary is provided below.

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<td>Ongoing</td>
<td>Project Lead</td>
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*including nurses, doctors, scientists, allied health

3.5 Sustainability strategy
Since project inception, the integration of the Positive Change for Life Survivorship project into the Leukaemia Foundation’s existing suite of services was identified as a critical factor for sustainability beyond the life of the current pilot. The project team has working collaboratively with the Leukaemia Foundation throughout to facilitate the development of a program that capitalises on the outcomes achieved to date through the Positive Change for Life pilot. The detailed sustainability strategy is available in Appendix 4.

Section 4: Evaluation Results

4.1 Participant Recruitment
32 participants (60%) were recruited from the existing Late Effects Clinic attendees with letters containing information about the Positive Change for Life program mailed to them with their routine clinic appointment information. 9 participants (17%) were referred by the Leukaemia Foundation, 3 from Peter MacCallum Cancer Centre and 2 from Barwon Health specifically for consideration of project participation. The remaining 7 participants were seen for the first time in the Late Effects Clinic as part of their scheduled long term follow up and recruited from that initial consultation.

During the recruiting period of July 2012 to July 2013, the Late Effects Clinic reviewed 30 new patients. 21 (70%) of these were recruited to project as outlined above. Of the remaining 9, one resides in Queensland and only travels to Melbourne annually for clinic review, 3 were transitioning from paediatric care and 2 were medically unsuitable for participation. The final 3 clinic attendees declined participation for personal reasons.

At the time of writing, 3 participants remain on project having not yet reached the 12 month evaluation time point. 17 participants are yet to reach the 18 month evaluation time point. Therefore, interim findings are presented for both 12 and 18 month time points.

To date, 3 participants have withdrawn from the project again citing personal reasons. 2 withdrew prior to the 6 month evaluation time point and one subsequently. This attrition rate of 6% is considered to be low. No adverse events were reported.
4.2 Professional nutritional advice
All participants received their initial face-to-face dietetic review at the time of project enrolment. The median duration of this consultation was 60 (range 45 – 80) minutes. 81% of the 2 week telephone follow-up sessions were successfully delivered lasting for a median of 30 (range 30-90) minutes. High rates of follow-up telephone sessions were delivered at 4 and 8 months (89% and 88% respectively). The median duration of these telephone calls was 55 (range 20-90) minutes for the 4 month review and 60 (range 9-120) minutes for the 8 month review. An inability in spite of a maximum 3 attempts to contact the participant by telephone or a lack of response from participants to messages left for them accounted for the small number of undelivered telephone sessions. The 12 month final face-to-face review has occurred for all participants meeting this time point to date with a median duration of 45 (range 30-90) minutes. Onward referral to community-based dietetic services has occurred for 17% of those participants completing project to date.

4.3 Individual physical activities
In total 47% of participants consulted with an exercise physiologist (36%) or a physiotherapist (11%) prior to initiation of physical activity. 34 full gymnasium memberships were established. Individually tailored alternatives to gymnasium memberships were sourced for 12 participants including personal training, swim passes, Pilates, boot camp and activity groups. 7 participants elected to continue with their current physical activities and 3 of these chose to continue self-funding.

28 gymnasium memberships were completed as at 28 February 2014 with attendance information available for 22 of these participants. The mean number of attendances over the 12 month membership for this group was 41 visits (range 1 – 144), or an average of 3.4 visits a month. Barriers to obtaining the remaining attendance records included centre/gymnasium privacy policies and complete 12 month attendance records not kept by the centre/gymnasium.

Of the 5 participants that had personal training sessions as their individual physical activity, the average number of sessions attended over the 12 month period was 30. The 3 participants that attended Pilates classes attended an average of 35 sessions over the 12 month period.

4.4 Group physical activities
A total of 10 group physical activity sessions occurring approximately every 6 weeks and lasting up to 2 hours were scheduled spanning a broad range of activities including scenic walks, Lawn Bowls, Cycling, Table Tennis and Croquet. Group activities were scheduled at diverse times, on different days and across various locations throughout south-east Melbourne in an attempt to maximise ease of attendance for participants accounting for the responses obtained from the planning feedback forms. In spite of this, 2 sessions in total were cancelled due to low attendance numbers and one session cancelled due to inclement weather.
The average attendance for all sessions was 17% of enrolled participants (range 8 - 35%) with a tendency for reductions in attendance over time. Partners and family members attended all group physical activity sessions with Positive Change for Life participants.

Subsequent feedback from participants has indicated that 68% were either 'highly satisfied' or 'satisfied' with the range of group activities provided. 64% were 'highly satisfied' or 'satisfied' with the location of these events. 59% expressed satisfaction with their enjoyment of the activities they attended. The main barriers to group physical activity participation reported were time constraints, conflict with other commitments and travel distance required to attend.

4.5 Educational Resources – Participant Handbook and Monthly Newsletter
91% of participants report being 'satisfied' or 'highly satisfied' with the project resources provided to them to assist in setting and monitoring goals. The physical activity training diary and the healthy eating guide were considered the most helpful resources with 62% and 61% of participants finding them either ‘extremely helpful’ or ‘very helpful’, respectively. ‘Practical tips on eating more healthily’ and ‘Project News’ were indicated as the most helpful aspects of the monthly newsletter.

4.6 Shared Care with Community General Practitioners

General Practitioner Communication

a) Survivorship Care Planning
All GPs were mailed information regarding their patient’s participation in the project and a copy of the survivorship care plan as per standard Late Effects Clinic practice. In spite of this, only 61% of GPs stated they have received a copy of the survivorship care plan. Of the GPs who commented on their overall impression of the survivorship care plan, responses were overwhelmingly positive with the document being perceived as comprehensive and beneficial. The ‘Summary of Recommendations’ was the most useful section with 86% of GPs rating it as ‘extremely’ or ‘very’ helpful. More than 80% of respondents also rated the ‘Post-transplant Complications’ and ‘Current Issues’ sections as ‘extremely’ or ‘very’ helpful. Very high numbers of respondents (89%) believed they had been provided with enough information to assist in the future management of their patient.

b) Newsletters, publications and presentations
General practitioners have been provided wide access to cancer survivorship educational materials and Positive Change for Life project information by distribution of promotional flyers via the Monash Division of General Practice, newsletters (RACGP, SMICS, and GPV), publications, Alfred Late Effects Clinic website, and Medicare Locals, Innovation and Consumer-Centred Care Conference.

General Practitioner Engagement
71% of participants report visiting their GP during their time on the Positive Change for Life project, however, only 50% of participants initiated discussion with their GP about their physical activity or nutrition goals. 71% of participants state that their GP asked them about their progress on the project and more than 50% report encouragement and feedback received from their GP. Perceived challenges in the provision of survivorship care by GPs appeared to relate to time, rather than knowledge constraints. Suggested improvements for assisting the primary care team in the delivery of survivorship care included inclusion of the GP as part of the team, continuing professional development activities around common issues faced and summarising information provided.

General Practitioner Education
The project team anticipated the delivery of a number of RACGP accredited educational opportunities to general practitioners and primary care teams to enhance knowledge and skill development in the provision of survivorship care within the primary care setting. This aspect of the project has remained particularly challenging with multiple ongoing attempts to deliver a general practitioner educational forum hindered by organisational constraints within the Medicare Local and lack of GP enrolment to numerous scheduled events.

4.7 Ongoing Annual Late Effects Clinic Attendance
All participants in the Positive Change for Life program have been reviewed in the Late Effects Clinic at project entry and following 12 months of project participation. 3 (6%) participants have withdrawn from the project to date and two of these have declined routine ongoing annual Late Effects Clinic follow-up. Participants who were new to the clinic at Positive Change for Life enrolment are offered annual review on an ongoing basis at the time of project completion regardless of original referral pathway and to date, all have accepted.
4.8 Participant Focus Group and In depth Interview Findings
Findings from the focus group and interviews with survivors showed the Positive Change for Life program was acceptable to and highly valued by participants. They reported changes to their lifestyle behaviours and satisfaction with the resources and support given during the program. Further, there were a number of instances where other family members also benefited from the survivors’ participation in the program. While the program was specifically designed to empower survivors to develop and maintain lifelong healthy eating and physical activity patterns in order to maximise wellness and quality of life, a notable gap identified by some was the lack of a specific emotional support component. The full report is attached as Appendix 5.

4.9 Carer’s perceptions
The overwhelming majority of carers (95%) responding to the survey mailed to them stated that they had observed positive changes in their family member’s general health and wellbeing as a direct result of their participation in Positive Change for Life program with a range of identified improvements particularly relating to improved fitness, improved energy and better physical activity habits. Further and importantly, 85% of respondents stated that they had personally benefited from their family member’s participation in the project again across a range of areas including enhanced awareness of benefits of physical activity and nutrition and improvements in their relationship.

4.10 Allied Health Service Providers perceptions
Interviews were conducted with allied health professionals and service providers who delivered services to participants in the Positive Change for Life project. The main value providers saw in the survivorship project was flexibility with the programming and budgeting for them to be able to offer individual and group sessions. Provider’s knowledge and previous contact with cancer survivors varied. Ongoing professional development around cancer and survivorship was welcomed by all providers, particularly in the area of adverse effects of treatment and fatigue.

4.11 Outcomes
Baseline Participants
Between June 2012 and July 2013, the project has enrolled 53 participants (28 female, 25 male) with a median age at project entry of 47.8 years (range, 24.7 – 67.6 years). 17 participants (32%) had undergone autologous stem cell transplantation and 36 (68%) allogeneic stem cell transplantation. The median time since either autologous or allogeneic transplantation was 5 years (range, 2 – 15.4 years). The dominant indication for autologous stem cell transplantation was lymphoma either Hodgkin or Non-Hodgkin and for allogeneic transplantation, the main indication was acute leukaemia.

Physical and Laboratory Assessments
Project participants were representative of Late Effects Clinic attendees in general with high numbers of risk factors for future health problems identified. 68% of participants were overweight or obese (BMI ≥25) at baseline and 85% met criteria for central obesity. 100% of participants had an unhealthy waist:hip ratio defined as >0.8 for women and >0.9 for men. Assessments of modifiable risk factors revealed a large proportion of participants at baseline had hypertension (58%), abnormal blood lipids (49%) and elevated blood glucose (17%). 40% of participants at baseline met criteria for the metabolic syndrome, and a further 34% had 2 or more individual components. There was no statistically significant difference between recipients of autologous or allogeneic stem cell transplantation in any measured parameter, therefore, the group was considered as a whole for all subsequent analyses and not divided by transplant type.

Quality of Life
Self-reported overall quality of life (FACT-G and FACT-BMT) and associated individual quality of life domains were not significantly different between autologous and allogeneic transplant recipients. Further analyses, therefore, relate to the group as a whole and are not divided by transplant type. The sample means of the four quality of life domains (physical, social, emotional, functional wellbeing) and FACT-G were converted to T-scores and compared to Australian general population norms. Relating to its specific nature, no general population norms are available for the BMT specific subscale and therefore, for the FACT-BMT which is a derived score.
Means, Standard Deviations and Ranges of Scores of Quality of Life Domains

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>T-score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Wellbeing</td>
<td>23.43</td>
<td>5.07</td>
<td>0-28</td>
<td>45.30</td>
</tr>
<tr>
<td>Social Wellbeing</td>
<td>22.39</td>
<td>4.31</td>
<td>0-28</td>
<td>54.90</td>
</tr>
<tr>
<td>Emotional Wellbeing</td>
<td>19.49</td>
<td>4.20</td>
<td>0-24</td>
<td>45.70</td>
</tr>
<tr>
<td>Functional Wellbeing</td>
<td>21.55</td>
<td>6.00</td>
<td>0-28</td>
<td>51.80</td>
</tr>
<tr>
<td>FACT-G score</td>
<td>86.86</td>
<td>17.18</td>
<td>0-108</td>
<td>50.60</td>
</tr>
<tr>
<td>BMT-specific concerns</td>
<td>29.39</td>
<td>5.26</td>
<td>0-40</td>
<td>-</td>
</tr>
<tr>
<td>FACT-BMT</td>
<td>116.25</td>
<td>21.50</td>
<td>0-148</td>
<td>-</td>
</tr>
</tbody>
</table>

* T-score distribution for the general population has a mean of 50 and standard deviation of 10

Although not statistically different, physical and emotional wellbeing scores for participants at baseline fell below the general population mean, while functional and particularly social wellbeing were above the population mean. As a result, the mean overall quality of life scores of the participants as measured by the FACT-G were close to that expected within the general population.

**Fatigue**

With possible scores ranging from 0 the worst possible fatigue, to 52 no fatigue at all, at baseline participants reported a median fatigue score of 43 (IQR=34-47.5; range, 5 - 52) with 15% reporting severe fatigue (score <30). There was no difference in reported fatigue scores by gender or type of stem cell transplantation. Further, fatigue scores did not correlate with age at study entry, age at time of transplant, baseline anthropometric or laboratory measures.

Associations between baseline fatigue and quality of life domains were analysed. Less baseline fatigue was strongly associated with better self-reported physical, social, emotional, functional, transplant-specific and overall quality of life (FACT-G and FACT-BMT) at project entry, all p<0.001.

**Barriers to Physical Activity**

The median baseline BARSE score was 51 (IQR=41.5-63.5) out of a possible score of 100 points indicating moderate confidence levels in ability to overcome common barriers to physical activity. Participants were most confident in their ability to exercise if they had to exercise when the weather was bad or if they had to exercise alone. They were least confident if they had difficulty in getting to their exercise location, had a schedule conflict or experienced pain or discomfort. Higher BARSE scores were reported by those who reported less fatigue (r = 0.355, p = 0.009) indicating better self-efficacy.

**Dietary Intake**

Assigning numerical values to the responses resulted in the generation of an overall REAP score with a possible range from 27 (poor dietary habits) to 81 (very good dietary habits). A median score of 62 (IQR=57-67) was reported by participants at entry to the project.

An average of 5 (IQR=2.5-7, range 0-20) unhealthy eating behaviours – such as skipping breakfast, eating large amounts of take away foods or less than the recommended amounts of healthy foods were reported by participants at baseline. 5 is the cut-off number that the scale uses to recommend referral to a dietitian. Participants reported high levels of willingness to make dietary changes to improve their health with a median score of 4 on a scale of 1 (not willing) to 5 (very willing). Participants reporting higher fatigue levels indicated they were more willing than participants with less fatigue to make dietary changes (r = -0.320, p=0.02).

**Leisure Time Physical Activity**

Prior to engaging in the Positive Change for Life project, participants generally reported low physical activity levels. The overall median weekly leisure activity score for the group was 19 (IQR=9-26.5, range 0 – 83) with higher scores indicating more physical activity.

Referencing only moderate and strenuous physical activities, the Godin Leisure-Time questionnaire demonstrated that 59% of participants reported insufficient levels of physical activity to contribute to health (< 7 kcal/kg/week). 26% of participants were moderately active at baseline (7 - 13.9 kcal/kg/week), however, only 15% were classified as sufficiently active to gain any substantial health benefits (approximately 14 kcal/kg/week or more).
6 Month Outcomes
6 month data collection is complete. Evaluations have been returned by 41 participants representing an 80% return rate of questionnaires. 2 participants withdrew prior to their 6 month evaluations. Participants who chose not to return their 6 month evaluations did not differ significantly in any examined characteristic from those completing and returning their questionnaires (data not shown).

Quality of Life
The minimal important difference (MID) in the quality of life domains of physical wellbeing, emotional wellbeing, functional wellbeing and overall quality of life have been determined and previously reported. Based on this, the number of participants with clinically meaningful improvement in their quality of life was analysed. 32% of participants reported improved functional wellbeing following 6 months of project participation. 27% reported clinically meaningful improvements in their emotional and physical wellbeing, respectively and 25% reported enhanced overall quality of life.

Fatigue
After 6 months of project participation, 32% of the group report clinically meaningful improvement in fatigue defined as an increase of at least 3 points on the FACIT-fatigue scale. Importantly, this includes all but one participant with severe fatigue at baseline.

Barriers to Physical Activity
There was no change in median BARSE scores or individual items of the survey at 6 months compared with baseline (52 [IQR=43-67.5] vs 54 [IQR=38-65]), p=0.15. At 6 months, participants remained most confident in their ability to exercise if they had to exercise alone or in bad weather conditions. By comparison to baseline responses, participants were least confident in their ability to exercise if they didn’t like the activity.

Dietary Intake
There was a statistically significant improvement in median overall nutrition scores for participants at 6 months, (63 [IQR=57-68] vs 67 [IQR=62-70]), p=0.001. Overall nutrition scores as reported by the REAP survey improved for 61% of participants at 6 months with a corresponding reduction in unhealthy eating behaviours in 56%. The median number of undesirable nutrition behaviours reduced from 4 (IQR=2-6.5) to 3.8 (IQR=2-4.5) following 6 months of project participation, p=0.03. Participants remained very willing to make dietary changes following 6 months of project participation.

Leisure Time Physical Activity
Significant improvements in median physical activity levels were identified at 6 months with marked increases in:

- Overall physical activity (19 [IQR=9.5-27.5] vs 34 [IQR=25.5-48.5]), p<0.001,
- Moderate and strenuous activity (10 [IQR=2.5-20] vs 27 [IQR=19-40]), p<0.001, and
- Frequency of activity sufficient to work up a sweat, p=0.005.

Notably, referencing only moderate and strenuous physical activities, at baseline only 20% of this group were sufficiently active to produce substantial health benefits and at 6 months this had increased substantially to 61% of participants.

Higher overall physical activity levels, in addition to moderate and strenuous activities, were significantly associated with:

- Improved physical wellbeing (r=0.366, p=0.019; r=0.403, p=0.009)
- Better functional wellbeing (r=0.301, p=0.05)
- Improved emotional wellbeing (r=0.411, p=0.008; r=0.407, p=0.008)
- Better overall quality of life FACT-G (r=0.339, p=0.03; r=0.322, p=0.04), and
- Better transplant related overall quality of life FACT-BMT (r=0.369, p=0.018; r=0.354, p=0.023).

Physical activity levels both overall and moderate and strenuous, were also strongly associated with a reduction in self-reported fatigue levels, (r=0.426, p=0.005; r=0.446, p=0.003).
6 month overall physical activity levels, in addition to moderate and strenuous activity levels were associated with the reporting of higher BARSE scores following 6 months participation in Positive Change for Life ($r=0.477$, $p=0.002$; $r=0.478$, $p=0.002$). This association was not seen at baseline and suggests that those participants who have increased their physical activity levels following 6 months of project participation report an associated increase in their confidence in their ability to continue to exercise in the face of common barriers.

**Interim 12 Month Outcomes**

With rolling recruitment, 12 month evaluations are currently available for 47 participants. 3 participants are yet to complete 12 months on project and 3 participants in total have withdrawn. A total of 38 participants have completed both 6 and 12 month evaluations for analysis.

**Quality of Life**

40% of participants reported clinically meaningful improvements in functional wellbeing at 12 months compared with their baseline reported score. 28% and 19% reported clinically meaningful improvements in their emotional and physical wellbeing, respectively and 30% reported improvements in their overall health-related quality of life following 12 months project participation.

**Fatigue**

After 12 months of project participation, 43% of the participants report clinically meaningful improvement in fatigue compared to baseline. For the 38 participants with complete 6 and 12 month evaluations, this improvement appears to have occurred by the 6 month time point with no further improvements in fatigue levels occurring between the 6 and 12 month evaluations as shown below.

**Barriers to Physical Activity**

There was no change in overall BARSE scores or individual items of the survey at 12 months compared with baseline (51 [IQR=41-64] vs 46 [IQR=35-62]), $p=0.20$.

Consistent with findings at baseline and 6 months, at 12 months participants remained most confident in their ability to exercise alone or in bad weather conditions. Participants remained least confident in their ability to exercise if they weren’t interested in the activity.

**Dietary Intake**

There was a statistically significant improvement in median overall nutrition scores as reported by the REAP survey for participants at 12 months compared with baseline (63 [IQR=57-68] vs 66 [IQR=62-70]), $p<0.001$. Overall nutrition scores improved for 81% (38/47) of participants at 12 months compared to baseline scores.

Overall a reduction in unhealthy eating behaviours following 12 months participation in Positive Change for Life was reported in 66% (31/47). A corresponding statistically significant reduction in the median number of undesirable nutrition behaviours from 5 (IQR=2-7) to 3 (IQR=2-5) was reported at 12 months compared with baseline, $p=0.001$.

Willingness to make dietary change scores did not change over time remaining high at all evaluation time points of the project.

For the 38 participants with completed 6 and 12 month evaluations, there was a statistically significant improvement in median overall nutrition scores ($p<0.001$) and number of reported undesirable nutrition behaviours ($p=0.002$) at 12 months compared with baseline, as shown below.
**Leisure Time Physical Activity**

Significant improvements in median physical activity levels were identified at 12 months with marked increases compared with baseline in:

- Overall physical activity (20 [IQR=9-27] vs 33 [IQR=19-45]), p<0.001
- Moderate and strenuous activity, (10 [IQR=0-20] vs 23 [IQR=10-37]), p<0.001, and
- Activities sufficient to work up a sweat, p=0.014.

For participants with completed evaluations at 6 and 12 months, changes in overall physical activity in addition to moderate and strenuous physical activities occurred over the first 6 months of project participation and were then maintained from the 6 to the 12 month evaluation time points.

Referencing only moderate and strenuous physical activities, the Godin Leisure-Time questionnaire at 12 months demonstrated ongoing improvement in the proportion of participants engaging in levels of physical activity sufficient to contribute to health compared with baseline assessments. For the participants with completed 6 and 12 month evaluations, only 21% were active at baseline compared with an impressive increase to 61% and 58% following 6 and 12 months of project participation, respectively. Correspondingly, the proportion of insufficiently active participants reduced from 53% at baseline to only 16% at 6 months and 21% at 12 months, respectively.
Higher overall physical activity levels at 12 months, in addition to moderate and strenuous activities were significantly associated with:

- Higher BARSE scores indicating greater self-efficacy (r=0.474, p=0.001; r=0.466, p=0.001),
- Overall improved nutrition as measured by REAP (r=0.512, p<0.001; r= 0.405, p=0.005), and
- Lower numbers of unhealthy eating behaviours (r=-0.467, p=0.001; r=-0.365, p=0.012).

Higher overall physical activity levels were associated with improved fasting lipid profiles measured at 12 months as follows:

- Lower total cholesterol levels (r=-0.309, p=0.034)
- Improved LDL cholesterol levels (r=-0.349, p=0.02).

Importantly, higher overall physical activity levels were significantly associated with reduced self-reported fatigue levels (r=0.302, p=0.039). Moderate and strenuous physical activity levels were also associated with reduced fatigue (r=0.356, p=0.014).

Higher overall physical activity levels at 12 months were associated with trends to improved physical wellbeing, functional wellbeing, transplant specific wellbeing, overall and transplant specific quality of life (p=0.058, 0.086, 0.052, 0.096 and 0.074, respectively). Higher moderate and strenuous physical activity levels at 12 months, however, were associated with statistically significant improvements in

- Physical wellbeing (r=0.384, p=0.008)
- Functional wellbeing (r=0.289, p=0.049)
- Transplant specific wellbeing (r=0.341, p=0.019)
- Overall quality of life (r=0.305, p=0.037), and
- Transplant specific quality of life (r=0.323, p=0.027).

**Anthropometric measures**

A summary of participant anthropometric measures at baseline and following 12 months of Positive Change for Life project participation is shown below.

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Baseline Median (IQR)</th>
<th>12 months Median (IQR)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight, kg</td>
<td>79 (68-90)</td>
<td>76 (66-89)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Body mass index, kg/m²</td>
<td>27.5 (23.7-30.5)</td>
<td>27.1 (23-29.8)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Abdominal circumference, cm</td>
<td>97.5 (89.8-106)</td>
<td>93.5 (88-103.3)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Hip circumference, cm</td>
<td>100.5 (95-109)</td>
<td>99.5 (93.75-107.3)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Waist:hip ratio</td>
<td>0.97 (0.9-1.02)</td>
<td>0.95 (0.87-1.0)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Systolic blood pressure, mmHg</td>
<td>128 (112-141)</td>
<td>125 (114-139)</td>
<td>0.425</td>
</tr>
<tr>
<td>Diastolic blood pressure, mmHg</td>
<td>80.62 (±12.16)*</td>
<td>79.23 (±10.02)*</td>
<td>0.287</td>
</tr>
</tbody>
</table>

*mean ± standard deviation

**Weight**

There was an overall weight loss for Positive Change for Life participants over the 12 months of project participation representing a statistically significant change in weight (p<0.001) and body mass index (p<0.001). In detail, 75% of participants had documented weight loss at their 12 month face-to-face evaluation with a mean weight loss of 4.0 kg (range, 1 to 20 kg) representing a 4.7% change in body weight (range, 1 to 17.4%). 8 participants had no weight change. Only 4 participants increased their weight (range, 1 to 7.5 kg).

**Abdominal circumference**

There was an overall reduction in participants’ abdominal circumference following 12 months of project participation representing a statistically significant change in abdominal measurement, p<0.001. In detail, 76% of participants in Positive Change for Life had documented reduction in their abdominal circumference at their 12 month face-to-face evaluation with a mean loss of 4 cm (range, 1 to 20 cm). 9 participants had stable abdominal measurements at 12 months. Only 2 participants had increased their abdominal circumference, each by 2 cm.

**Hip measurement**

There was an overall reduction in hip measurements for Positive Change for Life participants at their 12 month face-to-face evaluation representing a statistically significant reduction, p<0.001. In detail,
52% of participants had documented reduction in their hip measurements with a mean loss of 2.9 cm (range, 1 to 9 cm). 17 participants had stable hip measurements, while 5 participants increased their hip measurement between 1 and 2 cm each.

**Waist:hip ratio**
Resulting from a reduction in both waist and hip measurements, 70% of Positive Change for Life participants had a documented improvement in their waist:hip ratio following 12 months of project participation. This finding indicates a reduction in the amount of visceral adiposity. For the group overall, there was a statistically significant reduction in waist to hip ratio (p<0.001) from baseline to 12 months.

**Systolic Blood Pressure**
A reduction in systolic blood pressure with a median drop of 1.0 mmHg (IQR=-8 to 6) for the group was observed at 12 months (p=0.425). 47% of participants reduced their systolic blood pressure by at least 4.0 mmHg.

**Diastolic Blood Pressure**
40% of Positive Change for Life participants had a reduced diastolic blood pressure of at least 4 mmHg following 12 months of project participation compared with their baseline measurement. Overall, there was a non-statistically significant diastolic blood pressure reduction for the group at 12 months with a median drop of 1.0 mmHg (IQR=-6 to 3) recorded.

**Laboratory Measurements**
A summary of participant laboratory measures at baseline and following 12 months of Positive Change for Life project participation is shown below.

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Baseline Median (IQR)</th>
<th>12 months Median (IQR)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>HDL cholesterol, mmol/L</td>
<td>1.35 (1.2-1.6)</td>
<td>1.35 (1.2-1.7)</td>
<td>0.017</td>
</tr>
<tr>
<td>Total cholesterol, mmol/L</td>
<td>5.4 (4.8-5.9)</td>
<td>5.3 (4.8-5.9)</td>
<td>0.963</td>
</tr>
<tr>
<td>Triglycerides, mmol/L</td>
<td>1.2 (0.9-1.6)</td>
<td>1.2 (0.9-1.6)</td>
<td>0.963</td>
</tr>
<tr>
<td>LDL cholesterol, mmol/L</td>
<td>3.2 (2.9-4)</td>
<td>3.3 (2.8-4)</td>
<td>0.373</td>
</tr>
<tr>
<td>Blood glucose, mmol/L</td>
<td>4.8 (4.53-5.2)</td>
<td>5.1 (4.6-5.3)</td>
<td>0.066</td>
</tr>
</tbody>
</table>

**Fasting Lipids**
No participant commenced or ceased lipid lowering therapy during the 12 months of their project involvement. There was a statistically significant improvement in median fasting HDL-cholesterol for the group following 12 months of project participation (1.4 [IQR=1.2-1.6] vs 1.3 [IQR=1.2-1.7]), p=0.017. 73% of participants with unhealthy HDL-cholesterol at baseline (<1.03 mmol/L in males and <1.29 mmol/L in females) improved their HDL cholesterol following 12 months of project participation with a mean increase of 15.6%.

With respect to fasting cholesterol, there was a statistically non-significant reduction from median baseline value of 5.4 (IQR=4.8-5.9) to 5.3 (IQR=4.8-5.9), p=0.96. 63% of participants with an elevated cholesterol at baseline (>5.5 mmol/L) improved their total cholesterol measurement following 12 months of project participation. Regarding the clinical significance of cholesterol reduction for individuals, it is known that for every 10% reduction in total cholesterol, there is a 13-15% decrease in the risk for coronary heart disease related mortality. Using these criteria, 37% of participants with baseline abnormal cholesterol and 23% of the entire group had reduced their cholesterol by at least 10% from baseline at their 12 month evaluation, thereby reducing their individual risk for heart disease mortality.

49% of the group overall and 55% of participants with elevated triglycerides at baseline (≥1.7 mmol/L) reduced their fasting triglyceride result at 12 months by an average of 22.9% and 34.5%, respectively. Similarly, improvement in LDL measurements at 12 months were recorded in 56% of those participants with an abnormal baseline value (>3.5 mmol/L) and for 43% for the group overall.

**Fasting blood glucose**
There was an absolute reduction in 12 month fasting blood sugar measurements for 80% of participants with an elevated fasting glucose (≥5.7 mmol/L) at baseline.
Comparator Group Physical and Laboratory Characteristics

To allow comparisons of physical and laboratory assessments to long term stem cell transplant survivors receiving general health advice but not engaging in a structured physical activity and dietary intervention, 50 Late Effects Clinic attendees with 2 or more consecutive annual Late Effects Clinic consultations who did not participate in the Positive Change for Life project were selected. These non-participating Late Effects Clinic attendees were well matched to project participants in regards to age at baseline, age at transplant, type of transplant (autologous or allogeneic), time since transplant, gender, and diagnoses. The non-participating group did not differ significantly from project participants with respect to baseline weight, body mass index, abdominal circumference (where recorded), systolic blood pressure, diastolic blood pressure or laboratory measures other than a higher triglyceride level in the comparator group ($p=0.005$). Further, the proportion of non-participating clinic attendees meeting criteria for metabolic syndrome and its individual components (central obesity, elevated fasting glucose, hypertension, reduced HDL-cholesterol, elevated triglycerides) were not statistically different at baseline to project participants.

By comparison to Positive Change for Life participants, the group of Late Effects Clinic attendees who did not engage in the project demonstrated an overall median increase in weight (1.5 kg), percentage weight gain (2.05%) and abdominal circumference (1.5 cm) over a 12 month period. There was no change in non-participating Late Effects Clinic attendee’s systolic or diastolic blood pressure readings over the 12 month observation period.

Weight change, percentage weight change and change in abdominal circumference over 12 months differed significantly between Positive Change for Life project participants and those Late Effects Clinic attendees not engaging in a structured exercise and nutrition intervention, all $p<0.001$.

Favourable changes in HDL cholesterol differed significantly between Positive Change for Life participants and the comparator group at 12 months, $p=0.015$.

A comparison of changes in anthropometric and laboratory measurements between Positive Change for Life participants and non-participating Late Effects Clinic attendees over 12 months is summarised below.

<table>
<thead>
<tr>
<th>Change in Parameter over 12 months</th>
<th>Participating group Median (IQR)</th>
<th>Comparator group Median (IQR)</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight change, kg</td>
<td>-1.5 (-4.0 to -0.5)</td>
<td>1.5 (-1.75 to 4.0)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Percentage weight change, %</td>
<td>-1.9 (-5.1 to -0.7)</td>
<td>2.05 (-1.83 to 5.23)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Body mass index change, kg/m$^2$</td>
<td>-0.5 (-1.4 to -0.2)</td>
<td>0.45 (-0.78 to 1.5)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Abdominal circumference change, cm</td>
<td>-2 (-5 to -0.75)</td>
<td>1.5 (-3.0 to 6.75)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Systolic blood pressure change, mmHg</td>
<td>-1 (-8 to 6)</td>
<td>0 (-8.5 to 14)</td>
<td>0.23</td>
</tr>
<tr>
<td>Diastolic blood pressure change, mmHg</td>
<td>-1.0 (-6 to 3)</td>
<td>0 (-5 to 8.5)</td>
<td>0.098</td>
</tr>
<tr>
<td>HDL cholesterol change, mmol/L</td>
<td>0.1 (0 to 0.2)</td>
<td>0 (-0.5 to 0.7)</td>
<td>0.015</td>
</tr>
<tr>
<td>Total cholesterol change, mmol/L</td>
<td>0 (-0.4 to 0.4)</td>
<td>-0.1 (-0.5 to 0.7)</td>
<td>0.878</td>
</tr>
<tr>
<td>Triglycerides change, mmol/L</td>
<td>0 (-0.3 to 0.3)</td>
<td>-0.2 (-0.6 to 0.45)</td>
<td>0.280</td>
</tr>
<tr>
<td>LDL cholesterol change, mmol/L</td>
<td>0 (-0.5 to 0.2)</td>
<td>0.1 (-0.45 to 0.5)</td>
<td>0.270</td>
</tr>
<tr>
<td>Blood glucose change, mmol/L</td>
<td>0.1 (-0.2 to 0.5)</td>
<td>-0.4 (0.2 to 0.53)</td>
<td>0.924</td>
</tr>
</tbody>
</table>

Interim 18 Month Outcomes

18 month evaluations have been distributed to 33 participants and returned by 25 representing a 76% questionnaire return rate. 17 participants are yet to complete 18 months on project. In spite of the relatively small numbers available for analysis currently, the positive benefits of project participation demonstrated at 6 and 12 months appear to have been maintained over time.

Quality of Life

A third of participants reported clinically meaningful improvements in their emotional and functional wellbeing following 18 months of project participation. 46% reported enhanced overall quality of life.

Fatigue

After 18 months of project participation, 36% of the group report clinically meaningful improvement in fatigue compared with baseline.
Barriers to Physical Activity
There remained no change in overall BARSE scores at 18 months compared with baseline (median score at baseline 54 (IQR=43-71) compared with 48 (IQR=37-67.5) at 18 months, p=0.26.

Dietary Intake
A statistically significant improvement in median overall nutrition scores for participants at 18 months was again demonstrated (64 [IQR=58-69.5] vs 69 [IQR=63.5-72.5]), p=0.001. Overall nutrition scores improved for 72% of participants at 18 months with a corresponding reduction in unhealthy eating behaviours in 72%. The median number of undesirable nutrition behaviours reduced from 4 (IQR=2-6) to 3 (IQR=1-4) following 18 months of project participation, p=0.005.

Leisure Time Physical Activity
Significant improvements in overall physical activity levels, in addition to moderate and strenuous physical activity levels continued to be reported at 18 months. 80% of participants had maintained increased overall activity levels compared with baseline. At baseline the median overall physical activity score was 19 (IQR=9-25.5) compared with 32 (IQR=17-42) at 18 months, p=0.001. Moderate and strenuous activity scores increased from a group median of 10 (IQR=0-20) at baseline to 20 (IQR=10-32) at 18 months, p=0.007.

Referencing only moderate and strenuous physical activities, at baseline only 20% of this group were sufficiently active to produce health benefits and 64% were inactive. The number of inactive participants has decreased to 28% at 18 months with a corresponding increase in the proportion of the group now active enough to produce substantial health benefits to 40% at 18 months.

Section 5: Sustainability considerations
Reflecting the success of the project’s collaborative endeavours, the most successful elements of the Positive Change for Life project have been integrated into the Leukaemia Foundation’s existing consumer programs as their Jump Start Program which will be suitable for a broader range of blood cancer survivors not only those who have undergone stem cell transplantation. The new program offered by the Leukaemia Foundation will retain the key components of nutritional guidance and physical activity following a baseline assessment by an exercise physiologist. The program will be of 12 weeks duration and provide regular opportunities for participants to engage with peers in addition to weekly phone contact and counselling to monitor progress. Participants will be provided with smart phone technology and a ‘fit bit’ device to facilitate health behaviour change and electronic capture of activity levels. Participants will be invited back at 12 weeks for a final review and to develop strategies for an ongoing healthy lifestyle.

Section 6: Potential scope for extension / spread of survivorship care
The growing field of research among cancer survivors and the resulting rapidly expanding associated literature clearly points toward incorporating more structured physical activity and nutrition interventions into cancer treatment and survivorship care. The conceptual framework for the current project was inspired by existing survivorship exercise programs operating internationally particularly in North America, but also in the United Kingdom and New Zealand e.g. Cancer Well-fit™. Many such programs were started by breast cancer survivors who were passionate about the importance of physical activity with a focus on providing fun group exercise opportunities, fitness education and peer support. Although many such programs continue to focus on breast cancer survivors (e.g. Team Survivor), an increasing number provide support for survivors of any cancer experience. A similar approach in blood cancer survivors has been successful in the Positive Change for Life pilot with additional benefits documented relating to the inclusion of nutritional support.

The current Positive Change for Life project pilot with appropriate resource support is perceived to be directly transferrable to most cancer types with the benefits of exercise already well documented in a number of cancers, namely in areas such as fatigue and physical functioning, both of which directly influence quality of life. The most robust evidence is for people who have completed active cancer treatment with minimal variation in exercise recommendations across cancer groups. This also supports the applicability and therefore transferability of the Positive Change for Life project model findings across tumour streams.
At a local level, to sustain other key project outputs and evaluate and validate the model in other health services, a roll out phase of the program to other transplant centres would be highly desirable.

**Section 7: Next steps for project locally – next 2 years**

The Alfred Late Effects Clinic will continue to provide high quality tailored survivorship care to long term survivors of blood cancer treated with stem cell transplantation. A modified version of the Positive Change for Life participant handbook will be given to all attendees of the clinic on their initial consultation in addition to those existing attendees who did not participate in the project.

The embedding of the Positive Change for Life model within the existing structure of the Alfred Late Effects Clinic is highly desirable. This, however, would require ongoing funding of dietetic support which has proven to be pivotal to the success of the current pilot. In place of financially supported individual exercise programs, the services of an exercise physiologist, not currently available within the clinic structure, would be beneficial to guide blood cancer survivors in their physical activity choices and programs.

The educational resources developed for this project have been highly valued by participants, however, ongoing provision of these resources is also dependent on ongoing funding.

**Section 8: Overview of Project Impact**

8.1 Conclusion

Optimising the health and quality of life for people who have survived cancer requires a continuing focus on risk factor identification and opportunities to modify behaviours to reduce lifestyle related health risks. Providing meaningful and practical support and education to survivors has the potential to facilitate consequential and impactful changes in behaviour and lifestyle, which may reduce the risk for a number of other diseases and conditions, including cardiovascular disease, diabetes and osteoporosis.

In support of these endeavours, the Positive Change for Life pilot project has achieved the following outcomes relating to the long term care of stem cell transplant survivors with much overlap and applicability evident to all cancer survivors:

1. Confirmation of the high prevalence of risk factors for the development of numerous health complications and chronic diseases, specifically cardiovascular disease, diabetes and osteoporosis, many of which are related to lifestyle and behavioural factors.
2. Identification of significant opportunities for health promotion and preventative action strategies.
3. Feasibility to deliver a comprehensive lifestyle intervention in a community-based accessible program.
4. Effectiveness and safety of the current model as a behaviour change intervention with high impact and demonstrable outcomes.
5. Reinforcement of importance of continued psychosocial evaluations to optimise support and counselling opportunities beyond the acute care phase of the cancer trajectory.
6. Enhanced awareness of the need and potential benefits of improving knowledge deficits in survivors and healthcare professionals alike.

The ultimate objective of quality cancer care is not only to survive but also to live well. Thus, important outcomes for survivors in addition to overall survival are functional status, quality of life and reduction of risk for future health problems. Although many cancer survivors, including stem cell transplant survivors, attain a high quality of life following completion of treatment, a significant number are faced with late effects and risks for medical problems similar to individuals with other chronic illnesses. As early diagnosis and treatment of cancer improves and as the population continues to age, the numbers of cancer survivors will continue to grow. Maximising the future health of this growing population is crucial both economically and from a public health perspective. The challenge to promote long-term health and motivate cancer survivors to care for themselves in order to prevent the complications associated with cancer and its treatment will allow survivors to achieve the best health status possible. The current pilot, Positive Change for Life, contributes much to these goals with feasible delivery, high impact and favourable outcomes.
8.2 Key learnings (in addition to the key learnings outlined on page 12)

- Traditional ‘shared care’ model with general practitioners not likely to work until reframed as chronic disease management
- Excess body weight, not under-nutrition, is the main nutritional concern facing the majority of cancer survivors.
- High risk survivors, such as those who have undergone stem cell transplantation, may ultimately be best served by ongoing annual review by the primary haematology/oncology team in a dedicated clinic setting.
- Greater success appears to have been achieved where weight loss management and risk factor reduction were targeted concurrently with a combined physical activity and dietary intervention.
- The majority of beneficial outcomes occurred with the first 6 months of project participation. Gratifyingly, these benefits appeared to have been maintained over time including up to 6 months after project participation was complete.
- Participants that wanted a partner or significant other involved found that they both achieved health benefits.
- The monthly newsletter is an effective, relatively time efficient means of maintaining contact and keeping participants engaged.
- The provision of survivorship care plans remains the cornerstone of communication with community care providers.

8.3 Top 10 tips

1. Ensure strong clinical leadership.
2. Clearly identify suitably qualified key staff with backgrounds relevant to the aims of the project.
3. Ensure contingency plans to sustain the project if one or more key members of the project team are absent for a period of time e.g. maternity leave.
4. The ‘Coach for Heart Health’ model is highly effective, inexpensive, safe and acceptable.
5. Where possible, attempt to consolidate individual physical activities with a single provider.
6. The combination of nutritional support and physical activity appears to provide greater benefits that either intervention alone.
7. A monthly newsletter is a relatively time efficient means of keeping participants engaged.
8. A 6 month lifestyle intervention is likely to yield similar outcomes to a longer program.
9. Ensure robust assessment and evaluation including the use of patient-reported outcomes.
10. Involve partners and family members at every opportunity – they too are likely to benefit.

Section 9: Recommendations

The following 10 recommendations are proposed as a means to continue to strive for the provision of effective lifestyle interventions integrated into high quality survivorship care.

Recommendation 1: Ongoing resource allocation to facilitate modifiable risk factor reduction through health promotion and behaviour change in cancer survivors

Although survivorship is to be celebrated, it is important to acknowledge that the impact of cancer is significant and associated with long term health and psychosocial sequelae. Compared with persons who have not had cancer, cancer survivors are at increased risk for developing other health conditions, such as cardiovascular disease, diabetes, osteoporosis, second malignancy and functional decline. Lifestyle interventions, such as Positive Change for Life promoting a healthful diet and an active lifestyle hold promise in reducing adverse cancer-related sequelae and co-morbidity among survivors and may also improve quality of life. The ongoing delivery of such important interventions will require:

- Committed financial resources to support health promotion action
- Allocation of human resources to advocate for health promotion principles and implement health-promoting action
- Availability of administrative and physical resources to support health promoting action.

Recommendation 2: Ongoing research relating to obesity and associated cardiovascular risk factors in cancer survivors

Historically, under-nutrition and cancer-related cachexia were the primary nutritional concerns in regard to cancer. While these issues remain important for some cancer survivors, excess body weight is the main nutritional concern facing most cancer survivors today. Due to the adverse
effects of being overweight or obese on cancer survival, general health outcomes and quality of life, weight management should now be considered a priority for quality survivorship care. The optimal dietary management and exploration of the underlying pathogenesis of obesity and metabolic syndrome in cancer survivors is an area of potential future research in turn forming the foundation for the development of more effective interventions specific to cancer survivors.

**Recommendation 3: Health economic evaluation of lifestyle intervention in cancer survivors allowing cost-effectiveness analysis**

Cancer survivorship is associated with a considerable and long-lasting economic impact, resulting in excess health care expenditures and lost productivity costs among survivors compared with individuals without a history of cancer. With the number of cancer survivors projected to increase the economic burden of cancer is also likely to increase.

Given that cancer survivors are at increased risk for the development of chronic health conditions, many of which are remediable by lifestyle intervention, the promotion of healthy behaviours is an important aspect of quality care and sustained intervention programs may help reduce the economic impact of cancer, but the cost and cost-effectiveness of these interventions are rarely evaluated. Examples of economic evaluation studies from the cardiac rehabilitation literature may have implications for evaluation of lifestyle interventions in cancer survivorship. Lifestyle counselling to prevent metabolic diseases has demonstrated cost-effectiveness, even for those with very high levels of lifestyle related risk factors. Similar findings of cost-effectiveness for lifestyle interventions in cancer survivors could reasonably be anticipated and represent an important platform to guide subsequent fiscally responsible policies.

**Recommendation 4: ‘Fill the gap between inpatient and outpatient cancer services’**

There remains a large service gap between inpatient and ambulatory allied health services across the continuum of cancer care, including the survivorship period. While the development of effective treatment models and methods to maximise health outcomes are clearly a prioritised need, there remains wide variation in the clinical care and organisation of services available to address the needs of cancer survivors with an often weak interface between inpatient and outpatient providers. Outpatient needs of cancer survivors are often underserved with one study demonstrating that patients are approximately 100 times more likely to receive rehabilitation care as an inpatient rather than an outpatient. This important observation relating to physiotherapy and exercise physiology, may equally apply to other allied health care services including but not limited to dietetics, social work, and psychology. The development and integration of these services into cancer centres and outpatient facilities would be instrumental in providing improved multidisciplinary survivorship care.

**Recommendation 5: Ongoing attempts to engage community general practitioners in the non-cancer aspects of survivorship care – Cancer as a chronic disease!**

General practitioners are ideally placed to provide survivorship care in the primary health care setting. Further, their greater focus on health promotion and health surveillance is particularly advantageous for cancer survivors with chronic disease management issues such as the target group of this pilot project.

For coordinated care to become standard practice, however, it has to satisfy the needs of all key stakeholders. While the core need will be better clinical outcomes for cancer survivors, other drivers and barriers require identification. This project has identified significant potential barriers to primary care and acute care facility collaboration around cancer survivorship care. Perceived shortcomings by general practitioners for managing cancer survivors include:

- Time constraints
- Low incidence and high acuity patient group requiring care
- Perception that care needs are not relevant to general practice
- Perception of care as ‘cancer-related’ and therefore out of scope rather than as chronic disease management where general practice expertise lies.

Potential strategies to engage general practitioners in coordinated care in the future might consider:

- The need to be perceived as important and relevant
- Manageability within a busy consultation
- Involvement of the whole general practice team particularly practice nurses, and critically
- Promotion of survivorship care as chronic disease management.
**Recommendation 6: Development, promotion and support for Nurse led survivorship clinics and other health promoting interventions**

Our experience highlights the problems associated with general practice based long term follow-up of cancer survivors at high risk of late effects. Such high risk survivors, such as those who have undergone stem cell transplantation, may ultimately be best served by ongoing annual review by haematology/oncology specialists in a dedicated clinic setting. It is clear, however, that the increasing number of survivors is a limitation to this model. The delivery of survivorship care in this setting, therefore, would be ideally suited to advanced nursing practice roles, in particular a nurse practitioner with an expert knowledge base, complex decision making skills and appropriate clinical competencies.

**Recommendation 7: Support for roll out phase of current model**

Following from the successful development and implementation of the current Positive Change for Life model, a roll out phase to evaluate and validate the model across other health services with malignant haematology departments including stem cell transplantation would be highly desirable.

**Recommendation 8: Improved professional education and training for allied health professionals and service providers regarding rehabilitation issues facing cancer survivors**

One problematic barrier to the provision of physical activity and rehabilitation to cancer survivors identified by this project is a lack of specific training in the subcategory of oncology rehabilitation for allied health and service providers. Becoming a skilled and effective provider can pose a daunting task for those already in practice who may feel overwhelmed by the knowledge they must accumulate to expertly treat cancer survivors. Opportunities to provide education to allied health care professionals to equip them to address the chronic health and rehabilitation issues facing cancer survivors are critical.

**Recommendation 9: Integration of family members and carers in future health behaviour interventions**

The long term impact of a cancer diagnosis on families and caregivers is increasingly recognised. Family members and caregivers often require, but do not necessarily receive, the health care and psychosocial assistance they need in meeting the long term needs of both themselves and the cancer survivor in their lives. The current pilot has demonstrated the value placed on lifestyle inventions by carers and the potential personal benefits to them of participation. Future healthy behaviour intervention programs should ideally target both cancer survivors and caregivers focussing on aspects relating to the unique challenges of being a caregiver in the survivorship stage and the way in which this may impact on behaviour change of both carer and survivor.

**Recommendation 10: Transfer of findings from the Positive Change of Life pilot project across other cancer survivor groups**

The current Positive Change for Life pilot project contributes further to the body of research highlighting the benefits of lifestyle modification including nutrition and physical activity, particularly relating to fatigue and physical functioning, both of which directly influence quality of life. Specific physical activity recommendations are available for patients with a variety of tumour types including breast, prostate, colon, gynaecologic, and haematological cancers both with and without prior stem cell transplant treatment with minimal variation in the recommendations across cancer groups. This supports the applicability and therefore transferability of the findings of the Positive Change for Life pilot project across tumour streams with appropriate resource support.
Appendix 1: References


Appendix 2: Evaluation Strategy – Positive Change for Life

Aim:
To provide a range of community-based physical activities, support and health education opportunities to enable survivors of stem cell transplantation at any fitness level to take an active role in their ongoing physical and emotional healing to benefit health, wellbeing and quality of life.

Objectives:
1. Implementation of an innovative program to address an area of identified need in stem cell transplant survivors
2. Delivery of quality survivorship care in a community-based accessible program integrated with specialist and peer support
3. Empowerment of survivors to be active participants in their own lifelong care through psychological, social and educational support
4. Promote awareness of cancer survivorship needs
5. Engagement of the wider community in survivorship care
6. Development of a program model transferable across tumour streams with commitment to sustainability

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Evaluation questions</th>
<th>Measures</th>
<th>Indicators</th>
<th>Data source</th>
<th>Data collection time point</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Patient health related outcomes</td>
<td>How has the program impacted on the health and wellbeing of survivors?</td>
<td>Impact on quality of Life</td>
<td>• Proportion of participants with improvements in quality of life outcome measures</td>
<td>1. Surveys: FACT-BMT, BARSE Questionnaire, Godin Leisure-Time Exercise Questionnaire, REAP Questionnaire, FACIT Scale</td>
<td>Baseline, 6, 12 &amp; 18 months</td>
<td>6 month data collection is complete 12 participants to complete 12 months 27 participants yet to complete 18 month evaluations Interviews and focus groups completed</td>
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<td>What have been the critical success factors in helping people achieve the outcomes?</td>
<td>Impact on disease status measures</td>
<td>• Proportion of participants with improvements in disease status measures</td>
<td>1. Laboratory measures 2. Anthropometric measures</td>
<td>Baseline &amp; 12 months</td>
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<td></td>
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<td>Value of program for participants</td>
<td>• Increased self-efficacy • Proportion of participants reported improvement in lifestyle factors • Increased community engagement and participation • Proportion of participants reporting</td>
<td>1. BARSE 2. Focus group 3. In-depth interviews 4. Participant outcomes survey</td>
<td>Baseline, 6, 12 &amp; 18 months completed 9 months</td>
<td>All surveys, interviews and focus groups completed</td>
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<td>increased satisfaction with health benefits</td>
<td>5. Satisfaction survey</td>
<td>9 months</td>
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<td></td>
<td></td>
<td></td>
<td>4 months</td>
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<tr>
<td></td>
<td>Achievement of participant goals</td>
<td></td>
<td>• Proportion of participants reporting achievement of nutrition and/or physical activity goals</td>
<td>1. Nutrition data</td>
<td>1, 4, 8 &amp; 12 months</td>
<td>As above</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Identification of enablers that helped participants reach their goals</td>
<td>2. Physical activity diary</td>
<td>12 months</td>
<td></td>
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<td></td>
<td></td>
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<td>3. In-depth interviews</td>
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<td>4. Participant outcomes survey</td>
<td>4. Participant outcomes survey</td>
<td>9 months</td>
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<td>Participation and uptake</td>
<td>What has been the level of interest and uptake of the program amongst survivors?</td>
<td>Rate of participant and project uptake</td>
<td>1. Mailing list database</td>
<td>1, 4, 8 &amp; 12 months</td>
<td>As above</td>
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<td>What percentage of the target group has received the program?</td>
<td>Rate of participant and project uptake</td>
<td>2. Participant database</td>
<td>12 months</td>
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<td>Has the uptake of the program included people from a variety of geographical locations and socioeconomic positions?</td>
<td>Rate of participant and project uptake</td>
<td>3. Enquiry tracking sheet</td>
<td>Completed</td>
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<td>Have program participants been satisfied with the program?</td>
<td>Rate of participant and project uptake</td>
<td></td>
<td>9 months</td>
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<tr>
<td></td>
<td>Participation &amp; uptake continued</td>
<td>Adherence in exercise programs</td>
<td>• % of group sessions attended</td>
<td>1. Attendance data at group sessions</td>
<td>6, 12 &amp; 18 months</td>
<td>As above</td>
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<td></td>
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<td>• Frequency of attendance/participation in local gym program</td>
<td>2. Attendance data from local gyms</td>
<td>12 months</td>
<td>28 completed gym or other physical activity memberships</td>
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<td>• Changes in the Leisure-Time activities</td>
<td>3. Training diaries</td>
<td>12 months</td>
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<td>• % of participants reporting continuation of their physical activity program</td>
<td>4. Godin Leisure-Time Questionnaire</td>
<td>12 months</td>
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<td>5. Participant outcomes survey</td>
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<td>Measures</td>
<td>Indicators</td>
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<td><strong>Adherence in nutrition program</strong></td>
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<td>• Average number of follow-up sessions with the Dietician</td>
<td>• Number of participants with reported change in healthy eating behaviours</td>
<td>1. Nutrition database 2. REAP</td>
<td>6, 12 &amp; 18 months</td>
<td>Data collection is ongoing and up to date</td>
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<td><strong>Project processes and design</strong></td>
<td>Has the program been implemented as intended? What were the barriers and enablers that impacted on the implementation?</td>
<td>Program development and implementation</td>
<td>• Number and types of resources developed for project participants</td>
<td>1. Document analysis</td>
<td>On completion</td>
<td>Data collection is ongoing</td>
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<td></td>
<td></td>
<td>• Delivery of a nutrition program based on the COACH for Heart Health Model</td>
<td>• Identification of successful strategies for engaging community service providers</td>
<td>2. Stakeholder interviews 3. Satisfaction survey</td>
<td>To be schedule 4 months post entry</td>
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<td></td>
<td></td>
<td>• Disciplines represented on Steering Group</td>
<td>• Proportion of meetings with a quorum</td>
<td></td>
<td>On completion</td>
<td></td>
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<tr>
<td><strong>Increased engagement with local community providers</strong></td>
<td></td>
<td>• Number of YMCA and non-YMCAs engaged in project</td>
<td>• Number of gym memberships</td>
<td>1. Gym membership database</td>
<td>1, 4, 6, 12 months &amp; on completion</td>
<td>Completed</td>
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<td></td>
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<td>• Number of allied health services accessed/referred to</td>
<td></td>
<td>2. Document analysis</td>
<td>12 months &amp; on completion</td>
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<td><strong>GP education and engagement</strong></td>
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<td>• Development of GP resources</td>
<td>• Number of GP workshops held</td>
<td>1. Document analysis</td>
<td>12 months &amp; on completion</td>
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<tr>
<td><strong>Has the program been implemented as intended? What were the barriers and enablers that impacted on the implementation of the program?</strong></td>
<td></td>
<td>• Identification and number of different types of communications used</td>
<td>• Number of presentations delivered to stakeholder groups</td>
<td>1. Document analysis</td>
<td>6, 12 months &amp; on completion</td>
<td>Data collection is ongoing nearing completion</td>
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<td></td>
<td>• Proportion of activities implemented as per the communication strategy</td>
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<td></td>
<td>12 months &amp; on completion</td>
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Appendix 8
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<tr>
<th>Dimension</th>
<th>Evaluation questions</th>
<th>Measures</th>
<th>Indicators</th>
<th>Data source</th>
<th>Data collection time point</th>
<th>Comments</th>
</tr>
</thead>
</table>
|           | Has the program engaged the community wider community in survivorship care?          | Community awareness | • Number of YMCA and non-YMCA gyms engaged  
• Number of new organisations engaged during the project | 1. Gym membership database  
2. Document analysis                                                                 | Ongoing       | Data collection is ongoing                                                                        |
|           | Acceptability to community and stakeholders                                          |          | • GP's perceptions of the program  
• Number of allied health services engaged | 1. Stakeholder interviews/GP Survey  
2. GP education sessions                                                                 | GP surveys completed  
Education event scheduled 26.3.14                  |                               |
|           | Has the program been cost effective for participants and for the project?            | Budget utilisation | • Systems utilised for tracking and monitoring of the budget  
• Participant satisfaction  
• Cost effectiveness of the program - cost to participate in program  
  - usual membership costs  
  - cost to visit GP  
  - cost to LEC | 1. Document analysis  
2. Participant outcomes survey                                                                 | Ongoing       | Surveys completed                                                                              |
| Sustainability | How can the impacts of the program be sustained beyond the funding timeframe?  
How can the model be transferred across to other tumour streams? | Sustainability | • Development of a sustainability strategy  
• Sustainability strategy and recommendations submitted to the Department of Health with Final Report | 1. Stakeholder interviews  
2. Steering Group meetings                                                                 | Ongoing       | Completed with transfer to Jump Start program                                                     |
Appendix 3: Communication Strategy

Communication plan

The communication plan aims to inform and update stakeholders of the project. It also provides a mechanism for interested potential participants or other stakeholders to contact the project team for further information. This communication plan is included within the project work plan.

Communicating with a wide range of people provides the opportunity for others to learn from our experience and allow us to celebrate the achievements of participants and the project team

Target audience for communication

- Survivorship Steering Committee, Department of Health, Victoria
- Alfred Health clinical services
- Southern Melbourne Integrated Cancer Service (SMICS) Haematological tumour group
- Leukaemia Foundation
- Divisions of General Practice
- General Practice Victoria
- Alfred Health, SMICS and Leukaemia Foundation consumer groups
- Alfred Supportive Care Committee
- SMICS Governance Committee
- SMICS Supportive Care Committee
- Victorian Integrated Cancer Services
- Victorian Cooperative Oncology Group (VCOG)
Communication methods

- Scheduled reports to Survivorship Steering Committee, Department of Health
- Briefings / progress reports to Governance Groups
- Alfred Health, Southern Health, Cabrini Health, Peninsula Health newsletters
- Project Steering Group newsletters
- Primary Care Newsletters (General Practice Victoria, Divisions)
- GP education forums
- Project reports/presentations to external stakeholder groups

Communication actions

<table>
<thead>
<tr>
<th>Communication channel</th>
<th>Date for action</th>
<th>Completed activities and progress</th>
<th>Comments/target groups</th>
</tr>
</thead>
</table>
| 1. Newsletters & reports | Feb 2012 – Oct 2013 | - Feb/March 2012 – article promoting project in *Alfred HealthLink*
- April 2012 - Monash Division of General Practice distributing promotional flyer through Networks
- March 2012 – overview of project included in SMICS newsletter
- May 2012 – Sara Andrews to submit a piece to the August edition of the LF newsletter *The Carer*
- June 2012 – Inclusion of article in the ACSC newsletter
- July 2012 – A submission sent to the RACGP Vic Faculty to include in their August e-newsletter. The article profiled the aims of the project and the inclusion criteria to help GPs identify suitable patients.
- August 2012 – submission of news piece to SMICS for dissemination to GPs within catchment area
- Submission into the 2012 Alfred Quality Care Report
- October 2012 Publication of a project article in GPV’s VicView | GPs
GPs, Practice Nurses
GPs
Consumers
GPs/ consumers
GPs, Medicare Locals
GPs
Alfred Health staff, community
Medicare Locals,
<table>
<thead>
<tr>
<th>Communication channel</th>
<th>Date for action</th>
<th>Completed activities and progress</th>
<th>Comments/target groups</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>• March 2013 - Article published in the RACGP Good Practice Publication March 2013 edition</td>
<td>GPs, Registrars</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• July 2013 – submission of article for the ACSC July 2013 newsletter featuring the VCSP projects</td>
<td>Health and medical professionals, other health services and community</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• August 2013 – submission of article into the SMICS 2013 Annual Report</td>
<td>SMICS, GPs, Community Organisations</td>
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<tr>
<td></td>
<td></td>
<td>• October 2013 – submission of article into LF newsletter <em>The Carer</em></td>
<td>Consumers</td>
</tr>
<tr>
<td>2. Articles in peer review journals</td>
<td>From 2014</td>
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<td></td>
<td></td>
<td>• HAA (Haematology Society of Australia and New Zealand, the Australian &amp; New Zealand Society of Blood Transfusion and the Australasian Society of Thrombosis and Haemostasis) – Asian-Pacific Society on Thrombosis and Haemostasis Annual Scientific Meeting, 28–31 October 2012, Melbourne (oral)</td>
<td>Nurses, Haematologists, Scientists, Allied Health</td>
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<tr>
<td></td>
<td></td>
<td>• Clinical Oncology Society of Australia Annual Scientific Meeting, 13-15 November, 2012, Brisbane (poster)</td>
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<td></td>
<td></td>
<td>• Inaugural Flinders Centre for Innovations in Cancer Survivorship Conference, 1–3 February 2013, Adelaide (poster)</td>
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<td></td>
<td>• Victoria Integrated Cancer Services Conference, 13–14 May 2013, Melbourne (oral)</td>
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*Note: The Carer*
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<tr>
<th>Communication channel</th>
<th>Date for action</th>
<th>Completed activities and progress</th>
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<tr>
<td></td>
<td></td>
<td>• 9th Annual Australian Disease Management Association National Conference, 22–23 August 2013, Sydney (oral)</td>
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<tr>
<td></td>
<td></td>
<td>• 10th National Allied Health Conference, 16-18 October 2013, Brisbane (oral)</td>
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<td></td>
<td></td>
<td>• HAA (Haematology Society of Australia and New Zealand, the Australian &amp; New Zealand Society of Blood Transfusion and the Australasian Society of Thrombosis and Haemostasis) Annual Scientific Meeting, 20-23 October, 2013, Gold Coast (oral)</td>
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<td></td>
<td></td>
<td>• Alfred Health Research week, 21-25 October 2013, Melbourne (poster)</td>
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<tr>
<td></td>
<td></td>
<td>• Advances in Cancer Survivorship Practice: A Conference for Health Care Professionals, 31 October–1 November 2013, Houston, Texas, USA (poster)</td>
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<td></td>
<td></td>
<td>• Australasian Society for Parenteral &amp; Enteral Nutrition (AuSPEN) conference -16 November 2013, Sydney</td>
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</table>
| 4. Other              | Feb 2012 – ongoing | Presentations have been delivered:  
- Alfred Clinic Services Department  
- SMICS Supportive Care Committees  
- VCOG  
- COP  
Other Presentations:  
- Victorian Cooperative Oncology Group (Haematology) – 8 November 2011, Melbourne  
- Bone Marrow Transplant Nursing Education Forum – 8 May 2012  
- Haematology Clinical Meeting – 13 June |
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<tr>
<th>Communication channel</th>
<th>Date for action</th>
<th>Completed activities and progress</th>
<th>Comments/target groups</th>
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<tr>
<td></td>
<td></td>
<td>2012</td>
<td>trainees, nurses, allied health</td>
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<td></td>
<td></td>
<td>• Survivorship Forum – June 2012</td>
<td>Specialists, trainees, nurses, allied health</td>
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<tr>
<td></td>
<td></td>
<td>• Australian Centre for Blood Diseases Annual Research Forum – 10 August 2012, Melbourne</td>
<td>Consumers</td>
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<tr>
<td></td>
<td></td>
<td>• Surviving Cancer (in collaboration with the Leukaemia Foundation) – 20 September 2012</td>
<td>Nurses</td>
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<td></td>
<td></td>
<td>• Australasian Leukaemia and Lymphoma Group Education for Data managers and Research Nurses – 13 November 2012</td>
<td>Specialists, trainees, nurses, allied health</td>
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<td></td>
<td></td>
<td>• Alfred Grand Rounds – 22 November 2012, Alfred Hospital, Melbourne</td>
<td>Consumers</td>
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<td></td>
<td></td>
<td>• Haematological Malignancy Study day – 27 November 2012</td>
<td>Nurses</td>
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<tr>
<td></td>
<td></td>
<td>• Leukaemia Foundation Bone Marrow Transplant Support Group – 4 April 2013</td>
<td>Specialists, trainees, nurses, allied health</td>
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<td>• Bone Marrow Transplant Nursing Education Forum – 7 May 2013</td>
<td>Consumers</td>
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<td></td>
<td></td>
<td>• Austin/Olivia Newton-John Cancer and Wellness Centre Cancer Survivorship Professional Development Day, - 5 June 2013</td>
<td>Nurses</td>
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<td></td>
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<td>• Austin/Olivia Newton John Cancer and Wellness Centre Bone Marrow Transplant Study Day, 18 September 2013</td>
<td>Specialists, trainees, nurses, allied health</td>
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<tr>
<td></td>
<td></td>
<td>• Haematological Malignancy Study day – 26 November 2013</td>
<td>Specialists, trainees, nurses, allied health</td>
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5. Project newsletter  
March 2012 – March 2014  
Project newsletters disseminated  
• July 2012
<table>
<thead>
<tr>
<th>Communication channel</th>
<th>Date for action</th>
<th>Completed activities and progress</th>
<th>Comments/target groups</th>
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<tr>
<td></td>
<td></td>
<td>- August 2012</td>
<td>Consumers GPs</td>
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<td>- September 2012</td>
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<td>- October 2012</td>
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<td>- Christmas edition 2012</td>
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<td>- January 2013</td>
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<td>- February 2013</td>
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<td>July 2013</td>
<td>- March 2013</td>
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<td>August 2013</td>
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<td>September 2013</td>
<td>- May 2013</td>
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<td>October 2013</td>
<td>- June 2013</td>
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<td>November 2013</td>
<td>- July 2013</td>
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<td>Dec/Jan 2014</td>
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<td>February 2014</td>
<td>- September 2013</td>
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<td>- November 2013</td>
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<td></td>
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<td>- Dec/Jan 2014</td>
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<td></td>
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<td>- February 2014</td>
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<tr>
<td></td>
<td></td>
<td>Project newsletters sent to ACSC, Steering Group, new participants and their GPs on entering the project Also available on Alfred Late Effects Clinic website</td>
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</tbody>
</table>
One Page Lay Summary

Every day in Australia, 31 people are diagnosed with a blood cancer such as leukaemia, lymphoma or multiple myeloma. Stem cell transplantation as an additional treatment to chemotherapy offers effective control and potential cure of a proportion of these blood cancers. Stem cell transplantation, however, is a highly aggressive and demanding medical intervention. Although many long term survivors enjoy good health, for others cure of their underlying disease is not accompanied by full restoration of their former health.

The Alfred Hospital's Late Effects Clinic is a multidisciplinary clinic dedicated specifically to the long term follow-up of stem cell transplant survivors, their families and carers. Through this clinic we have identified a large number of common risk factors for future health problems such as heart disease that may be able to modified and therefore reduced by healthy eating, sensible physical activity and weight management. The Positive Change for Life survivorship project is a lifestyle modification program for long term survivors of blood cancer that aims to promote sustainable changes in diet, physical activity and health behaviours to maximise future health, wellbeing and quality of life.

Within the setting and work flow of the Alfred Late Effects Clinic, each project participant entered a 12 month program integrating the key components of individually tailored community-based physical activity, group physical activity, general practitioner support, education, motivational strategies and a structured program of dietetic consultation. Participation in the physical activity and nutrition programs were supported by health information and education, monthly newsletters, a weekly exercise diary, meal planners, food diaries and charts to help measure and monitor weight changes.

Between June 2012 and July 2013, the project enrolled 53 long term survivors of blood cancer treated with stem cell transplantation. At the start of the project 68% of participants were overweight or obese. Assessments of modifiable risk factors revealed a large proportion of participants had high blood pressure (58%), abnormal blood fats (49%) and high blood sugar (17%). Severe fatigue was also reported by 15% of participants. Prior to engaging in the project a high number of unhealthy eating behaviours were reported by participants and physical activity levels were low.

Encouraging improvements in health outcomes occurred for most participants within the first 6 months of project participation with enhanced energy and quality of life reported. Marked improvements in physical activity levels were evident with striking increases compared with baseline in overall physical activity, moderate and strenuous physical activity and activity sufficient enough to work up a sweat. Higher physical activity levels were associated with better quality of life and more energy.

Nutrition scores and unhealthy eating behaviours also improved progressively throughout the 12 months of project participation. As a result three quarters of participants lost weight and overall body measurements. Also observed was a healthy reduction in blood pressure, blood fats and blood sugar in the majority of participants. These changes did not occur in a similar group of cancer survivors who received general health advice but did not participate in Positive Change for Life.

The Positive Change for Life program was highly valued by participants who demonstrated readiness to participate in the program with strong themes emerging of a desire to improve health, increase fitness and lose weight. Participants that wanted a partner or family member involved found that they both achieved health benefits.

Health promotion and lifestyle modification is an essential part of caring for cancer survivors to offset the effects of treatment, reduce the risk of future illness and promote long term wellness. The Positive Change for Life project demonstrates the potential of an individualised community-based physical activity program coupled with nutritional advice to improve healthy lifestyle behaviours, promote weight loss and enhance quality of life and reduce fatigue levels in long term survivors of stem cell transplants. It is anticipated that many other cancer survivors, not only those with blood cancers, would benefit from a similar program.

‘The program has given me the confidence to make good lifestyle choices’

‘I feel much fitter, not tired all the time’

‘I regret not doing something similar for myself years ago’

‘The gym membership has boosted his self-esteem and fitness levels, thank you’
**Two Paragraph Summary**

The Positive Change for Life survivorship project is a nutrition and lifestyle intervention for long term survivors of blood cancer treated with stem cell transplantation that promotes sustainable changes in diet, physical activity and health behaviours to maximise future health, wellbeing and quality of life. 53 long term survivors of blood cancer participated in the Positive Change for Life project. Participants received an individually tailored community-based physical activity program aligned with their goals and abilities. Participants also received ongoing dietary advice and health coaching from a dietician. Participation in the physical activity and nutrition programs were supported by health information, a weekly exercise diary, meal planners, food diaries, monthly newsletters and charts to measure and monitor progress. Group physical activities were also conducted with participant’s families welcome to attend.

Encouraging improvements in health outcomes occurred for most participants within the first 6 months of project participation with enhanced energy and quality of life reported. Marked increases in physical activity levels were evident. Participants also reported making healthier food and dietary choices which have resulted in weight loss for the majority and overall health benefits. Participants that wanted a partner or significant other involved found that they both achieved health benefits. The Positive Change for Life project demonstrates the potential of an individualised community-based physical activity program coupled with nutritional advice to improve healthy lifestyle behaviours, promote weight loss and enhance quality of life and reduce fatigue levels in long term survivors of stem cell transplants.
Appendix 4: Sustainability Strategy – Positive Change for Life

Project Aim:
To provide a range of community-based physical activities, support and health education opportunities to enable survivors of stem cell transplantation at any fitness level to take an active role in their ongoing physical and emotional healing to benefit health, wellbeing and quality of life.

Project Outcomes:

1. Implementation of an innovative program to address an area of identified need in stem cell transplant survivors
2. Delivery of quality survivorship care in a community-based accessible program integrated with specialist and peer support
3. Empowerment of survivors to be active participants in their own lifelong care through psychological, social and educational support
4. Promote awareness of cancer survivorship needs
5. Engagement of the wider community in survivorship care
6. Development of a program model transferable across tumour streams with commitment to sustainability

<table>
<thead>
<tr>
<th>Project Outcome</th>
<th>Outputs</th>
<th>Stakeholders</th>
<th>Possible strategies and actions</th>
<th>Timeframes</th>
<th>Who needs to be involved?</th>
<th>Comments/Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implementation of an innovative program to address an area of identified need in stem cell transplant survivors</td>
<td>Engagement of the Alfred Nutrition Department &amp; delivery of a nutrition program based on COACH for heart health Gym memberships established across a wide number of YMCA’s and other Leisure Centres</td>
<td>Nutrition Dept Late Effects Clinicians YMCA Victoria &amp; local YMCA Centres</td>
<td>Development of a proposal for the appointment of a Dietician to provide ongoing nutrition services to all SCT recipients attending the Alfred LEC Development of a partnership between LF and YMCA that enables ongoing access to discounted memberships for existing project participants and members of the LF</td>
<td>February 2014 September 2013</td>
<td>Dietician LEC Clinicians Alfred Executive</td>
<td>Dietician LEC Clinicians Alfred Executive</td>
</tr>
<tr>
<td>Delivery of quality survivorship care in a community-based accessible program integrated with specialist and peer support</td>
<td>Informal peer support networks established amongst participants</td>
<td>PCFL project participants</td>
<td>Invite participants to contact the LF to explore opportunities to attend LF support groups – communicate through the PCFL project newsletters</td>
<td>Ongoing</td>
<td>LF Alfred LEC</td>
<td>Refer focus group findings. Interest expressed from a single attendee to retain contact</td>
</tr>
<tr>
<td>Empowerment of survivors to be active participants in their own lifelong care through psychological, social and educational support</td>
<td>Development of participant handbook and production Dissemination of a monthly project newsletter</td>
<td>Participants</td>
<td>Modify existing project handbook into a generic resources that can be made available to attendees of the LEC Make resources and worksheets available on the LEC website and load onto patients PEHCR Ongoing provision of information and recommendations for follow-up (through the SCP) following annual LEC attendance.</td>
<td>March 2014 March 2014 Ongoing</td>
<td>Project team LEC Clinicians</td>
<td>Will require some funding to modify and print handbook</td>
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<td>---------------------------------------------------------------</td>
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<tr>
<td>Promote awareness of cancer survivorship needs</td>
<td>Implementation of Communication Strategy including conference presentations, external newsletter submissions</td>
<td>Refer to communication strategy</td>
<td>Development of a communication strategy to disseminate project evaluation findings Abstract submissions Peer reviewed journals Stakeholder publications Continue representation on steering groups, advisory committees and reference groups Alfred Supportive Care Committee SMICS Governance Committee SMICS Supportive Care Committee Development of a GP fact sheet communicating the needs of SCT recipients. Disseminate to GPs along with the SCP following their patients attendance at the LEC and make available on LEC website</td>
<td>September 2013 Ongoing</td>
<td>LEC Clinicians GPs Practice Nurses Bayside Medicare Local GPV ACSC</td>
<td>Refer Communication Strategy</td>
</tr>
<tr>
<td>Engagement of the wider community in survivorship care</td>
<td>Increased access to community based allied health services Increased engagement with Medicare Locals, GPV and primary care providers Increased referrals from external organisations (LF and Peter Mac)</td>
<td></td>
<td>Develop database of exercise physiologists and physiotherapists referred to during the project for ongoing use by the LEC. Ongoing provision of information and recommendations for GP follow-up through the SCP following annual LEC attendance.</td>
<td>August 2013 Ongoing</td>
<td>Project Manager LEC Clinicians</td>
<td></td>
</tr>
<tr>
<td>Development of a program model transferable across tumour streams with commitment to sustainability</td>
<td>Physical activity and nutrition program transferable across tumour streams</td>
<td>Alfred Late Effects Clinic Leukaemia Foundation YMCAs Project Participants Existing patients of LEC not engaged in project Other blood cancer survivors outside of the Alfred LEC</td>
<td>Adoption and Integration of the PSCFL program by the LF. Development of a referral pathway and supporting tools for the LEC and LF. Meeting with YMCA Victoria regarding partnership opportunities</td>
<td>September 2013 September 2013</td>
<td>LF LEC Clinicians YMCA Victoria</td>
<td>Completed with transfer to Jump Start program</td>
</tr>
</tbody>
</table>
Appendix 5: Participant Focus Group and In Depth Interview Findings

Positive Change for Life

Participant Focus Group and In Depth Interview Findings
October 2013

Dr Jill Beattie

Performance Enhancement Consultancy, Victoria
ACKNOWLEDGEMENTS

Thank you to the participants who gave of their time and so willingly shared their experiences of the Positive Change for Life project.

Thanks also to the Leukaemia Foundation for providing the venue to conduct the focus groups.

Funding for conduct of the focus group was provided through the Positive Change for Life project, with support for the conduct of the interviews provided through the Southern Melbourne Integrated Cancer Service (SMICS).

The project is a Victorian Cancer Survivorship Pilot Project and is funded by the Victorian Government Department of Health.

Reference Citation:

Focus Group and In Depth Interview Findings

Background

Although curative for many people with blood cancer, stem cell transplant survivors may carry a burden of associated morbidity. A critical need to address lifestyle to minimise risk for future chronic illness has been identified in long-term survivors of blood cancer treated with stem cell transplantation.

Consequently, a 12-month Positive Change for Life project was developed and integrated dietary advice, tailored individual and group exercise, motivational strategies and general practitioner support. A community-based approach was used to promote sustainable changes in diet, physical activity and health behaviours. The aim of the program was to empower survivors to develop and maintain lifelong healthy eating and physical activity patterns in order to maximise wellness and quality of life.

A number of strategies such as an online survey and a focus group and individual interviews were used to evaluate the program. Ethical approval to conduct the evaluation was obtained from the Alfred Hospital Ethics Committee. This document reports the focus group and interview findings with Positive Change for Life participants.

Method

Focus groups are frequently used in evaluation research, and in this project assisted in collecting information about participants’ experiences, attitudes, feelings and behaviours during their participation in the Positive Change for Life project. Focus groups were chosen as a method of data collection to stimulate conversation as a group, share experiences, serve as prompts, and generate ideas about any gaps and changes recommended for future programs. The skills of the facilitator ensure that all participants contribute to the discussion. Participants who were unable to participate in the focus group were offered the opportunity to attend an interview.

The focus group and interview questions were developed by the Positive Change for Life Project staff in consultation with Southern Melbourne Integrated Cancer Services (SMICS) staff and the independent consultant, and were based on the aims and content of the program. Identical questions were used for the focus group and interviews.

The focus group was conducted over two hours with a 20 minute break. Two observers also took notes during the session. The interviews were conducted over a 1 hour period. The focus group and interviews were digitally recorded and transcribed. The transcripts was entered into the NVivo7 qualitative data management computer software system and thematic analysis was conducted to identify themes related to the semi-structured questions.

Recruitment of Participants

Participants who had been involved in the project for a minimum of six months as of 23 May 2013 were identified and invited to attend a focus group. Thirty-seven participants were sent a letter of invitation accompanied by a patient information and consent form detailing the focus group background and methodology. Six months was selected as the cut-off point as participants are more likely to have had an opportunity to experience and reflect on some of the challenges, benefits and learnings associated with their participation in the lifestyle modification program. Participants who were unable to participate in the focus group were offered the opportunity to attend an interview.
Findings

Participant sample

Eight participants (5 males and 3 females) attended the focus group and the median duration of participation in the program was 9.75 months. The median age of participants at the time of the focus group was 55 years and time since either autologous (38%) or allogeneic (62%) transplant was 5.5 years.

Nine participants (4 males, 4 females) attended an interview and the median duration of participation in the program was 11.8 months. The median age of participants at the time of the interviews was 50.4 years and time since either autologous (13%) or allogeneic (87%) transplant was 4.4 years. 1 wife of a project participant also attended an interview.

The most important factors that helped participants to achieve their goals

Having access to the resources within the Positive Change for Life program was the most important factor helping participants to achieve their lifestyle goals and changed participants’ ability to make lifestyle choices (Table 1). Indeed, participants expressed gratitude for being able to participate in such a program:

I think it’s wonderful that the hospital is able to provide these services so that all of us can enjoy the benefits of what the hospital is offering. I think it’s just been absolutely sensational, and personally I’m very grateful to be involved, and I’m very happy to be involved, and I can see the benefits of being involved. All I’ve got is praise, basically, for what the hospital has done (ID7).

The encouragement from the project has given me reassurance that I’ve been on the right track (ID9).

Examples of valuable people resources included medical specialist support (ID5, ID6, ID10), particularly at the commencement of the program, and also the dietician (ID10, ID11, ID13, ID16), exercise physiologist and trained gym staff (ID10, ID16, ID17, ID18), as well as the project staff (ID15). Financial support was also considered an important factor in helping to achieve goals (ID15, ID16), and also acted as a motivator for some:

I think it was the fact that the Alfred were paying for my membership at water aerobics and I felt a bit obliged by agreeing to take part in the project that I would try and follow through what they’re wanting me to follow through, if that makes sense? (ID15).

Helpful material resources included receiving regular newsletters (ID10) and keeping the diary that was provided during the program to monitor progress (ID1, ID15).

The second most important factor was having the support of others within the household, for example in following nutrition and attending exercise sessions with the participant. In addition, feeling fitter generally gave participants the energy to continue with the program (refer Table 1 for details).
The greatest challenges faced by participants during the program

As shown in Table 2, the greatest challenges faced by participants during the program included: getting motivated to get going, low level of pre-program fitness and fatigue; competing commitments; going through the program alone; coping emotionally; being unwell; the gym environment; making nutritional changes; and the distant location of social activities.

One participant found the program harder than they initially thought it would be because they “didn’t do any exercise before and was having to try to fit it in” in managing a household and children (ID3). Competing priorities with part-time work and attending appointments was also a challenge (ID1, ID10, ID12, ID14, ID17). Another found that over the 12 months they started to get tired with the constant going backwards and forwards, attending a UVA clinic for treatment of GVHD\(^4\) twice a week, sometimes on the same day as their gym session (ID9). Even so, this participant reported that they “enjoyed it all” (ID9). Others found the program was as they thought it would be (ID8, ID7), had “no real expectations” (ID6) or did not “quite know what [they were] signing up for” (ID5); having read the materials about the program they had “decided it was a good idea” (ID5).

In relation to the gym environment, three issues were identified: 1) The inside environment, 2) the gym culture, and 3) variability in assistance from personal trainers. One participant had enjoyed walks outside prior to commencing the program and was not “willing to sacrifice” their hour long daily walk to go to the gym, so the challenge was to fit both in three times a week (ID2). Participants reported that the gym culture is ‘alive and well’ with people looking at themselves in mirrors and talking on mobile phones rather than acknowledging each other. The variability in assistance from personal trainers, or trainers on the floor to ensure correct and safe use of equipment is a very important issue that may need to be addressed in future programs.

When participants were unwell, some attempted to keep up the habit of exercise in some form, for example more gentle walking (ID2), stretching and yoga (ID5, ID9).

Some participants identified that the program covered nutrition and physical exercise, but did not cover emotional coping strategies, and for them, this was a major challenge. For example, coping with daily stress, people and groups of people without appearing to be rude (ID16). Refer to Table 2 for further details.

One area that was identified as important to understanding the challenges to motivation and carrying out, or attending activities in the program was the presence of any pre-existing conditions and/or lifestyle choices. For example, for those who had in the past been involved in various activities (ID2, ID6, ID7), motivation and making the extra effort to attend social programs was more accepted as a challenge to be met. However, one participant reported that they had experienced depression for some time, even before their illness, and while they talked frequently about wanting to connect socially, they found it difficult to take up these opportunities, reporting distance to travel to social events and time of the day as challenges. This participant particularly enjoyed the interaction within the focus group context and during the break.

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\(^4\) Graft versus host disease (GVHD) is a common complication after allogeneic stem cell transplantation. It occurs when immune cells from the donor recognise the recipient’s body as foreign and attack the patient’s normal cells. Acute GVHD usually occurs within the first 3 months after transplant. Chronic GVHD usually begins more than 3 months after transplant and can last a lifetime.

Appendix 25
The greatest health benefits of participation in the program

As shown in Table 3, the greatest health benefits of participation in the program for the survivors were: increased motivation to participate in activities and nutritional support and feeling fitter and younger than previously. Participants experienced increased wellbeing, not only in themselves, but also of family members. For example, they experienced alleviation of symptoms such as headache and stress, and improved mobility, mood, sleep, and self-confidence. Other benefits included receiving holistic care and follow-up; improved relationships and increased awareness of the impact of their illness on family members; and increased opportunities for social connection.

Greatest lessons learnt from participation in the program

Participants responded to this question in two ways: 1) the greatest lessons they learnt from participation in the program, and also, 2) the greatest lessons they had learnt from having their illness.

The greatest lessons participants learnt from participation in the program were that: you are capable of more than you think you are, have more grit and determination than you may have thought, and your body is so resilient. Participants’ learnt that you can develop a more positive outlook on life even though you have a serious illness, and that you can accept help and don’t have to lock yourself away. The importance of movement and diet was a valuable learning for some as a way of looking after their body. One participant was particularly more aware of when they were moving from patient to non-patient roles, and just how normal the non-patient role then felt (Table 4).

Participants agreed that having their illness had changed their lives in many ways, and agreed that having hope of recovery was important to their wellbeing. In particular one participant had finally bought a farm they had wanted from childhood and was growing organic vegetables, all giving a new sense of purpose in life. This participant reported that the greatest lessons they had learnt from experiencing their illness were: that as humans we are entitled to be happy and to look after ourselves as well as our family, even though family is very important. Another participant reported being in the process of writing a book: “What I Learned from Cancer”.

Gaps in care for people who have undergone stem cell transplants and recommendations

Participants reported that it was difficult for them to discuss gaps when they found the care and the Positive Change for Life program to be so accessible and beneficial. In addition, it was difficult for them to discuss because they felt that their treatment and needs were all so very different. Some participants were unaware of some of the resources that were available, for example that there was a late effects clinic website that has health information for survivors and health professionals.

As shown in Table 5, the time-limited nature of the program was discussed and a number of participants reported how important it was now to maintain the continuity and momentum that they had developed over the preceding months.

Participants were unsure of how and when their progress in the program was being measured and what documentation (e.g. their diary) would be required at the end of the program to measure outcomes. In addition, some participants would have liked more frequent face-to-face review to monitor improvement, make changes if they were not shown to be improving, and as a motivator to keep going. It was also agreed that a partner survey might be useful to provide further information about outcomes. More
partner involvement in the program at commencement and throughout was also recommended (Table 6).

Reformatting the diary to add space for monitoring their daily steps was requested. Participants agreed that an ongoing newsletter, particularly if the program was not to be continued, would be of benefit in providing information and as a reminder “to prick one’s conscience” and as a motivator “giving people a nudge” to keep going. It was also suggested that survivors themselves could contribute to the newsletter (Table 6). Participants were clear that they did not want SMS reminders for such things as activities and appointments.

Gaps in care for people who have undergone stem cell transplants included having a fast track card to enable fast tracking to the appropriate ward/unit on emergency service presentation; an integrative medicine clinic, or approach to care which included massage etc.; and social networking using information technology (IT) to increase contact with others in similar situations. One participant suggested survivors being invited to write down a summary of their treatment and journey, so that others could access this, for example for strategies in how others managed the challenges (ID9).

Summary and Conclusion

Findings from the focus group and interviews with survivors showed that they welcomed the Positive Change for Life program, reporting changes to their lifestyle behaviours and satisfaction with the resources and support during the program. Having others in the household who supported them was an important factor in their continued motivation. Further, there were a number of instances where other family members also benefited from the survivors’ participation in the program. In contrast, the participant who lived alone did find the lack of home support an issue and identified it as a gap in the program, however was unable to offer a solution.

A number of participants reported that they already followed good nutrition and exercise patterns prior to commencement of the program. However, in further discussion, it was revealed that once they had seen the dietician for example, some did make dietary changes such as reducing salt and sugar, and others instigated a more regular mobility regimen. Thus, support and information provided in the program educated participants on healthier lifestyle patterns.

While the program was specifically designed to empower survivors to develop and maintain lifelong healthy eating and physical activity patterns in order to maximise wellness and quality of life, a notable gap identified by some was the lack of a specific emotional support component. Participants were grateful of the support given by various project team members and providers, however, they identified occasions when they were stressed, frustrated, impatient, sad and possibly depressed. Consequently, the addition of individual emotional support by social workers, mental health nurses, counsellors and mindfulness-based individual and group programs may be a valuable addition to the Positive Change for Life program. Mindfulness-based group programs have been used to improve stress, anxiety and depression in cancer patients and survivors and is worth investigating further as a valuable addition to a continuing Positive Change for Life program.
Recommendations from the Participants’ Focus Group and In Depth Interviews

The recommendations for future Positive Change for Life or similar programs included:

- To continue providing the Positive Change for Life program
- Include emotional support mechanisms, for example social workers, counsellors and/or group programs for those who wish to attend
- More clarity at the commencement of the program around how progress and outcomes will be measured
- More frequent face-to-face contact to review progress
- Partners involved at the commencement of the program, throughout, and in measuring the survivor’s progress
- Provision of an ongoing newsletter
- Stronger links with the Leukaemia Foundation
<table>
<thead>
<tr>
<th>Factors that helped achieve goals</th>
<th>Example responses from participants</th>
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<tbody>
<tr>
<td>Access to resources in the Positive Change for Life program</td>
<td>I'd just like to say how good it is that the Alfred have got on board with the drives and the fitness things, because they were both my downfalls. I'm not a gym person, and there didn't seem to be a lot else around. If it's up to me, forget that, but now I'm in with this group and they're a good bunch of people, and even though I've only been a couple of weeks, it's going good (ID8). There's a difference between people that you've never met before that are genuinely concerned, genuinely want to help you, genuinely want to get you right (ID17).</td>
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<tr>
<td>Financial Support</td>
<td>It's been great doing that [gym membership], otherwise I wouldn't have done it, because ... you can't really afford all these things when you're not working (ID16). I think it was the fact that the Alfred were paying for my membership at water aerobics and I felt a bit obliged by agreeing to take part in the project that I would be - try and follow through what they're wanting me to follow through, if that makes sense? (ID15).</td>
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<tr>
<td>Regular newsletters</td>
<td>[The newsletter was] a regular point of contact, just to touch base, but just advice about diet and exercise, just healthy eating tips. There will often be recipes, information about nutritional contents of food - and having contact details of people if you wanted to follow up on a question or speak to somebody, the newsletter has been quite useful in that respect. ... I've used it to get in touch with the dietician and to follow up with Sharon, the haematologist, and a couple of others (ID10).</td>
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<tr>
<td>Keeping the diary - some did and others did not</td>
<td>Keeping that diary that we had (ID1). I was one of the people that did fill it in. ... it is strange because I’m not usually a structured person, but that diary did help me be a bit more structured. ... I was just recording what I did each day without adding the weekly or monthly or whatever (ID15). We’re filling out an exercise diary, which I am doing religiously because that’s just me (ID16). I didn’t use the diary. I didn’t get that one, but I think that’s a great idea (ID5).</td>
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<tr>
<td>Medical specialist support</td>
<td>Whoever we were with - we owe being here to her [Haematologist] and the people at Alfred - and I take my hat off to them. (ID5) I think at the start of the project where I got some benefit and following on from there, which is still ongoing now, was the initial interview with ... the Haematologist doctor. Yes, having that interview with her to start with - we discussed other health issues (ID6).</td>
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Table 1: Factors that helped achieve lifestyle goals and example responses from participants continued…

<table>
<thead>
<tr>
<th>Factors that helped achieve goals</th>
<th>Example responses from participants</th>
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<tbody>
<tr>
<td>Nutritional support:</td>
<td>… the nutrition thing was great, and having that reinforced by nutritionists (ID5).</td>
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<tr>
<td>• provision of recipes</td>
<td>I really like the recipes. I've got a vegetarian daughter, … so I was really keen to try them, and my children liked it, so it made it even better to know that they were eating something that was healthy for them (ID3).</td>
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<td>• information</td>
<td>Just simply make an effort to use less butter on your toast in the morning, and perhaps not eat as much cheese as I would otherwise. Just really a conscious effort (ID7).</td>
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<td>• strategies</td>
<td>I'd just get too busy at work, but I've got a drink bottle [now] and left it at the desk (ID1). Beth told me to drink another glass of water a day and another piece of fruit (ID9).</td>
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<tr>
<td>Household support</td>
<td>The thing that helped me was the household regime. We've always done exactly what we're still doing today. I mean there's nothing in the exercise and dietary that's really changed. There's a few things; like I was eating too much sugar; so sugar, I don't eat at all apart from a few sweets; I got rid of salt. … if your family's doing it, which our family does, then that's your best chance. … I'd hate to do it if I didn't have my family just doing it as a norm. It must be tough (ID5).</td>
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<td></td>
<td>My wife's always been to most of the hospital visits that I've had, so she's well aware of what I suppose we're trying to maintain, and she does that at home, and I suppose, there's only two of us at home now so it's quite easy to maintain that healthy diet and healthy exercise (ID6).</td>
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<td></td>
<td>I'm the wife and I've always done the cooking, and we had a pretty healthy regime before illness, and it just continues on … Cook from scratch and cook with fresh ingredients (ID2).</td>
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<td>Every time I went to my session I would take my daughter, so it actually helped her too - to get out and get a bit of exercise (ID3).</td>
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<td>Feeling fitter</td>
<td>Just because I'm starting to get a bit more active and a bit fitter (ID8).</td>
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### Table 2: The greatest challenges faced by participants during the program

<table>
<thead>
<tr>
<th>The greatest challenges</th>
<th>Example responses from participants</th>
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<tbody>
<tr>
<td>Getting motivated, low level of pre-program fitness and fatigue</td>
<td>Getting motivated. Getting up and doing exercise. At first it was very challenging because I was so unfit, but then I could see the benefits of getting fitter as it went on, and getting addicted to wanting to go to the classes (ID1).</td>
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<td></td>
<td>Drive and fitness were my downfall (ID8).</td>
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<tr>
<td>Competing commitments e.g. Working shift work, childcare etc.</td>
<td>Finding the type of exercises I could accommodate in my busy schedule of working part-time and attending medical appointments (ID10).</td>
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<td>“was having to try to fit it in” in managing a household and children (ID3).</td>
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<td></td>
<td>… challenging because I work shift work, so I’d have to try to fit around that (ID1).</td>
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<td></td>
<td>I work full-time, so there’s only so much time I get (ID12).</td>
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<td></td>
<td>Even though he feels a bit better, he works long hours, so he’d have to exercise in the dark, pretty much, if we went walking, and it’s cold and wet. Whereas, next year, we’ll have a lot more choices when he does those things [when he retires] (ID14).</td>
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<td>I didn’t want to take time off work (ID17).</td>
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<td>Going through the program alone</td>
<td>Going through it by yourself. … That was a bit of a battle for me (ID8).</td>
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<tr>
<td>Coping emotionally</td>
<td>My biggest challenge is more my emotional side - coping with stress, coping with people, groups. I don’t seem to have as much patience as I did beforehand, but that’s not really part of the program. … sometimes I just get to the stage - and I can be rude, which is embarrassing. You know, I have to apologise to people afterwards, because it might be something trivial that you’re talking about, and all of a sudden, it really gets to me and I just tell them what I think. I’ve sort of got to think later, that was a bit harsh (ID16).</td>
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<td></td>
<td>It's not the chemo, it's not TBI, it's not all those things. It's the mental side for me … having someone at your side or having someone that's got your back, and having someone that - I mean, everyone I know wants to help me (ID17).</td>
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<tr>
<td>The greatest challenges</td>
<td>Example responses from participants</td>
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<tr>
<td>Being unwell e.g.</td>
<td>I do have a problem with exercise now, because I still get infections and I get sick. So, just when you’re back on your bike, and just about to go back to the gym, you spend a week, two weeks and you have to start again, and that’s difficult under that sort of regimen. In fact, I received a membership to the gym and still haven’t activated it (ID5). I’ve had a cold - trying to struggle to get over that - so bit short of breath and that sort of thing. Basically, that’s what’s been stopping me (ID6). I’m having trouble because I had a total hip replacement in 2010, and I’m due to have my other hip replaced. I just fractured my knee as well, three days ago, so I’ve really struggled …I was getting to the pool twice a week, then our pool shut down and was being renovated, so I had to go somewhere else and I just found it a challenge getting there. I have four children; I’m really busy anyway, but I haven’t really been able to do the 30 minutes of exercise every day. It’s just the pain. Because of the pain in my hip - I was fine in the pool, but to try to go for walks, really, the pain is too much. There is another pool, but it’s further for me to go, and I found it hard getting there. I’m not supposed to drive (ID3).</td>
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<tr>
<td>The gym environment</td>
<td>I’d always been good at exercise. I walked every day. My challenge was moving it into a gym for at nearly 54, I’d never set foot in a gym in my life, so that was a challenge for me; to take it indoors. Just that gym culture. Mirrors. Buff. (ID2). Yes, they don’t talk to you. They just look in the mirror and look at their mobile phones. Nobody smiles at you. Nobody talks to you. Nobody gives you any encouragement - and the personal trainers - well, where I go at Oakleigh they don’t have personal trainers on the floor - so you could be doing something wrong, and really going to hurt yourself eventually, and they’re not there (ID9). I chose not to go in the gym area after two weeks because I didn’t enjoy it, but I’ve chosen to do all the classes and I really enjoy those. … Boxing classes, really high cardio yoga, all different. It’s challenging at first, but I’ve really got into it (ID1). The greatest challenge for me was determining which gym to go to - it was wonderful that they were able to give us a choice, and I went to about three or four gyms in my area, and I selected the gym that I felt most comfortable in and … it’s been sensational for me. I tend to go probably about three times a week on average, so I’m really taking advantage of this great opportunity (ID not captured).</td>
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<tr>
<td>Nutrition</td>
<td>I’ve struggled with that a little bit. … Probably just a bit guilty of eating the wrong stuff. Just makes you think about what you eat, and if you want to lose some weight and get fitter, which I do, they go hand in hand, don’t they? (ID8)</td>
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<tr>
<td>Location of social activities</td>
<td>What I found difficult was the social side, because I live in Woodend. … That’s only an hour away but then you chuck in bad traffic … and you’re an hour and a half. So you add three or so hours on to whatever you’re going to do in the city. If you had an event at lunch-time, when I was working, could I get to it or not, maybe I could have, but because most of the events were at five o’clock, getting down there and getting back was too hard. So I didn’t go to anything, and I would have liked to have gone to some of the social events (ID5).</td>
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### Table 3: Greatest health benefits experienced by participants as a result of their participation in the program

<table>
<thead>
<tr>
<th>Greatest health benefit</th>
<th>Example responses from participants</th>
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<tbody>
<tr>
<td>Increased motivation</td>
<td>Over the last six months I’ve seen myself improve in some aspects and so it’s been really motivating for me … it’s encouraged me to go out there and push myself a bit more (ID7). The fact that I’ve started with the fitness thing and watching my diet (ID8).</td>
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<tr>
<td>Fitter and feeling younger</td>
<td>I just feel much fitter, not as tired all the time. I just feel a lot better (ID1). I have lung issues, so I know that I’m fitter and stronger because I can get up a hill and still manage to breathe at the top of the hill where previously I would have had to have multiple stops along the way, gasping for breath, so I know I’m fitter and stronger (ID2). The benefits are that you feel better, you feel stronger, you feel fitter; you look at yourself in the mirror and you like what you see as opposed to not liking what you see. It’s a whole gamut of things really (ID7). I feel better for it. … Just everyday stuff. Just knowing you’re feeling better … If you go for a walk or a jog or something like that, you just know that you’re doing better than what you used to (ID8).</td>
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</table>
| Increased wellbeing of survivors e.g. alleviation of symptoms & improved mobility; mood; sleep; self-confidence | … when I was in the water it made me feel better, it made me feel lighter, and it made me feel like I was actually doing something positive, whereas before I wouldn’t have done that. I always just thought running around after four kids is enough exercise, but it wasn’t because my heart rate wasn’t getting up there (ID3). It [Pilates] helps with posture, it helps with symptoms like headaches, migraines, stress relief (ID10). … more comfortable in my body it’s not as tight. … posture’s getting better with all of the weights and exercise and things like that, and I think that’s affected my quality of life. I’ve got more energy, and my memory is getting a bit better. … I am feeling better physically and mentally (ID11). I certainly can walk better (ID15). Generally feeling better about myself … feeling more confident. A bit more normal (ID16). The program has given them the confidence to make good lifestyle choices. Feels better about own body image, has more energy and feels stronger. I am doing something I absolutely love and am happier (ID18). I’ve got heaps more energy than what I used to. Even simple things like getting up out of a chair … I can get straight up out of a chair without touching the arms. I know it sounds small, but in the overall scheme of things, it's...
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<tr>
<th>Section</th>
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<tbody>
<tr>
<td>Increased wellbeing of family members</td>
<td>Things like when you turn around to look if there's any traffic coming, I can twist all the way around now…. You get more flexibility, move a lot more freely than what I used to (ID17).</td>
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<td></td>
<td>If I've had a bad day at work or something's getting me down for some reason, I go to the gym and I'm different. … I feel much, much better than what I did, and the things that were getting me down aren't getting me down anymore, or they're very insignificant now, all for an hour in the gym. I know my mental state is massively improved (ID17).</td>
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<td>She'd often do some laps while I was doing mine. They love trying the different foods, so it made everybody healthier and they didn't know it. I think that was good (ID3).</td>
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<td>We've found that it's my wife that's had more benefit because we believe we've got a pretty good diet, and both go to the same exercise class - although she doesn't do the gym - but following the regime I've been on she's lost 10 kilos - so she feels a lot healthier in herself. It's a side benefit. … she does the cooking. I give her breakfast (ID9).</td>
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<tr>
<td>Improved relationships and awareness of impact on significant others</td>
<td>It definitely improved it [relationship with daughter]. She felt like it was something that we connected with, together, and she loved helping me do that, but it was good because it helped her too (ID3).</td>
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<td></td>
<td>I knew while I was going through it all that my husband was going through it all too, with me. … You realise, it's not just one of you. Those people that looked after you too are involved as well. So it helped that way, too. You feel you've got support and you don't feel as selfish, and you don't think just of yourself. There's a lot more people out there too (ID16).</td>
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<tr>
<td>Social contact</td>
<td>There's this other side of me that's come out through the program. I'd really like to be in touch with these people, but I didn't feel as if we had that opportunity. But I learned that. Would I join the Leukaemia Foundation? … but there's nothing like just that 30 second conversation with [name] and listening to your story [over the tea break] to make the difference for me (ID5).</td>
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Table 4: Greatest lessons learnt from participation in the program

<table>
<thead>
<tr>
<th>Greatest lessons learnt from participation in the program</th>
<th>Example responses from participants</th>
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<tr>
<td>Capable of more than you think; body's resilience, more grit and determination</td>
<td>That if you push yourself you're capable of more than what you think you are (ID3). I've got more grit and determination than I thought I had to go to the gym three days a week (ID2). But one thing that has really, really taught me a lot is, the body can be so resilient. ... But a simple thing in your body's composition like white blood cells, if they're through the roof, it doesn't matter how many rugby games you've played. ... your body is so resilient, but it can be just as fragile (ID17).</td>
</tr>
<tr>
<td>More positive outlook on life</td>
<td>I suppose maybe just a different outlook on life. I know when I first came out of hospital - it was actually a bit later when I started driving again. I was driving nicely and easily and all these cars were rushing past and I thought there are a lot more important things to life, so just take it easy (ID7). I think it made me be more positive, because when I found out I had leukaemia and I had a two and a half and a three year old, and a seven year old and a ten year old - I just went, &quot;Whoa, it's not going to beat me,&quot; and, &quot;I'm not going to die.&quot; I just pushed forward ... I had days where I broke down and cried and had bad times, but it just made me more positive. Every time I have a bad day - I still have them now - kick yourself up the bum, get up and get on with it because no-one's going to do it for you (ID3). I found that I was very blinkered and self-centred in recovery, and through this program I've become really good mates with my wife by going to the gym and sharing the exercises and going for walks with her, and to talk about good foods and diet. So it's kind of given me back my 20-20 rather than that blinkered - she used to say you've just got this blinkered vision - she was really trying to help me but she couldn't penetrate through the blinkers. I've found that this has been very helpful to share this exercise ... it was for both of us (ID9).</td>
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<tr>
<td>Accept help and you don't have to lock yourself away</td>
<td>I think it's also promoted myself to realise that okay, you've been sick; you don't have to lock yourself away. Go out and socialise, and by joining groups at the gym, found enjoyment through socialising and exercise to be happy. We've all been through enough trauma, so I think to be able to find that secret is very important (ID9). I've learned from my partial experience in the program or my partial commitment to the program, is that I'd really like to be involved in an easy-to-access support group (ID5).</td>
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<tr>
<td>The importance of movement and diet: to look after your body</td>
<td>Just generally look after your body (ID1). I didn't realise that walking was so beneficial, and that I should be moving more. With the food I'm eating ... I've seen people who really do well and get very fit when they have more raw and less cooked food. I just didn't realise how much, saturated fats and everything are in all the foods. You don't realise how much sugar ...</td>
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</table>
| Being aware of moving from patient to non-patient | because I have got a sweet tooth (ID11).

Sometimes when you come into a hospital, you get pulled back into feeling like a patient, and I find that that starts me sort of feeling like a patient for a day or two. Then I've got to get back to feeling like a non-patient, a normal human being who doesn't have to come in and get jabbed with this. Because, I think, when you're going through all of the tests and everything, you just feel a lot of pain through your body, and it's nice to get back to feeling the sort of pleasure in your body, and non-pain rather than discomfort. When I'm at the gym ... I'm at a place that focuses on health, but not on illness. ... it was nice just to get away from the illness, sort of symptom, "you're sick", type (ID11). |
Table 5: Gaps in the Positive Change for Life program and recommendations

<table>
<thead>
<tr>
<th>Gaps in the program: recommendations</th>
<th>Example responses from participants</th>
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| Need for emotional support           | I think there’s a great need for counselling … to work through the issues that it was bringing up for me, and just to have some support … I think the tiredness, maybe a bit depressed or sad sometimes. … That helped me to get back to work quickly, and to sort of function and things like that. So, I think that's really missing in the program … I'd add a component of regular group sessions where people didn't have to come, but they could come and talk about how they were feeling. (ID11).  
if we had have had someone trained or even just to hear us out, because often we would lose people we weren’t even able to attend funerals because we were either not well enough. … it would be too hard to probably organise (ID15).  
I think the biggest gap is in dealing with it. … I don't know whether it'd be depressed. Perhaps it is. You get really down, and it'd just be nice to have somebody that you could know that you could go and talk to, without having to make a big thing of it - without having to go to a doctor and this and that, and tell everybody. I just thought that was one thing - they did in nutrition, and they did the exercise. I just felt that that other side of it was lacking, for me anyway. … But my GP, I could sort of talk to (ID16).  
You can feel very much alone when you're not having regular appointments. … you can find yourself feeling a bit isolated and lonely. It's a lonely disease, graft versus host, to deal with. I've looked around for support groups and I haven't really found much (ID10). |
| Time-limited                        | So, the exercise thing was great, even though - I didn't know this was actually going to come to an end - I thought we were going to be in this for a long time (ID5). |
| Continuity and momentum             | I know that I'll keep going, because having come this far, why stop and go backwards, so to me it’s continuity and momentum. If the continuity of the program continued, there may be people that continue on. The people that have not been a part of the program - they have the opportunity to see where people are at after 12 months on the program, and it may be motivational for them to commence doing something on a routine, regular basis. (ID2) |
| Measuring progress                  | Is somebody going to, at the end of each of us finishing our program, is anybody going to download all of the information out of the diary so that they could, say, measure the ability against the age, and try to use that as a scale? (ID9).  
I can't really think of anything at the moment, but I presume - whether there's going to be an online questionnaire or session or meeting - or the final meeting with Sharon at the end? Whether this is the sort of thing that if we can't think of anything now, whether we can - give us a bit of time to actually think about it (ID6).  
I think the gaps in the system - there isn't necessarily sort of a regular follow-up with patients (ID10). |
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<tr>
<th>Gaps in the program: recommendations</th>
<th>Example responses from participants</th>
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<td><strong>More frequent face to face review of progress</strong></td>
<td>My next review at the late effects clinic is October, maybe, so I think somewhere, mid-range, it would have been good to have a more serious review of where I was at in relation to the program, as opposed to the helpful telephone call from Beth. To be formally reviewed in person, in what would be a routine 12 months, whilst going through the program you’re reviewed at six months. Because I think you’re looking for improvement, so to have officially had some improvement would motivate people for the next six months, and if there isn’t any improvement in that time then we have to look at ways of implementing change in processes so that they do see some improvement (ID2).</td>
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<td><strong>Partners to be involved in the program</strong></td>
<td>... partners to be involved in the program from day one. That would have made a big difference to mine (ID5). I remember talking about spouses. After the transplant, Dr [name unclear] who’s the head of transplant at the Alfred - he said to my wife that when you lose all your muscle tone, the only way you’ll ever get it back is doing weight bearing exercise. He said he’ll never get it back unless he goes out and does it, so she's pushed me - particularly in this to go and do it. You should see my muscles now (D9).</td>
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<td><strong>Reformat book/diary to include steps</strong></td>
<td>I'd also make a suggestion for another column in the book and that would be for the pedometer, because I know that mine’s collected dust on a shelf, but if we were more disciplined about wearing the pedometer, we’re not only capturing activity at the gym or selected program, but you’re also collecting the movement for how much you do in a day. I believe it’s 10,000 steps is ideal - and if that was measured, or we wrote it down like we do the other activities, I believe there could be some benefit in that. Perhaps people that aren’t so committed to the gym may have seen an increase in their steps or movement (ID2).</td>
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<td><strong>Activities for those who are working</strong></td>
<td>In this project, I haven't really had an opportunity to meet other patients, because the group sessions that have been run have been at a time that I work and isn't convenient for me. ... if there had been more of them and they'd been at different times, I would have certainly tried to attend them. I think the ball is sort of left in their court, as to how they reach out and use certain services, if they're available. I think if there was a central point where patients could exchange information if they wanted to, or seek resources, that might be helpful (ID10).</td>
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<td><strong>Ongoing newsletter with survivors contributions</strong></td>
<td>I think the newsletter serves to prick one's conscience (ID2). Maybe we could contribute to it? Something small, just saying this is what I'm doing now (ID3). I wonder if it [a newsletter] would go some of the way to giving people a nudge. Winter is a classic time of the year. It's cold, it's frosty, the car's iced up - do you want to go out at 6:00 am before work or 6:00 pm at night after work and go to the gym. It really - once you step out that door you're on your way, but it's getting through the door. It's easy to say, &quot;I'll go tomorrow.&quot; (ID1).</td>
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Table 6: Gaps in care for people who had undergone stem cell transplants

<table>
<thead>
<tr>
<th>Gaps in care: recommendations</th>
<th>Example responses from participants</th>
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<td>Absence of information</td>
<td>I think one of the things is maybe just a fuller - more fuller explanation of what can happen when you're having a transplant, maybe some of the side effects ... the complications that can happen. I don't think that was so fully explained. So, the difference between an autograft and an allograft, implications on your health ... Maybe we weren't as informed as we could have been. As we've gone into that, we've found that it's been a very different experience and a lot of complications - whereas with the autograft, there was next to none. ... We've got no regrets and we don't feel like we were misled, there was just a gap in terms of information (ID13).</td>
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<td>Integrative Medicine Clinic</td>
<td>They also had a clinic where they did Reiki and reflexology and massage and everything when you were in that hospital. They had all this. It didn't cost you anything, and they were trying that to see if it helped make you feel better. I've had it once in this hospital ... a lovely lady came over and said would I like to have my feet massaged - reflexology - and I went, &quot;Yeah, sure, go for it.&quot; That's the first and only time I've ever seen it and I've been here for eight years. ... it's all run by volunteers. ... if you could put it out there and get certificates for doing it for helping people (ID3).</td>
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<td>Social Networking using IT</td>
<td>A self-organising group teaches itself - it's a peer network where peer-to-peer is as important as the job the doctor does or that Beth does ... The only other thing I'd say is don't underestimate the self-organising capability of a peer network - so I guess the program has to have - whatever program it is annual or forever program - has to have some sort of rules. A group of - just a group of people - who wants to self-organise itself, whether it be via email or there's a whole bunch of different stuff ... Don't underestimate how powerful that can be, and how cheap it can be. (ID5) Networking, I think, is very important (ID9).</td>
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Appendix 7: Abbreviations

ACSM    American College of Sports Medicine
BARSE   Barriers Specific Self-Efficacy Scale
BMI     Body mass index
BMT     Bone marrow transplant
cm      Centimetre
DHS     Department of Human Services
EFT     Equivalent full time
FACIT-Fatigue Functional Assessment of Chronic Illness Therapy – Fatigue
FACT    Functional Assessment of Cancer Therapy
FACT-BMT Functional Assessment of Cancer Therapy – Bone Marrow Transplant
FACT-G  Functional Assessment of Cancer Therapy – General
GP      General Practitioner
GPV     General Practice Victoria
GVHD    Graft versus host disease
HDL     High density lipoprotein
HIV     Human immunodeficiency virus
Hg      Mercury
ID      Identification
IT      Information technology
IQR     Interquartile range
Kcal    kilocalorie
Kg      Kilogram
Km      Kilometre
LDL     Low density lipoprotein
LEC     Late effects clinic
MET     Metabolic equivalent of task
MID     Minimal important difference
mm      Millimetre
QoL     Quality of life
PC      Personal computer
PT      Physiotherapy
RACGP   Royal Australian College of General Practitioners
REAP    Rapid Eating Assessment for Patients
SCP     Survivorship care plan
SCT     Stem cell transplantation
SD      Standard deviation
SMICS   Southern Melbourne Integrated Cancer Service
TBI     Total Body Irradiation
UVA     Ultraviolet A
VCSP    Victorian Cancer Survivorship Program