Abstract of dissertation entitled

“Does A Survivorship Care Programme (SCP) Improve the Quality of Care in Cancer Patients?”

Submitted by

LAI KA YAN ODELIA

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In 2006, Institution of Medicine (IOM) report highlighted there are long term challenges in Cancer survivors due to unmet needs and gaps in care, therefore they have recommended survivorship care plans for all the cancer survivors. The SCP ha been implemented in other countries around 8 years, while survivorship care program (SCP) in Hong Kong is not yet implemented.

The objective of this literature review is to find out the survivorship care programme able to improve the quality of health care or not, that is improve patient heath needs by coordinating with other health care professionals’ team so as to reduce the problem of care from cancer patients and their care givers. A systematic literature search has been revealed ten studies SCP intervention on different cancer survivors that met the selection criteria of the dissertation. Methodological quality of the selected studies was evaluated according to the method developed by the Scottish Intercollegiate Guidelines
Network and data were extracted and synthesized. Five of the trials were of moderate to good methodological quality and they demonstrated that SCP is able to reduce psychological distress, fill the gap in survivors’ unmet needs and improve their satisfaction with medical service.

Guidelines for SCPs in a nurse-led lymphoma clinic were subsequently developed, using not only standardized written treatment summaries, but also nursing consultations, to provide education on the late effects of treatment and set up survivor care plans to maintain the continuity of cancer care. This programme also included individualized rehabilitation programme for cancer patients. An implementation plan was designed in which team members in a nurse-led lymphoma clinic will initiate and guide the proposed change through a communication plan. A pilot study will be conducted to confirm the feasibility of the protocol. An evaluation plan including patient, healthcare provider and system outcomes will help ensure the effectiveness and sustainability of the SCP.
Does A Survivorship Care Programme (SCP) Improve the Quality of Care in Cancer Patients?

by

LAI KA YAN ODELIA

BSc(Hons) NURS, R.N.

A dissertation submitted in partial fulfillment of the requirements for the Degree of Master of Nursing at The University of Hong Kong

July 2015
Declaration

I declare that this thesis thereof represents my own work, except where due acknowledgement is made, and that it has not been previously included in a thesis, dissertation or report submitted to this University or to any other institution for a Degree, diploma or other qualifications.

Signed ………………………………………………………..

LAI KA YAN ODELIA
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I would also like to present my sincere thanks to Ms. Rowena Kwok, Advanced Practicing Nurse of my former unit, for her support and information sharing on providing individual section with new diagnose lymphoma patients. Here I must show my gratefulness to my supervisors and all my colleagues for their cooperation and patience during my study period.

At last but not least, I would like to express my grateful thanks for my family who supporting me especially I got dominant hand injury since June 2015.
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Does a Survivorship Care Programme (SCP) Improve the Quality of Care in Cancer Patients?

Chapter 1 Introduction

1.1 Background

What is Cancer Survivorship Care?

Survivorship care focuses on the health and life of a person with cancer after treatment until the end of life. It covers the physical, psychosocial and economic issues of cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, the late effects of treatment, secondary malignancies and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience. (National Cancer Institute, 2014)

The Institute of Medicine (IOM) definition of quality is “the degree to which health services for individuals and populations increase the likelihood of a desired outcome and are consistent with current professional knowledge” (Ganz, Casillas, & Hahn, 2008). In 1999, an IOM report, “Cancer Care in the United States” evaluated disparities in service delivery. The IOM (Committee on Quality of Health Care) issued two key reports which set the foundations and insight for improvement in the quality of health care. (Ganz et al., 2008). Quality health care was described as safe, effective, patient-centred, timely, efficient and equitable. In 2004, the National Cancer Policy Board and IOM set up a committee on cancer survivorship assessment which aimed to improve survivor care and quality of life (QoL). They decided survivorship care should focus on quality of care needs for patients with cancer who have completed the acute
phase of treatment and are living with cancer and its aftermath as a chronic disease (Ganz et al., 2008; Spinks et al., 2012).

1.2 Affirming the need

The IOM report recommends the development and utilisation of a treatment summary and survivorship care plan (SCP) that describes a patient’s cancer treatment experience, and provides guidance for future care to the patient and provider. Therefore an SCP should always include a cancer treatment history, the potential long-term and late effects of treatment, recommended surveillance for long-term and late effects and recommended surveillance for recurrent and new malignancies (Ganz et al., 2008). Furthermore, the period of treatment and transition to a life without intensive care could induce various emotional and physical challenges that impact QoL. (Bazzell, Spurlock, & McBride, 2014). General health information and wellness for the cancer patient are also included in the SCP (Ganz et al.s, 2008; Bazzell et al., 2014). These core items can help improve communication about patient education and empowerment between oncologists and other health care disciplinary teams. (Ganz et al.s, 2008; Spinks et al., 2012; Bazzell et al., 2014)

The Department of Health reports that the leading cause of death in Hong Kong is malignant neoplasm, and it is responsible for about one third of deaths (Department of Health, 2012). However cancer survival rates in Hong Kong are improving. In 2012, the mortality rate from colorectal cancer was around 20-30% (Department of Health, 2014b), breast cancer 5% (Department of Health, 2014a), prostate cancer 10.9% (Department of Health, 2014c) and lymphoma 40% (Hong Kong Cancer Registry,
Due to improvements in diagnosis and advances in medical treatment, the overall mortality rate has been reduced more than 60% since the 1970s (Hodgson, Grunfeld, Gunraj, & Del Giudice, 2010; Ganz et al., 2008; John & Armes, 2013).

When survival rates improve and the numbers of patients who live with cancer increase, cancer patients at the end of active treatment often report being "lost in translation". That is, they experience both physical and emotional changes in the transition from cancer patient to survivor, (Ganz et al., 2008; Spinks et al., 2012; Brothers, Easley, Salani, & Andersen, 2013; Bazzell et al, 2014). as there is no specific standard follow-up protocol for late effects of treatment. Hong Kong public hospitals often provide follow-up care by oncologists. However cancer patients have unmet needs for psychological, chemotherapy late-effect and rehabilitation support (Ganz et al., 2008; Gates, Seymour, & Krishna, 2012; John & Armes, 2013; Jones et al., 2013), which cannot be covered in outpatient clinics and day centres. This is because the systematic treatment of cancer itself has both short and long-term impacts on patients and their families. Even though most cancer cure rates are relatively high, treatment-related side effects can develop in the short term. For example, oral mucositis can influence dietary intake and bone marrow suppression can lead to fatigue and infection Therefore physicians need to evaluate pain management and nutritional support. About 50-70% of patients suffer psychological distress, secondary malignancies, cardiac dysfunction, endocrine dysfunction, impaired organ function, and limitations in mobility, communication and cognition (Ganz et al., 2008; Smith, Crespi, Petersen, Zimmerman, & Ganz, 2010; Letourneau et al., 2012; Dieperink et al., 2013).
In Hong Kong, there are certain standardised chemotherapy protocols but public hospitals do not have standardised survivorship care. For example in the first cancer cycle, patients are hospitalised for observation. If this cycle is uneventful, most chemotherapy will then be given in chemotherapy day centres with follow up at outpatient clinics. Access to comprehensive - posttreatment care and late effects monitoring is limited. Outpatient clinics do not have the capacity to cope with the demand. There is little data illustrating that routine cancer follow up has benefits in the early diagnosis of relapse, but there is evidence showing that many recurrences are detected by patients between scheduled clinic visits (John & Armes, 2013). The survivorship phase has increased, but research also points out survivors have limited awareness of their health risks and ability to adopt self-protective and healthy behaviours (Gates et al., 2012). SCP might be able to fill in these unmet health needs by providing psychological support and enhancing patient empowerment.

The posttreatment phase of survivorship has been recognised as a distinct phase in the continuity of cancer care. It occurs at the end of active treatment and encompasses the domains of psychological and supportive care, health promotion, surveillance and long-term monitoring, and early intervention for late and long-term effects (Spinks et al., 2012). In addition, high-quality survivorship should include holistic assessment. Survivorship care should be tailor-made to meet survivors’ needs (John & Armes, 2013). However in Hong Kong, this is not feasible in physician-led clinics because current service capacity cannot cope with demands from increasing numbers of patients.

1.3 Objectives and Significance
The objective of this review is to determine whether a survivorship care programme is able to improve the quality of health care, i.e. improve patient health needs by coordinating health care professional teams to reduce cancer care problems for patients and their care caregivers, in addition to follow-up by physicians.

An SCP is different from a standardised written treatment summary in that it is able to facilitate information sharing on a patient’s progress by a multidisciplinary healthcare team to maintain continuity of cancer care. It is also an individualised rehabilitation programme for cancer patients.

Most cancer patients would like to know their prognosis, especially cure rates and prospects for long-term survival. An SCP is used to inform them about their physical assessment, treatment and procedures and prognosis, and is also able educate them about late effects from particular systematic treatments. This can reduce uncertainty about problems which cancer patients deal with. Psychological distress can be reduced by providing specific information. By filling the health information gap from active treatment to rehabilitation, patients can be helped to explore cancer care resources and set health goals, which would also enable them to reduce stress. Long-term effects of systematic treatment could be monitored through SCP services. Survivors have a high chance of developing cardiovascular disease, endocrine issues, infertility, secondary malignancies and other psychosocial issues. SCP could help in early detection by referring patients to specialists for monitoring and providing health education to modify risky health behaviour. (Gates et al., 2012)
Chapter 2 Critical Appraisal

2.1 Data Search

The PubMed, Cochrane library, EBSCO and ISI Knowledge electronic databases were searched for evidence, all from 2004 to 2014. Reference lists of related papers were also screened for additional citations.

The search terms were based on survivorship care related to postchemotherapy treatment, and follow-up care and also made use of the abbreviation SCP. In addition, quality of care related to healthcare, quality care and study design for implementing SCPs, to identify randomised controlled trials (RCT), were used. Language limits were not applied. In PubMed, specific search terms used in clinical trials were initially identified

2.2 Selection criteria

Primary evidence was selected for inclusion in the review if it focused on whether adult cancer survivorship can improve quality of care. SCP could not only be implemented by physicians, but also nurse practitioners and other health care professionals. For quality of care, as the IOM suggested to focus on survivors’ health needs and patient empowerment, therefore the outcome measures including health needs, health care quality, and self-reported outcomes were are also considered in the screening. However studies targeting evaluation of multiple SCP outcomes on health service were prioritised.
The inclusion criteria were adult cancer patients 18 years old or above, intervention effectiveness, RCTs and non-randomised perspective studies that included SCP studies done no longer than 10 years previously.

The exclusion criteria were paediatric cancer survivor populations, pharmacological interventions or diagnostic testing in cancer patients, qualitative studies, reviews, opinion papers, letters and editorials.

2.3 Data extraction

Data initially extracted included the study design. Six studies were RCTs and four were non-randomized perspective studies. Those studies were done in a single clinic, multicenters or cross clusters; data extracted also included sample size, adult cancer patient characteristics, study objectives, description of the interventions in all experimental groups, types of measurement tools and effect size. Please refer to the Table of evidence P.12 - 15.

2.4 Appraisal strategies

The quality of the RCTs and non randomised perspective studies were appraised by SIGN guidelines to evaluate whether the study used standard criteria for RCT and cohort studies.

2.5 Results

The electronic literature search was done from March 10, 2014 to Sept 25, 2014 in PubMed, Cochrane Library, EBSCO and ISI Knowledge using the keywords shown in
Appendix 1. PubMed generated 46 studies, Cochrane Library 44, EBSCO 71 and ISI Web Knowledge 62. Titles, abstracts, content and reference lists were reviewed. The results and evaluation of two registry RCT studies had not yet been released and these studies were omitted. After duplications were omitted, six RCTs which provided evidence-based studies on SCP (Grunfeld et al., 2006; Grunfeld et al., 2011; Dieperink et al., 2013; Hershman et al., 2013; Jones et al., 2013; Wagner et al., 2014) and four non-randomised observational studies (Jefford et al., 2011; Oeffinger et al., 2011; Spain et al., 2012; Blinder et al., 2013) were included.

2.5.1 Overview of Studies

Four studies evaluated SCP in breast cancer (Grunfeld et al., 2006; Grunfeld et al., 2011; Blinder et al., 2013; Hershman et al., 2013), two in adult survivors of lymphoma in childhood (Oeffinger et al., 2011; Spain et al., 2012), one in colorectal cancer (Jefford et al., 2011), and one in prostate cancer survivors (Dieperink et al., 2013). Two studies had mixed cancer survivors, one of breast cancer or haematological disease (Jones et al., 2013), and one of colorectal, lung or breast cancer (Wagner et al., 2014). Most studies were conducted in adult cancer survivors, except for one of young adult survivors who had previously had paediatric cancer treatment. (Spain et al., 2012).

Four studies were conducted in the United States (Spain et al., 2012; Blinder et al., 2013; Herhman et al., 2013; Wagneret al., 2014), two in Canada (Grunfeld et al., 2006; Grunfeld et al., 2011), one in Australia (Jefford et al., 2011), one in Denmark (Dieperink et al., 2013), one in the United Kingdom (Jones et al., 2013) and one recruited survivors from both the United States and Canada (Oeffinger et al., 2011). The time points of recruitment differed in these studies. For example, some of the studies recruited
survivors after they have been diagnosed with cancer or during treatment (Blinder et al., 2013; Dieperink et al., 2013), while some studies recruited survivors several years after they completed cancer treatment (Grunfeld et al., 2006; Grunfeld et al., 2011). A paper format for the SCP was used for cancer survivors, except in the Dieperink et al. (2013) and Jones et al. (2012) studies. The SCP consisted of 2 parts, a treatment summary and a long term care plan. In addition to the SCP, interventions also included other educational components, such as booklets or DVDs explaining the late effects of treatment, health information, supportive care (physical or psychological aspects) from health care professionals or follow-up care guidelines (Grunfeld et al., 2006; Grunfeld et al., 2011; Oeffinger et al., 2011; Jefford et al., 2011; Blinder et al., 2013; Dieperink et al., 2013; Hershman et al., 2013; Jones et al., 2013; Wagner et al., 2014). While the SCP and intervention were a primary resource for cancer survivors, copies were also delivered to family physicians, oncologists or other allied health team members (Grunfeld et al., 2006; Grunfeld et al., 2011; Jefford et al., 2011; Oeffinger et al., 2011; Spain et al., 2012; Blinder et al., 2013; Dieperink et al., 2013; Hershman et al., 2013; Jones et al., 2013; Wagner et al., 2014). The format for most SCPs was standardised templates. Some studies used the American Society of Clinical Oncology SCP template (Blinder et al., 2013), one used IOM templates (Jefford et al., 2011) and some studies developed or used existing templates in clinical settings (Grunfeld et al., 2006; Grunfeld et al., 2011; Oeffinger et al., 2011; Spain et al., 2012; Hershman et al., 2013; Jones et al., 2013; Dieperink et al., 2013; Wagner et al., 2014).
2.5.2 RCT studies

All subjects in RCTs were randomly allocated to the intervention or control group. In two studies, a third party monitored randomisation (Dieperink et al., 2013; Jones et al., 2013) and in four studies computer generated sequences were used (Grunfeld et al., 2006; Grunfeld et al., 2011; Hershman et al., 2013; Wagner et al., 2014).

Demographic and characteristic analysis of the intervention and control groups was done in all the studies to minimize sampling bias. Although all the studies claimed participants and investigators were blinded, they did not report how they did this. It is quite difficult to blind both sides. Cancer patients are often in support care groups, and those groups communicate via social media apps, so it is likely they will know which groups they are in. Investigators can distinguish between intervention and control groups when interviewing patients, and therefore blinding might not have been possible in the RCT studies. These factors could have affected the measured outcomes.

The dropout rates in studies ranged from 5% - 12% which were on low side, and therefore they had no significant influence on the statistical power in the studies. In data collection, both the intervention and control groups were evaluated with the same assessment tools, and no performance bias was mentioned in those studies. The Jones et al. study (2013) had a small sample group, which might have affected the statistical power. Sample size issues were not mentioned in the other studies.
2.5.3 Non-randomized observational studies

The samples in the four non-randomized perspective studies were selected from the entire cancer group which fit their inclusion criteria, and therefore shared similar characteristics. All studies had demographic and characteristic analysis to reduce study bias.

The dropout rates for three of these studies were within 4% to 20%. Blinder et al's (2013) dropout rate was 40%. Attrition bias might have occurred as remaining participants might have been prone to providing positive feedback, because of higher awareness of health issues, or because they found the programme useful, so they stayed in the study.

As in the RCTs, blinding might not have been possible for either participants or investigators. These studies did not report blinding, so the outcome measurements might have been affected.
Table 1: Table of Evidence

<table>
<thead>
<tr>
<th>Bibiographic Citation</th>
<th>Study type</th>
<th>Adult Cancer Patient Characteristic</th>
<th>Sample size</th>
<th>Study objectives</th>
<th>Intervention</th>
<th>Control</th>
<th>Length of follow up</th>
<th>Outcome measures</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Wagner et al. (2014)</td>
<td>Cluster RCT</td>
<td>Newly diagnosed with breast, colorectal, or lung cancer</td>
<td>109</td>
<td>Determine whether a nurse navigator intervention improves quality of life and patient experience with care in people with recent diagnosis of breast, colorectal, or lung cancer</td>
<td>Nurse navigator support for 4 months - structured patient summary (entered into group health electronic medical system) - psychosocial health and depression support</td>
<td>Usual care: continuous physician follow up</td>
<td>16 weeks</td>
<td>Primary outcome: 1) QoL by FACT-G* 2) Depressive Symptoms by PHQ-9 3) Patient experience by PACIC 4) Report problems in care by Picker subscale</td>
<td>1) B coefficients: 0.8, 95% CI -2.6 to 4.3 at 4 months B coefficients: 0.6, 95% CI -2.2 to 3.5 at 12 months, both are not significant 2) B coefficients: 0.4, 95% CI 1.4 to 0.6 at 4 months B coefficients: 0.1, 95%CI 0.9 to 1.1 at 12 months, reported fewer depressive symptoms 3) B coefficients: 0.3, 95% CI 0.02 to 0.6 at 4 months B coefficients: 0.3, 95%CI 0.01 to 0.5 at 12 months, both are significant 4) B coefficients: -7.0, 95%CI -13.0 to 1.0 at 4 months B coefficients: -6.0 95%CI -12.1 to 0.2, both are significant with fewer reported problems</td>
</tr>
<tr>
<td>2 Dieperink et al. (2013)</td>
<td>RCT</td>
<td>Prostate cancer without prostatectomy in Denmark 2) no other clinical trial protocol</td>
<td>112</td>
<td>Study the effectiveness of multidisciplinary rehabilitation on treatment- related adverse effects after radiotherapy completed in patients with prostate cancer</td>
<td>Usual care + 2 nursing counselling sessions &amp; 2 physical therapist counselling sessions</td>
<td>Usual care: physician Follow up from 4 weeks after radiotherapy; no systematic education provided</td>
<td>22 weeks</td>
<td>Primary outcome : 1) urinary irritative sum score by EPIC-26 Secondary outcome : 2) QoL by SF-12 3) urinary incontinence, bowel, sexual and hormonal sum scores by EPIC-26 4) pelvic floor assessment by a) modified Oxford scale b) electromyography</td>
<td>1) 5.8 points; (Cohen's d= 0.40; P =0.011) 2) Significant improvement Cohen's d=0.35; P=0.02 3) Significant urinary sum score (Cohen’s d=0.34; P=0.023) hormonal sum score (Cohen’s d=0.19; P=0.018) 4) No significant change in either group</td>
</tr>
<tr>
<td>3 Hershman et al. (2013)</td>
<td>RCT</td>
<td>1) Stage 0-III breast cancer 2) within 6 weeks of completion of initial adjuvant treatment 3) Hispanic and non-Hispanic ethnic groups in US</td>
<td>141</td>
<td>1) Study the effect of an in-person survivorship intervention following adjuvant breast cancer therapy on health worry, treatment satisfaction and the impact of cancer 2) Determine differences between Hispanic and non-Hispanic ethnic groups</td>
<td>Manual + 1 hour individual meeting with nurse practitioner and nutritionist to receive personalized treatment summary, surveillance recommendations, discussion of risk for late effects and toxicities and screening and lifestyle recommendations</td>
<td>National Cancer Institute Publication 24 page manual</td>
<td>24 weeks</td>
<td>1) Treatment satisfaction by FACIT-TS-PS 2) impact of cancer by IOCS, ASC, FACT-B, CES-D</td>
<td>1) No significant difference 2) IOCS, FACT-B, CES-D: no significant difference ASC: significantly reduced worry control: intervention= 2.69:2.28 Hispanic women had higher rates than non-Hispanic women for health worry (p=0.0008B); social life interference (p=0.009); meaning of cancer scales (p=0.0004) and more trust of medical professionals (p=0.03)</td>
</tr>
<tr>
<td>Bib graphic Citations</td>
<td>Study Type</td>
<td>Adult Cancer Patient Characteristics</td>
<td>Sample Size</td>
<td>Study Objectives</td>
<td>Intervention</td>
<td>Control</td>
<td>Length of follow up</td>
<td>Outcome Measures</td>
<td>Effect size</td>
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<tr>
<td>4 Jone s et.al (2013)</td>
<td>RCT</td>
<td>Active progressive, recurrent hematological and breast malignancies in UK</td>
<td>41</td>
<td>Test the clinical and cost effectiveness of a rehabilitation intervention for patients with advanced, recurrent cancer</td>
<td>Rehabilitation intervention by multidisciplinary team (MDT): 1) Systematic clinical assessment 2) Goal setting 3) Weekly MDT meetings to review patient progress 4) Patient/clinician discussion in clinics according to goal setting progress and evaluation</td>
<td>Usual care: ongoing review by oncologists and access to community service</td>
<td>12 weeks</td>
<td>Primary outcome: 1) psychological subscale by SCNS 2) secondary outcome: 2) psychological status by K10 3) Continuity of care by experienced continuity in cancer care 4) quality of life by i) ED5D &amp; ii) EQ-VAS 5) Effectiveness by ICER</td>
<td></td>
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<tr>
<td>5 Grunfeld et.al (2011)</td>
<td>Multi-centre, RCT</td>
<td>Early stage breast cancer; primary treatment completed at least 3 months previously</td>
<td>408</td>
<td>Determine if an SCP for breast cancer survivors improves patient-reported outcomes</td>
<td>Routine follow up - a comprehensive SCP that consisted of the prescribed elements</td>
<td>Routine follow up from PCPs and specialists</td>
<td>52 weeks</td>
<td>1) Cancer-related distress by IES 2) General psychological distress by POMS 3) QoL by PCS and MCS 4) Patient satisfaction continuity/coordination of care and health service by MOS-PSQ</td>
<td></td>
</tr>
<tr>
<td>6 Grunfeld et.al. (2006)</td>
<td>Multi-centre RCT</td>
<td>Early stage breast cancer. Completed adjuvant treatment. Disease free between 9 -15 months after diagnosis</td>
<td>968</td>
<td>Determine whether follow up by family physician is a safe, acceptable alternative to specialist follow up</td>
<td>Follow up from their own family physician who provided SCP -- treatment summary, recommended follow-up care on physical exam and medical history + investigation/referral to cancer center if there was indication of recurrence</td>
<td>Routine follow up in cancer care as usual practice</td>
<td>260 weeks</td>
<td>Primary: 1) Recurrence 2) Death 3) Serious clinical events (SCEs) Secondary: 4) Health related quality of life (HRQL)</td>
<td></td>
</tr>
<tr>
<td>Bibio graphic Citations</td>
<td>Study type</td>
<td>Adult cancer patient characteristics</td>
<td>Sample size</td>
<td>Study objectives</td>
<td>Intervention</td>
<td>Control</td>
<td>Length of follow up</td>
<td>Outcome measures</td>
<td>Effect size</td>
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<tr>
<td>7 Blind et al. (2013)</td>
<td>Multi centre non randomised prospective study</td>
<td>ASCO Breast Cancer Registry (BCR) pilot program - Newly diagnosed breast cancer patients with stage 0 to III</td>
<td>174</td>
<td>Evaluate quality impact on patient perspectives of the integration of treatment plans and summaries (TPSS) based on ASCO templates in clinical care</td>
<td>Patient receives chemotherapy TPS as separate plan and summary documents (TPSS) at the beginning and end of treatment Telephone survey after document received</td>
<td>2-4 weeks after receiving TPS</td>
<td>1) Perception about communication with/among physicians 2) Perceptions about peace of mind 3) Perceptions about future use of document 4) Perception about support 5) Perceptions about preparedness for treatment 1-4 survey by American Society of Clinical Oncology Volunteers, staff and expert consultants</td>
<td>1) 96.1% understood the document; 94% reported document improved communication between themselves and their physicians, 82% had improved communication between health care providers 2) 72% had greater peace of mind 3) 56% very likely to use again 4) 70% received right amount support; 69% received right amount of information on cancer and treatment 5) 97% felt oncologist listened to them and answered their questions; 92% felt prepared for what to expect from treatment; 96% understood plan or treatment</td>
<td></td>
</tr>
<tr>
<td>8 Span et al. (2012)</td>
<td>Non-randomised prospective study</td>
<td>Adult survivors of pediatric and young adult cancer; currently cancer free and without neurocognitive, visual or hearing deficit</td>
<td>111</td>
<td>Determine whether treatment summary and care plan can improve survivors’ understanding of cancer treatment, potential late effects and recommended screening</td>
<td>One-page treatment summary and follow-up care plan (SCP) provided to adult survivors in routine consultation Telephone survey after document received</td>
<td>1-6 weeks after receiving SCP</td>
<td>1) Retention of documents 2) Understand SCP 3) Value of SCP 4) Dissemination of documents 5) Health-related worry by Memorial Symptom Assessment Scale 6) Health concerns caused by SCP 7) Preferences for document format</td>
<td>1) 95% retained document 2) 95% understood SCP 3) 93% felt SCP is valuable 4) 44% disseminated copies in their own personal circle 5) 17% constantly worried in past week 6) 14% caused concern, while 86% were not concerned 7) 95% interested in online or wallet card version of SCP</td>
<td></td>
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<tr>
<td>9 Jefford et al. (2011)</td>
<td>Pilot test</td>
<td>Colorectal cancer (CRC) patients completing primary treatment with curative intent</td>
<td>10</td>
<td>Develop and pilot test an innovative supportive care program for people with potentially curative CRC 1) Promotion of patient involvement and engagement 2) Tailored to specific needs of individual patients 3) Evidence-based strategies to promote well being</td>
<td>Survivor care intervention: - Provision of information - Individualized survivorship care plan (SCP) for survivor - Face-to-face nurse-led end of treatment session - 3 follow-up phone calls</td>
<td>8 weeks</td>
<td>1) Psychological Distress by BSI-18 2) Unmet needs by CASUN scale 3) Quality of life by QLQ-30 / QLQ-CR29 4) Satisfaction of intervention 5) Interventions feasibility</td>
<td>1) Baseline: 30%; after follow up: 37% 2) Baseline: 7 for unmet needs, after follow up: average score 4 3) Baseline: mean 71; after follow up: 69 4) All report positive experience, high satisfaction 5) Feasible but workload for logistic and information preparation increased</td>
<td></td>
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<tr>
<td>Bibiographic Citation</td>
<td>Study type</td>
<td>Adult cancer patient characteristics</td>
<td>Sample size</td>
<td>Study objectives</td>
<td>Intervention</td>
<td>Control</td>
<td>Length of follow up</td>
<td>Outcome measures</td>
<td>Effect size</td>
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<tr>
<td>Oeffinger et al. (2010)</td>
<td>Non-randomized prospective study</td>
<td>Hodgkin lymphoma survivors &gt;= 5 years, treated with chest radiation and/or anthracycline chemotherapy</td>
<td>72</td>
<td>Whether SCP enhances late effect screening for breast cancer and cardiac surveillance</td>
<td>Mailed personalized one-page survivorship care plan and education online website</td>
<td></td>
<td>24 weeks</td>
<td>1) Use of SCO 2) Screening practices 3) Physician outreach 4) Virtual information center website usage 5) Psychological effect by POMS (profile of mood status)</td>
<td>1) 78% remembered receiving SCP, 44% female and 45% male shared SCP with physician 2) SCP: 41% survivors asked for mammography; 20% for echocardiography; no SCP: 32% asked for mammography, 12% asked for echocardiography 3) Among 77% of survivors who provided contact with physician, 19% of physicians agreed to join the study 4) 29% used website, low use rate 5) POM Tension/anxiety Female SD (Baseline: 6.7, follow up: 5.4; P=0.95); Male SD (Baseline: 4.3, follow up: 6.8; P=0.52) Depression Female SD (Baseline: 5.7, follow up: 7.3; P=0.86); Male SD (Baseline: 9.5, follow up: 11.8; P=0.74) Anger Female SD (Baseline: 5.0, follow up: 6.7; P=0.22); Male SD (Baseline: 6.4, follow up: 9.9; P=0.61) Vigor Female SD (Baseline: 6.2, follow up: 6.3; P=0.12); Male SD (Baseline: 6.9, follow up: 5.7; P=0.66) Fatigue Female SD (Baseline: 5.9, follow up: 6.1; P=0.96); Male SD (Baseline: 5.7, follow up: 6.1; P=0.02) Confusion Female SD (Baseline: 4.0, follow up: 4.0; P=0.38); Male SD (Baseline: 3.0, follow up: 4.8; P=0.39) Total mood disturbance Female SD (Baseline: 20.1, follow up: 19.3; P=0.88); Male SD (Baseline: 20.8, follow up: 40.4; P=0.54) No significant change in mood anxiety level</td>
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2.6 Summary and Synthesis

2.6.1 Quality of life

There were 6 RCT studies. Grunfeld et al. (2006) evaluated SCP in breast cancer survivors and compared follow up by a family doctor with existing practice by a specialist. There were no significant differences in cancer recurrence, the death rate, or health-related quality of life (HRQOL) between groups. In 2011, they evaluated an individualised SCP in a similar setting. There were no significant differences in HRQOL between groups but more patients in the intervention group than the control group were able to identify that their primary care physician was primarily responsible for their follow-up care. Similarly in another breast cancer survivor study, the primary outcomes were not significantly different between the intervention and control groups, but there was a statistically significant difference in reducing cancer-related anxiety in the SCP breast cancer group (Hershman et al., 2013). In Wagner et al.’s study (2014), the SCP showed no significance in improving QoL but patients reported fewer problems in care. A non-randomized study of colorectal cancer survivors showed similar HRQOL, but after implementation of the SCP and nurse-led consultation, cancer survivors’ unmet needs were reduced (Jefford et al., 2011). Even though most of the studies did not prove their hypotheses. Dieperink et al.’s and Jones et al.’s studies, with mixed interventions for psychological support, late effect treatment and symptom-related relief or functional strengthening counselling, showed significant results in improving survivors’ QoL.
2.6.2 Psychological distress

Most of the RCT studies showed the intervention group had significantly less psychological distress than the control group when the SCP involved coordination among different health care professionals. The intervention mainly provided individualised consultations with nurse practitioners who delivered tailor-made knowledge to cancer survivors and their caregivers after active treatment. By filling in the knowledge gap, psychological distress or health worry was reduced (Wagner et al., 2014; Dieperink et al., 2013; Hershman et al., 2013; Grunfeld et al., 2011). One non-randomized perspective study showed distress in breast cancer patients might be reduced as 72% reported greater peace of mind (Blinder et al., 2013). There was no difference in psychological distress between the intervention and control groups in Grunfeld et al.’s 2006 study; in Oeffinger et al.’s study (2010), there was no difference in the mood state scores before and after receiving the SCP interventions. However, in Jefford et al.’s (2013) and Spain et al.’s studies (2013), SCP alone might have increased survivors’ psychological distress.

2.6.3 Self-report problems

Self-report problems in three studies (Wagner et al., 2014; Jones et al., 2013; Hershman et al., 2013) varied and were related to the duration of the individualized SCP. Hershman et al.’s study provided one hour consultations with a nurse practitioner for the intervention group and a systematic treatment manual of late effects based on guidelines for both groups and found no difference between groups. However, Wagner et al. (2014) and Jones et al. (2013) provided continuing individual
consultations with nursing practitioners, and reported improvement in self-reported problems and facilitation with health care staff to reach health goals.

2.6.4 Patient Satisfaction with SCP

Overall, cancer survivors reported high levels of satisfaction with SCP. In Jefford et al.’s study (2011), colorectal cancer survivors showed a high level of satisfaction after nurse-led consultations, while in Grunfeld et al.’s study (2006), breast cancer survivors showed a high level of satisfaction with follow-up care consultation. In Hershman et al.’s study (2013), there was no difference in the satisfaction level between the intervention and control groups.

2.6.5 Cost-effectiveness

There were no definitive results on the cost-effectiveness of SCP. SCP was cost-effective in Jones et al.’s study, while in Wagner et al.’s study, SCP saved costs only for lung cancer, but not breast or colorectal cancer patients. One possible reason for the differences is that studies were conducted in different countries, with different health care systems. Jones et al.’s study was done in the UK where health service is provided by the government. When the service provided in the existing cancer setting of hospital or clinic, if the intervention is effective, it could reduce expenditures for other types of health service. For example, hospitalisations could be reduced if patients were more aware of the late effects of treatment. Therefore SCP could help save costs in the health care system.

Wagner et al.’s study was done in the US, where two-thirds of health care is provided by private hospitals or clinics. Patients have to pay for follow-up services, and costs,
for each patient to clinic would be increase as there would be new measurement and setup with this new service, as services that patients will be used, e.g. hospitalisation or psychological counselling, are not included. Moreover, the researchers did not report how costs would be offset if the clinic provided care on a long-term basis, as the longer a clinic has the service, the lower the set-up costs over time. The studies were only on a short-term basis, with expenditures for implementation in the first year as an indicator, the cost figures seem high and would not favor carrying out SCP.

2.7 Insights from studies

2.7.1 Utilization of sensitive measuring tools

Spinks et al.'s review reported there are more than 150 cancer-related tools which measure quality of care, but they mainly focus on process and fail to assess the rest of the care cycle. These tools establish standards for preventive, diagnostic and therapeutic care but are limited in scope and apply to brief segments of care, such as diagnostic and staging accuracy, multidisciplinary treatment planning, and post-therapy management (Spinks et al., 2012). Based on the above studies, it would be better to make use of disease-related outcomes. For example, Dieperink et al focused on a QoL outcome measurement, urinary system function. Patient-defined QoL could also be used. In the Jones et al. study, patients self-reported their health status with the ED-50 (see appendix 2) during an interview.
2.7.2 Dosage of SCP intervention

Since cancer has become a chronic disease due to enhancement of survival rates, systematic treatment affects daily living as it can induce different types of physical distress (Dieperink et al., 2013; John & Armes, 2013; Gates et al., 2012). Poor appetite, generalised fatigue, poor self-image from physical changes after surgery, skin colour changes after radiotherapy and doubts about sexual activities, together with uncertainty whether the disease itself will relapse can induce psychological distress (Jones et al., 2013; American Society of Clinical Oncology, 2009). The dosage of the individualised intervention affects the outcomes. Hershman et al.’s (2013) study included one hour individualised consultation with a nurse and a nutritionist. Wagner et al.’s (2014), Dieperink et al.’s (2013), Jones et al.’s (2013) and Jefford et al.’s (2011) studies included periodic individual consultations with nurses and members of other health disciplinary teams to provide continuing support, evaluate the patient’s progress, provide further information and set health goals. Continuing tailor-made interventions could enhance SCP by fulfilling unmet needs to improve the quality of care.

The severity of the disease itself can affect evaluation of a programme because of a patient’s own interpretation of the disease and needs. In Dieperink et al.’s study, patients had severe impairment from prostate cancer, and after the SCP, their physical quality of life improved a lot. This might be because patients reported significant symptoms to health care staff. By identifying the problem and providing information on how to tackle it, patients could find the intervention more useful than patients with less severe symptoms.
Hershman et al.’s study only involved a one-hour consultation with health care professionals such as a nurse and nutritionist, with follow up mainly by physicians, and SCP interventions were not statistically effective. In Jefford et al.’s, Jones et al.’s and Dieperink et al.’s studies, interventions not only involved physicians but also coordination with other health care team members. By periodically evaluating patient progress, health goals can be altered. In individual counselling sessions, physicians or nurses can discuss health goals with cancer survivors and assist them in reaching targets by providing information or referrals to other specialists. By enhancing communication between health care professionals and survivors, the intervention would be able to meet survivors’ health needs by providing relevant health information, as well as improving self-reported health outcomes.

2.7.3 Staff training

Training of health care staff and resource support are crucial in these studies. To provide quality service, health care professionals have to be well-trained and experienced so they are capable of identifying patient care needs and providing suitable interventions and referrals. As postcancer care is complicated and involves holistic care, the role of nurse practitioners is essential to identify late effects and health needs, to coordinate different health care parties and reduce health risks.

When care service involves members of different health care teams, managerial support to encourage multidisciplinary teamwork is also important. Periodic multidisciplinary team meetings are needed for updates on the progress of cancer
survivors. In some circumstances, the workload of these departments increases, and extra manpower is required.

2.8 Evidence-based recommendations

A review of these SCP studies showed it is possible to improve quality of care by understanding a patient’s physical and psychological needs. Suitable education can be provided to empower them with health knowledge. In addition, interdisciplinary team referrals can enhance health care delivery. Survivors encounter psychological as well as physical distress. In addition to providing solutions to reduce late effects from systematic therapy, health care providers also need to identify the psychological needs of survivors and caregivers.

In the previous section, we mentioned studies showed a multidisciplinary team is needed to carry out an SCP. In some studies, nurse practitioners were involved as educators and coordinators (Wagner, et al., 2014; Dieperink et al., 2013; Hershman et al., Jefford et al., 2011; Jefford et al., 2013; Grunfeld, et al., 2011). Some reviews have reported that nurses can carry out SCP in patients with common cancers such as breast, colorectal, and lung. Some evidence shows that nurses are well placed to provide SCP. (Spinks et al., 2012; John & Armes, 2013)

Nurse practitioners need to identify patients' health care needs and psychological needs to facilitate programme delivery. Patients participate in goal setting with health care professionals to work on problems and reduce both physical and psychological distress.
In Hong Kong hospitals, cancer practice mainly focuses on systematic treatments, and there is no SCP to assist cancer patients in the transition period. Therefore individual nursing counselling is suggested. This counselling aims to identify issues based on the disease experience of the cancer patients and their caregivers to provide psychological support. By meeting with patients and caregivers, information needs on the adverse effects of systematic treatment can be identified based on hospital guidelines and an individual SCP based on patient goals can be established.

2.9 Target Group

Lymphoma is rated as number nine killer among cancers in Hong Kong. The cure rate is around 60% (Hospital Authority, 2014). For some types of lymphoma, e.g. follicular lymphoma, the overall survival rate at 10 years is 70.7% (Horn & Campbell, 2010). Base on 2012 Hospital Authority figures, the haematologist to population ratio in the Hong Kong West Cluster (HKWC) is 1:103.5 (Cheong, et.al., 2013). Outpatient clinics that are led by physicians with high patient demand are not feasible to implement SCP. In the HKWC, a new clinic that led by lymphoma nurse has been set up, this venue can fill in this service gap by providing individual nursing counselling sessions for patients who have completed the acute phase of treatment. As lymphoma is a systemic cancer, the treatment dosage of chemotherapy is high (Spinks et al., 2012) (Jones et al., 2013), there is a high chance of both short- and long term effects in survivors, and therefore there is a need for SCP in this nurse-led clinic. By identifying emotional distress in individual meetings with cancer patients and caregivers, nurse practitioners are able to work on referrals to medical specialists, clinical
psychologists, and physiotherapists. In Chapter 3, we will further discuss the implementation of an SCP via suggested evidence-based studies and guidelines.

Chapter 3 Implementation potential

3.1 Introduction

Cancer survival rates have improved and it is now being treated as a chronic disease. Some lymphoma patients have to live with diseases such as chronic lymphocytic leukemia and the long-term effects of high-dose chemotherapy. Because of high workloads in outpatient clinics and a high hematologist to population ratio (Cheong, et.al., 2013) it is difficult for physicians to implement SCP. In this setting, there is an opportunity for nurses to coordinate and establish individualized SCP to fill in the current service gap (Lewis et al., 2009; Howell et al., 2012; Horn & Campbell, 2010; Gates et al., 2012; John & Armes, 2013).

3.2 Target setting and audience

It is suggested this programme be implemented in a nurse-led lymphoma clinic to monitor for late effects of the disease and chemotherapy. According to figures from the Hospital Authority (HA), the Hong Kong West Cluster has than 1000 lymphoma patients in outpatient clinics. There is one nurse-led clinic headed by an Advance Practice Nurse (APN). The target audience will be lymphoma patients who have completed primary chemotherapy treatment (details provided in EBP guidelines).

3.3 Transferability of the findings to a nurse-led lymphoma clinic

3.3.1 Existing findings
According to the literature review, all the SCP use the IOM- suggested framework (see Appendix 3), with a standardized treatment summary and follow-up care plan (see Appendix 4 for format reference). These care plans mainly focus on monitoring late effects and reducing psychological distress. The settings for SCP intervention in the reviewed studies were either oncology centres or outpatient clinics, which match our target setting. The study groups in the RCTs were adults. The participants in three studies had mixed ethnicities including Caucasians, blacks, Asians, and American Indians. One study focused on Scandinavians (Dieperink et al., 2013) while the other studies did not specify ethnicity (Grunfeld, et al., 2011; Grunfeld, et al., 2006). Gender was not a criteria in the reviewed studies. Therefore, it fits the Hong Kong setting, which includes both genders and mainly Asian clients.

Two studies had patients with mixed types of cancers (Jones et al., 2013; Wagner et al., 2014), four with breast cancer (Blinder, et al., 2013; Hershman, et al., 2013; Grunfeld, et al., 2011; Grunfeld, et al., 2006), two with lymphoma (Spain, et al., 2012; Oeffinger, et al., 2011); one with colorectal cancer (Jefford, et al., 2013), and one with prostate cancer (Dieperink et al., 2013). Since SCP can be applied to different types of cancer, it will fit the target audience.

3.3.2 Philosophy of care

According to the World Health Organization, one of the main goals in cancer treatment is to ensure the best possible quality of life for cancer survivors. (World Health Organization, 2014) Two of the visions of the HA are to "enable outpatients to enjoy
the best-possible health and quality of life” and to provide focused care (Hospital Authority, 2014). Hence, they share the same goals to enhance quality of care by fulfilling patients’ unmet health needs.

The proposed innovation is compatible with the target setting, and the objectives of the reviewed articles. These objectives promote quality of care by fulfilling survivors’ unmet health needs, such as providing a written treatment summary, psychological support for patients and their caregivers and education on the side effects of chemotherapy. Four out of six studies suggested SCP is statistically significant in improving a patient’s quality of life by providing additional counselling on health knowledge, and reducing physical and psychological distress. Therefore, objectives that improve quality of care can be achieved by SCP implementation.

3.3.3 Number of clients benefitting from SCP

Lymphoma is mainly divided into the Hodgkin and non-Hodgkin types. The survival rate for Hodgkin lymphoma is up to 90% (American Cancer Society, 2014; Cancer Research UK, 2014a) and for non-Hodgkin lymphoma is around 50-70% (American Cancer Society, 2014; Cancer Research UK, 2014b). In Hong Kong, lymphoma survival rates are similar to those in the US and UK. More than 1000 lymphoma patients are seen in outpatient departments every year. The incidence rate for lymphoma in HK is around 864 per 100,000 persons every year (Hong Kong Cancer Registry, 2014a). Since the number of survivors increases every year, implementing SCP in a nurse-led lymphoma clinic could benefit significant numbers of patients. Therefore, transferability of the findings of SCP is recommended.
3.3.4 Duration of implementation and evaluation

SCP is a lifelong follow-up programme. Based on the review of the RCT studies, 24 weeks would be an average time to evaluate whether SCP can improve patients’ unmet health needs. Therefore, the duration for the pilot study should also be 24 weeks.

3.4 Feasibility

3.4.1 Organizational climate

One of the priorities of the HA is to ensure service quality and safety. Therefore evidence-based practices (EBP) are encouraged in clinical practice. Another priority is to better manage the growing demand for service. Because of the increased number of outpatients in cancer treatment, follow-up care of survivors and their caregivers should increase. Management encourages nursing staff in the haematology oncology unit to take specialty courses and pursue a master’s degree to facilitate EBP and improve nursing care.

3.4.2 Freedom of implementation

SCP will be implemented by an APN in a nurse-led lymphoma clinic, which will not influence current operations in the haematology oncology wards and medical wards. This clinic already monitors postchemotherapy blood counts and provides neutropenic support under a protocol with haematologists. Furthermore, the APN also can expand EBP care services to maintain high quality nursing care. Standardized treatment summaries and care plan templates can be set up through the Out Patient
Administrative System (OPAS). Thus implementation of an SCP will not involve extra administrative staff.

3.4.3 Resistance

SCP involves multidisciplinary team cooperation. For example, the APN needs to work closely with haematologists and allied health team members on specific cases, so arranging multidisciplinary team meetings to facilitate individualized SCP implementation will be a challenge. This is because the current workload of team members is demanding in public settings, so cross departmental management support is needed.

SCP requires a set of tools to assess patients’ unmet health needs. A treatment summary must be created by haematologists at the beginning of cancer treatment or before treatment is completed. A care plan will be generated using the national assessment and care planning framework of the National Health Service of the UK (as shown in appendix 5). Extra time is needed for doctors and nurses to do documentation. Therefore there could be mild resistance to the programme. If the treatment summary templates are user friendly, this can be minimized.

Extra manpower is needed, since the APN not only works in the clinic but is also in charge of the outpatient clinic. To facilitate SCP, at least one registered nurse (RN) with basic haematology training is needed, especially when the APN is away from the clinic for training or is doing consultations. If no extra human resources are provided, a nurse from the haematology/oncology units who has been trained in outpatient
operations will be needed as a temporary replacement. This entails extra costs for the medical department, or reduction of at least one nurse in the ward.

3.4.4 Skills requirements

The APN needs formal training in SCP, for example in the UK. In addition to advanced assessment skills and cancer care communication, nurse specialists (NS) need at least 20 hours of training to work with medical consultants. Furthermore, competencies would be authorized by the hospital governance committee, after the APN completes 3 cases and assessed by three different medical consultants to ensure the team is satisfied with the nurse’s competence (John & Armes, 2013). Overseas training is included in the HA training budget, and the cluster has a yearly budget for applicants. Therefore, resistance to the programme may not be strong.

After gaining qualification from overseas training, the trained APN will work closely with and be monitored by haematology oncology management and medical consultants to guarantee quality service for cancer survivors. To make sure the nurse-led clinic has medical support, it can also be held in the outpatient clinic. Thus, cross departmental cooperation in delivering nurse-led service is essential.

3.4.5 Evaluation tools

Different tools are used to evaluate the effectiveness of SCP. As mentioned in part one, there are more than a hundred types of evaluation tools. The goal of this SCP is to monitor the late effects of treatment and provide psychological support, so it mainly focuses on supportive care. Therefore assessment of supportive care needs, psychological distress scales, a questionnaire on patient satisfaction with the service,
and an audit of waiting time are needed. (Specific tools will be recommended in Chapter 5 EBP guidelines section.)

3.5 Cost/benefit ratio of the innovation

3.5.1 Potential risks of the innovation A multidisciplinary team is needed to implement SCP. Miscommunication among the different parties involved could lead to duplication of care or missed care (Salz et.al., 2012). Therefore, the SCP team needs clear documentation and periodic updates on specific cases.

The nurse-led survivorship care concept is new to local patients. The public has certain stereotypes of the image and role of the nurse. Time to build effective communication and rapport is needed between the APN and cancer survivors and caregivers. During the treatment process, patients need to know the importance of long-term follow up after intensive treatment is completed.

3.5.2 Potential benefits of the innovation

In physician-led clinics, doctors manage multiple health issues. They have limited time to provide detailed health information, recommend healthy behaviours and detect psychological distress in survivors (Salz et.al., 2012; Howell et al., 2012; Gates et al., 2012). AN SCP would be a suitable platform for an APN to assess and explore unmet health needs, and let survivors address concerns.

Because chemotherapy dosages are higher for haematology oncology than other cancers, survivors have a high chance of developing cardiovascular disease or a secondary malignancy (Smith et al., 2010). With periodical monitoring and health
education, an SCP can improve health outcomes. It has been associated with a significant reduction in health service resource use and improvement in a survivor’s quality of life by reducing hospitalizations (Jones, et al., 2013).

3.5.3 Risk maintaining current practices

An SCP can fill in the service gap by monitoring late effects and providing health education to prevent comparatively more severe illness from chemotherapy. Without an SCP, health service costs might increase due to increased hospitalizations for survivors with cardiac issues and other problems. If a patient does not have a comprehensive treatment summary and does not see the importance of periodic follow up, there could be a delay in finding and treating a secondary malignancy.

3.5.4 Material costs of innovation implementation

The nurse-led clinic is already in operation. Treatment summaries and follow-up care plans can be set up and printed out in the OPAS system after gaining agreement by patients and caregivers. Evaluation questionnaires are also needed for intervention analysis. The treatment summary and care plan framework are 26 pages. The cost per sheet of A4 paper is $0.25, and printer toner is $0.19 per page. Each printing would be around $11.44. A booklet “Life after Treatment” would also be designed and provided to patients. With A5 size 4 C printing, and assuming the booklet is 60 pages, each page would cost around $0.5, so the booklet would be around $30.

The supportive care needs survey, psychological distress questionnaire and patient satisfaction questionnaire are estimated to be a maximum of 20 pages. With printing
costs of $0.5 per page, the questionnaires would be $10 per person. Ten cancer survivors will be recruited in the pilot test, so the total document cost would be $514.40.

Chapter 4 Developing EBP guidelines

Based on the literature review of the 10 selected studies, EBP guidelines would be set up as follow:

4.1 Title:

Implementing SCP in a nurse-led lymphoma clinic

4.2 Objectives:

1. Provide holistic assessment of a patient’s physical, psychological and financial needs.

2. Ensure late treatment effects are being properly monitored and investigated.

3. Provide high quality written information on the care plan and related health topics to survivors and caregivers

4. Coordinate multidisciplinary team to carry out SCP to provide quality service

5. Encourage survivors and caregivers to engage in health care planning and promote self-care behaviour

4.3 Target group:

1. Diagnosis of lymphoma
2. Primary chemotherapy treatment completed

3. Age over 18 years

4. Referral by haematologists

5. No secondary diagnosis

4.4 Recommendations

Grade of recommendation and level of evidence of the intervention will be assessed using SIGN guidelines (Appendix 6).

Intervention

1. SCP implemented after survivor has completed chemotherapy (Grade A)

   Available Evidence:
   
   The posttreatment phase of survivorship is now recognized as a distinct phase in the cancer continuum occurring at the end of primary treatment and encompassing the domains of psychosocial and supportive care, health promotion, surveillance and long-term monitoring, with early intervention for late effects. (Howell et al., 2012) (1+)

2. SCP includes standardised written summary of completed treatment (Grade B) (Appendix 4)

   Available Evidence:

   • An SCP involves a multidisciplinary team. Copies are frequently sent to the primary-care physician, oncologist and other health professionals involved in care, and survivors. (Brennan et al., 2014) (1+)
• Patients sometimes do not remember the treatment and dosages due to complications of treatment (American Society of Clinical Oncology, 2014) (4)

• Creation of an effective and informative SCP depends on obtaining a primary source treatment record. (Ganz et al., 2008) (4)

3. Implement a systematic clinical assessment and care planning framework (Grade A) (Appendix 5)

Available Evidence:

• Systematic questioning allows needs to be identified and addressed (Ahmed, Ahmedzai, Collins, & Noble, 2014) (1+)

• Provide educational opportunities for health care providers to address health care needs and quality of life issues faced by cancer survivors (Howell et al., 2012) (1+)

4. Ensure survivors and caregivers are involved and agree with goal setting after needs are identified (Grade A)

Available Evidence:

Patient empowerment is important for survivors to actively participate in self care (Howell et al., 2012) (1+)

Evaluation

5. Support Care Needs Survey form (SCNS) will be utilized as measuring tool (Grade B) (Appendix 7)

Available Evidence:

• This tool has good psychometric properties and is widely used in supportive care research in cancer. (Jones et al., 2013) (1+)
• The Chinese version of the Supportive Care Needs Survey has a suitable factor structure and psychometric properties for use in assessing psychosocial needs (Au, et al., 2011) (2-)

6. Health Promotion Lifestyle Profile-II (HPLP II) will be utilized to measure health behavioral change (Grade C)

Available Evidence:

• This tool is useful for evaluating health-promoting lifestyles and the effectiveness of health-promoting programs. (Sousa, Gaspar, Vaz, Gonzaga, & Dixe, 2015) (2-)

• This tool is reported to have sufficient validity and reliability for use among various populations (Lee & Loke, 2005) (2-)

7. Patient Assessment of Chronic Illness Care to assess cancer care (Grade B) (Appendix 8)

Available evidence:

• This tool is well-organized and consistent with patient situations and values. (Wagner, et al., 2014) (1-)

8. Cancer Adaptation of the Pickers institute Subscale to assess patients’ problems in care (Grade B) (Appendix 9)

Available evidence:

• This tool is well-organized and consistent with patient situation and values. (Wagner et al., 2014) (1-)
Chapter 5 Implementation plan

In previous chapters, it was shown that the an SCP s is able to improve the quality of care of cancer survivors. A well-designed plan is important to implement this programme in the newly set-up nurse-led clinic. An effective survivorship program relies on multidisciplinary team collaboration (Dieperink et al., 2013; Jones et al., 2013; Gates et al., 2012). Therefore networks and communication are needed to facilitate the innovation across different departments (Kadu & Stolee, 2015). To maintain a strong network and communication with different teams, it is essential that an APN provides clear guidelines and assessment results for different teams to work together.

5.1 Communication plan with potential users

A multidisciplinary team will be involved in the SCP, and therefore effective and efficient communication between teams is crucial. A lymphoma APN needs to work as a coordinator to set up the framework of the project and explain how the care program should run. At the same time, she also needs to gather team members’ opinions to modify the program and reduce barriers during implementation. When introducing an SCP, the coordinator has to gain support from stakeholders by explaining the current service gap and disadvantages. These include the importance of integrated cancer treatment documentation, long waiting hours in a medical-led clinic, and patient lack of awareness of postchemotherapy side effects, which can lead to risky health behavior and unexpected expenditures for hospitalization. Moreover, the potential benefits also need to be explained to patients, healthcare providers and the management team to facilitate program implementation.
5.1.1 Identify stakeholders

Communication with several potential stakeholders is needed to facilitate the plan.

In the current nurse-led clinic, there are several groups of stakeholders:

1) Administrators who are responsible for department operations, ensure resource allocation and direct human resources within the department (Tessaro et al., 2013). The management team has the authority to approve or reject implementation of new programs. These administrators include the department operations manager (DOM) and the ward manager (WM) of the haematology oncology unit

2) Haematologists who work in the outpatient clinic are responsible for case screening based on agreed selection criteria and referral of appropriate lymphoma survivors to the nurse-led clinic. They will be part of the working team and provide feedback on case screening (John & Armes, 2013; Tessaro, et al., 2013; Salz, et al., 2012)

3) The APN in the nurse-led clinic is responsible for implementation of the innovation by explaining the benefits of the innovation to administrators, providing clear guidelines on case screening, and coordinating SCP implementation with the multidisciplinary team. In addition, she also needs to lead the frontline staff in carrying out the innovation (John & Armes, 2013; Tessaro, et al., 2013; Salz, et al., 2012).

4) Frontline staff including RNs and clerks that work in the clinic will form a working team with the APN. RNs interview patients for evaluation questionnaires. Clerk
will organize patient appointments and data input from the measurement outcomes

5.1.2 Communication Process

In the initial phase, the APN needs to present the SCP findings and conclusions from the systematic review of cancer survivors, and show that it can improve quality of care by enhancing patient satisfaction with service (Hershman et al., 2013) (Brothers et al., 2013) and reducing health worries (Hershman et al., 2013) psychological distress (Wagner et al., 2014) (Dieperink et al., 2013; Hershman et al., 2013; Grunfeld et al., 2011), waiting time and hospitalizations (John & Armes, 2013). She will also explain transferability of the findings (Hershman et al., 2013; Brothers et al., 2013) to gain support from the hematology oncologist and subordinates.

The selection criteria checklist and referral form will be given to the haematology oncologist to further cross check any amendments. Guidelines, flowcharts and questionnaires will be provided for the RNs and data collection and baseline assessment will be explained during a briefing session. The APN will explain the operation flow and timeline to the clerks, so they can arrange patient appointments and prepare needed documents and materials. Feedback and enquiries can be collected and handled.

After amendment, the second phase will be presented to administrators in departmental meetings to seek DOM approval, and endorsement from the DOM and WM. Highlights
will include the positive impacts in improving quality of care by enhancing patient satisfaction with service (Hershman et al., 2013; Brothers et al., 2013) reduced waiting hours, reduced hospitalizations and cost effectiveness (John & Armes, 2013).

After approval from the management level, the working team will be official. The haematology oncologist will provide final feedback on the screening process and encourage other medical officers to work with him; the APN will be a communication link between different parties for progress updates and carry out the SCP. The APN and RN will prepare quick reference flow charts on SCP, referral forms and checklists for case screening.

The APN will further train RNs on care need assessment and evaluation questionnaires, recommended community resources such as patient resource centers, free cancer link services, self-financed home care services, and self-help groups. They will also prepare educational materials and recommend websites and book lists. Before full implementation, the APN will carry out a pilot test of the feasibility of the programme to determine if any amendment is needed.

After the pilot test, patient feedback will be collected and evaluations will be completed. An analysis will be presented to administrators and related team members to get approval for the last phase – the official launch of the SCP service. Then, factors such as follow-up waiting time and cost saving will be assessed regularly. Extra human resources might be requested in department meetings when the patient pool increases.
5.2 Pilot testing

Before fully implementing the SCP, a pilot test will evaluate the feasibility of the new program, identify unforeseen obstacles, adjust human resources and evaluate whether the program can be effectively and efficiently implemented in the current setting. Further amendment will be done before the service is officially launched (Tessaro et al., 2013).

According to tables of evidence, the intervention implemented within 1 to 260 weeks, the pilot programme will take 20 weeks and 5 patients will be recruited. The working team will consist of a medical officer who will screen patients using the lymphoma survivor criteria checklist in the outpatient clinic and an RN who will approach them after medical consultation. A team member will explain the details and potential benefits of the program and confirm patient eligibility. If a patient agrees to join, a consent and baseline assessment will be obtained, and the pilot test commence.

The SCP will be delivered in the clinic by one trained APN and one RN. The pilot test will follow the timeline in Appendix 11. Two individual intervention appointments will be scheduled every Wednesday or Friday, and each appointment will last for 1.5 hours. The first appointment will include assessment of cancer survivor needs and postchemotherapy knowledge. Education on postchemotherapy side effects and a post-test will be given to patients and their care caregivers. Health promotion materials, community resources, recommended websites and book lists will be
provided. A phone call will be made to patients before the second appointment to reinforce the healthy behaviour intervention, and do a physical and psychological evaluation.

At the second appointment, patients will be educated based on surveillance results, referrals will be initiated after the SCP has been completed, and evaluation will also be done. Two weeks after the second appointment, a telephone follow up will be done to assess the progress of referral, difficulties in sustaining healthy behaviour and further evaluation of physical and psychological needs.

Chapter 6 Evaluation plan

6.1 Identifying outcomes

6.1.1 Patient outcomes

The primary patient outcome is to reduce psychological distress, and the secondary outcomes are to reduce survivor health needs and improve healthy behaviour. The Short-Form Supportive Care Needs Survey Questionnaire (SCNS-sf34) (Appendix 7) will be used to evaluate psychological distress and survivor health needs, before the first intervention and after intervention. It has a 5 point scale and covers five domains of need: psychological (10 items), health system and information (11 items), physical and daily living (5 items), patient care support (5 items) and sexuality (3 items). Higher scores indicate a higher perceived need or more distress; the scale can also be used to obtain information on the presence/absence and number of perceived unmet needs (Uchida, et al., 2010). Health behaviour will be measured by the Health Promotion
Lifestyle Profile-II (HPLP II). It has a 4 point scale, with higher scores indicating a greater frequency of health-promoting behaviors (Bi et al., 2014).

6.1.2 Healthcare provider outcomes
The major targets of healthcare provider outcomes are the frontline medical officers and RNs who work under the guidelines. Their satisfaction level and compatibility in carrying out the new guidelines will influence the effectiveness of the new program. Therefore it is crucial to assess their satisfaction and compatibility levels regularly. The MO will give feedback. RNs will be interviewed individually about experiences and difficulties during implementation as well as provide feedback on evaluation. After recruitment of the first batch of patients and SCP implementation, the APN should seek feedback from medical officers and RNs to see if any adjustments or improvements are needed.

6.1.3 System outcomes
Waiting time will be assessed during recruitment and after the second appointment by checking the average waiting time on the patient satisfaction questionnaire. Subscales from the Patient Assessment of Chronic Illness Care (PACIC) (Appendix 8) using Likert scales will be used to evaluate whether the SCP is well-organized and consistent with the patient situation. The Cancer Adaptation of the Picker Institute Survey (Picker)
6.2 Determining the nature and number of clients

The inclusion criteria indicate that lymphoma patients should be over 18 years old, have completed primary chemotherapy treatment and have no secondary diagnosis and will be continuously followed up at the lymphoma outpatient clinic. Recruitment is based on medical officer referral. A consent form is needed from patients and caregivers, and therefore convenience sampling will be used. The primary outcome is to reduce psychological distress. The distress level will be measured by the SCNS-sf34 psychological domain. If the mean score in that domain is 13 points lower after intervention than at baseline (Jones et al., 2013), the intervention will be considered effective. Results will be analyzed by a two-tailed paired t test, with a power setting at 0.8 and a level of significance of 0.05. The sample size should be 34 (Lenth, 2015).

Each month, about 20 patients in the lymphoma outpatient clinic complete primary chemotherapy and are diagnosed as recovered after PET scans and bone marrow examinations. Therefore sample recruitment will last for a half year.

6.3 Deciding when and how often to take measurements

Demographic data, the HPLP II and SCNS-sf34 will be used at recruitment for short-term measurement of patient outcomes. Assessment with the HPLP II and SCNS-sf34 will be done at week 0, week 8 and week 18.
For healthcare provider outcomes, individual interviews with RNs will take around 10-15 minutes after case consultation. For system outcomes, PACIC and Pickers will be done at week 0, week 4 and week 16. Please see the table below for easy reference.

**Table 2 Outcome measurement timeline**

<table>
<thead>
<tr>
<th>Week</th>
<th>Outcome measure</th>
</tr>
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<tbody>
<tr>
<td>0</td>
<td>HPLP II, SCNS- sf 34, PACIC, Pickers</td>
</tr>
<tr>
<td>4</td>
<td>PACIC, Pickers</td>
</tr>
<tr>
<td>8</td>
<td>HPLP II, SCNS- sf 34</td>
</tr>
<tr>
<td>16</td>
<td>PACIC, Pickers</td>
</tr>
<tr>
<td>18</td>
<td>HPLP II, SCNS- sf 34</td>
</tr>
</tbody>
</table>

6.4 Specifying how data will be analyzed

All quantitative data will be analyzed by IBM SPSS software. Patient demographic data will be described using means and standard deviations (SD). A paired two sample t test will be used to measure pre and post intervention scores for the HPLP II, SCNS-sf34, PACIC and Pickers. The results will be used to determine whether SCP improves quality of care by enhancing healthy behavior, reducing psychological distress, and improving patient satisfaction with hospital service. Qualitative data collected from individual interviews will be summarized and analyzed for content.

6.5 Conclusion
On what basis will the guidelines/protocol be considered effective?

The effectiveness of the SCP is determined by previously defined primary outcomes – such as whether the SCNS-sf34 has improved. Outcomes for timepoints will be measured by calculating post-baseline scores minus baseline scores. A positive value for the HPLP II indicates improvement from baseline; a negative value on the SCNS-sf 34 indicates improvement from baseline.

RN feedback and personal feelings will be recorded and the content will be analyzed. Positive feedback will indicate effectiveness of the SCP.

If scores for patient satisfaction on the PACIC and Picker are higher post intervention than pre intervention, the programme will be considered effective. If waiting time is reduced more than 30 minutes, it will be considered effective.
References


health care provider reported outcomes (ROGY Care): study protocol for a pragmatic cluster randomized controlled trial. *Trials, 12*(1), 256.


## Appendix

### Appendix 1

### Literature search results

<table>
<thead>
<tr>
<th>Database</th>
<th>Search Results</th>
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<tbody>
<tr>
<td>Pub med</td>
<td>51 articles</td>
</tr>
<tr>
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<td>51 articles</td>
</tr>
<tr>
<td>ISI web knowledge</td>
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</tr>
<tr>
<td>EBSCO host</td>
<td>96 articles</td>
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</table>

By keyword search:
1. Survivorship care plan* or Survivorship car* or Survivorship care program* or Survivorship or Survivorship care intervention* or Supportive car* or Cancer car* or Follow up car* or post treatment car* or post chemotherapy car*
2. Health care quality or Quality of Care or Quality care
3. Randomized Controlled Trial* or RCT or cohort

<table>
<thead>
<tr>
<th>Search Parameters</th>
<th>Search Results</th>
</tr>
</thead>
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<td>1. Survivorship care plan* or Survivorship car* or Survivorship care program* or Survivorship or Survivorship care intervention* or Supportive car* or Cancer car* or Follow up car* or post treatment car* or post chemotherapy car*</td>
<td>51 articles</td>
</tr>
<tr>
<td>2. Health care quality or Quality of Care or Quality care</td>
<td>18 articles</td>
</tr>
<tr>
<td>3. Randomized Controlled Trial* or RCT or cohort</td>
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Review by titles:

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<th>Database</th>
<th>Articles</th>
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<tr>
<td>Pub med</td>
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</tr>
<tr>
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<td>13 articles</td>
</tr>
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</tr>
<tr>
<td>ISI web knowledge</td>
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Review by full paper and reference lists:

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</tr>
</thead>
<tbody>
<tr>
<td>Pub med</td>
<td>7 articles</td>
</tr>
<tr>
<td>Cochrane library</td>
<td>8 articles</td>
</tr>
<tr>
<td>ISI web knowledge</td>
<td>3 articles</td>
</tr>
<tr>
<td>EBSCO host</td>
<td>4 articles</td>
</tr>
</tbody>
</table>

Total Articles for review after elimination of duplication and incomplete RCT studies: 10 articles
Under each heading, please tick the ONE box that best describes your health TODAY.

**MOBILITY**
I have no problems in walking about
I have slight problems in walking about
I have moderate problems in walking about
I have severe problems in walking about
I am unable to walk about

**SELF-CARE**
I have no problems washing or dressing myself
I have slight problems washing or dressing myself
I have moderate problems washing or dressing myself
I have severe problems washing or dressing myself
I am unable to wash or dress myself

**USUAL ACTIVITIES** *(e.g. work, study, housework, family or leisure activities)*
I have no problems doing my usual activities
I have slight problems doing my usual activities
I have moderate problems doing my usual activities
I have severe problems doing my usual activities
I am unable to do my usual activities

**PAIN / DISCOMFORT**
I have no pain or discomfort
I have slight pain or discomfort
I have moderate pain or discomfort
I have severe pain or discomfort
I have extreme pain or discomfort

**ANXIETY / DEPRESSION**
I am not anxious or depressed
I am slightly anxious or depressed
I am moderately anxious or depressed
I am severely anxious or depressed
I am extremely anxious or depressed
- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =
## Appendix 3

### IOM SCP frameworks

<table>
<thead>
<tr>
<th>Category of analysisa</th>
<th>Criteria for determining if category was present</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Treatment summary</strong></td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Mention of diagnosis</td>
</tr>
<tr>
<td>Dates of treatment</td>
<td>Mention of dates of treatment</td>
</tr>
<tr>
<td>Tumour characteristics</td>
<td>Any mention of tumour site, size, stage, (Gleason) score, nodes, pathology findings, hormonal markers (applicable for some specific tumour sites), hematology, stem-cell transplantation</td>
</tr>
<tr>
<td>Treatment history</td>
<td>Mention of treatments received (that is, surgery, chemotherapy, radiotherapy, hormonal therapy, others)</td>
</tr>
<tr>
<td>Supportive services provided (psychosocial, nutrition, others)</td>
<td>Mention of any supportive services provided during treatment</td>
</tr>
<tr>
<td>Full contact information for treating institutions and key individual providers</td>
<td>Name of treating health care provider and contact information for the treating centre (or the direct telephone number of the treating health care provider)</td>
</tr>
<tr>
<td>Identification of a key point of contact and coordinator of continuing care</td>
<td>Mention of coordinator of continuing care</td>
</tr>
<tr>
<td><strong>Follow-up care plan</strong></td>
<td></td>
</tr>
<tr>
<td>Treatment-related side effects (short-term)</td>
<td>Mention of any short-term (side) effects of treatment or the likely course of recovery</td>
</tr>
<tr>
<td>Periodic tests and schedule</td>
<td>Suggestions of tests that are needed in the coming months and years</td>
</tr>
<tr>
<td>Late and long-term side-effects</td>
<td>Mention of late or long-term effects and how to deal with them</td>
</tr>
<tr>
<td>Signs of recurrence or second tumour</td>
<td>Mention of signs and symptoms of recurrence</td>
</tr>
<tr>
<td>Psychosocial concerns</td>
<td>Reference in the care plan to effects on sexual functioning, relationships, anxiety, fatigue, sadness, depression</td>
</tr>
<tr>
<td>Financial concerns</td>
<td>Any mention of financial issues (insurance, cost of medication, work)</td>
</tr>
<tr>
<td>Recommendations for healthy behaviour</td>
<td>Any mention of variations in after-treatment care, self-management, or lifestyle</td>
</tr>
<tr>
<td>Genetic counselling, if appropriate</td>
<td>Mention of genetic testing as part of follow-up care, including referrals</td>
</tr>
<tr>
<td>Chemoprevention, if appropriate</td>
<td>Any mention of possible future cause for preventive pharmaceutical therapies (for example, tamoxifen, aspirin)</td>
</tr>
<tr>
<td>Referrals</td>
<td>Any referrals to specific care providers (including primary care providers or support groups)</td>
</tr>
<tr>
<td>Resource lists</td>
<td>Any lists of cancer-related information and resources (Internet- or telephone-based)</td>
</tr>
</tbody>
</table>

Based on recommendations from the U.S. Institute of Medicine

(Daudt, et al., 2014)
<table>
<thead>
<tr>
<th><strong>General Information</strong></th>
<th></th>
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<tbody>
<tr>
<td>Patient Name:</td>
<td>Patient DOB:</td>
</tr>
<tr>
<td>Patient phone:</td>
<td>Email:</td>
</tr>
</tbody>
</table>

**Health Care Providers** (Including Names, Institution)

<table>
<thead>
<tr>
<th>Provider Type</th>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Provider</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgeon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation Oncologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Oncologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Providers</td>
<td></td>
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</tr>
</tbody>
</table>

**Treatment Summary**

**Diagnosis**

<table>
<thead>
<tr>
<th>Cancer Type/Location/Histology subtype:</th>
<th>Diffuse Large B-Cell Lymphoma</th>
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<tr>
<td>Diagnosis Date (year):</td>
<td></td>
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<table>
<thead>
<tr>
<th>Stage</th>
<th>Sites of involvement:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ I</td>
<td>☐ II ☐ III ☐ IV</td>
</tr>
</tbody>
</table>

**Molecular Markers:**

- MYC rearrangement ☐ Yes ☐ No ☐ Unknown
- BCL-2 rearrangement ☐ Yes ☐ No ☐ Unknown
- BCL-6 rearrangement ☐ Yes ☐ No ☐ Unknown

<table>
<thead>
<tr>
<th>Maximal tumor diameter (cm):</th>
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</table>

| International Prognostic Index: | ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 |

**Treatment Completed**

<table>
<thead>
<tr>
<th>Biopsy</th>
<th>Yes ☐ No ☐</th>
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</thead>
<tbody>
<tr>
<td>Biopsy Date(s) (year):</td>
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**Biopsy procedure/location/findings:**

<table>
<thead>
<tr>
<th>Radiation</th>
<th>Yes ☐ No ☐</th>
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</thead>
<tbody>
<tr>
<td>Body area treated:</td>
<td></td>
</tr>
<tr>
<td>End Date (year):</td>
<td></td>
</tr>
</tbody>
</table>

**Systemic Therapy (chemotherapy, immunotherapy, other):**

<table>
<thead>
<tr>
<th>Yes ☐ No ☐</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Names of Agents Used</th>
<th>End Dates (year)</th>
</tr>
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<td>Cyclophosphamide</td>
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</tr>
<tr>
<td>Doxorubicin</td>
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</tr>
<tr>
<td>Etoposide</td>
<td></td>
</tr>
<tr>
<td>Prednisone</td>
<td></td>
</tr>
<tr>
<td>Rituximab</td>
<td></td>
</tr>
<tr>
<td>Vincristine</td>
<td></td>
</tr>
<tr>
<td>Other</td>
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Persistent symptoms or side effects at completion of treatment: □ No □ Yes (enter type(s)) :

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<th>Treatment Ongoing</th>
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<tbody>
<tr>
<td>Need for ongoing (adjuvant) treatment for cancer</td>
</tr>
<tr>
<td>Additional treatment name</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Follow-up Care Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schedule of Clinical Visits</td>
</tr>
<tr>
<td>Coordinating Provider</td>
</tr>
<tr>
<td></td>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>Cancer Surveillance or other Recommended Tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coordinating Provider</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
</tr>
</tbody>
</table>
Please continue to see your primary care provider for all general health care recommended for a (man) (woman) your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:
1. Anything that represents a brand new symptom;
2. Anything that represents a persistent symptom;
3. Anything you are worried about that might be related to the cancer coming back.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:
- Weakening of the heart presenting as:
  - shortness of breath and
  - swelling of legs (rare) and
  - numbness and tingling

  It is important to remember that these symptoms can be due to other causes like diabetes or with normal aging.

- Other:

Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

| ☐ Anxiety or depression | ☐ Insurance | ☐ Sexual Functioning |
| ☐ Emotional and mental health | ☐ Memory or concentration loss | ☐ Stopping Smoking |
| ☐ Fatigue | ☐ Parenting | ☐ Weight changes |
| ☐ Fertility | ☐ Physical functioning | ☐ Other |
| ☐ Financial advice or assistance | ☐ School/work | |

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

| ☐ Alcohol use | ☐ Physical activity | ☐ Other |
| ☐ Diet | ☐ Sun screen use | |
| ☐ Management of my medications | ☐ Tobacco use/cessation | |
| ☐ Management of my other illnesses | ☐ Weight management (loss/gain) | |

Resources you may be interested in:
- www.cancer.net
- Other:

Other comments:

Prepared by:                               Delivered on:
Appendix 5 National assessment and care planning framework template from NHS

Self Assessment Template

You are nearing the end of your initial treatment phase for your cancer. (Add in relevant statement for late effects or active disease patients and carers)

At this stage you may still be experiencing the effects either of your cancer and / or its treatment.

We would like to help you in planning the ongoing monitoring, care and support that you, your partner or family would feel helpful once your treatment is finished.

To help us with this, we would be grateful if you could consider some of the issues for you in this situation. These may include concerns, fears about the condition or simply about the practical help and support that you might find helpful as part of your ongoing care.

To help you with this we have listed some issues that are raised by patients or carers in this situation – you may have others and you can discuss these directly with the person that has arranged to meet with you to discuss this next stage of your care.

What are the issues that concern you most about completing your treatment? Do they relate to:

Continuing to feel symptoms that you feel are due to your cancer or its treatment/ For example these might include - fatigue, pain, sleep disturbance, breathlessness, hot flushes, diet, feeling or being sick etc.

Emotional Support that you may need? Eg if you are feeling tense, worried, irritable or depressed etc.

Practical Support that you may need? Eg Help with house work, shopping, personal care gardening, travel etc.

Information, advice, help or support to return to work, seek alternative employment or early retirement?

Information, advice, help or guidance in managing the household finances?
Information, advice, help or support with benefit claims?

Fears that the cancer may return or that you may not feel any better than you do now?

Your relationships with your family and friends?

The commitments you have and whether you will still be able to cope with them all?

How you will re-establish your social life?

Other Issues/ Concerns not addressed by the above questions.

What would you most like to change about the issues/ concerns/ difficulties that you have identified?

What are you most looking forward to being able to do once you have completed your initial treatment for your cancer?

What help and support might be needed to help you to do this?
Considering your answers and the things you feel you are most looking forward to doing - What are the first 3 goals you would set yourself?

1.

2.

3.

Please add some more goals if you want to:

Do you have any initial thoughts as to how you might achieve these goals?
Carer Contact Details

Assessment completed by:
Name: Title: Contact Details:

Assessment

What are the patient and their carer hoping for in the near and long term?

Physiological:

Diagnosis: Histology/ Staging/ Grade:

Disease New Remission Progressive Recurrent Metastatic

Status: (Tick Diagnosis appropriate box)

Prognosis:

Likely Risk of Recurrence: High Medium Low

Initial Treatment Summary:

Symptom Profile/ Impact of Current Treatment: (Include fatigue, pain breathlessness, balance, sleep disturbance etc)
Functional Status:

Functional Impairment Disability Cognitive ability independence

Nutritional Status: (include special diets eg vegetarian or specific food intolerances / allergies etc)

Lifestyle Behaviours eg alcohol consumption, smoking, weight, exercise, time for self:

Patients Name: Record Number:

Psychological:

The hope the patient/ carer has for their life and the strengths they can employ to achieve them:

Beliefs, values, spiritual and cultural systems:

Dynamics and relationships with others eg family, friends and colleagues:
Patient and Carers Perception of:

Illness: Quality of Life:

History of coping patterns ie reaction to previous stressful events and crisis management:

Patients Strengths:

Strategy agreed with Patient and Carer for Managing Concerns, Fears and Achieving Life Goals

Social:

Support Systems Currently in Place:

Support System Interventions agreed with Patient and or Carer:

Employment History and Flexibility of Employment:

Financial Concerns:

Benefits advice, information, support given: Yes: (Please Specify) No:
Patient able to Live: Independently: Independently with Support Services:
   With Carer Support: With Carer Support and Support Services:

Equipment Requirements:

Ability of Carer to Manage Care Burden i.e. Is Carers own health compromised?

Availability of others to support care burden:

**Patients Name:** **Record Number:**

**Interventions:**

Respite Care offered to Carer / Family Yes: (Please Specify) No:

Guardianship Arrangements for Dependent Children:

End of Life Preferences (if applicable)

Do Not Resuscitate Wishes/ Decision Discussed:

Patient Requires Access To:
Residential Care

Nursing Home: Sheltered

Accommodation: Long Term Care:

Community Hospital Convalescence Place:
  Hospice In Patient: Hospice Respite: Day Care:

Specialist Palliative Care Team Support:

Community End of Life Care Team Support:

**Referrals made to Services:**

GP: Practice Nurse: Dietician: Physiotherapist: Occupational Therapist: Speech & Language Therapist:

Specialist Service eg Stoma, Fertility clinic etc:
  Counsellor: Bereavement Counsellor: CMHT: Psychologist: Psychiatrist:

Social Worker: Financial/ Benefits Advice Service: Buddying/

Befriending Scheme Local Self Help & Support Group Healthy Life style Initiative Services within locality: Specialist Palliative Care Team:

Holistic/

Complementary

Therapy Services:

Information Services: Other:

**Self Management Programmes Referrals:**

Information: On Line Tools: Face to Face:

Additional Comments:

Assessment Summary:
Planned Follow Up/ Supportive Management Plan:

Management and Support Plan

Patient Demographics

Carer Contact Details

Assessment completed by:
Name: Title: Contact Details:

This Management and Support Plan has been developed in conjunction with yourself and / or your carer. It provides a summary of the information about your diagnosis, treatment and your ongoing follow up and supportive care requirements. The plan also provides information on the symptoms you should be aware of and act upon as well as steps that you can take to stay healthy.

You should show this plan to the doctors, nurses and other professionals involved in your care so that they are aware of the care you are receiving or require and can update the information with your agreement if necessary.

You have agreed that the information within this care plan can be shared with:

The following members of your family: The following care providers:
If you require access to a professional for general queries, advice or support; you should contact:

If you require access to a member of the specialist team involved in your cancer care; you should contact:
Normal working hours: Out of Normal Working Hours:

Initial Treatment and Management Plan Summary:

You have identified the following key concerns, care needs or goals that you would like to see addressed, improved or achieved. (Please specify):
1. 
2. 
3. 
4. 
5. 

As an outcome of the discussion relating to the care needs and concerns you identified and those discussed relating to your ongoing care, support and the goals you wish to achieve it was agreed:

Management and Support Plan

Name:                      Record Number:

Your Follow Up / Monitoring Requirements:
Your Likely course of Recovery from Treatment:

Ongoing Services or treatment that you will be receiving:

The medicines that you have been prescribed need to be reviewed by: (Please Tick appropriate Box) Within the following specified period or stated date:

Your Consultant: | Your GP:

Services you have been referred to:

Self Management Programmes that you have been advised to access to assist your recovery:
Healthy Lifestyle Advice that has been given to you: (include virus protection, sunscreen advice, nutrition, exercise etc as appropriate)

Signs and Symptoms to look out for and seek advice on:

Information given to you (include verbal and written information)

Date of Next Review

Signature of Patient/ Carer: Signature of Professional:

Appendix 6

Key to Evidence Statement and Grades of Recommendations from Scottish Intercollegiate Guidelines Network (SIGN) (2008)

Level of evidence

1++ High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias
1+ Well-conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias
1-  Meta-analyses, systematic reviews, or RCTs with a high risk of bias
2++  High quality systematic reviews of case control or cohort or studies

High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is Causal
2+    Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal
2-    Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal
3    Non-analytic studies, e.g. case reports, case series
4    Expert opinion

Key to Evidence Statement and Grades of Recommendations from Scottish Intercollegiate Guidelines Network (SIGN) (2004)

Grade of recommendation

Note: the grade of recommendation relates to the strength of the evidence on which the recommendation is based. It does not reflect the clinical importance of the recommendation.

At least one meta-analysis, systematic review, or RCT rated as 1++, and directly applicable to the target population; or
A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results
A body of evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; or
Extrapolated evidence from studies rated as 1++ or 1+
A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or
Extrapolated evidence from studies rated as 2+
Evidence level 3 or 4; or
Extrapolated evidence from studies rated as 2+

Good practice points

Recommended best practice based on the clinical experience of the guideline development group.
INSTRUCTIONS

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. Put a circle around the number which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

| NO NEED | 1 | Not applicable – This was not a problem for me as a result of having cancer. |
|         | 2 | Satisfied - I did need help with this, but my need for help was satisfied at the time. |
| SOME NEED | 3 | Low need - This item caused me concern or discomfort. I had little need for additional help. |
|          | 4 | Moderate need – This item caused me concern or discomfort. I had some need for additional help. |
|          | 5 | High need - This item caused me concern or discomfort. I had a strong need for additional help. |

For example

<table>
<thead>
<tr>
<th>In the last month, No need Some need what was your level of need for help with:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not</td>
</tr>
<tr>
<td>1. Being informed about things you can do to help yourself to get well</td>
</tr>
</tbody>
</table>

If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.
Now please complete the survey on the next 2 pages.

<table>
<thead>
<tr>
<th></th>
<th>No need</th>
<th>Some need</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not applicable</td>
<td>Satisfied</td>
</tr>
</tbody>
</table>

In the last month, what was your level of need for help with:

1. Pain
   - 1
   - 2
   - 3
   - 4
   - 5

2. Lack of energy/tiredness
   - 1
   - 2
   - 3
   - 4
   - 5

3. Feeling unwell a lot of the time
   - 1
   - 2
   - 3
   - 4
   - 5

4. Work around the home
   - 1
   - 2
   - 3
   - 4
   - 5

5. Not being able to do the things you used to do
   - 1
   - 2
   - 3
   - 4
   - 5

6. Anxiety
   - 1
   - 2
   - 3
   - 4
   - 5

7. Feeling down or depressed
   - 1
   - 2
   - 3
   - 4
   - 5

8. Feelings of sadness
   - 1
   - 2
   - 3
   - 4
   - 5

9. Fears about the cancer spreading
   - 1
   - 2
   - 3
   - 4
   - 5

10. Worry that the results of treatment are beyond your control
    - 1
    - 2
    - 3
    - 4
    - 5
<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>11.</td>
<td>Uncertainty about the future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12.</td>
<td>Learning to feel in control of your situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13.</td>
<td>Keeping a positive outlook</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14.</td>
<td>Feelings about death and dying</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15.</td>
<td>Changes in sexual feelings</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16.</td>
<td>Changes in your sexual relationships</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17.</td>
<td>Concerns about the worries of those close to you</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18.</td>
<td>More choice about which cancer specialists you see</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19.</td>
<td>More choice about which hospital you attend</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20.</td>
<td>Reassurance by medical staff that the way you feel is normal</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21.</td>
<td>Hospital staff attending promptly to your physical needs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22.</td>
<td>Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

| No need | Some need |
In the last month, what was your level of need for help with:

<table>
<thead>
<tr>
<th></th>
<th>Not applicable</th>
<th>Satisfied</th>
<th>Low need</th>
<th>Moderate need</th>
<th>High need</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>23.</strong></td>
<td>Being given written information about the important aspects of your care</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>24.</strong></td>
<td>Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>25.</strong></td>
<td>Being given explanations of those tests for which you would like explanations</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>26.</strong></td>
<td>Being adequately informed about the benefits and side-effects of treatments before you choose to have them</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>27.</strong></td>
<td>Being informed about your test results as soon as feasible</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>28.</strong></td>
<td>Being informed about cancer which is under control or diminishing (that is, remission)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>29.</strong></td>
<td>Being informed about things you can do to help yourself to get well</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
30. Having access to professional counselling (eg, psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it

31. Being given information about sexual relationships

32. Being treated like a person not just another case

33. Being treated in a hospital or clinic that is as physically pleasant as possible

34. Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up

Thank you for completing this survey
Assessment of Care for Chronic Conditions

Staying healthy can be difficult when you have a chronic condition. We would like to learn about the type of help with your condition you get from your health care team. This might include your regular doctor, his or her nurse, or physician’s assistant who treats your illness. Your answers will be kept confidential and will not be shared with your physician or clinic.

Over the past 6 months, when I received care for my chronic conditions, I was:

<table>
<thead>
<tr>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>Always</th>
</tr>
</thead>
</table>

1. Asked for my ideas when we made a treatment plan.  
   - 1
   - 2
   - 3
   - 4
   - 5

2. Given choices about treatment to think about.  
   - 1
   - 2
   - 3
   - 4
   - 5

3. Asked to talk about any problems with my medicines or their effects.  
   - 1
   - 2
   - 3
   - 4
   - 5

4. Given a written list of things I should do to improve my health.  
   - 1
   - 2
   - 3
   - 4
   - 5

5. Satisfied that my care was well organized.  
   - 1
   - 2
   - 3
   - 4
   - 5

6. Shown how what I did to take care of myself influenced my condition.  
   - 1
   - 2
   - 3
   - 4
   - 5

7. Asked to talk about my goals in caring for my condition.  
   - 1
   - 2
   - 3
   - 4
   - 5
8. Helped to set specific goals to improve my eating or exercise.

9. Given a copy of my treatment plan.

10. Encouraged to go to a specific group or class to help me cope with my chronic condition.

11. Asked questions, either directly or on a survey, about my health habits.

Over the past 6 months, when I received care for my chronic conditions, I was:

<table>
<thead>
<tr>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>Always</th>
</tr>
</thead>
</table>

12. Sure that my doctor or nurse thought about my values, beliefs, and traditions when they recommended treatments to me.

13. Helped to make a treatment plan that I could carry out in my daily life.

14. Helped to plan ahead so I could take care of my condition even in hard times.

15. Asked how my chronic condition affects my life.

16. Contacted after a visit to see how things were going.
17. Encouraged to attend programs
in the community that could
help me.  

18. Referred to a dietitian, health
educator, or counselor.  

19. Told how my visits with
other types of doctors, like
an eye doctor or other
specialist, helped my
treatment.  

20. Asked how my visits with other
doctors were going.  

Copyright 2004 The MacColl Center for Health Care Innovation, Group Health Cooperative. The Improving Chronic Illness Care program is supported by The
Robert Wood Johnson Foundation, with direction and technical assistance provided by Group Health's MacColl Center for Health Care Innovation. For more
information go to www.improvingchroniccare.org

Retrieved on 31\textsuperscript{st} may 2015 http://www.improvingchroniccare.org/index.php?p=PACIC_survey&s=36
Appendix 9 Cancer Adaptation of the Picker Institute Survey (Represent items by Subscale)

Cancer Adaptation of the Picker Institute Survey (Represent items by Subscale)

Coordination of care subscale
- How often were the doctors, nurse and other providers who cared for you familiar with you most recent medical history?

Confidence in providers subscale
- Do you think your doctors knew enough about cancer treatment?

Treatment information subscale
- Were you given as much information as you wanted about the treatment options for treating your cancer?

Health information subscale
- Did you get as much information as you wanted about your nutritional needs?

Access to Cancer care
- How often were you able to see the specialists you wanted to see?

Psychological care
- Did a doctor, nurse or social worker go out of their way to make you feel better emotionally?

(Jones, et al., 2013)
### Appendix 10 Study Design

<table>
<thead>
<tr>
<th>Studies</th>
<th>Design</th>
</tr>
</thead>
</table>
Appendix 11 Timeline of the pilot study

<table>
<thead>
<tr>
<th>Time</th>
<th>Study Group:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>Study Group:</td>
</tr>
<tr>
<td>T0</td>
<td>Baseline assessment:</td>
</tr>
<tr>
<td></td>
<td>1. Demographic assessment</td>
</tr>
<tr>
<td></td>
<td>2. Health Promoting Lifestyle Profile II (HPLP II)</td>
</tr>
<tr>
<td></td>
<td>3. Supportive Care Needs Questionnaire (SCNS-SF34)</td>
</tr>
<tr>
<td></td>
<td>4. Waiting time assessment</td>
</tr>
<tr>
<td></td>
<td>5. Patient Assessment of Chronic Illness Care (PACIC)</td>
</tr>
<tr>
<td></td>
<td>6. Patient experience measures from Pickers Subscale</td>
</tr>
<tr>
<td>Week 4</td>
<td>First intervention appointment</td>
</tr>
<tr>
<td></td>
<td>Evaluation</td>
</tr>
<tr>
<td></td>
<td>Knowledge of postchemotherapy side effects</td>
</tr>
<tr>
<td></td>
<td>Education package to survivors and caregivers</td>
</tr>
<tr>
<td></td>
<td>- Postchemotherapy side effects (based on existing protocols)</td>
</tr>
<tr>
<td></td>
<td>- provide health promotion material</td>
</tr>
<tr>
<td></td>
<td>- introduce existing community support</td>
</tr>
<tr>
<td></td>
<td>- recommend websites and readings</td>
</tr>
<tr>
<td></td>
<td>Evaluation</td>
</tr>
<tr>
<td></td>
<td>1. Patient Assessment of Chronic Illness Care (PACIC)</td>
</tr>
<tr>
<td></td>
<td>2. Patient experience measures from Pickers Subscale</td>
</tr>
<tr>
<td></td>
<td>3. Knowledge of postchemotherapy side effects</td>
</tr>
<tr>
<td>Week 6</td>
<td>Phone call to reinforce and follow up intervention progress</td>
</tr>
<tr>
<td>T1</td>
<td>Evaluation via phone call</td>
</tr>
<tr>
<td>Week 8 - 12</td>
<td>1. Health Promoting Lifestyle Profile II (HPLP II)</td>
</tr>
<tr>
<td></td>
<td>2. Supportive Care Needs Questionnaire (SCNS-SF34)</td>
</tr>
<tr>
<td>Week 16</td>
<td>Second intervention Appointment</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
</tr>
<tr>
<td></td>
<td>- Survivorship care plan by APN</td>
</tr>
<tr>
<td></td>
<td>- educate based on surveillance results</td>
</tr>
<tr>
<td></td>
<td>- initiate and complete specialist referrals</td>
</tr>
<tr>
<td></td>
<td>- initiate and complete community referrals e.g CNS</td>
</tr>
<tr>
<td></td>
<td>- provide medical summary for GP</td>
</tr>
<tr>
<td></td>
<td>- reinforce intervention</td>
</tr>
<tr>
<td></td>
<td>Evaluation</td>
</tr>
<tr>
<td></td>
<td>1. Patient Assessment of Chronic Illness Care (PACIC)</td>
</tr>
<tr>
<td></td>
<td>2. Patient experience measures from Pickers Subscale</td>
</tr>
<tr>
<td></td>
<td>3. Waiting time assessment</td>
</tr>
<tr>
<td>T2</td>
<td>Phone call to reinforce and follow up intervention progress</td>
</tr>
<tr>
<td>Week 18 - 20</td>
<td>Evaluation via phone call</td>
</tr>
<tr>
<td></td>
<td>1. Health Promoting Lifestyle Profile II (HPLP II)</td>
</tr>
<tr>
<td></td>
<td>2. Supportive Care Needs Questionnaire (SCNS-SF34)</td>
</tr>
</tbody>
</table>
Appendix 12 Lymphoma survivor referral criteria checklist

- Age over 18 years at first diagnosis of lymphoma
- Completed primary chemotherapy treatment
- Confirmed complete remission by PET-CT and bone marrow examination
- No secondary diagnosis
- Verbal consent from patient and caregiver

➢ If you fulfill all of the above criteria, please fill in survival care referral form below and give it to the lymphoma clinic APN

Survival care referral form

For Nurse led clinic use:

Case number:

Date of referral:

Diagnosis:

Primary Chemo protocol:
## Appendix 13 Implementation Timeline

<table>
<thead>
<tr>
<th>Task/Time</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presentation to opinion leaders and frontline staff</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Seek approval from management</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preparation of staff and patient education materials</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training in empathic listening skills and behavioral strategies to assess and address patient distress</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pilot study</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<td></td>
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<tr>
<td>Pilot study evaluation, amendment of protocols and documentation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full implementation</td>
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