Preface

This thesis marks the end of the theoretical part of the clinical program in psychology. It has been an interesting and challenging process, during which I have learnt a lot.

The thesis and research questions are based on data collected by SINTEF for the study *Health– and welfare services for adolescents under and after cancer treatment* in 2012. In addition, control group data was collected winter 2016 by the author. I am grateful to all the young adult cancer survivors and individuals in the control group who participated in this study, and for permission to use the dataset from SINTEF.

All analyses presented in the results section are conducted by myself, but not without advice and discussions of statistical issues with Odin Hjemdal and Trude Reinfjell. Kyrre Svarva did a great job helping me with the layout on questionnaires for the control group, and designing the SPSS file. I want to thank Trude Reinfjell for guiding me through the work on this thesis. You have given me thorough feedback, valuable advice and willingly shared your knowledge.

Janne Fagervoll Halvorsen
Trondheim, October 2016

This study has used data from the Cancer Registry of Norway. The interpretation and reporting of these data are the sole responsibility of the author, and no endorsement by the Cancer Registry of Norway is intended nor should be inferred.

Abbreviations

AYA = adolescents and young adults

CCSS = Childhood Cancer Survivor Study

CRN = Cancer Registry of Norway

HRQOL = Health-Related Quality of Life

HSCL = Hopkins Symptom Checklist

PedsQL™ = Pediatric Quality of Life Inventory

SINTEF = The Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology

Health-related quality of life and psychological distress in young adult survivors of cancer in adolescence or young adulthood

Abstract

Background: This study investigated health-related quality of life (HRQOL) and psychological distress among young adult survivors of cancer in adolescence. *Methods:* Participants included cancer survivors (*n*=230) recruited though The Cancer Registry of Norway (CRN) and healthy controls (*n*=223) recruited from a student population at the Norwegian University of Science and Technology (NTNU). All participants completed self-report questionnaires with the Pediatric Quality of Live Inventory (PedsQL™) 4.0 as a measure of HRQOL and the Hopkins Symptom Checklist-10 (HSCL-10) as a measure of distress. *Results:* Survivors reported HRQOL and distress at the same level as controls, except from poorer self-reported physical functioning. Survivors in general and female survivors specifically were more probable than controls to report symptoms of distress, but survivors did not show higher levels of distress compared to controls. Female survivors reported poorer HRQOL and higher levels of distress than female controls. Survivors reporting distress above cut-off for psychological distress, reported significantly poorer HRQOL than controls scoring above cut-off. Some differences in HRQOL and distress related to types of treatment were found. For cancer survivors, demographic variables and numbers of undergone self-reported treatment modalities predicted HRQOL and distress. *Conclusion:* Gender, educational level, perceived economic situation and numbers of undergone treatment modalities significantly predicted HRQOL and distress. A developmental perspective helps recognize the special challenges of young adult survivors of cancer in adolescence, and there is a need for long-term follow up for this group.

Key words: HRQOL, psychological distress, cancer, AYA, adolescence, young adults

Health-related quality of life and psychological distress in young adult survivors of cancer in adolescence or young adulthood

Introduction

Approximately 0.8% of total cancer incidence, an equal proportion in males and females, occurs in young adults age 15-24 years. In 2014, 674 males and 549 females this age were diagnosed with cancer in Norway (Cancer Registry of Norway, 2015). Coping with cancer while transitioning from childhood to adulthood adds an array of complexities and conflict to existence, that create unreasonable stress for the patient, family, friends and caregivers (Bleyer, Budd, & Montello, 2006). Adolescents and young adults (AYA) living with cancer faces challenges unique to the developmental period they are in, and the psychosocial concerns are distinct and different from the concerns of the paediatric and older adult population (D'Agostino, Penney, & Zebrack, 2011). A majority of children diagnosed with cancer will become long-term survivors (Armstrong et al., 2009). Within the paediatric cancer community, survivorship is often defined as surviving at least five years from last evidence of disease and at least two years from discontinuation of therapy (Meadows, 2003). Life expectancy among cancer patients increases and cancer care continues to advance (Cancer Registry of Norway, 2015). New treatments efforts for cancer in childhood have resulted in significant improvements in terms of average 5-years survival rate in recent years at 80% for most children (Phillips et al., 2015). The relative survival (RS) rates of the most commonly occurring cancers in children and AYAs in Norway; testis cancer, CNS (central nervous system) cancer and Hodgkin lymphoma, are very high (Cancer Registry of Norway, 2015). In other words, there is a growing subgroup of childhood and AYA cancer survivors in the adult population that did not exist a few decades ago (Armstrong et al., 2009).

Late effects of cancer treatment

Improvements in survival rates have contributed to an increased focus on identification of late effects of cancer treatment among long-term survivors. As AYA survivors mature into adulthood, they are at risk for long-term complications of cancer treatment (e.g. cardiopulmonary dysfunction, learning difficulties, and additional cancers) (Gleeson & Shalet, 2001; Hudson, 2008; Lipshultz et al., 1991; Meister & Meadows, 1993; Neglia et al., 2001). Research shows that survivors of childhood cancer have a high rate of illness owing to chronic health conditions. Oeffinger et al. (2006) found that among 10 397 childhood cancer survivors 62,3% had at least one chronic condition, 37,6% had two or more, and 27,5% had a severe or life-threatening condition. Damage to the organ systems of children caused by chemotherapy and radiation therapy may not become clinically evident for many years. Compared to men, women who survived childhood cancer were reported to have a greater risk of diminished health status (Oeffinger et al., 2006). Although serious problems may occur during cancer therapy or soon after (long-term effects), the majority do not become clinically apparent until many years after the cancer has been cured (late effects) (Oeffinger, Nathan, & Kremer, 2010). It is therefore critical for AYA survivors to be evaluated for late effects as they transition into adult-centered health-care (Casillas et al., 2010), and previous research reveals that the majority of AYAs do not receive risk-based survivorship care to assess physical and psychosocial late effects (Aziz & Rowland, 2003; Nathan et al., 2009; Oeffinger & Hudson, 2004). As the developing brain and behavioural and cognitive systems mature at different rates, and under the control of biological processes, this developmental period is often one of increased vulnerability (Christie & Viner, 2005). Developmental perspectives are therefore important to consider when studying AYA cancer survivors.

Developmental perspectives

Adolescence and young adulthood represent periods of great changes in life, and AYAs are faced with potentially challenging physical, psychological, cognitive, and social development (Choudhury, Blakemore, & Charman, 2006; Steinberg, 2005). In addition to changes in attachment relationships, identity development is especially a major concern during adolescence and emerging adulthood (Allen, 2008; Arnett, 2000; Erikson, 1977). Key developmental tasks include establishing autonomy from parents, a personal set of values and identity; forming strong peer relationships, including intimate and sexual relationships, and obtaining adequate preparation to join the workforce (D'Agostino et al., 2011). The adolescents evolves from being a receiver of care to becoming a self-sufficient adult and potential caregiver to peers, romantic partners and offspring (Allen, 2008). With adult tasks ahead and faced with a physiological revolution within themselves, adolescents are primarily concerned with what they appear to be in the eyes of others compared with what they feel they are. This integration is central to identity development (Erikson, 1977).

Being diagnosed with cancer during adolescence involves coping with cancer treatment while accomplishing tasks unique to the developmental period (Zeltzer, 1993), and all this at a stage in life when the onset of many mental health disorders peaks (Kessler et al., 2007). Older adolescence and young adulthood is increasingly recognized as a distinct age group with unique medical and psychosocial needs (Bleyer et al., 2006), and survivors diagnosed during adolescence and young adulthood face different challenges than cancer survivors diagnosed as children. Relative to children, AYAs are more likely to talk directly with their health care team about illness and treatment, participate in treatment decisions, and understand the broader implications of their illness and treatment (Abrams, Hazen, & Penson, 2007; Kazak & Noll, 2015). At the same time, the demands of cancer treatment can effect conflicts between parent and adolescent, such as struggles over autonomy and independence (Abrams et al., 2007; Kazak & Noll, 2015). The disruption of the adolescents lives can be particularly stressful, and side effects of treatment can lead to multiple concerns regarding treatment-associated changes, such as physical appearance and popularity and acceptance within their peer group (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010). Keeping the important developmental tasks of adolescence in mind, high rates of survivors increase the need for knowledge on how disease and treatment effects later psychological functioning as well as health-related quality of life.

Health-related quality of life (HRQOL) and psychological distress

Although sometimes used interchangeably, one can distinguish between the constructs Quality of Life (QOL) and Health-Related Quality of Life (HRQOL). QOL is considered a holistic, more general conceptual term also related to non-health aspects of life, such as material, physical, social, emotional and productive well-being (Wallander, Schmitt, & Koot, 2001). HRQOL is considered to be a multidimensional construct covering physical, emotional, mental, social and behavioural components of well-being and functioning as perceived by patients (Bullinger, 2002). HRQOL refers specifically to the impact health and illness may have on the well-being of an individual. While definitions of HRQOL have varied, there is agreement about the multidimensionality of the construct and its incorporation of the subjective appraisal of one's functioning and well-being (Wallander & Koot, 2016). A generic HRQOL instrument must be multidimensional, consisting at the minimum of the physical, psychological (including emotional and cognitive) and social health dimensions delineated by the World Health Organization (U.S. Department of Health and Human Services FDA:, CDER, CBER, & CDRH, 2006; Varni & Limbers, 2009; World Health Organization, 1948).

Anxiety is closely linked to depression in the adolescent population. Though it has been discussed whether adolescent anxiety and depression are two distinct syndromes or the same disorder on a continuum of severity (Lee & Rebok, 2002), other evidence points towards anxiety and depression as two distinct disorders with parallel growth processes (Hale, Raaijmakers, Muris, Van Hoof, & Meeus, 2009). Still, the two disorders are frequently comorbid. Earlier research have found that 25-50% of adolescents with a depressive disorder also have a comorbid anxiety disorder, and that 10-15% of adolescents with an anxiety disorder have a comorbid depressive disorder (Axelson & Birmaher, 2001; Brady & Kendall, 1992; Cole, Truglio, & Peeke, 1997). Due to the above-mentioned factors, in some contexts it is meaningful to talk about psychological distress as a wider and more inclusive construct than the two separate disorders of anxiety and depression. Psychological distress refers to the unpleasant subjective states of depression and anxiety, which have both emotional and physiological manifestations (Mirowsky & Ross, 2003). Several screening instruments loading on dimensions of anxiety and depression, but also other dimensions like somatization, have been developed to measure psychological distress (de Haes, van Knippenberg, & Neijt, 1990; Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974; Derogatis & Melisaratos, 1983; Zigmond & Snaith, 1983).

Several long-term follow-up studies of childhood cancer survivors suggest that although most adult survivors are psychologically healthy, subgroups are at risk for experiencing significant psychological distress, including symptoms of depression, anxiety and somatisation (Brinkman et al., 2013; Michel, Rebholz, Von Der Weid, Bergstraesser, & Kuehni, 2010; Zebrack et al., 2004; Zeltzer et al., 2008). Others emphasize that childhood cancer survivors have an increased risk of using antidepressants, but finds no indication that survivors are more vulnerable regarding other risk factors for psychopathology, such as familial psychiatric disease or low socioeconomic position (Lund et al., 2015). Thus, an increased likelihood of using antidepressants may indirectly reflect an increased underlying risk of mental health conditions among survivors (Deyell et al., 2013). Further, female survivors, survivors in young adulthood and those more than 20 years post-treatment are found to have an increased use of antidepressants (Deyell et al., 2013). Other research have found individuals diagnosed between the ages of 15 and 20 to be nearly twice as likely to use antidepressant medication as individuals diagnosed before the age of 5 (Barnett et al., 2016).

In a 10-year follow-up study of survivors diagnosed during adolescence, Ander et al. (2015) found non-linear development in HRQOL and symptoms of depression and anxiety, including high individual variability in sub-clinical anxiety. This indicates difficulties in predicting who will suffer reduced HRQOL and/or psychological distress during extended survival phase. Ten years after diagnosis almost a third reported sub-clinical anxiety (Ander et al., 2015). This is in accordance with earlier findings on childhood cancer survivors (Brinkman et al., 2013) showing that a sub-group of survivors reported clinically relevant psychological distress decades following diagnosis (Ander et al., 2015; Brinkman et al., 2013). A review of results from Childhood Cancer Survivor Study (CCSS) concluded that a significant proportion of survivors reported symptoms of global distress and poorer physical, but not emotional, domains of HRQOL (Zeltzer et al., 2009). Other than brain tumour survivors, most survivors reported both good present and expected future life satisfaction. Risk factors for psychological distress and poor HRQOL were female sex, lower educational attainment, unmarried status, annual household income less than $20 000, unemployment, lack of health insurance, presence of a major medical condition, and treatment with cranial radiation and/or surgery (Zeltzer et al., 2009). But overall, most survivors were psychologically healthy and reported satisfaction with their lives (Zeltzer et al., 2009).

Capable of abstract thinking, deductive reasoning and conceptual thinking (Abrams et al., 2007) AYAs have greater cognitive capacities than children to understand the severity of their illness. Because of this, adolescents may demonstrate persistent distress and anxiety over recurrence, death or late effects (Zebrack, 2011; Zebrack & Zeltzer, 2001). Adolescent childhood cancer survivors who are more likely to recall their treatment experiences are also more likely to have had grater realization of the seriousness of their illness, and thus have more posttraumatic stress symptoms (Kazak et al., 2010). Survivors who have undergone the highest level of treatment intensity are found to have greater anxiety and fewer positive health beliefs than those with less intense treatments (Kazak et al., 2010).

Despite these problems, AYAs may show considerable resilience. Young people who are able to accept and cope with cancer may gain greater appreciation of life as a result of their illness experience, may mature faster than their peers, and can become better emotionally equipped to handle the everyday challenges of life (Parry & Chesler, 2005; Zebrack, 2011). For teen survivors, perceptions of greater current and past life threat and perception of intensity of treatment are shown to be associated with identifying positive aspect of the cancer experience (Barakat, Alderfer, & Kazak, 2006). Investigating survivors aged 15-25 (mean age 18,96 years), treated for cancer before the age of 18, and at least 5 years having lapsed since the last day of therapy, Tremolada et al. (2016) found cancer survivors to report significantly better HRQOL in almost all Short-Form Health Survey (SF-36) scales compared to controls. Survivors reported less support, particularly from family and significant others, even though they reported a higher level of functioning on the social scale of SF-36. AYA survivors endorsed positive HRQOL, despite diminished educational attainment and perceived social support compared to controls. Survivors demonstrated an even better perception of their lives than controls, and according to the authors this finding illustrates a profile of relatively good psychological health and resilience in paediatric cancer survivors (Tremolada et al., 2016). The results indicate that AYAs can have normal development in health perceptions compared to their peers (Tremolada et al., 2016). Other evidence is more discouraging. A population-based case-control study of female adolescent and young adult survivors of breast and gynaecological cancer, found survivors to report poorer physical and mental health status than females without a history of cancer (Phillips-Salimi & Andrykowski, 2013). With a mean of 17 years since diagnosis, survivors reported consistently poorer mental health outcomes; greater lifetime, recent, and current prevalence of a variety of medical conditions; more health-related disability; and greater functional limitations, relative to the control group. Further, survivors were four times more likely than the control group to meet criteria for serious psychological distress (Phillips-Salimi & Andrykowski, 2013).

Age and gender are important determinants of health-related quality of life (Fosså, Hess, Dahl, Hjermstad, & Veenstra, 2007). Investigating an European population using Kidscreen 52, Bisegger et al. (2005) found children to report very good quality of life largely independent of gender, and children had higher HRQOL than adolescents in many aspects. After the age of 12, HRQOL were found to decrease, and a stronger decrease was found for females than for males regarding physical and psychological dimensions. With increasing age, HRQOL was frequently worse for females than for males (Bisegger et al., 2005).

For cancer survivors, negative psychosocial outcomes and poor HRQOL are associated with female gender (Blaauwbroek et al., 2007; Chan et al., 2014; Reulen et al., 2007; Tremolada et al., 2016; Zeltzer et al., 2008, 2009) and young age at diagnosis (Lund, Schmiegelow, Rechnitzer, & Johansen, 2011). Others have found older age at time of assessment to be associated with worse physical and mental adaptation (Chan et al., 2014; Reulen et al., 2007; Tremolada et al., 2016). Evidence from CCSS points to age and gender as important factors affecting health status among childhood cancer survivors (Armstrong, Sklar, Hudson, & Robison, 2007; Hudson et al., 2015). Prevalence of poor health status is found to be higher among survivors than siblings, increasing with age, particularly among female participants, and to be related to an increasing burden of chronic health conditions (Hudson et al., 2015). In excess of what reported by siblings, childhood cancer survivors experience increasing prevalence of impairment with age in general health, functional status, and activity limitations. But prevalence of distress and moderate-to-extreme cancer-related pain or anxiety are not found to increase with age, (Hudson et al., 2015). A review of survivors diagnosed in adolescence or young adulthood (age 15-39) found females to demonstrate greater internalized mental health outcomes (Barnett et al., 2016). Female AYAs scored significantly poorer than healthy peers on mental health outcomes and were more likely than peers to meet criteria for serious psychological distress. Further, females were more likely to report experiencing persistent struggles, such as post-traumatic stress symptoms, anxiety, pain, fatigue, depression, and fears of recurrence (Barnett et al., 2016). According to the authors, the gender difference highlights moderators that can impact outcomes, such as greater physical activity, treatment type (i.e., bone morrow transplant, chemotherapy) or age at diagnosis (Barnett et al., 2016). AYAs in general reported significantly lower HRQOL compared to those diagnosed at younger ages, leukaemia or sarcoma survivors, or healthy controls (Barnett et al., 2016).

As mentioned shortly, the field of research has taken interest in investigating whether different cancer diagnoses or treatment modalities (e.g. chemotherapy, radiation, surgery), are associated with certain outcomes. A review of studies on psychosocial late effects of childhood cancer, reported that survivors of haematological childhood cancers and solid tumours achieved education, employment, and marriage at levels similar to peers (Lund et al., 2011). CNS tumour survivors on the other hand, were psychosocially affected in almost all aspects (Lund et al., 2011). Results from the CCSS generally identify brain tumour survivors as a particular vulnerable group, whose members report more psychological distress, fatigue, cognitive problems and diminished life satisfaction (Zeltzer et al., 2009). Cranial radiation therapy (CRT) is associated with negative psychosocial outcomes such as unemployment, repeating school grade, not entering college, and poor HRQOL (Lund et al., 2011; Zeltzer et al., 2008, 2009). A combination of chemo-and radiation therapy (Blaauwbroek et al., 2007), diagnosis of haematological disorder or haematopoietic stem cell transplantation (Tremolada et al., 2016), bone tumour diagnosis or brain tumour diagnosis (Reulen et al., 2007), are all found to be risk factors for poor HRQOL. Some evidence claims chemotherapy have little effect on psychosocial outcome (Lund et al., 2011), other evidence claims chemotherapy to be associated with long-term effects in cognitive functions (Kanellopoulos et al., 2016). 7-40 years after treatment, Norwegian ALL survivors treated with chemotherapy only, showed significant deficit on a group level in processing speed, executive functions, and working memory compared to peers. General intellectual ability did not significantly differ from peers (Kanellopoulos et al., 2016).

In accordance with results from CCSS, a Norwegian study of long-term survivors of childhood acute lymphoblastic leukaemia (ALL) and lymphoma found 32% of survivors reporting poor HRQL versus 19 % in norms (Kanellopoulos, Hamre, Dahl, Fosså, & Ruud, 2013). No significant associations between higher treatment burden (radiotherapy, high-dose anthracyclines, and relapse) and poor HRQOL was found. Neither did they observe significant associations between type of cancer and poor HRQOL (Kanellopoulos et al., 2013). Psychosocial, lifestyle-and health-related variables, but not type of malignancy, treatment factors or socio-demographic factors were clinically significantly associated with poor quality of life. Levels of fatigue, anxiety and depression, as well as obesity and insomnia were significantly associated with poor HRQOL (Kanellopoulos et al., 2013). Others investigating impact of ALL have concluded that children in remission from ALL on average shows significantly more problems regarding meatal health and psychosocial adjustment as reported by parents and compared to healthy controls (Reinfjell, Lofstad, Nordahl, Vikan, & Diseth, 2009).

European studies tend to show weaker relations between somatic and psychosocial problems than Canadian and US studies, and this is hypothesized to be explained by cultural and national differences in health care and rehabilitation, in addition to differences in study design (Lund et al., 2011). Some evidence claims survivors in Europe may attain higher education than the background population, and that CNS tumour survivors reach compulsory levels of schooling at a near normal level, although the burdens of disease and treatment seem to be similar in Europe and North America (Koch, Kejs, Engholm, Johansen, & Schmiegelow, 2004; Lund et al., 2011). On the other hand, later research on Norwegian cancer survivors diagnosed in young age, claims survivors have an increased risk of being economically dependent and unemployed (Gunnes et al., 2016).

In sum, perceptions of illness, age, gender, types of treatments and diagnosis can affect psychological distress and HRQOL of cancer survivors. Survivors diagnosed during adolescence may be a particularly vulnerable group due to the rapid development both physically and emotionally in this phase. As demonstrated above, literature on psychosocial outcomes of childhood-, adolescent- and young adult cancer survivors yields varied, and sometimes contradictory results. The inconsistency in outcomes can be caused by small sample sizes, varied outcome measures used across studies, and selection of population norms for the comparison group (Zeltzer et al., 2009). Subgroups of siblings, as used in CCSS, may have their own set of psychological effects, but are similar to cancer survivors in ethnicity, culture, community, socioeconomic status, genetics and family environment (Zeltzer et al., 2009). Among other things, the studies mentioned above differs from each other regarding control groups, sample size, age and diagnosis of survivors, research design, and in outcome measures. But a common feature between the studies is the desire to predict, identify and describe the psychosocial effects of cancer.

Despite the special circumstances of AYAs, little research attention has been given to survivors of cancer in adolescence and young adulthood (Abrams et al., 2007; Bleyer et al., 2006; Smith et al., 2013), and the majority of past research has focused on survivors of childhood cancers (Barnett et al., 2016). There is only one known 10-year follow up regarding HRQOL for survivors diagnosed during adolescence (Ander et al., 2015). Relatively few empirical studies examine the effect of cancer on unique aspects of young adulthood such as treatment outcomes and physical symptoms, psychosocial adjustment, coping and quality of life issues (Zebrack, 2011; Zebrack, Mills, & Weitzman, 2007). There are several reasons for the limited data on psychological distress and HRQOL of AYA survivors (Mertens & Marchak, 2015). First, because of limited number of these survivors, research often combines children and adolescents, or adolescents and adults, into a single research sample (Mertens & Marchak, 2015). More recent data has mostly focused on the mental health status of these survivors once they become adults. Further, due to diversity in the survivor population regarding diagnosis, treatment, and age at diagnosis, studies often generate disparate findings (Mertens & Marchak, 2015). Due to the above-mentioned challenges, and to ensure covering of the most central issues, it has been chosen to include articles regarding both childhood, adolescent and young adult cancer survivors when working on this thesis.

To provide high quality health care services to cancer survivors, it is essential to broaden the knowledge of long term effects of cancer during adolescence or young adulthood. Our study contributes to this by investigating a population of cancer survivors who have been given little research attention earlier (Barnett et al., 2016; Bleyer et al., 2006). The sample size of this study strengthens its generalizability to the Scandinavian population, and enables analysis of sub-groups of survivors. To the best of my knowledge, there are no earlier studies investigating these research questions in a Norwegian population this age group.

Aims and hypotheses

The aim of this study is to examine the late effects of cancer survival on self-reported health-related quality of life (HRQOL) and psychological distress, and its association to treatment modalities and demographic factors. More specifically, the study first aims to investigate whether cancer survivors and controls differ in levels of HRQOL and psychological distress. Secondly, to investigate possible gender differences in these constructs. Thirdly, to investigate differences in symptoms of psychological distress (scores above cut-off) between survivors and controls. Fourth, to investigate differences in HRQOL and distress related to treatment modalities for survivors. Finally, to investigate whether treatment modalities and demographic factors predict HRQOL and distress for cancer survivors.

Based on the somewhat inconsistent literature presented above, it is hypothesized that survivors rate themselves with better or just as good HRQOL as controls, but with somewhat poorer physical health and higher levels of distress. Further, it is expected that female survivors will have lower HRQOL and higher distress compared to female controls. Regarding symptoms of distress, it is expected that survivors will be more probable than controls to score above cut-off for distress. It is expected to find differences in relation to treatment modalities, and to find age and gender (female) as significant predictors for HRQOL and distress.

Methods

Participants

Participants were recruited through the Cancer Registry of Norway (CRN). A total of *n*=536 survivors were invited to participate in the study, of which *n*=230 equal to a response rate of 42.9% participated. 52,6 % (*n*= 121) of survivors were females and 47,4% (*n* = 109) males. Mean age survivors were 26,9 ±3,6 years, ranging from 18 to 32 years. Of these, a majority (*n*=129) were older than or equal to 27 years of age. Consequently, fewer (*n*=99) were younger than 27 years old. 2 participants did not report age. The population of cancer survivors had a relatively high level of education (table 1), making students a suitable control group. Control group participants (*n*=335) consisted of first through third year bachelor and clinical program psychology students, and fourth grade master degree teacher students. Control group participants were recruited through lectures at the Norwegian University of Science and Technology (NTNU), and were excluded by earlier or ongoing illness and age. To better match mean age in the survivor group, girls younger than or equal to the age of 22 were excluded, remaining girls age 23 and older. Thus, there remained *n*=223 control group participants with a mean age of 24.9 ± 2.1 years, ranging from 20 to 32 years. 35.0% (*n*= 78) of control group participants were male and 65.0% (*n* =145) female.

Procedures

Except one, all hospitals in Norway participated in the study. Each hospital appointed a person from the medical staff, a doctor or nurse, at the cancer department to keep contact with the project. CRN sent a record of relevant patients to the contact persons, with a request to indicate which patients should be included or excluded from the study. The following inclusion criteria were applied: Birth cohort 1980-1992 or survivors age 10 years or older at time of diagnosis, all cancer diagnoses included in statistics from *Cancer in Norway* (Cancer Registry of Norway, 2015) were included, it should be the first diagnosis per person, and only survivors who were alive were included. Benign CNS tumours were excluded. Possible mistakes in the records were also marked (e.g. patients did not have cancer, has not been a patient at this hospital). Patient records were then returned to Cancer Registry of Norway, who wrote address tags on postage paid envelopes already prepared by SINTEF. The envelopes contained all information necessary to ask the patients if they would participate in the study, the questionnaire, and a letter with the name of the project manager and person of contact in the particular hospital. Respondents were informed that the Cancer Registry of

Norway was used to identify them. CRN posted the envelopes addressed to respondents, who in turn sent the questionnaires to SINTEF. One round of reminders was planned.

Control group: To collect control group data, permission from REK (Regional Committees for Medical and Health Research Ethics) was obtained, see appendix A. Students from Norwegian University of Science and Technology were approached during lectures and invited to participate by completing a questionnaire. After participants had given their consent to participate and completed the questionnaire, questionnaires were scanned and anonymised data exported to SPSS for statistical analyses. The control group data file was merged with the file from SINTEF.

Measures

Survivors' questionnaires were more comprehensive than for controls, containing items regarding cancer and earlier treatment. Questionnaires are found in appendix B and C. The questionnaires and selected items were based on a focus group interview conducted in 2009. 10 cancer survivors, with mean age 25.9 (range 18-42) years, all from the youth group of the Norwegian Cancer Society participated in the interview conducted by SINTEF.

Socio demographic questions included items regarding gender, age, living arrangements, economic situation (a lower value indicates better perceived economy), education, main occupation and parent's education. Stressful life events were measured by 5 items from EASQ (Early Adolescence Stress Questionnaire) (Sund, Larsson, & Wichstrøm, 2003), where respondents reported whether they had experienced 4 serious life-events (4 questions regarding loss and 1 question regarding life threat) the past 12 months, and whether the respondent had any reactions to these events for the past 7 days. For the control group, one question regarding severe illness was added. Treatment modalities were self-reported by survivors, indicating which of 7 different treatments they had received. Other illness was also self-reported by survivors. In addition to the already mentioned items and measures, and other measures not relevant for this paper, the questionnaire completed by controls and survivors consisted of the following earlier validated measures:

Pediatric Quality of Live inventory (PedsQL™) 4.0 originally developed by Varni, Seid, and Rode (1999), was utilized as a measure of health-related quality of life, and covers central factors in the HRQOL concept; physical, emotional, social and school/education/occupational functioning. A version of PedsQL is earlier evaluated for measuring psychosocial health of AYA cancer survivors (Clinton-McHarg, Carey, Sanson-

Fisher, Shakeshaft, & Rainbird, 2010). The PedsQL is translated and validated for Norwegian conditions (Reinfjell, Diseth, Veenstra, & Vikan, 2006). In our study a young adult version (18-25 years), translated and linguistically validated in 2011, was used. The validation of the adolescent version, practically identical to the young adult version, showed good psychometric properties (Reinfjell et al., 2006). Varni and Limbers (2009) tested the PedsQL™ Young Adult Version on students ages 18-25 and found excellent reliability for the total scale score, and acceptable reliability for subscale scores. Further, PedsQL distinguished between healthy young adults and young adults with chronic health conditions (Varni & Limbers, 2009).

In PedsQL, participants are asked to rate how much a problem each item has been during the past month. A five point Likert response scale is utilized (0=never a problem; 1= almost never a problem; 2= sometimes a problem; 3 = often a problem; 4 almost always a problem) (Varni & Limbers, 2009). For items in PedsQL, sub-grouping the questions enables assessment of the four HRQOL-domains: Physical functioning, emotional functioning, social functioning and school functioning. In addition, a physical health summary score (eight items), which equals the physical functioning scale (Varni & Limbers, 2009) and a psychosocial health summary score (15 items) was computed. For the psychosocial health summary scale, mean is computed as the sum of items divided by the number of items answered in the Emotional, Social and Work/School Functioning Scales. Items were reverse-scored and linearly transformed on a scale ranging from 0-100, in which higher scores indicate better HRQOL. Scale scores are computed as the sum of the items divided by the number of items answered (Varni & Limbers, 2009). In line with the research questions outlined in the introduction, it was chosen to focus attention to physical functioning/physical health scale, psychosocial scale and total scale. Scale internal consistency was measured by Cronbach's alpha, varying between α=.80 and α=.92 for survivors and α=.75 and α=82 for controls on subscales of PedsQL, which is considered satisfactory (Reinfjell et al., 2006). For main scale PedsQL Cronbach's α=.94 for survivors and α=.90 for controls.

The Hopkins Symptom Checklist-10 (HSCL-10) measures psychological distress and is shown to be a valid measure of detecting depressed young people in primary health care (Haavet, Sirpal, Haugen, & Christensen, 2010). The HSCL-10 covers depressive and anxiety symptoms with five items each. Each items is rated on a scale from 1 (not at all) to 4 (extremely) (Lien, Haavet, & Dalgard, 2010). Average item score was calculated by dividing the total score on number of items answered. Records with three or more missing items were excluded. Cut-off point for psychological distress was set to 1,85 as recommended by others (Strand, Dalgard, Tambs, & Rognerud, 2003). A higher value on HSCL indicates higher level of reported distress. On HSCL Cronbach's α= .92 for cancer survivors and α=.88 for controls, values equal or higher than demonstrated by Strand et al. (2003).

Statistical analyses

IBM SPSS (Statistical Package for the Social Sciences (version 23)) was utilized to conduct statistical analyses. Two-sided *p*-values <.05 were considered statistically significant, and 95% confidence intervals (CI) reported where relevant. Regarding significance level and multiple comparisons, Bonferroni correction was not applied because of the risk of over-correcting for type I errors and the increase in likelihood of type II errors (Perneger, 1998). Cohen's *d* and odds-ratio were used to assess effect-size when suitable. Regarding Cohen's *d*; were homoscedasticity could not be assumed the *s* (sample std. deviation) of the control group was used to calculate effect size, as recommended (Field, 2013; Grissom & Kim, 2014). Interpretation of *d* was also inspired by these (Field, 2013; Grissom & Kim, 2014). Note that *d* used in this article therefore reflects the relative difference of the means compared to the standard deviation of the control group. For one way analysis of variance (ANOVA) conducted where homogeneity in variance could not be assumed, Welch's *F*, due to its power (Field, 2013), was used for interpreting significance.

Descriptive analyses were conducted. Independent samples t-test and Pearson's chi-square test in crosstabs were used to estimate sociodemographic differences between survivors and controls. Cronbach's alpha (α) was used to assess internal consistency of the questionnaires.

The first research question was investigated using independent samples t-test to assess differences between mean scores on PedsQL and subscales and HSCL for survivors and controls. The second research question was investigated by independent samples t-test for gender differences. Pearson's chi square was utilized to assess association between gender and scores above cut-off for HSCL. Third research question: Pearson's chi square was utilized to look at association between group membership and scores above cut-off on HSCL. Independent samples t-test was conducted to look at differences in PedsQL between survivors and controls scoring above cut-off for distress. Fourth research question was investigated using independent samples t-test and ANOVA. For the fifth research question, multiple regression analyses were conducted using enter/forced entry as method.

Results

Characteristics of participants

As depicted in table 1, independent samples t-test and Pearson's chi square resulted in significant differences (*p*<.05) on all demographic variables**.** Cancer survivors reported better perceived economic situation than controls, and controls reported higher levels of education for both parents (table 1). 46.1 % of survivors and 42.3% of controls reported one or more stressful life event the past year, 14.9% of survivors and 15.3% of controls reported moderate or high levels of reactions to this the past 7 days.

For survivors, average years since diagnosis was 7 years (*SD*=4.4), and time since diagnosis ranged from 0 to 21 years ago. Mean age at diagnosis were 19.8 (*SD*=5.4) years. The majority of survivors were diagnosed with lymphomas, and the majority had been treated with chemotherapy and/or surgery. At point of assessment, 57.0% of survivors reported being recovered from cancer and 31.3% had finished treatment. 15 survivors reported having had more than one type of cancer, and none reported having had more than two types of cancer. 15.7% of survivors reported a chronic illness, e.g. allergy, diabetes, epilepsy or migraine, and 15.7% reported fatigue or depression (as considered by the survivor itself) at point of assessment. 22.2% reported side-effects, complications or injuries from treatment such as sterility, pains, dyspepsia/digestive troubles or hypothyroidism, at point of assessment. Further, 11.3% reported lasting injuries from cancer or treatment at point of assessment. Additional characteristics of the survivor group is depicted in table 2.

Table 1: Demographic characteristics and differences between survivors and controls

Characteristic		Survivors (*n*=230)		Controls (*n*=223)			
		Frequency	%	Frequency	%	*t* or χ^2	*p*
Gender	Female	121	52.6	145	65.0	χ^2 (1)=7.20	.007
	Male	109	47.4	78	35.0		
Age;	mean (*SD*)	26.90 (3.64)		24.91 (2.05)		*t*(360) = 7.16	.000
Educational level	Not completed compulsory education	1	0.4	0	0.0	*t*(390)=-7.34	.000
	Completed compulsory education	17	7.5	0	0.0		
	Upper secondary school (11-13)	76	33.3	18	8.1		
	College/university < 4 years	68	29.8	101	45.5		
	College/university > 4 years	62	27.2	102	45.9		
	Other	4	1.8	1	0.5		
Main occupation	Working full time	113	49.3	0	0.0	χ^2 (8)=232,86	.000
	Working part time	22	9.6	24	10.8		
	Student	55	24.0	198	89.2		
	Sick leave	6	2.6	0	0.0		
	Social security benefit	25	10.8	0	0.0		
	Other	8	3.5	0	0.0		
Living together with	Both parents	18	7.8	4	1.8	χ^2 (6)=103,74	.000
	One parent	10	4.3	7	3.1		
	Living alone	56	24.4	41	18.4		
	Spouse	68	29.6	82	36.8		
	Spouse and children	53	23.0	4	1.8		
	Alone with children	8	3.5	0	0		
	Other	15	6.5	76	34.1		
Perceived economic situation	Very much above average	8	3.5	1	0.5	*t*(444)= -4,36	.000
	Above average	45	20.0	24	10.9		
	average	112	49.8	102	46.2		
	Under average	47	20.9	72	32.6		
	Very much below average	13	5.8	22	10.0		
Children	No	173	75.2	218	97.8	χ^2 (1)=48,70	.000
	Yes	57	24.8	5	2.2		
Mother's educational level	Not completed compulsory education	2	0.9	1	0.4	*t*(420)=-6.12	.000
	Completed compulsory education	30	13.2	9	4.0		
	Upper secondary to 12th grade	100	439	40	17.9		
	College/university	84	36.8	168	75.3		
	Other	9	3.9	2	0.9		
	Don't know	3	1.3	3	1.3		
Father's educational level	Not completed compulsory education	2	0.9	2	0.9	*t*(439)=-2,47	.014
	Completed compulsory education	33	14.5	18	8.1		
	Upper secondary up to 12th grade	86	37.7	57	25.8		
	College/university	91	39.9	136	61.5		
	Other	9	3.9	4	1.8		
	Don't know	7	3.1	4	1.8		

Note: All *p*-values <.05

Table 2: Disease characteristics cancer survivors (*n*=230)

		Frequency	%
Leukaemia		25	10.9
Brain tumour		21	9.1
Spinal cord cancer		1	0.4
Testicular cancer		48	20.9
Ovarian cancer		4	1.7
Skin cancer/melanomas		9	3.9
Lymphoma		70	30.4
Cervical cancer		8	3.5
Breast cancer		7	3.0
Other		51	22.2
Not received medical treatment		6	2.6
Waiting for medical treatment		0	0.0
Surgery or surgical procedure		146	63.5
Chemotherapy		161	70.0
Radiation		80	34.8
Hormonal treatment		20	8.7
Other treatment prescribed by doctor		15	6.5
Other treatments		28	12.2
Years since diagnosis	0-3	51	23.3
	4-5	52	23.7
	6-7	38	17.4
	8-9	23	10.5
	over 10	55	25.1
Mean years since diagnosis (*SD*)		7 (4.4)	

Survivors vs controls

Independent samples t-test comparing survivors and controls means on PedsQL and HSCL revealed no significant differences on total scale PedsQL $t(379)=-1.349$, $p=.178$, or HSCL $t(423)=1.053$, $p=.293$. On physical functioning, mean score for survivors was lower ($M=79.35$, $SD=23.71$) than for controls ($M=83.74$, $SD=14{,}18$). This difference -4.4, 95% CI [-7.99, -0.78] was significant $t(374)=-2.39$, $p=.017$, and represent a small effect $d=-0.31$. (table 3).

Gender

Investigating group differences between female survivors and controls using independent samples t-test (equal variances not assumed) female cancer survivors scored significantly lower on PedsQL and HSCL than female controls. There were significant differences on: PedsQL physical functioning/health $t(186)=-2.71$, $p=.007$, total scale $t(188)=-2.47$, $p=.014$, total psychosocial scale $t(193)=-2.08$, $p=.039$, and also a significant difference on HSCL $t(219)=2.33$, $p=.021$.

Using Pearson's Chi square to investigate female participants scoring above or below cut-off for distress on HSCL, there was a significant association between being in the survivor or control group and whether or not the respondents scored above or below cut-off for distress on HSCL, $\chi^2(1)=12.170$, $p=.001$. 42.9% ($n=51$) of female cancer survivors ($n=119$) scored above cut-off for distress, while 22.8 % ($n=33$) of female controls ($n=145$) scored above cut-off for distress. Based on odds ratio, the odds of scoring above cut-off were 2.55 times higher for female cancer survivors than for controls, equal to $d=0.52$, considered a medium effect.

For male survivors and controls, independent samples t-test resulted in no significant differences between means on PedsQL or HSCL, all $ps>.05$. Pearson's chi square test did not reveal any significant association between type of group (cancer or controls) and whether or not respondents scored above or below cut-off for distress $\chi^2(1)=.104$, $p=.834$. Actually, 13.9% of male cancer survivors, and 15.6% of male controls scored above cut-off.

Cut-off HSCL

As indicated by Pearson's chi square there was a significant association between belonging to the survivor group or control group and whether one scored above or below cut-off for distress on HSCL $\chi^2(1)=4.675$, $p=.037$. In other words: there was a significant difference in the pattern of responses. Based on the odds-ratio, the odds of scoring above cut-off were 1.61 higher for cancer survivors than for controls, equivalent to a $d=0.26$, a small effect size.

29,1% (*n* =66) of survivors (*n*=227) reported symptoms at a level consistent with distress (scores above cut-off), while 20,3% (*n* =45) of controls (n=222) did the same. 4 participants missing from analysis.

Regarding the respondents scoring above cut-off on HSCL, there were significant differences between survivors and controls on PedsQL, as illustrated by independent samples t-test: Physical functioning $t(107.74)=-2.86$, $p=.005$, total scale $t(107)=-3.12$, $p=.002$ and psychosocial functioning $t(107)=-2.98$, $p=.004$. There was no difference on mean level HSCL $t(109)=1.43$, $p=.156$ (table 3). Effect sizes can be considered medium to large for PedsQL scales.

Table 3: Means and *p*-values for PedsQL and HSCL from independent samples t-test and Pearson's Chi square

		Survivors vs controls					Female					Above cut-off				
Scale		Survivors	Controls	*t*	*p*	*d*	Survivors	Controls	*t*	*p*	*d*	Survivors	Controls	*t*	*p*	*d*
Physical health	N	229	223				120	145				65	45			
	M	79.35	83.74	-2.39	.017*	-0.31	75.06	82.01	-2.71	.007**	-0.47	61.11	71.42	-2.86	.005**	-0.63
	(*SD*)	(23.71)	(14.18)				(24.68)	(14.68)				(25.05)	(16.43)			
Total PedsQL	N	228	223				119	145				64	45			
	M	78.40	80.32	-1.35	.178	-0.17	74.10	78.95	-2.47	.014*	-0.42	60.08	68.38	-3.12	.002**	-0.69
	(*SD*)	(18.21)	(11.20)				(18.69)	(11.47)				(14.69)	(12.05)			
Psychosocial health summary	N	228	223				119	145				64	45			
	M	77.77	78.50	-0.53	.598	-0.06	73.38	77.32	-2.08	.039*	-0.34	59.27	66.22	-2.98	.004**	-0.61
	(*SD*)	(17.68)	(11.32)				(17.87)	(11.48)				(12.44)	(11.35)			
HSCL	N	227	222				119	145				66	45			
	M	1.59	1.53	1.05	.293	0.11	1.76	1.58	2.33	.021*	0.35	2.42	2.29	1.43	.156	0.28
	(*SD*)	(0.64)	(0.49)				(0.68)	(0.52)				(0.51)	(0.46)			
HSCL Cut-off	N	227	222				119	145								
	M				.037*			.001**								
	(SD)				(chi)			(chi)								

Note: *= *p*<.05, **=*p*<.01

Table 4: Means and *p*-values from independent samples t-test for selected subscales and treatment modalities (ANOVA for number of treatment modalities)

		Surgery					Radiation					Chemotherapy					Number of treatment modalities						
Scale		Yes	No	*t*	*p*	*d*	Yes	No	*t*	*P*	*D*	Yes	No	*t*	*p*	*d*	One	two	>2	*F*	*p*	η^2	*d*
Physical	N	146	83				80	149				161	68				86	87	56				
health	*M*	79.26	79.51	0.08	.937	-0.01	74.77	81.81	2.10	.038*	-0.31	77.28	84.27	2.21	.028*	-0.34	83.42	81.17	70.27	5.22	.007**	0.049	0.45
	(*SD*)	(23.12)	(24.87)				(25.08)	(22.65)				(24.71)	(20.50)				(21.73)	(23.10)	(25.53)		(welch)		
Total	N	146	82				80	148				160	68				86	86	56				
PedsQL	*M*	78.50	78.21	-0.11	.910	0.01	74.91	80.29	2.01	.046*	-0.33	77.12	81.41	1.63	.104	-0.26	81.01	80.59	71.03	6.39	.002**	0.050	0.46
	(*SD*)	(17.01)	(20.28)				(20.67)	(16.50)				(18.74)	(16.63)				(17.01)	(17.91)	(18.76)				
Psycho-	N	146	82				80	148				160	68				86	86	56				
social health	*M*	78.07	77.23	-0.33	.742	0.04	74.97	79.28	1.64	.103	-0.27	76.84	79.92	1.20	.230	-0.18	79.75	79.93	71.40	4.98	.008**	0.042	0.42
summary	(*SD*)	(16.40)	(19.86)				(20.32)	(15.95)				(18.02)	(16.77)				(16.79)	(17.78)	(17.64)				
HSCL	N	145	82				79	148				159	68				86	85	56				
distress	*M*	1.55	1.66	1.24	.217	-0.16	1.67	1.55	-1.22	.221	0.22	1.63	1.50	-1.41	.161	0.80	1.52	1.54	1.78	3.36	.036*	0.029	0.35
	(*SD*)	(0.60)	(0.71)				(0.76)	(0.56)				(0.66)	(0.56)				(0.55)	(0.65)	(0.70)				

Note: *= *p*<.05, **=*p*<.01 for t-test/ANOVA

Treatment modality

Differences in PedsQL and HSCL related to different types of treatments were investigated using independent samples t-test and ANOVA. Cohens *d* were calculated and η^2 transformed into *d* for comparative purposes. As depicted in table 4, there were no significant differences on PedsQL total, psychosocial health scale or HSCL for survivors who had undergone surgery or not. Survivors who had undergone radiation scored significantly lower on physical health $t(148)=2.10$, $p=.038$ and PedsQL total scale $t(134)=2.01$, $p=.046$. Survivors who had undergone chemotherapy scored significantly lower $t(151)=2.21$, $p=0.28$ on physical functioning/health. Effect sizes can be considered small to medium. Looking at numbers of treatment modalities, there were significant differences between having undergone one, two or more than two treatment modalities, on physical $F(2,133)=5.22$, $p=.007$, total $F(2,225)=6.39$, $p=.002$ and psychosocial PedsQL $F(2,225)=4.98$, $p=.008$, as well as HSCL $F(2,224)=3.36$, $p=.036$. Effect sizes were considered medium.

Regression: Predicting PedsQL and HSCL

Due to small significant results and minor contributions to the model (multicollinearity problems) it was chosen to exclude chemotherapy, surgery and radiation from the regression analysis, and to model the relationship between demographic variables and numbers of self-reported treatment modalities as predictors and PedsQL total scale as outcome.

Before running the multiple regression analysis, assumptions of collinearity were investigated. For PedsQL total scale and predictors, no correlations had an absolute value above $r=.325$. Correlations varied between $r=-.315$ and $r=.325$. Correlations were significant at $p=.05$ level or lower, with exceptions from this being correlations between the following: Age and PedsQL total scale ($p=.166$), gender and age ($p=.095$), gender and education ($p=.340$), age and number of treatment modalities ($p=.092$), education and number of treatment modalities ($p=.352$), number of treatment modalities and perceived economic situation ($p=.330$). In the regression analysis, VIF (variance inflation factor) for all values were below 10 and tolerance statistic above 0.2 for all values, which allows one to conclude that there are no problems associated with collinearity in the data (Field, 2013).

As depicted in table 5, a multiple regression analysis with demographic variables; gender, age, education, economic situation, and number of treatment modalities ranging from

1 to 5 as predictors, significantly predicted PedsQL total scale *F*(5,218)=15.224, $p<.001$, further $R^2=.263$, *SE*=15.948 $p<.000$.

Using the same rationale as above for HSCL and predictors, no correlations had an absolute value above $r=.287$. Correlations varied between $r=-.264$ and $r=.287$. Correlations were significant at $p=.05$ level or lower with exceptions from this being the correlation between the following: Age and HSCL ($p=.076$), gender and age ($p=.079$), education and gender ($p=.438$), age and number of treatment modalities ($p=.083$), education and number of treatment modalities ($p=.405$), perceived economic situation and number of treatment modalities ($p=.329$). In the regression analysis, VIF for all values were below 10 and tolerance statistic above 0.2 for all values, which indicates that there are no problems associated with collinearity in the data (Field, 2013).

As illustrated by table 6, a multiple regression analysis with demographic variables; gender, age, education, perceived economic situation, and numbers of treatment modalities ranging from 1 to 5 as predictors, significantly predicted variance in outcome HSCL *F*(5,217)=10.09, $p<.001$, further $R^2=.192$, *SE*=.579, $p=.018$.

Table 5: Multiple regression analysis predicting PedsQL total scale (n=219)

	U.std. Coefficients		Std. Coefficients		
Predictor	B (95% CI)	Std. Error	Beta	t	*p*
Gender	6.525 (2.123, 10.927)	2.233	.178	2.922	.004**
Age	-.406 (-1.020, .207)	.311	-.080	-1.306	.193
Education	5.587 (3.322, 7.853)	1.149	.299	4.861	.000**
Perceived economic situation	-4.914 (-7.401, -2.426)	1.262	-.238	-3.894	.000**
Number of treatment modalities	-3.837 (-5.973, -1.701)	1.084	-.213	-3.541	.000**

Note: Dependent Variable: PedsQL total scale. R^2=.057 for Step 1, R^2=.059 Step 2, R^2=.169 Step 3, R^2=.220 Step 4, R^2=.263 step 5 (all ps <.001, except model 2 (p=.498)).
*= p<.05, ** = p<.01

Table 6: Multiple regression analysis predicting HSCL (n=218)

	U.std. Coefficients		Std. Coefficients		
Predictor	B (95% CI)	Std. Error	Beta	t	*p*
Gender	-.263 (-.422, -.103)	.081	-.206	-3.236	.001**
Age	.003 (-.019, .025)	.011	.017	.271	.787
Education	-.127 (-.208, -.046)	.041	-.199	-3.105	.002**
Perceived economic situatuion	.159 (.067, .250)	.046	.219	3.431	.001**
Number of treatment modalities	.094 (.017, .172)	.039	.151	2.392	.018*

Note: Dependent Variable: HSCL. R^2=.069, p<.001for Step 1, R^2=.075, p=.270 step 2, R^2=.126, p<.001 step 3, R^2=.170, p=.001 step 4, R^2=.192 , p=.018 for step 5.
*=p<.05, ** = p<.01

Discussion

The current inquiry aimed to investigate late effects of cancer survival on self-reported HRQOL and psychological distress, and its association to treatment modalities and demographic factors. In sum, survivors report HRQOL and distress at a level consistent with controls, but demonstrates poorer self-reported physical functioning. As hypothesized, survivors in general and female survivors specifically are more probable than controls to report symptoms of distress. Female survivors report poorer HRQOL and higher levels of distress than female controls. Most survivors do not report being distressed, but those who report being distressed also reports significantly poorer HRQOL than controls. For survivors, some differences in HRQOL and distress related to types of treatment were found, in addition to significant differences in levels of HRQOL and distress over numbers of self-reported treatment modalities. For cancer survivors, demographic variables and numbers of undergone self-reported treatment modalities predict distress and HRQOL.

Given both intensity and duration of cancer treatment, finding similar levels on PedsQL total, PedsQL psychosocial and HSCL for survivors and controls are somewhat counterintuitive, but may have several explanations. One explanation may be that survivors consciously or unconsciously report fewer negative outcomes because of adaptive repression or denial, and thus may be unable to distinguish between genuine mental health and the façade created by psychological defences (Shedler, Mayman, & Manis, 1993). Another explanation of the possible discrepancy between true level of psychosocial problems and self-reported HRQOL may be response shift. The phenomenon of response shift is described as altered internal standards, values or conceptualization of quality of life, resulting from changes in health, whereby survivors expect their quality of life to be lower, thus making their goals easier to reach (Schwartz & Sprangers, 1999). This could be a consequence of significantly greater psychological distress and fewer positive health beliefs among survivors diagnosed as adolescents, and possibly in young adulthood too, than those diagnosed earlier in life (Kazak et al., 2010). Alternatively, findings may represent true positive cognitive changes due to the survivors life-threatening experience, known as positive growth (Barakat et al., 2006). Adolescents are more likely to understand and appreciate the support and encouragement they receive during treatment and to understand that they have shown strength in face of treatment related adversities, thus resulting in more positive outcomes in form of positive growth (Barakat et al., 2006). Our findings regarding levels of HRQOL and psychological distress could thus support earlier research regarding effects of positive growth and resilience (Barakat et al., 2006; Zebrack & Chesler, 2002; Zebrack & Landier, 2011), suggesting that these effects could also manifest itself for survivors diagnosed during adolescence and young adulthood. Alternatively, the results can also be an effect of low scores in the control group, which is further elaborated on in the limitations section.

Demonstrating no significant differences between survivors and controls regarding psychosocial functioning, our study complements earlier findings where survivors report higher social functioning, but less social support, and this is seen in relation to resilience (Tremolada et al., 2016). At the same time, we find female survivors to score significantly lower than female controls on psychosocial health. Actually, female survivors score lower on all measures; physical health, total HRQOL, psychosocial health and higher on distress. Without drawing conclusions about causal relations for this difference, one can note that earlier research identifies female sex as associated with an increased risk of impairment in several health status domains (Blaauwbroek et al., 2007; Chan et al., 2014; Hudson et al., 2015; Michel et al., 2010; Reulen et al., 2007). It has been suggested that these findings may result from greater vulnerability to cancer treatment-related toxicities among women (Armstrong et al., 2007; Hudson et al., 2015), or may simply reflect similar trends in the general population (Hudson et al., 2015). This underscores the importance of looking at sub-groups when investigating cancer survivors, and to be aware of the possible long standing struggles of these groups (Brinkman et al., 2013). After all, being female is a pretty constant quality.

Depression is a serious mental illness associated with impaired HRQOL and psychosocial functioning (Lund et al., 2015). In line with what hypothesized, our findings demonstrate a significant difference among survivors and controls in the probability of scoring above cut-off for distress. A higher proportion of survivors than controls scored above cut-off for distress, and the odds of scoring above cut-off were 1.61 times higher for cancer survivors than for controls. This may seem counter intuitive given the non-significant difference between the two groups in means of distress, but can be explained by a higher variance in the survivor group. 29,1% of survivors and 20,3% of controls reported symptoms at a level consistent with psychological distress. The proportion scoring above cut-off is relatively high compared to the population sample of Strand et al. (2003), where only 11,4% scored above cut-off. Bearing in mind the relatively high cut-off for distress used in our study, compared to others using lower cut-off (Haavet et al., 2010), it is especially interesting that such a high percentage of the investigated population scores above cut-off. This implies that our population, both controls and survivors, differs from the general population regarding levels of psychological distress. It can also be seen in relation to higher levels of antidepressant use among cancer survivors (Lund et al., 2015) and higher levels of depression among students (Nedregård & Olsen, 2014). It indicates that a subgroup of survivors is more vulnerable, and struggle more with symptoms of depression and anxiety. One can also see this finding in relation to Brinkman et al. (2013) who found that subgroups of childhood survivors were at risk of persistent distress over the course of survivorship. The subgroups at risk were survivors with either persistently elevated distress or survivors with emerging distress symptoms over time (Brinkman et al., 2013). Consistent with earlier research and our hypotheses, female survivors score lower on HRQOL and higher on distress (Barnett et al., 2016; Bisegger et al., 2005; Lund et al., 2011; Tremolada et al., 2016; Zeltzer et al., 2009). Based on odds ratio, female survivors were more probable than survivors in general, and more probable than female controls to score above cut-off. The odds of scoring above cut-off were 2.55 times higher for female cancer survivors than for female controls. This is in accordance with Phillips-Salimi and Andrykowski (2013), who found that female survivors were four times more probable than controls to score above cut-off. This further emphasizes that females, as a group, are especially vulnerable.

For participants scoring above cut-off for distress, there were significant differences between survivors and controls on PedsQL physical, total and psychosocial scale, but no significant difference in means on above cut-off scores of HSCL. The medium effect sizes for the differences on PedsQL, but low effect size for the difference in HSCL (table 3) further underscores this finding. In other words, distressed cancer survivors are not necessarily *more* distressed than distressed controls, but distressed survivors report poorer HRQOL than distressed controls. One should be careful inferring causality from these finding, but they may imply that clinical symptoms of distress can affect HRQOL differently on a group level: Cancer survivors are more vulnerable for reduced HRQOL, and the control group maintains a stable HRQOL despite clinical symptoms of distress. Bearing in mind the co-occurring challenges for the survivor group; the cancer experience, treatment and late effects, and in addition to this an increased level of distress possibly caused by the aforementioned factors, a higher vulnerability for low HRQOL among distressed survivors is not a surprising finding, and complements earlier research (Brinkman et al., 2013; Hudson et al., 2015; Lund et al., 2015). Further, our findings imply that distressed survivors are more inhibited in their day to day routines than controls. It demonstrates the importance of addressing and measuring

HRQOL when working with cancer survivors, and to be aware of the more practical consequences of low HRQOL, especially among survivors who exhibit signs of distress. One can see these findings in relation to Ander et al., (2015) who found a decreasing level of HRQOL and an increasing level of symptoms of anxiety from four to 10 years after diagnosis, underscoring the importance of long-term follow up for survivors.

Finding survivors reporting poorer physical functioning is in line with earlier research on childhood survivors (Blaauwbroek et al., 2007; Chan et al., 2014; Reulen et al., 2007; Zeltzer et al., 2008, 2009) and research on AYA population diagnosed during adolescence (Barnett et al., 2016). AYA survivors are found to have poorer health behaviours, engage more in smoking, and to have less leisure-time physical activity as measured the past month (Barnett et al., 2016). This can be an explanation for the lowered physical health reported by survivors in our study. Besides, the high rate of chronic conditions and late-effects from cancer therapy among cancer survivors (Oeffinger et al., 2006), probably contributes to lowered levels of physical health. Chronic health conditions have also been associated with psychological outcomes (Zebrack et al., 2004; Zeltzer et al., 2009). 15.7 % of survivors in our study reported having a chronic condition at point of assessment, and 22.2 % reported lasting side-effects from cancer treatment. This is considerably less than reported by Oeffinger et al. (2006). With the relatively low rate of chronic conditions in mind, there is reason to question how much of lowered physical health is explained by chronic illness or other late effects, and how much can be explained by lack of health promoting behaviours. Other unknown factors could also contribute to the lowered physical health. Further research should look into predictors of lowered self-reported physical health, with the aim of investigating which predictors would be easier to manipulate, and thereby increase levels of physical health among survivors. There is probably a complex interplay between late effects from cancer and engagement in health promoting behaviours. For example are increasing distress symptoms found to be predicted by survivors' perception of worsening physical health over time (Brinkman et al., 2013). Because physical health and psychological functioning are closely related, it is important to address both when working with lowered perceived physical health among cancer survivors. In addition to the direct role of cancer diagnosis and specific treatments, earlier research emphasize the role of recovery, chronic health conditions, fatigue and sleep in impacting psychological functioning and adjustment in long-term survivors (Zeltzer et al., 2009). Follow-up care of survivors should also include secondary and tertiary prevention, e.g. strategies to promote tobacco cessation or avoidance, physical activity and proper weight management, and management of chronic disease (Oeffinger et al., 2006). This further emphasize the importance of targeting health promoting behaviours and addressing physical late effect of cancer when working with survivors.

In the field of research it is common to investigate if different types of diagnoses, and hence different kinds of treatments are associated with or can predict levels of HRQOL, distress or other psychosocial outcomes (Bisegger et al., 2005; Kanellopoulos et al., 2016; Lund et al., 2011; Tremolada et al., 2016). In accordance with the hypothesis, we found differences in HRQOL between survivors who had or had not received chemotherapy or radiation. This contrasts earlier research which does not identify survivors treated with chemotherapy, or intensity of chemotherapy, as a particularly vulnerable group (Kanellopoulos et al., 2013; Lund et al., 2011). On the other hand, others have found alkylating-agent exposure associated with adverse health status and anthracycline exposure associated with poor general health, activity limitations, cancer-related pain and cancer-related anxiety (Hudson et al., 2015). Few treatments other than cranial irradiation and intrathecal administration of chemotherapy have been identified as risk factors for mental late effects in studies within the CCSS (Lund et al., 2015, 2011; Zebrack et al., 2002). Others have not found specific treatments, combinations of therapy, or intensity of treatment to be associated with mental late effects or use of antidepressants (Deyell et al., 2013; Lund et al., 2015). In other words, cancer treatment with chemotherapy, radiation or surgery are not found to significantly impact the likelihood of antidepressant use (Deyell et al., 2013). This is in line with our findings of no differences in levels of psychological distress for the treatment modalities investigated. Further, our findings of significant differences in HRQOL and distress over numbers of treatment modalities can be seen in relation to findings emphasizing the combination of chemo-and radiation therapy as a risk factor for lower HRQOL (Blaauwbroek et al., 2007; Smith et al., 2013). However, our findings should be interpreted with caution, especially because of the small effect sizes for the different treatment modalities. Nevertheless, significant differences in HRQOL and distress over numbers of treatment modalities and significant results from regression analyses, gives reason to assume that an increase in number of treatment modalities is associated with lowered HRQOL and higher levels of distress.

Because of diversities and sample size in diagnoses in our dataset (table 2), it was chosen not to examine the effect of diagnoses on HRQOL and distress. Our findings pertaining to treatment modalities must be considered with cautiousness. Only self-reported on a general level, one cannot disregard the possibility that these results are hampered by confounding variables, inaccurate reporting or a result of interaction-effects. Even so, we gave it a try by investigating whether several types of treatments could predict levels of HRQOL and distress. Results obtained from the former research questions, in combination with literature as mentioned in the introduction, gave reason to model the relationship between demographic variables and treatment modality as predictors, and HRQOL or distress as outcome for cancer survivors (table 5 and 6). Our findings of predicting levels of HRQOL and distress from demographic variables and numbers of treatment modalities is by and large in accordance with Zeltzer et al. (2009). But age at time of assessment as a non-significant predictor does not support earlier research conducted on AYA survivors (Tremolada et al., 2016), where being older at time of assessment was identified as a risk for lower HRQOL. Hudson et al. (2015) also points to increasing age as a determinant of HRQOL among childhood cancer survivors. For our investigated population, survivors' age at time of assessment was not of significance for distress or HRQOL.

Results from regression analyses supports a conclusion of the following: Being lower educated, female, having lower perceived economy, and having undergone several treatment modalities are associated with lower levels of HRQOL and higher levels of distress. The models explain some of the variance in these two constructs. The significance of treatment modalities in our findings may contrast earlier findings (Kanellopoulos et al., 2013) regarding lack of significant associations between higher treatment burden and poor quality of life. But as mentioned earlier, it could support findings regarding combinations of therapy (Blaauwbroek et al., 2007). Finding numbers of treatment modalities predict HRQOL and distress does not necessarily contradict earlier findings of treatment intensity not associated with mental late effects (Lund et al., 2015, 2011). This because we only measure mental health at one point in time, and treatment data are not gathered through medical protocols but is self-reported. As illustrated above, research regarding treatment burden seems to contribute with contradictory findings, and more research on clearly defined groups and treatment protocols is necessary.

The regression analyses identify educational level as the best determinant for HRQOL and perceived economy as the best determinant for distress. This can be seen in relation to earlier findings proposing that factors other than treatment intensity could be more important determinants of quality of life in the survivor group (Kanellopoulos et al., 2013). In line with other research, our findings propose gender, educational level and perceived economic situation as these determinants (Chan et al., 2014; Reulen et al., 2007; Smith et al., 2013; Zeltzer et al., 2008, 2009). These findings are interesting because it would be plausible to assume that gender or educational differences would not account for such differences in HRQOL or distress in a Norwegian population. This due to the delivery of equal levels of treatment and educational opportunities regardless of gender, insurance or income. However, newer findings demonstrates that Norwegian survivors of cancer in young age have an increased risk of being economically dependent and unemployed (Gunnes et al., 2016). This could possibly explain our findings related to the importance of educational level and economy.

To deliver developmentally appropriate psychosocial care when working with AYA survivors, it is of special importance to consider the key developmental tasks facing adolescents and young adults (D'Agostino et al., 2011). From a developmental perspective, achieving independence from caregivers, both economically and emotionally, are important developmental goals during adolescence (D'Agostino et al., 2011). By illustrating the significance of educational level and perceived economy as predictors for HRQOL and distress, our results demonstrate some of the impact cancer may have on achieving these developmental goals. As emphasized by others (Ander et al., 2015; Brinkman et al., 2013) there are subgroups of vulnerable survivors, and it is probably these survivors who notice the late effects of cancer in shape of a lowered HRQOL and higher levels of distress, possibly due to lower perceived economy and lower levels of education. Conclusions pertaining to whether this is a causal relationship, a consequence of underlying vulnerabilities, or a consequence of other factors, can be investigated in future research.

As mentioned above, it has been suggested that HRQOL in cancer survivors may be more strongly related to subjective perceptions of cancer in one's life than to prevalent cancer-related factors (Zebrack & Landier, 2011). In this way, long-term survivor's experience of their HRQOL may be more influenced by their resilience and coping strategies than by previous cancer and treatment burden (Kanellopoulos et al., 2013; Zebrack & Landier, 2011). If this is the case, close psychosocial support during treatment and follow-up, including interventions directed toward better coping strategies could have a positive effect on long-term survivor's HRQOL (Kanellopoulos et al., 2013). This would be of special importance for survivors at risk, or less resilient than others. Routine screening of psychological distress in cancer survivors should be a goal, especially for survivors who experience physical health morbidities (Brinkman et al., 2013). Knowing that levels of distress and HRQOL fluctuates over time after survival (Ander et al., 2015), it is important with routine screening to discover and possibly treat anxiety or depression at an early stage. However, one should be aware that earlier findings have concluded it is premature to recommend implementation of routine screening. This due to the lack of evidence of beneficial effects from screening cancer patients for distress (Meijer et al., 2013). Clearly, more research on AYA survivors is needed to determine the potential preventive effect of screening for distress or low HRQOL. One should also note the importance of such screening actually leading to improvements in patient outcomes beyond existing standard care (Meijer et al., 2013). The use of antidepressants in this group have been questioned, promoting CBT as a better choice for the challenges specific to cancer survivors (Brinkman et al., 2013). CBT could possibly contribute positively to survivor's perception of cancer and thereby also to improved HRQOL and lower levels of distress. Neither should one forget the effect of covering informational needs, knowing that satisfied patients, patients with fulfilled informational needs, and patients who experience less information barriers, in general have better HRQOL and less anxiety and depression (Husson, Mols, & Poll-Franse, 2011).

In delivering developmentally appropriate care, health care professionals caring for the AYA population need to have an appreciation for emerging adulthood (Arnett, 2000; D'Agostino et al., 2011). To minimize disruption caused by the cancer experience and to maximize HRQOL, young individuals with cancer need opportunities to participate as much as possible in AYA activities and to master the developmental tasks of adolescence and emergent adulthood (D'Agostino et al., 2011). Schools and universities are key places for young adults to socialize, make friends and meet romantic partners; these social relationships provide support (Tremolada et al., 2016). Because of this, one cannot strongly enough emphasize the importance of detecting psychosocial or distress related difficulties at an early stage, thereby preventing long-term survivors from falling out of school or work. There is not a single, clear ideal model for care for AYA survivors, but it is crucial that health care providers are sensitive and responsive to each patient's level of maturity and independence and use a flexible interaction style and approach (D'Agostino et al., 2011).

Results from our study indicates that sub-groups: females, survivors with low perceived economy, low education or high treatment burden, are at risk for higher levels of distress and lower levels of HRQOL than others. Hopefully, with the right kinds of interventions, more CBT and less antidepressants according to some (Bisegger et al., 2005; Lund et al., 2015), one can prevent some of the suffering by identifying and intervene at an early stage. Even so, knowing that levels of depression and anxiety fluctuates 10 years after survival (Ander et al., 2015) it is necessary to ensure long-term follow up of survivors. An implication of this is the need for more resources in long-term follow up, and to enhance knowledge among health care personnel about these late effects.

Limitations and future research

Limitations of this study includes the use of self-report, which does not provide objective data. At the same time, subjective experience is an essential part of HRQOL and distress. Respondents may show signs of social desirability or self-serving bias, and poor memory for earlier events can also affect accuracy. This may interfere with average tendencies but also individual differences. Measurement of treatment modalities and number of treatment modalities is based solely on survivors' self-report, and is thereby the subjective experience of which treatments they have undergone. This must be taken into consideration when interpreting results from this study. To obtain accurate data, collecting data from medical journals would be preferable. Another limitation is not dividing survivors in to groups based on cancer diagnosis. Regarding statistical limitations of this study, robust tests were conducted whenever necessary to cope with heteroscedasticity and lack of normal distributed residuals. A large difference in group size for ANOVA and a somewhat skewed distribution for HSCL in regression could have affected the results. Small effect sizes further limit the study. Regarding participants, excluding the youngest girls in the control group may have affected results, as well as differences between survivors and controls in age and other demographic qualities (table 1).

The use of different control groups such as siblings, norms or peers can lead to different results across studies, and contribute to difficulties in generalizing findings. As a reflection of studying a young, relatively highly educated population of cancer survivors, where nearly a quarter of them were still students (table 1), university students were considered suitable as controls in our study. Based on means of PedsQL and HSCL-10 and qualitative comparison to earlier studies using these measures (Reinfjell et al., 2006; Strand et al., 2003; Winger et al., 2015) it seems our control group scores lower on HRQOL and higher on distress, and is thus more vulnerable than expected. Scores on PedsQL of our control group are more in line with earlier findings from a student population (Varni & Limbers, 2009). Even though students as a population have high levels of distress (Nedregård & Olsen, 2014), one can still argue students to be a good comparison group for the survivors, because of the high levels of students and educational level in the survivors population. A relatively high proportion of the general population in this age group are students (SSB/Statistics Norway, 2016), and there is thus reason to reckon the results generalizable to the AYA population. One should also bear in mind that PedsQL have not yet been validated for this age group in Norway, and this is the first time the Norwegian version of the instrument is presented to a population of this age group. Future research should validate and investigate qualities of this version of PedsQL for this age group. One cannot exclude the possibility that the results are a consequence of measurement error.

AYA cancer survivors require psychometrically rigorous measures to assess their psychosocial well-being. Without methodologically adequate scales the accuracy of information obtained on the prevalence of needs or predictors of risk, can be questioned (Clinton-McHarg et al., 2010). As mentioned by Zeltzer et al. (2009) one of the reasons results from different studies are contradictory, is the use of different instruments when measuring e.g. HRQOL. According to some (Varni & Limbers, 2009) PedsQL young adult version is significantly correlated with the SF-8, a widely used measure of HRQOL. Still, the use of different measurements prevents comparisons between studies. Future research should therefore concentrate on developing standards for measurement of psychosocial health. Better collaboration between different institutions both nationally and internationally could promote the use of more standardized instruments, and enhance the sample size of studies.

The very low response rate of the study limits its conclusions. One can hypothesize it's only the healthier survivors who have responded. If this is the case it can explain the relatively small differences in HRQOL and distress between survivors and controls. It is challenging to assess whether the acquired response rate is at a level of what one could expect, and whether there are other conditions which could explain the response rate. The AYA population is very mobile and can be difficult to track, even with considerable available resources (Tonorezos & Oeffinger, 2011). As opposed to young children or older adults who have survived cancer, the AYA population may be lost to follow-up, and may not even appreciate the need for follow up (Tonorezos & Oeffinger, 2011). In a shorter follow-up study of AYA survivors, Harlan et al. (2011) found that 43% of the eligible patients responded, and extensive efforts were required for most potential respondents. But despite the response rate, those who participated adequately reflected the population of AYA cancer survivors (Harlan et al., 2011). Hopefully, this is also the case for our study.

A cross-sectional design limits the conclusions of this study. Longitudinal studies are required to broaden knowledge about psychological distress and HRQOL of AYA cancer survivors. Because of difficulties recruiting AYAs, there is a need for large, population-based studies with national coverage, including non-cancer comparisons (Gunnes et al., 2016). Strengths of our study includes a large number of survivor participants and representation from the majority of Norwegian hospitals. Another strength is the amount of time elapsed since diagnosis, which is an advantage when looking at the late effects of cancer on HRQOL and distress. One should be careful applying results from group-research, such as this study, to the individual.

Future research should look further into the significance of sociodemographic factors like economy and education in prediction of HRQOL and distress. Research on the increased vulnerability of lowered HRQOL among distressed survivors should also be conducted. Further, predictors of physical health and the interplay between health promoting behaviours and late effects of cancer should be investigated. Development of validated easy-to-use screening tools for health care personnel and programs for coping strategies for survivors at risk, could be of value to survivors who struggle.

Conclusion

A developmental perspective helps recognize the special challenges of young adult survivors of cancer in adolescence, and there is a need for long-term follow up for this group. Norwegian survivors report poorer physical, but not total or psychosocial HRQOL than controls. Neither are they more distressed than control. This could be an effect of resilience, positive growth or lowered expectations. Still, survivors in general are more probable to report psychological distress than controls, and distressed survivors exhibit poorer HRQOL than distressed controls. Confirming earlier research, females are a group at risk. Female survivors score significantly lower on all measures, and have higher odds of being distressed than female controls. Gender, education, perceived economic situation and numbers of undergone treatment modalities significantly predicts HRQOL and distress. Insights from this study can be used to identify and deliver long term follow-up to survivors at risk. Assuming usefulness of screening, levels of HRQOL and distress should be screened during follow up to ensure early intervention, especially for survivors at risk for lowered HRQOL or psychological distress. More research on AYA cancer survivors is needed, especially on the connection between achieving developmental tasks like independence in economy and education, and the impact on HRQOL and distress.

References

Abrams, A. N., Hazen, E. P., & Penson, R. T. (2007). Psychosocial issues in adolescents with cancer. *Cancer Treatment Reviews*, 33(7), 622–630. https://dx.doi.org/10.1016/j.ctrv.2006.12.006

Allen, J. P. (2008). The Attachment System in Adolescence. In J. Cassidy & P.R. Shaver (Eds.), *Handbook of Attachment. Theory, Research, and Clinical Applications* (2nd ed.,pp 419-435). New York: Guilford Press.

Ander, M., Grönqvist, H., Cernvall, M., Engvall, G., Hedström, M., Ljungman, G., … von Essen, L. (2015). Development of health-related quality of life and symptoms of anxiety and depression among persons diagnosed with cancer during adolescence: a 10-year follow-up study. *Psycho-Oncology*, 25(5), 582–589. https://dx.doi.org/10.1002/pon.3965

Armstrong, G. T., Liu, Q., Yasui, Y., Neglia, J. P., Leisenring, W., Robison, L. L., & Mertens, A. C. (2009). Late Mortality Among 5-Year Survivors of Childhood Cancer: A Summary From the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, 27(14), 2328–2338. https://dx.doi.org/10.1200/JCO.2008.21.1425

Armstrong, G. T., Sklar, C. A., Hudson, M. M., & Robison, L. L. (2007). Long-Term Health Status Among Survivors of Childhood Cancer: Does Sex Matter? *Journal of Clinical Oncology*, 25(28), 4477–4489. https://dx.doi.org/10.1200/JCO.2007.11.2003

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469–480. https://dx.doi.org/10.1037/0003-066X.55.5.469

Axelson, D. A., & Birmaher, B. (2001). Relation between anxiety and depressive disorders in childhood and adolescence. *Depression and Anxiety*, 14(2), 67–78. https://dx.doi.org/10.1002/da.1048

Aziz, N. M., & Rowland, J. H. (2003). Trends and advances in cancer survivorship research: challenge and opportunity. *Seminars in Radiation Oncology*, 13(3), 248–266. https://dx.doi.org/10.1016/S1053-4296(03)00024-9

Barakat, L. P., Alderfer, M. A., & Kazak, A. E. (2006). Posttraumatic Growth in Adolescent Survivors of Cancer and Their Mothers and Fathers. *Journal of Pediatric Psychology*, 31(4), 413–419. https://dx.doi.org/10.1093/jpepsy/jsj058

Barnett, M., McDonnell, G., DeRosa, A., Schuler, T., Philip, E., Peterson, L., … Ford, J. S. (2016). Psychosocial outcomes and interventions among cancer survivors diagnosed during adolescence and young adulthood (AYA): a systematic review. *Journal of Cancer Survivorship*, 1–18. https://dx.doi.org/10.1007/s11764-016-0527-6

Bisegger, C., Cloetta, B., Bisegger, U. von, Abel, T., Ravens-Sieberer, U., & Group, the E. K. (2005). Health-related quality of life: gender differences in childhood and adolescence. *Sozial- Und Präventivmedizin*, 50(5), 281–291. https://dx.doi.org/10.1007/s00038-005-4094-2

Blaauwbroek, R., Stant, A. D., Groenier, K. H., Kamps, W. A., Meyboom, B., & Postma, A. (2007). Health-related quality of life and adverse late effects in adult (very) long-term childhood cancer survivors. *European Journal of Cancer,* 43(1), 122–130. https://dx.doi.org/10.1016/j.ejca.2006.08.003

Bleyer, A., Budd, T., & Montello, M. (2006). Adolescents and young adults with cancer. *Cancer*, 107(S7), 1645–1655. https://dx.doi.org/10.1002/cncr.22102

Brady, E. U., & Kendall, P. C. (1992). Comorbidity of anxiety and depression in children and adolescents. *Psychological Bulletin*, 111(2), 244–255. https://dx.doi.org/10.1037/0033-2909.111.2.244

Brinkman, T. M., Zhu, L., Zeltzer, L. K., Recklitis, C. J., Kimberg, C., Zhang, N., … Krull, K. R. (2013). Longitudinal patterns of psychological distress in adult survivors of childhood cancer. *British Journal of Cancer*, 109(5), 1373–1381. https://dx.doi.org/10.1038/bjc.2013.428

Bullinger, M. (2002). Assessing health related quality of life in medicine. An overview over concepts, methods and applications in international research. *Restorative Neurology and Neuroscience*, *20*(3,4), 93–101.

Cancer Registry of Norway. (2015). *Cancer in Norway 2014 - Cancer incidence, mortality, survival and prevalence in Norway*. Oslo: Cancer Registry of Norway.

Casillas, J., Kahn, K. L., Doose, M., Landier, W., Bhatia, S., Hernandez, J., & Zeltzer, L. K. (2010). Transitioning childhood cancer survivors to adult-centered healthcare: insights from parents, adolescent, and young adult survivors. *Psycho-Oncology*, *19*(9), 982–990. https://dx.doi.org/10.1002/pon.1650

Chan, C. W. H., Choi, K. C., Chien, W. T., Cheng, K. K. F., Goggins, W., So, W. K. W., … Li, C. K. (2014). Health-related quality-of-life and psychological distress of young adult survivors of childhood cancer in Hong Kong. *Psycho-Oncology*, *23*(2), 229–236. https://dx.doi.org/10.1002/pon.3396

Choudhury, S., Blakemore, S.-J., & Charman, T. (2006). Social cognitive development during adolescence. *Social Cognitive and Affective Neuroscience*, *1*(3), 165–174. https://dx.doi.org/10.1093/scan/nsl024

Christie, D., & Viner, R. (2005). Adolescent development. *BMJ*, *330*(7486), 301–304.

Clinton-McHarg, T., Carey, M., Sanson-Fisher, R., Shakeshaft, A., & Rainbird, K. (2010). Measuring the psychosocial health of adolescent and young adult (AYA) cancer survivors: a critical review. *Health and Quality of Life Outcomes*, *8*(25), 1–13. https://dx.doi.org/10.1186/1477-7525-8-25

Cole, D. A., Truglio, R., & Peeke, L. (1997). Relation between symptoms of anxiety and depression in children: A multitrait-multimethod-multigroup assessment. *Journal of Consulting and Clinical Psychology*, *65*(1), 110–119. https://dx.doi.org/10.1037/0022-006X.65.1.110

D'Agostino, N. M., Penney, A., & Zebrack, B. (2011). Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer*, *117*(S10), 2329–2334. https://dx.doi.org/10.1002/cncr.26043

de Haes, J. C., van Knippenberg, F. C., & Neijt, J. P. (1990). Measuring psychological and physical distress in cancer patients: structure and application of the Rotterdam Symptom Checklist. *British Journal of Cancer, 62*(6), 1034–1038.

Derogatis, L. R., Lipman, R. S., Rickels, K., Uhlenhuth, E. H., & Covi, L. (1974). The Hopkins Symptom Checklist (HSCL): A self-report symptom inventory. *Behavioral Science*, *19*(1), 1–15. https://dx.doi.org/10.1002/bs.3830190102

Derogatis, L. R., & Melisaratos, N. (1983). The Brief Symptom Inventory: an introductory report. *Psychological Medicine*, *13*(3), 595–605. https://dx.doi.org/10.1017/S0033291700048017

Deyell, R. J., Lorenzi, M., Ma, S., Rassekh, S. R., Collet, J.-P., Spinelli, J. J., & McBride, M. L. (2013). Antidepressant use among survivors of childhood, adolescent and young adult cancer: A report of the childhood, adolescent and young adult cancer survivor (CAYACS) research program. *Pediatric Blood & Cancer*, *60*(5), 816–822. https://dx.doi.org/10.1002/pbc.24446

Erikson, E. H. (1977). *Childhood and Society*. London: Paladin Grafton Books.

Field, A. (2013). *Discovering Statistics Using IBM SPSS Statistics,* (4th ed.). London: SAGE Publications Ltd.

Fosså, S. D., Hess, S. L., Dahl, A. A., Hjermstad, M. J., & Veenstra, M. (2007). Stability of health-related quality of life in the Norwegian general population and impact of chronic morbidity in individuals with and without a cancer diagnosis. *Acta Oncologica*, *46*(4), 452–461. https://dx.doi.org/10.1080/02841860601182641

Gleeson, H., & Shalet, S. (2001). Endocrine complications of neoplastic diseases in children a... : Current Opinion in Pediatrics. *Current Opinion in Pediatrics*, *13*(4), 346–351.

Grissom, R. J., & Kim, J. J. (2014). *Effect Sizes for Research: A Broad Practical Approach*. New York and London: Psychology Press Taylor & Francis Group.

Gunnes, M. W., Lie, R. T., Bjørge, T., Syse, A., Ruud, E., Wesenberg, F., & Moster, D. (2016). Economic independence in survivors of cancer diagnosed at a young age: A Norwegian national cohort study. *Cancer*, n/a-n/a. https://dx.doi.org/10.1002/cncr.30253

Haavet, O. R., Sirpal, M. K., Haugen, W., & Christensen, K. S. (2010). Diagnosis of depressed young people in primary health care—a validation of HSCL-10. *Family Practice*, *28*(2), 233-237. https://dx.doi.org/10.1093/fampra/cmq078

Hale, W. W., Raaijmakers, Q. A. W., Muris, P., Van Hoof, A., & Meeus, W. H. J. (2009). One factor or two parallel processes? Comorbidity and development of adolescent anxiety and depressive disorder symptoms. *Journal of Child Psychology and Psychiatry*, *50*(10), 1218–1226. https://dx.doi.org/10.1111/j.1469-7610.2009.02115.x

Harlan, L. C., Lynch, C. F., Keegan, T. H. M., Hamilton, A. S., Wu, X.-C., Kato, I., … Group, the A. H. S. C. (2011). Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. *Journal of Cancer Survivorship*, *5*(3), 305–314. https://dx.doi.org/10.1007/s11764-011-0173-y

Hudson, M. M. (2008). Survivors of Childhood Cancer: Coming of Age. *Hematology/Oncology Clinics of North America*, *22*(2), 211–231. https://dx.doi.org/10.1016/j.hoc.2008.01.011

Hudson, M. M., Oeffinger, K. C., Jones, K., Brinkman, T. M., Krull, K. R., Mulrooney, D. A., … Ness, K. K. (2015). Age-Dependent Changes in Health Status in the Childhood Cancer Survivor Cohort. *Journal of Clinical Oncology*, *33*(5), 479–491. https://dx.doi.org/10.1200/JCO.2014.57.4863

Husson, O., Mols, F., & Poll-Franse, L. V. van de. (2011). The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Annals of Oncology*, *22*(4), 761–772. https://dx.doi.org/10.1093/annonc/mdq413

Kanellopoulos, A., Andersson, S., Zeller, B., Tamnes, C. K., Fjell, A. M., Walhovd, K. B., … Ruud, E. (2016). Neurocognitive Outcome in Very Long-Term Survivors of

Childhood Acute Lymphoblastic Leukemia After Treatment with Chemotherapy Only. *Pediatric Blood & Cancer*, *63*(1), 133–138. https://dx.doi.org/10.1002/pbc.25690

Kanellopoulos, A., Hamre, H. M., Dahl, A. A., Fosså, S. D., & Ruud, E. (2013). Factors associated with poor quality of life in survivors of childhood acute lymphoblastic leukemia and lymphoma. *Pediatric Blood & Cancer*, *60*(5), 849–855. https://dx.doi.org/10.1002/pbc.24375

Kazak, A. E., DeRosa, B. W., Schwartz, L. A., Hobbie, W., Carlson, C., Ittenbach, R. F., … Ginsberg, J. P. (2010). Psychological Outcomes and Health Beliefs in Adolescent and Young Adult Survivors of Childhood Cancer and Controls. *Journal of Clinical Oncology*, *28*(12), 2002–2007. https://dx.doi.org/10.1200/JCO.2009.25.9564

Kazak, A. E., & Noll, R. B. (2015). The integration of psychology in pediatric oncology research and practice: Collaboration to improve care and outcomes for children and families. *American Psychologist*, *70*(2), 146–158. https://dx.doi.org/10.1037/a0035695

Kessler, R. C., Amminger, G. P., Aguilar-Gaxiola, S., Alonso, J., Lee, S., & Ustun, T. B. (2007). Age of onset of mental disorders: A review of recent literature. *Current Opinion in Psychiatry*, *20*(4), 359–364. https://dx.doi.org/10.1097/YCO.0b013e32816ebc8c

Koch, S. V., Kejs, A. M. T., Engholm, G., Johansen, C., & Schmiegelow, K. (2004). Educational attainment among survivors of childhood cancer: a population-based cohort study in Denmark. *British Journal of Cancer*, *91*(5), 923–928. https://dx.doi.org/10.1038/sj.bjc.6602085

Lee, L.-C., & Rebok, G. W. (2002). Anxiety and Depression in Children: A Test of the Positive-Negative Affect Model. *Journal of the American Academy of Child & Adolescent Psychiatry*, *41*(4), 419–426. https://dx.doi.org/10.1097/00004583-200204000-00014

Lien, L., Haavet, O. R., & Dalgard, F. (2010). Do mental health and behavioural problems of early menarche persist into late adolescence? A three year follow-up study among adolescent girls in Oslo, Norway. *Social Science & Medicine*, *71*(3), 529–533. https://dx.doi.org/10.1016/j.socscimed.2010.05.003

Lipshultz, S. E., Colan, S. D., Gelber, R. D., Perez-Atayde, A. R., Sallan, S. E., & Sanders, S. P. (1991). Late Cardiac Effects of Doxorubicin Therapy for Acute Lymphoblastic Leukemia in Childhood. *New England Journal of Medicine*, *324*(12), 808–815. https://dx.doi.org/10.1056/NEJM199103213241205

Lund, L. W., Schmiegelow, K., Rechnitzer, C., & Johansen, C. (2011). A systematic review of studies on psychosocial late effects of childhood cancer: Structures of society and methodological pitfalls may challenge the conclusions. *Pediatric Blood & Cancer*, *56*(4), 532–543. https://dx.doi.org/10.1002/pbc.22883

Lund, L. W., Winther, J. F., Cederkvist, L., Andersen, K. K., Dalton, S. O., Appel, C. W., … Johansen, C. (2015). Increased risk of antidepressant use in childhood cancer survivors: A Danish population-based cohort study. *European Journal of Cancer*, *51*(5), 675–684. https://dx.doi.org/10.1016/j.ejca.2015.01.001

Meadows, A. T. (2003). Pediatric cancer survivors: past history and future challenges. *Current Problems in Cancer*, *27*(3), 112–126. https://dx.doi.org/10.1016/S0147-0272(03)00025-4

Meijer, A., Roseman, M., Delisle, V. C., Milette, K., Levis, B., Syamchandra, A., … Thombs, B. D. (2013). Effects of screening for psychological distress on patient outcomes in cancer: A systematic review. *Journal of Psychosomatic Research*, *75*(1), 1–17. https://dx.doi.org/10.1016/j.jpsychores.2013.01.012

Meister, L. A., & Meadows, A. T. (1993). Late effects of childhood cancer therapy. *Current Problems in Pediatrics*, *23*(3), 102–131. https://dx.doi.org/10.1016/0045-9380(93)90019-9

Mertens, A. C., & Marchak, J. G. (2015). Mental health status of adolescent cancer survivors. *Clinical Oncology in Adolescents and Young Adults*, *5*, 87–95.

Michel, G., Rebholz, C. E., Von Der Weid, N. X., Bergstraesser, E., & Kuehni, C. E. (2010). Psychological Distress in Adult Survivors of Childhood Cancer: The Swiss Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, *28*(10), 1740–1748.

Mirowsky, J., & Ross, C. E. (2003). *Social Causes of Psychological Distress* (2nd ed.). New York: Aldine DeGruyter. Retrieved from https://books.google.no/books?hl=no&lr=&id=uhgzSFcYdsoC&oi=fnd&pg=PA1&dq=psychological+distress&ots=5G6kpVT7gA&sig=1cAnRc7iQ9NqhexPRcLYS0lZFN4&redir_esc=y#v=onepage&q=psychological%20distress&f=false

Nathan, P. C., Ford, J. S., Henderson, T. O., Hudson, M. M., Emmons, K. M., Casillas, J. N., … Oeffinger, K. C. (2009). Health Behaviors, Medical Care, and Interventions to Promote Healthy Living in the Childhood Cancer Survivor Study Cohort. *Journal of Clinical Oncology*, *27*(14), 2363–2373. https://dx.doi.org/10.1200/JCO.2008.21.1441

Nedregård, T., & Olsen, R. (2014). *SHoT 2014 Studentenes helse- og trivselsundersøkelse* (p.142). Trondheim/Oslo: TNS Gallup. Retrieved from http://www.sib.no/no/helse/shot-2014

Neglia, J. P., Friedman, D. L., Yasui, Y., Mertens, A. C., Hammond, S., Stovall, M., … Robison, L. L. (2001). Second Malignant Neoplasms in Five-Year Survivors of Childhood Cancer: Childhood Cancer Survivor Study. *Journal of the National Cancer Institute*, *93*(8), 618–629. https://dx.doi.org/10.1093/jnci/93.8.618

Oeffinger, K. C., & Hudson, M. M. (2004). Long-term Complications Following Childhood and Adolescent Cancer: Foundations for Providing Risk-based Health Care for Survivors. *CA: A Cancer Journal for Clinicians*, *54*(4), 208–236. https://dx.doi.org/10.3322/canjclin.54.4.208

Oeffinger, K. C., Mertens, A. C., Sklar, C. A., Kawashima, T., Hudson, M. M., Meadows, A. T., … Robison, L. L. (2006). Chronic Health Conditions in Adult Survivors of Childhood Cancer. *New England Journal of Medicine*, *355*(15), 1572–1582. https://dx.doi.org/10.1056/NEJMsa060185

Oeffinger, K. C., Nathan, P. C., & Kremer, L. C. M. (2010). Challenges After Curative Treatment for Childhood Cancer and Long-Term Follow up of Survivors. *Hematology/Oncology Clinics of North America*, *24*(1), 129–149. https://dx.doi.org/10.1016/j.hoc.2009.11.013

Parry, C., & Chesler, M. A. (2005). Thematic Evidence of Psychosocial Thriving in Childhood Cancer Survivors. *Qualitative Health Research*, *15*(8), 1055–1073. https://dx.doi.org/10.1177/1049732305277860

Perneger, T. V. (1998). What's wrong with Bonferroni adjustments. *BMJ*, *316*(7139), 1236–1238. https://dx.doi.org/10.1136/bmj.316.7139.1236

Phillips, S. M., Padgett, L. S., Leisenring, W. M., Stratton, K. K., Bishop, K., Krull, K. R., … Mariotto, A. B. (2015). Survivors of Childhood Cancer in the United States: Prevalence and Burden of Morbidity. *Cancer Epidemiology and Prevention Biomarkers*, *24*(4), 653–663. https://dx.doi.org/10.1158/1055-9965.EPI-14-1418

Phillips-Salimi, C. R., & Andrykowski, M. A. (2013). Physical and mental health status of female adolescent/young adult survivors of breast and gynecological cancer: a national, population-based, case-control study. *Supportive Care in Cancer*, *21*(6), 1597–1604. https://dx.doi.org/10.1007/s00520-012-1701-7

Reinfjell, T., Diseth, T. H., Veenstra, M., & Vikan, A. (2006). Measuring health-related quality of life in young adolescents: Reliability and validity in the Norwegian version of the Pediatric Quality of Life Inventory^{TM} 4.0 (PedsQL) generic core scales. *Health and Quality of Life Outcomes*, *4*(61). https://dx.doi.org/10.1186/1477-7525-4-61

Reinfjell, T., Lofstad, G. e., Nordahl, H. m., Vikan, A., & Diseth, T. h. (2009). Children in remission from acute lymphoblastic leukaemia: mental health, psychosocial adjustment and parental functioning. *European Journal of Cancer Care*, *18*(4), 364–370. https://dx.doi.org/10.1111/j.1365-2354.2008.00954.x

Reulen, R. C., Winter, D. L., Lancashire, E. R., Zeegers, M. P., Jenney, M. E., Walters, S. J., … Hawkins, M. M. (2007). Health-status of adult survivors of childhood cancer: A large-scale population-based study from the British childhood cancer survivor study. *International Journal of Cancer*, *121*(3), 633–640. https://dx.doi.org/10.1002/ijc.22658

Schwartz, C. E., & Sprangers, M. A. G. (1999). Methodological approaches for assessing response shift in longitudinal health-related quality-of-life research. *Social Science & Medicine*, *48*(11), 1531–1548. https://dx.doi.org/10.1016/S0277-9536(99)00047-7

Shedler, J., Mayman, M., & Manis, M. (1993). The illusion of mental health. *American Psychologist*, *48*(11), 1117–1131. https://dx.doi.org/10.1037/0003-066X.48.11.1117

Smith, A. W., Bellizzi, K. M., Keegan, T. H. M., Zebrack, B., Chen, V. W., Neale, A. V., … Lynch, C. F. (2013). Health-Related Quality of Life of Adolescent and Young Adult Patients With Cancer in the United States: The Adolescent and Young Adult Health Outcomes and Patient Experience Study. *Journal of Clinical Oncology*, JCO.2012.47.3173. https://dx.doi.org/10.1200/JCO.2012.47.3173

SSB/Statistics Norway. (2016). *Nøkkeltall for utdanning (key statistics education)*. Retrieved September 13, 2016, from http://www.ssb.no/utdanning/nokkeltall

Steinberg, L. (2005). Cognitive and affective development in adolescence. *Trends in Cognitive Sciences*, *9*(2), 69–74. https://dx.doi.org/10.1016/j.tics.2004.12.005

Strand, B. H., Dalgard, O. S., Tambs, K., & Rognerud, M. (2003). Measuring the mental health status of the Norwegian population: A comparison of the instruments SCL-25, SCL-10, SCL-5 and MHI-5 (SF-36). *Nordic Journal of Psychiatry*, *57*(2), 113–118. https://dx.doi.org/10.1080/08039480310000932

Sund, A. M., Larsson, B., & Wichstrøm, L. (2003). Psychosocial correlates of depressive symptoms among 12–14-year-old Norwegian adolescents. *Journal of Child Psychology and Psychiatry*, *44*(4), 588–597. https://dx.doi.org/10.1111/1469-7610.00147

Tonorezos, E. S., & Oeffinger, K. C. (2011). Research challenges in adolescent and young adult cancer survivor research. *Cancer*, *117*(10), 2295–2300. https://dx.doi.org/10.1002/cncr.26058

Tremolada, M., Bonichini, S., Basso, G., & Pillon, M. (2016). Perceived social support and health-related quality of life in AYA cancer survivors and controls. *Psycho-Oncology*, n/a-n/a. https://dx.doi.org/10.1002/pon.4072

U.S. Department of Health and Human Services FDA:, CDER, CBER, & CDRH. (2006). Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. *Health and Quality of Life Outcomes*, *4*(79), 1–20. https://dx.doi.org/10.1186/1477-7525-4-79

Varni, J. W., & Limbers, C. A. (2009). The PedsQL^{TM} 4.0 Generic Core Scales Young Adult Version Feasibility, Reliability and Validity in a University Student Population. *Journal of Health Psychology*, *14*(4), 611–622. https://dx.doi.org/10.1177/1359105309103580

Varni, J. W., Seid, M., & Rode, C. (1999). The PedsQL^{TM}: Measurement Model for the Pediatric Quality of Life Inventory. *Medical Care*, *37*(2), 126–139.

Wallander, J. L., & Koot, H. M. (2016). Quality of life in children: A critical examination of concepts, approaches, issues, and future directions. *Clinical Psychology Review*, *45*, 131–143. https://dx.doi.org/10.1016/j.cpr.2015.11.007

Wallander, J. L., Schmitt, M., & Koot, H. M. (2001). Quality of life measurement in children and adolescents: Issues, instruments, and applications. *Journal of Clinical Psychology*, *57*(4), 571–585. https://dx.doi.org/10.1002/jclp.1029

Williamson, H., Harcourt, D., Halliwell, E., Frith, H., & Wallace, M. (2010). Adolescents' and Parents' Experiences of Managing the Psychosocial Impact of Appearance Change During Cancer Treatment. *Journal of Pediatric Oncology Nursing*, *27*(3), 168–175. https://dx.doi.org/10.1177/1043454209357923

Winger, A., Kvarstein, G., Wyller, V. B., Ekstedt, M., Sulheim, D., Fagermoen, E., … Helseth, S. (2015). Health related quality of life in adolescents with chronic fatigue syndrome: a cross-sectional study. *Health and Quality of Life Outcomes*, *13*(96). https://dx.doi.org/10.1186/s12955-015-0288-3

World Health Organization. (1948). *Constitution of the World Health Organization: Basic document* (48th ed.). Geneva, Switzerland: World Health Organization. Retrieved from http://apps.who.int/gb/bd/PDF/bd48/basic-documents-48th-edition-en.pdf

Zebrack, B. J. (2011). Psychological, social, and behavioral issues for young adults with cancer. *Cancer*, *117*(S10), 2289–2294. https://dx.doi.org/10.1002/cncr.26056

Zebrack, B. J., & Chesler, M. A. (2002). Quality of life in childhood cancer survivors. *Psycho-Oncology*, *11*(2), 132–141. https://dx.doi.org/10.1002/pon.569

Zebrack, B. J., Gurney, J. G., Oeffinger, K., Whitton, J., Packer, R. J., Mertens, A., … Zeltzer, L. K. (2004). Psychological Outcomes in Long-Term Survivors of Childhood Brain Cancer: A Report From the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, *22*(6), 999–1006. https://dx.doi.org/10.1200/JCO.2004.06.148

Zebrack, B. J., & Landier, W. (2011). The perceived impact of cancer on quality of life for post-treatment survivors of childhood cancer. *Quality of Life Research*, *20*(10), 1595–1608. https://dx.doi.org/10.1007/s11136-011-9893-8

Zebrack, B. J., Mills, J., & Weitzman, T. S. (2007). Health and supportive care needs of young adult cancer patients and survivors. *Journal of Cancer Survivorship*, *1*(2), 137–145. https://dx.doi.org/10.1007/s11764-007-0015-0

Zebrack, B. J., & Zeltzer, L. K. (2001). Living beyond the sword of Damocles: surviving childhood cancer. *Expert Review of Anticancer Therapy*, *1*(2), 163–164.

Zebrack, B. J., Zeltzer, L. K., Whitton, J., Mertens, A. C., Odom, L., Berkow, R., & Robison, L. L. (2002). Psychological Outcomes in Long-Term Survivors of Childhood Leukemia, Hodgkin's Disease, and Non-Hodgkin's Lymphoma: A Report From the Childhood Cancer Survivor Study. *Pediatrics*, *110*(1), 42–52.

Zeltzer, L. K. (1993). Cancer in adolescents and young adults psychosocial aspects. Long-term survivors. *Cancer*, *71*(S10), 3463–3468. https://dx.doi.org/10.1002/1097-0142(19930515)71:10+<3463::AID-CNCR2820711753>3.0.CO;2-B

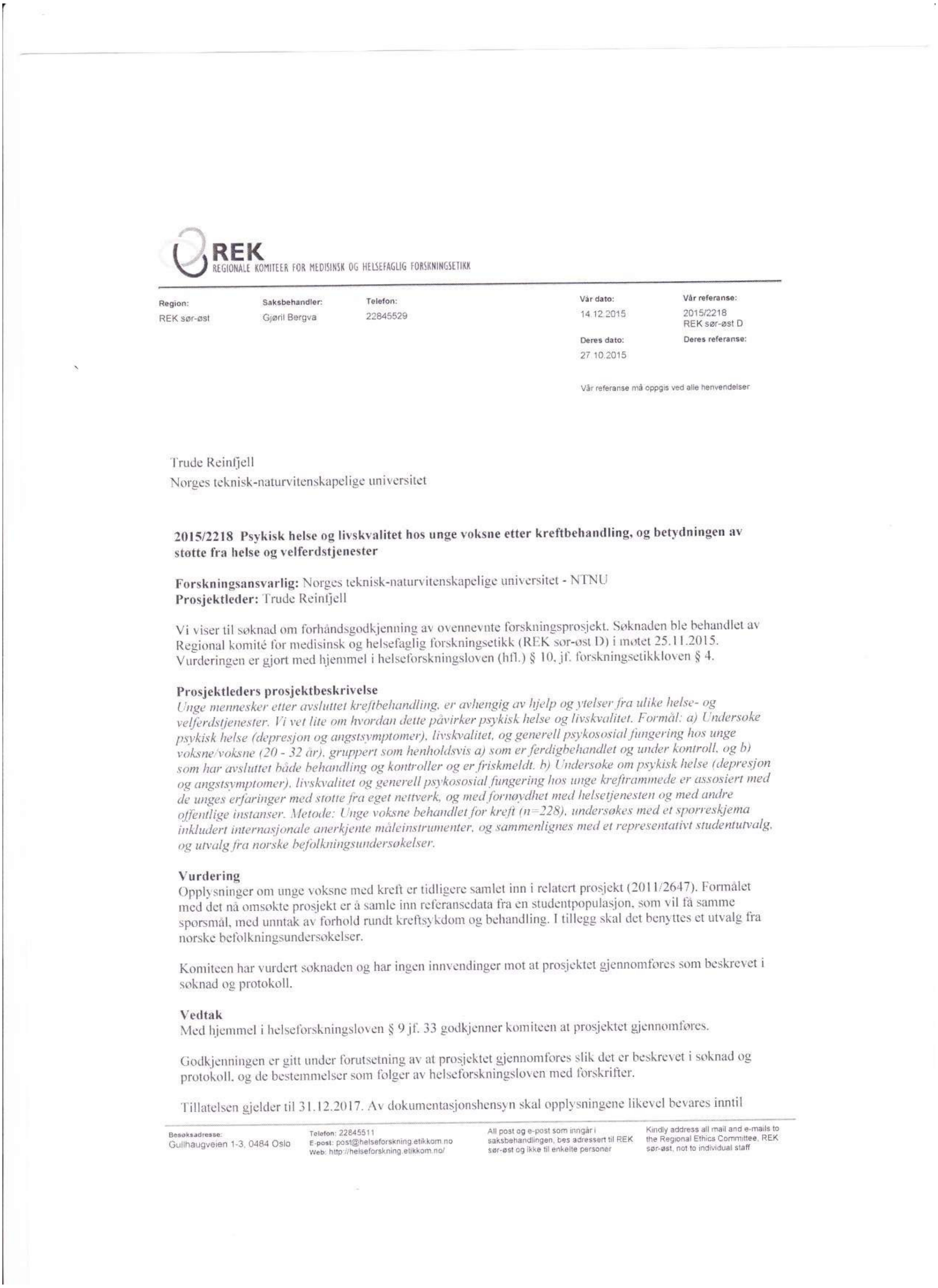
Zeltzer, L. K., Lu, Q., Leisenring, W., Tsao, J. C. I., Recklitis, C., Armstrong, G., … Ness, K. K. (2008). Psychosocial Outcomes and Health-Related Quality of Life in Adult Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study. *Cancer Epidemiology Biomarkers & Prevention*, *17*(2), 435–446. https://dx.doi.org/10.1158/1055-9965.EPI-07-2541

Zeltzer, L. K., Recklitis, C., Buchbinder, D., Zebrack, B., Casillas, J., Tsao, J. C. I., … Krull, K. (2009). Psychological Status in Childhood Cancer Survivors: A Report From the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, *27*(14), 2396–2404. https://dx.doi.org/10.1200/JCO.2008.21.1433

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361–370. https://dx.doi.org/10.1111/j.1600-0447.1983.tb09716.x

Appendix

Appendix A: Approval from REK (Regional Committees for Medical and Health Research Ethics) to collect control group data.



REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region: REK sør-øst
Saksbehandler: Gjøril Bergva
Telefon: 22845529
Vår dato: 14.12.2015
Vår referanse: 2015/2218 REK sør-øst D
Deres dato: 27.10.2015
Deres referanse:

Vår referanse må oppgis ved alle henvendelser

Trude Reinfjell
Norges teknisk-naturvitenskapelige universitet

2015/2218 Psykisk helse og livskvalitet hos unge voksne etter kreftbehandling, og betydningen av støtte fra helse og velferdstjenester

Forskningsansvarlig: Norges teknisk-naturvitenskapelige universitet - NTNU
Prosjektleder: Trude Reinfjell

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst D) i møtet 25.11.2015. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektleders prosjektbeskrivelse
Unge mennesker etter avsluttet kreftbehandling, er avhengig av hjelp og ytelser fra ulike helse- og velferdstjenester. Vi vet lite om hvordan dette påvirker psykisk helse og livskvalitet. Formål: a) Undersoke psykisk helse (depresjon og angstsymptomer), livskvalitet, og generell psykososial fungering hos unge voksne/voksne (20 - 32 år), gruppert som henholdsvis a) som er ferdigbehandlet og under kontroll, og b) som har avsluttet både behandling og kontroller og er friskmeldt. b) Undersoke om psykisk helse (depresjon og angstsymptomer), livskvalitet og generell psykososial fungering hos unge kreftrammede er assosiert med de unges erfaringer med stotte fra eget nettverk, og med fornøydhet med helsetjenesten og med andre offentlige instanser. Metode: Unge voksne behandlet for kreft (n=228), undersøkes med et sporreskjema inkludert internasjonale anerkjente måleinstrumenter, og sammenlignes med et representativt studentutvalg, og utvalg fra norske befolkningsundersøkelser.

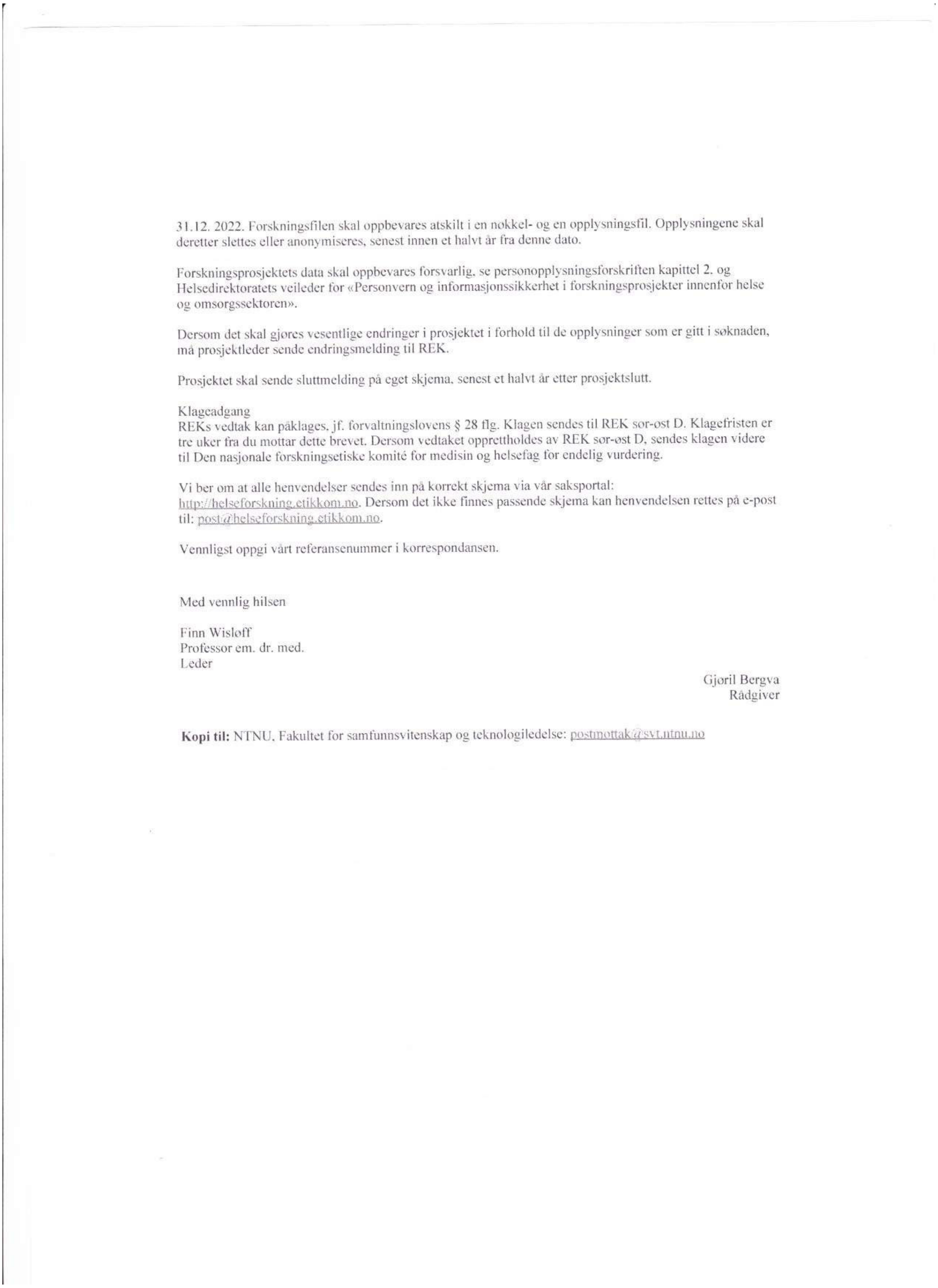
Vurdering
Opplysninger om unge voksne med kreft er tidligere samlet inn i relatert prosjekt (2011/2647). Formålet med det nå omsøkte prosjekt er å samle inn referansedata fra en studentpopulasjon, som vil få samme sporsmål, med unntak av forhold rundt kreftsykdom og behandling. I tillegg skal det benyttes et utvalg fra norske befolkningsundersøkelser.

Komiteen har vurdert søknaden og har ingen innvendinger mot at prosjektet gjennomføres som beskrevet i søknad og protokoll.

Vedtak
Med hjemmel i helseforskningsloven § 9 jf. 33 godkjenner komiteen at prosjektet gjennomføres.

Godkjenningen er gitt under forutsetning av at prosjektet gjennomfores slik det er beskrevet i soknad og protokoll, og de bestemmelser som folger av helseforskningsloven med forskrifter.

Tillatelsen gjelder til 31.12.2017. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil



31.12. 2022. Forskningsfilen skal oppbevares atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse og omsorgssektoren».

Dersom det skal gjøres vesentlige endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK.

Prosjektet skal sende sluttmelding på eget skjema, senest et halvt år etter prosjektslutt.

Klageadgang
REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst D. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst D, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn på korrekt skjema via vår saksportal: http://helseforskning.etikkom.no. Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Finn Wisløff
Professor em. dr. med.
Leder

Gjøril Bergva
Rådgiver

Kopi til: NTNU, Fakultet for samfunnsvitenskap og teknologiledelse: postmottak@svt.ntnu.no

Appendix B: Questionnaire answered by controls. Also answered by survivors as part of larger questionnaire.

PSYKISK HELSE OG LIVSKVALITET HOS UNGE VOKSNE ETTER KREFTBEHANDLING, OG BETYDNINGEN AV STØTTE FRA HELSE OG VELFERDSTJENESTER

NTNU
Kunnskap for en bedre verden
Psykologisk institutt

Dette er et spørsmål til deg om å delta i et forskningsprosjekt som har som mål å undersøke hvordan unge voksne som tidligere har hatt kreft har det med hensyn til livskvalitet og psykisk helse. For å kunne si noe om hvordan denne delen av befolkningen har det, er vi avhengig av å vite hvordan livskvalitet og psykisk helse til unge voksne som ikke har hatt kreft er. Som ung voksen er du derfor invitert til å delta i studien. Undersøkelsen gjennomføres ved Psykologisk institutt, Norges teknisk-naturvitenskapelige universitet (NTNU).

Hva innebærer prosjektet? Å delta innebærer å fylle ut dette spørreskjemaet. Det inneholder spørsmål om din alder, kjønn, bo- og livssituasjon, utdanning, økonomi og hvor i Norge du bor. Opplysningene vil bli sammenlignet med innsamlede data fra unge som har hatt kreft.

Mulige fordeler og ulemper: Det er ingen kjente ulemper ved å delta i studien. En fordel ved å delta er at du bidrar til viktig forskning på kreftfeltet, som kan gi oss mer kunnskap om mennesker som har gjennomgått kreftbehandling og deres situasjon og behov.

Frivillig deltakelse og mulighet for å trekke sitt samtykke: Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen nederst på denne sida. Du kan når som helst, og uten å oppgi noen grunn, trekke ditt samtykke. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål om prosjektet, kan du ta kontakt med Trude Reinfjell, tlf 73 59 76 93, e-post: trude.reinfjell@svt.ntnu.no.

Hva skjer med informasjonen om deg? Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennbare opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og for at opplysningene om deg blir behandlet på en sikker måte. Informasjonen om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

Godkjenning: Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, REK (2015/ 2218-3).

Takk for at du er villig til å delta!
Janne Fagervoll Halvorsen, psykologstudent
Trude Reinfjell, førsteamanuensis, veileder

Samtykke til deltakelse i prosjektet:

Jeg er villig til å delta i prosjektet!

Datoen i dag: ⇩	Din signatur: ⇩

Ditt navn med trykte bokstaver: ⇩ *Bruk* STORE BLOKKBOKSTAVER, *ett tegn pr. felt.*

KS-16
2-3

Undersøkelsen gjennomføres med bistand fra SVT-IT, NTNU

1

Før du fortsetter: Kontroller at du ikke har glemt noe på denne sida.

LES DETTE FØR DU STARTER!	Skjemaet skal leses maskinelt. Vennligst følg disse reglene: • *Bruk svart/blå kulepenn. Skriv tydelig, og ikke utenfor feltene.* ***Kryss av slik:*** ☒. • *Feilkryssinger kan annulleres ved å fylle hele feltet med farge. Kryss så i rett felt.* • *Sett bare ett kryss på hvert spørsmål om ikke annet er oppgitt.*

A. LIVSKVALITET OG SOSIALE FORHOLD

Vi vil nå stille deg en rekke spørsmål som handler om hvordan du har det og hvordan du trives mer generelt, det vi kan kalle for livskvalitet. De fleste opplever at dette er noe som kan variere over tid, noen ganger trives man bedre med seg selv og andre enn andre ganger. Her spør vi både om ting som kan oppleves som vanskelige og om ting som kan oppleves som fine. Vi ber deg svare så godt du kan på alle spørsmålene.

1. Har du måttet trappe ned med fritidsaktiviteter og/eller å treffe venner på grunn av sykdom/skade/smerte i løpet av *de siste 12 månedene?* ⇨

	Ja 1	Nei 2
1. Fritidsaktiviteter....	☐	☐
2. Treffe venner........	☐	☐

2. Hvordan har din fysiske aktivitet i fritiden vært det siste året? Tenk deg et ukentlig gjennomsnitt for året.

	Ingen 1	*Under 1 time* 2	*1 - 2 timer* 3	*3 - 5 timer* 4	*Over 5 timer* 5
1. Lett aktivitet (ikke svett/andpusten)	☐	☐	☐	☐	☐
2. Hard fysisk aktivitet (svett/andpusten)	☐	☐	☐	☐	☐

3. Under finner du en liste over ulike plager. Har du opplevd noe av dette de siste to ukene?

	Ikke plaget 1	*Litt plaget* 2	*Ganske mye plaget* 3	*Veldig mye plaget* 4
1. Plutselig frykt uten grunn...	☐	☐	☐	☐
2. Føler deg redd eller engstelig	☐	☐	☐	☐
3. Matthet eller svimmelhet ...	☐	☐	☐	☐
4. Føler deg anspent eller oppjaget	☐	☐	☐	☐
5. Lett for å klandre deg selv.	☐	☐	☐	☐

	Ikke plaget 1	*Litt plaget* 2	*Ganske mye plaget* 3	*Veldig mye plaget* 4
6. Søvnproblemer..........	☐	☐	☐	☐
7. Nedtrykt, tungsindig (trist)...	☐	☐	☐	☐
8. Følelse av å være unyttig, lite verd..........	☐	☐	☐	☐
9. Følelse av at alt er et slit ...	☐	☐	☐	☐
10. Følelse av håpløshet mht. framtida	☐	☐	☐	☐

4. Så ber vi deg ta stilling til noen utfordringer som en kan oppleve noen ganger. Ved hver påstand krysser du av for det svaret som passer for deg.

	Helt galt 1	*Nokså galt* 2	*Nokså riktig* 3	*Helt riktig* 4
1. Jeg klarer alltid å løse vanskelige problemer hvis jeg prøver hardt nok	☐	☐	☐	☐
2. Hvis noen motarbeider meg, så kan jeg finne måter og veier for å få det som jeg vil..........	☐	☐	☐	☐
3. Det er lett for meg å holde fast på planene mine og nå målene mine	☐	☐	☐	☐
4. Jeg føler meg trygg på at jeg ville kunne takle uventede hendelser på en effektiv måte.......	☐	☐	☐	☐
5. Takket være ressursene mine så vet jeg hvordan jeg skal takle uventede situasjoner	☐	☐	☐	☐
6. Jeg kan løse de fleste problemer hvis jeg går tilstrekkelig inn for det..........	☐	☐	☐	☐
7. Jeg beholder roen når jeg møter vanskeligheter fordi jeg stoler på mestringsevnen min......	☐	☐	☐	☐
8. Når jeg møter et problem, så finner jeg vanligvis flere løsninger på det..........	☐	☐	☐	☐
9. Hvis jeg er i knipe, finner jeg vanligvis en vei ut	☐	☐	☐	☐
10. Samme hva som hender, så er jeg vanligvis i stand til å takle det	☐	☐	☐	☐

Før du fortsetter: Kontroller at du ikke har glemt noe på denne sida.

Husk: Bare ett kryss på hvert spørsmål.

5. Her kommer noen påstander som handler om ditt forhold til andre mennesker. Hvordan stemmer dette for deg? Ta utgangspunkt i hvordan du har det nå.

	Helt enig 1	*Nokså enig* 2	*Både og* 3	*Nokså uenig* 4	*Helt uenig* 5
1. Jeg føler meg nært knyttet til vennene mine	☐	☐	☐	☐	☐
2. Vennene mine legger vekt på mine meninger	☐	☐	☐	☐	☐
3. Jeg kan regne med vennene mine når jeg trenger hjelp	☐	☐	☐	☐	☐
4. Jeg har god støtte i mine foreldre/foresatte	☐	☐	☐	☐	☐

6. Hvor stort problem har dette vært for deg i løpet av den *siste* måneden?

Helse og Aktiviteter (problemer med …)	*Aldri* 1	*Nesten aldri* 2	*Noen ganger* 3	*Ofte* 4	*Nesten alltid* 5
1. Det er vanskelig for meg å gå en tur	☐	☐	☐	☐	☐
2. Det er vanskelig for meg å løpe	☐	☐	☐	☐	☐
3. Det er vanskelig for meg å delta i idrettsaktiviteter eller trening	☐	☐	☐	☐	☐
4. Det er vanskelig for meg å løfte noe tungt	☐	☐	☐	☐	☐
5. Det er vanskelig for meg å bade eller dusje alene	☐	☐	☐	☐	☐
6. Det er vanskelig for meg å gjøre husarbeid	☐	☐	☐	☐	☐
7. Jeg har vondt eller smerter (*Hvis ja: Hvor?*⇩)	☐	☐	☐	☐	☐
8. Jeg har lite overskudd og energi	☐	☐	☐	☐	☐

9. Hvis du har vondt eller smerter: Hvor?⇩ STORE BLOKKBOKSTAVER, *ett tegn pr. felt.*

Følelsene mine (problemer med …)	*Aldri* 1	*Nesten aldri* 2	*Noen ganger* 3	*Ofte* 4	*Nesten alltid* 5
10. Jeg føler meg redd eller skremt	☐	☐	☐	☐	☐
11. Jeg føler meg nedfor og trist	☐	☐	☐	☐	☐
12. Jeg føler meg sint	☐	☐	☐	☐	☐
13. Jeg har problemer med å sove	☐	☐	☐	☐	☐
14. Jeg bekymrer meg over hva som vil skje med meg	☐	☐	☐	☐	☐

Hvordan jeg kommer overens med andre (problemer med …)	*Aldri* 1	*Nesten aldri* 2	*Noen ganger* 3	*Ofte* 4	*Nesten alltid* 5
15. Jeg har problemer med å komme overens med andre unge voksne	☐	☐	☐	☐	☐
16. Andre unge voksne vil ikke være venner med meg	☐	☐	☐	☐	☐
17. Andre unge voksne erter meg	☐	☐	☐	☐	☐
18. Jeg kan ikke gjøre ting som andre unge voksne på min alder kan	☐	☐	☐	☐	☐
19. Det er vanskelig å holde følge med vennene mine	☐	☐	☐	☐	☐

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Undersøkelsen gjennomføres med bistand fra SVT-IT, NTNU

3

Før du fortsetter: Kontroller at du ikke har glemt noe på denne sida.

Husk: Bare ett kryss på hvert spørsmål.

Arbeid og Skole (problemer med …)	*Aldri* 1	*Nesten aldri* 2	*Noen ganger* 3	*Ofte* 4	*Nesten alltid* 5
20. Det er vanskelig for meg å følge med i arbeid/skole	☐	☐	☐	☐	☐
21. Jeg glemmer ting	☐	☐	☐	☐	☐
22. Jeg har problemer med å gjøre mitt arbeid/skole	☐	☐	☐	☐	☐
23. Jeg er borte fra arbeid/skole fordi jeg ikke føler meg i form	☐	☐	☐	☐	☐
24. Jeg er borte fra arbeid/skole fordi jeg skal til lege/sykehus	☐	☐	☐	☐	☐

7. Spørsmålene under omhandler alvorlige livshendelser siste 12 måneder

	Ja 1	*Nei* 2
1. Har det vært dødsfall i nær familie?	☐	☐
2. Har det vært alvorlig sykdom i nær familie?	☐	☐
3. Har du vært i overhengende livsfare pga. alvorlig ulykke, katastrofe, voldssituasjon eller krig?	☐	☐
4. Har du hatt samlivsbrudd i ekteskap eller i (lengre) samboerforhold?	☐	☐
5. Har du opplevd samlivsbrudd hos dine foreldre?	☐	☐
6. Har du selv hatt en alvorlig sykdom?	☐	☐

7. Hvis du selv har hatt en alvorlig sykdom: Hva slags?⇩ STORE BLOKKBOKSTAVER, *ett tegn pr. felt.*

	Ikke i det hele tatt 1	*Litt* 2	*I moderat grad* 3	*I høy grad* 4
8. Hvis du har svart ja på et eller flere av spørsmålene ovenfor (spm. 7 om alvorlige livshendelser), i hvilken grad har du hatt negative reaksjoner på dette de siste 7 dagene? ⇨	☐	☐	☐	☐

B. BAKGRUNNSOPPLYSNINGER

1. Hva er din høyeste utdanning i dag?

- Har ikke fullført grunnskole ☐ 1
- Grunnskole (1-9/10 år) ☐ 2
- Videregående opplæring (10/11-12/13 år) ☐ 3
- Høyskole/universitet mindre enn 4 år ☐ 4
- Høyskole/universitet mer enn 4 år ☐ 5
- Annet (*Hva slags?*⇩) ☐ 6

2. Dersom du planlegger å ta mer utdanning? Hvilken? *NB: Her kan du sette flere kryss.*

- 1. Grunnskole (1-9/10 år) ☐
- 2. Videregående opplæring (10/11-12/13 år) ☐
- 3. Høyskole/universitet mindre enn 4 år ☐
- 4. Høyskole/universitet mer enn 4 år ☐
- 5. Annet (*Hva slags?*⇩) ☐

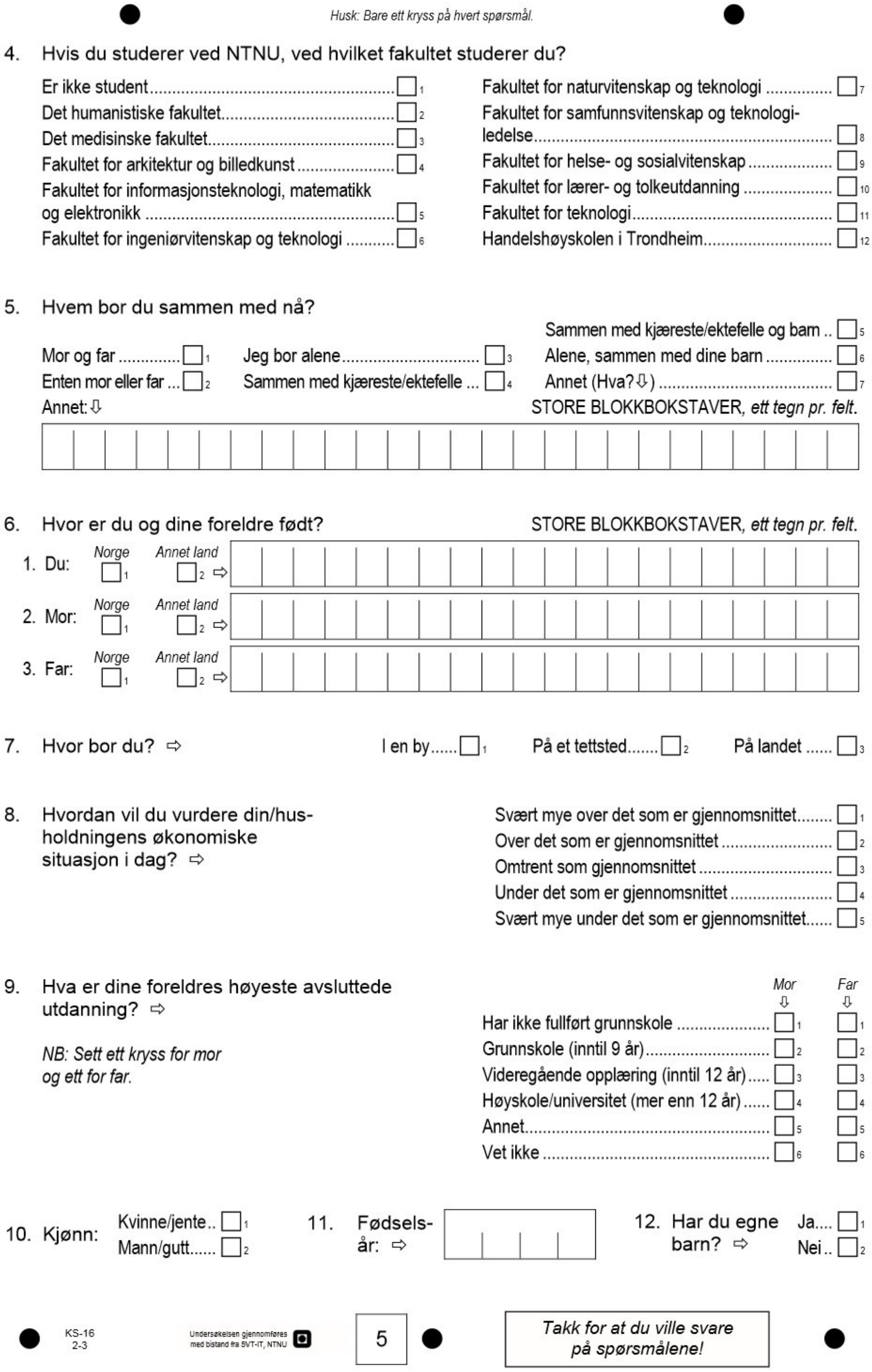
Annen type utdanning: ⇩ STORE BLOKKBOKSTAVER, *ett tegn pr. felt.*

3. Hva er din hovedbeskjeftigelse i dag? *Sett ett kryss for det som passer best.*

- I fulltidsjobb ☐ 1
- I deltidsjobb ☐ 2
- Student/elev ☐ 3
- Sykmeldt ☐ 4
- Overgangsstønad ☐ 5
- Arbeidsavklaring/attføring (NAV) ☐ 6
- Arbeidsledig (mottar dagpenger) ☐ 7
- Arbeidsledig (uten rett til dagpenger) ☐ 8
- Uføretrygdet ☐ 9
- Sosialhjelp som livsopphold ☐ 10
- Annet (*Hva?*⇩) ☐ 11

Annet: ⇩ STORE BLOKKBOKSTAVER, *ett tegn pr. felt.*

Før du fortsetter: Kontroller at du ikke har glemt noe på denne sida.



Husk: Bare ett kryss på hvert spørsmål.

4. Hvis du studerer ved NTNU, ved hvilket fakultet studerer du?

- Er ikke student ☐ 1
- Det humanistiske fakultet ☐ 2
- Det medisinske fakultet ☐ 3
- Fakultet for arkitektur og billedkunst ☐ 4
- Fakultet for informasjonsteknologi, matematikk og elektronikk ☐ 5
- Fakultet for ingeniørvitenskap og teknologi ☐ 6
- Fakultet for naturvitenskap og teknologi ☐ 7
- Fakultet for samfunnsvitenskap og teknologiledelse ☐ 8
- Fakultet for helse- og sosialvitenskap ☐ 9
- Fakultet for lærer- og tolkeutdanning ☐ 10
- Fakultet for teknologi ☐ 11
- Handelshøyskolen i Trondheim ☐ 12

5. Hvem bor du sammen med nå?

- Mor og far ☐ 1
- Enten mor eller far ☐ 2
- Jeg bor alene ☐ 3
- Sammen med kjæreste/ektefelle ☐ 4
- Sammen med kjæreste/ektefelle og barn ☐ 5
- Alene, sammen med dine barn ☐ 6
- Annet (Hva?⇩) ☐ 7

Annet: ⇩ STORE BLOKKBOKSTAVER, *ett tegn pr. felt.*

6. Hvor er du og dine foreldre født? STORE BLOKKBOKSTAVER, *ett tegn pr. felt.*

1. Du: *Norge* ☐ 1 *Annet land* ☐ 2 ⇨
2. Mor: *Norge* ☐ 1 *Annet land* ☐ 2 ⇨
3. Far: *Norge* ☐ 1 *Annet land* ☐ 2 ⇨

7. Hvor bor du? ⇨ I en by ☐ 1 På et tettsted ☐ 2 På landet ☐ 3

8. Hvordan vil du vurdere din/husholdningens økonomiske situasjon i dag? ⇨

- Svært mye over det som er gjennomsnittet ☐ 1
- Over det som er gjennomsnittet ☐ 2
- Omtrent som gjennomsnittet ☐ 3
- Under det som er gjennomsnittet ☐ 4
- Svært mye under det som er gjennomsnittet ☐ 5

9. Hva er dine foreldres høyeste avsluttede utdanning? ⇨

NB: Sett ett kryss for mor og ett for far.

	Mor ⇩	*Far* ⇩
Har ikke fullført grunnskole	☐ 1	☐ 1
Grunnskole (inntil 9 år)	☐ 2	☐ 2
Videregående opplæring (inntil 12 år)	☐ 3	☐ 3
Høyskole/universitet (mer enn 12 år)	☐ 4	☐ 4
Annet	☐ 5	☐ 5
Vet ikke	☐ 6	☐ 6

10. Kjønn: Kvinne/jente ☐ 1 Mann/gutt ☐ 2

11. Fødselsår: ⇨

12. Har du egne barn? ⇨ Ja ☐ 1 Nei ☐ 2

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Undersøkelsen gjennomføres med bistand fra SVT-IT, NTNU

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Takk for at du ville svare på spørsmålene!

Appendix C: Questionnaire answered by cancer survivors.

SINTEF NTNU

Du kan vinne et reise-gavekort På NOK 8 000!

Forespørsel om deltakelse i forskningsprosjekt "Helse- og velferdstjenester til ungdom under og etter kreftbehandling"

Du inviteres til å delta i et forskningsprosjekt for å undersøke unge som har eller har hatt kreft sine **erfaringer med helse- og velferdstjenestene** (sykehus, fastlege, skole, NAV, arbeidsplass, etc.) Deltakelse innebærer at du fyller ut vedlagte spørreskjema.

Du får denne henvendelsen fordi du i følge våre opplysninger er **mellom 18 og 30 år**, og fikk en kreftdiagnose etter at du fylte 10 år. Skulle dette være feil ber vi deg se bort i fra denne henvendelsen.

Hensikten med undersøkelsen er å **få økt kunnskap om de behov kreftrammet ungdom/unge voksne har,** både når det gjelder helsemessig oppfølging og tilrettelegging for utdanning og jobb. Undersøkelsen vil gi et kunnskapsgrunnlag for å bedre det offentlige tjenestetilbudet til denne gruppen.

Vi er med andre ord opptatt av å undersøke hvordan livet har vært, og er, etter at man har vært gjennom en kreftbehandling som barn, ungdom eller ung voksen. For noen har dette hatt liten betydning for videre skolegang og yrkesaktivitet, mens det for andre har vært avgjørende hvilken hjelp man har fått fra det offentlige tjenesteapparatet. **Vi er interessert i alle typer erfaringer gjort av deg som er eller har vært rammet av kreft, og håper du tar deg tid til å svare på skjemaet om dine erfaringer er gode eller mindre bra.** Jo flere som velger å delta jo bedre grunnlag får vi for å gjøre tjenestene enda bedre i fremtiden. Studien er finansiert gjennom forskningsmidler fra Kreftforeningen, og gjennomføres av forskningsstiftelsen SINTEF, Avdeling Helse, i samarbeid med forskere fra Norges teknisk-naturvitenskapelige universitet (NTNU).

Prosjektet er meldt inn til personvernombudet ved Norsk samfunnsvitenskapelig datatjeneste (NSD) og er godkjent av Regional komité for medisinsk og helsefaglig forskningsetikk (REK), sør-øst. REK har gitt tillatelse til at Kreftregisteret kan brukes til å finne frem til deg, og ditt sykehus har gjennomgått listen med ditt navn for å bekrefte at du er rett mottaker av vedlagte spørreskjema. Navnet ditt er ikke kjent for forskergruppen som utfører denne studien. Alle opplysningene vil bli behandlet uten navn og personnummer eller andre direkte gjenkjennelige opplysninger. For at det skal være mulig å gjøre oppfølgingsstudier, vil datamaterialet oppbevares i 10 år og slettes i 2022. Det vil **ikke** være mulig å identifisere deg i resultatene av studien når disse publisere.

Informasjonen du oppgir gjennom å fylle ut vedlagte spørreskjema skal kun brukes slik som beskrevet i hensikten med studien. Alle svarene behandles konfidensielt av SINTEF, som er databehandlingsansvarlig. Det er selvfølgelig helt frivillig å delta i studien. Hvis det er enkelte spørsmål du ikke kan eller ønsker å svare på så kan du hoppe over disse. **Ved at du sender inn skjemaet samtykker du til å delta i studien.** Som deltaker i studien har du rett til å få informasjon om utfallet/resultatet av studien.

Som takk for innsatsen kan du delta i trekningen av et reisegavekort på en reise av verdi på kr 8 000. Du kan selv velge om du vil delta i trekningen eller ikke ved å krysse av på det siste spørsmålet i skjemaet. Ønsker du å delta må du oppgi navn og telefonnummer/epost for at vi kan ta kontakt med deg om du er vinneren.

Vi håper at du kan avse ca 25-30 minutter til å besvare vedlagte spørreskjema. **Du kan også besvare det via nett** ved å gå inn på nettsiden www.sintef.no/ungeogkreft og klikke på lenke til spørreskjemaet.

Dersom du har spørsmål til studien eller til utfylling av spørreskjemaet kan du kontakte prosjektleder Heidi Jensberg på tlf 450 65 666 eller e-post heidi.jensberg@sintef.no. Hvis du ellers er bekymret for helsen din eller ønsker å snakke med noen om det vi spør om, oppfordrer vi deg til å ta kontakt med fastlegen din.

Heidi Jensberg, prosjektleder

Forsker, SINTEF Helse

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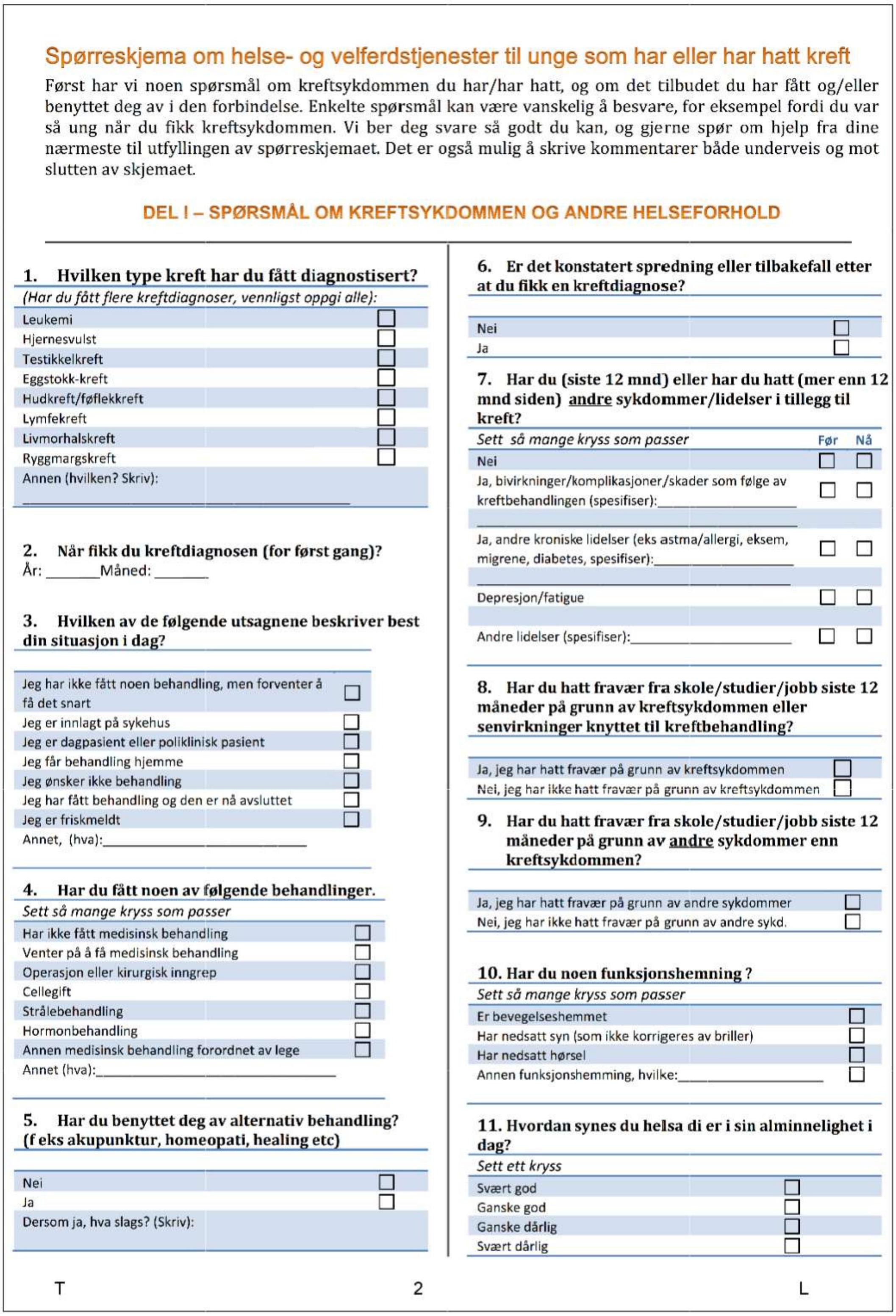

Spørreskjema om helse- og velferdstjenester til unge som har eller har hatt kreft

Først har vi noen spørsmål om kreftsykdommen du har/har hatt, og om det tilbudet du har fått og/eller benyttet deg av i den forbindelse. Enkelte spørsmål kan være vanskelig å besvare, for eksempel fordi du var så ung når du fikk kreftsykdommen. Vi ber deg svare så godt du kan, og gjerne spør om hjelp fra dine nærmeste til utfyllingen av spørreskjemaet. Det er også mulig å skrive kommentarer både underveis og mot slutten av skjemaet.

DEL I – SPØRSMÅL OM KREFTSYKDOMMEN OG ANDRE HELSEFORHOLD

1. Hvilken type kreft har du fått diagnostisert?

(Har du fått flere kreftdiagnoser, vennligst oppgi alle):

- Leukemi ☐
- Hjernesvulst ☐
- Testikkelkreft ☐
- Eggstokk-kreft ☐
- Hudkreft/føflekkreft ☐
- Lymfekreft ☐
- Livmorhalskreft ☐
- Ryggmargskreft ☐
- Annen (hvilken? Skriv):
  ____

2. Når fikk du kreftdiagnosen (for først gang)?

År: _______Måned: _______

3. Hvilken av de følgende utsagnene beskriver best din situasjon i dag?

- Jeg har ikke fått noen behandling, men forventer å få det snart ☐
- Jeg er innlagt på sykehus ☐
- Jeg er dagpasient eller poliklinisk pasient ☐
- Jeg får behandling hjemme ☐
- Jeg ønsker ikke behandling ☐
- Jeg har fått behandling og den er nå avsluttet ☐
- Jeg er friskmeldt ☐
- Annet, (hva):___________________________

4. Har du fått noen av følgende behandlinger.

Sett så mange kryss som passer

- Har ikke fått medisinsk behandling ☐
- Venter på å få medisinsk behandling ☐
- Operasjon eller kirurgisk inngrep ☐
- Cellegift ☐
- Strålebehandling ☐
- Hormonbehandling ☐
- Annen medisinsk behandling forordnet av lege ☐
- Annet (hva):_________________________________

5. Har du benyttet deg av alternativ behandling? (f eks akupunktur, homeopati, healing etc)

- Nei ☐
- Ja ☐
- Dersom ja, hva slags? (Skriv):

6. Er det konstatert spredning eller tilbakefall etter at du fikk en kreftdiagnose?

- Nei ☐
- Ja ☐

7. Har du (siste 12 mnd) eller har du hatt (mer enn 12 mnd siden) andre sykdommer/lidelser i tillegg til kreft?

Sett så mange kryss som passer	Før	Nå
Nei	☐	☐
Ja, bivirkninger/komplikasjoner/skader som følge av kreftbehandlingen (spesifiser):___________________ _______________________________________	☐	☐
Ja, andre kroniske lidelser (eks astma/allergi, eksem, migrene, diabetes, spesifiser):__________________ _______________________________________	☐	☐
Depresjon/fatigue	☐	☐
Andre lidelser (spesifiser):______________________	☐	☐

8. Har du hatt fravær fra skole/studier/jobb siste 12 måneder på grunn av kreftsykdommen eller senvirkninger knyttet til kreftbehandling?

- Ja, jeg har hatt fravær på grunn av kreftsykdommen ☐
- Nei, jeg har ikke hatt fravær på grunn av kreftsykdommen ☐

9. Har du hatt fravær fra skole/studier/jobb siste 12 måneder på grunn av andre sykdommer enn kreftsykdommen?

- Ja, jeg har hatt fravær på grunn av andre sykdommer ☐
- Nei, jeg har ikke hatt fravær på grunn av andre sykd. ☐

10. Har du noen funksjonshemning ?

Sett så mange kryss som passer

- Er bevegelseshemmet ☐
- Har nedsatt syn (som ikke korrigeres av briller) ☐
- Har nedsatt hørsel ☐
- Annen funksjonshemming, hvilke:____________________ ☐

11. Hvordan synes du helsa di er i sin alminnelighet i dag?

Sett ett kryss

- Svært god ☐
- Ganske god ☐
- Ganske dårlig ☐
- Svært dårlig ☐

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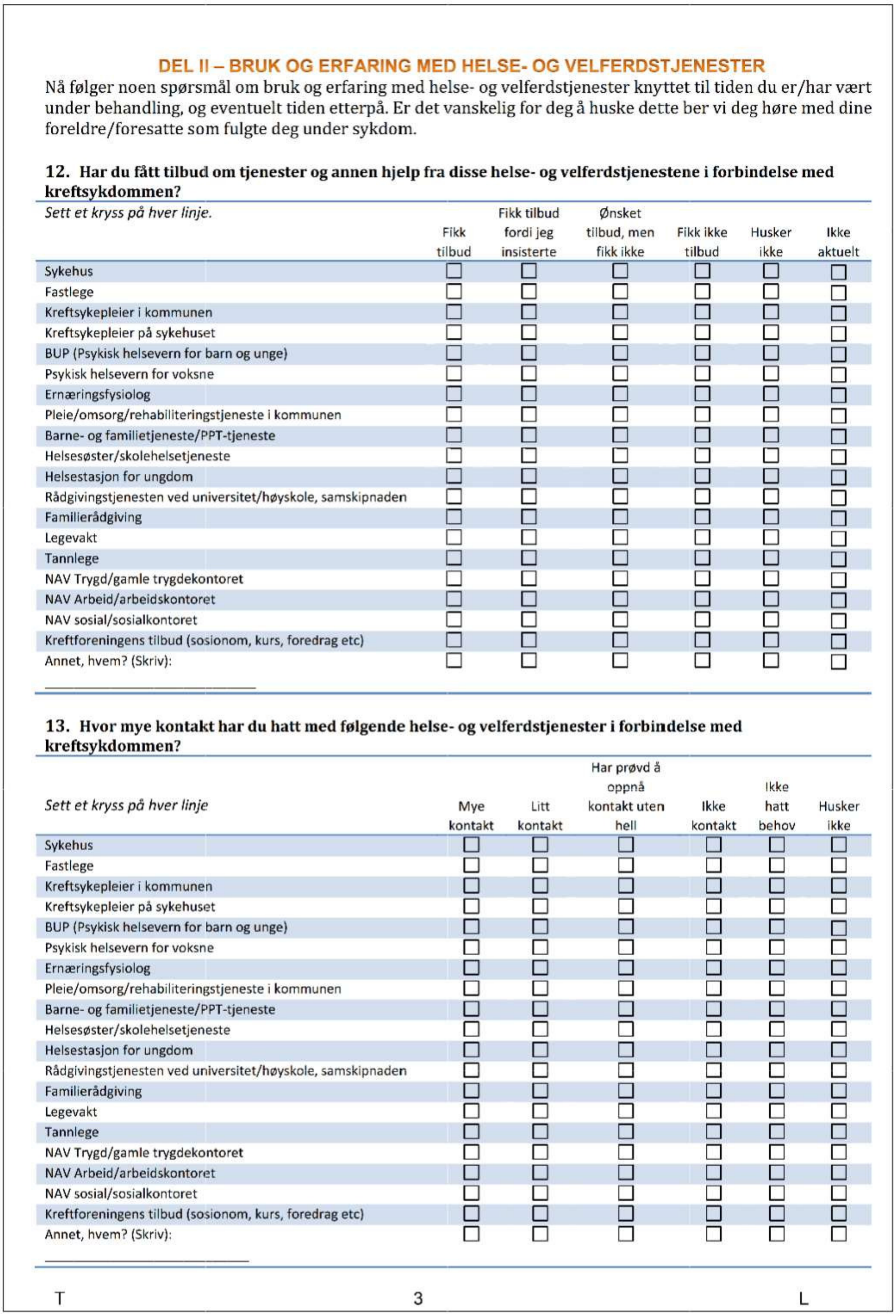

DEL II – BRUK OG ERFARING MED HELSE- OG VELFERDSTJENESTER

Nå følger noen spørsmål om bruk og erfaring med helse- og velferdstjenester knyttet til tiden du er/har vært under behandling, og eventuelt tiden etterpå. Er det vanskelig for deg å huske dette ber vi deg høre med dine foreldre/foresatte som fulgte deg under sykdom.

12. Har du fått tilbud om tjenester og annen hjelp fra disse helse- og velferdstjenestene i forbindelse med kreftsykdommen?

Sett et kryss på hver linje.	Fikk tilbud	Fikk tilbud fordi jeg insisterte	Ønsket tilbud, men fikk ikke	Fikk ikke tilbud	Husker ikke	Ikke aktuelt
Sykehus	☐	☐	☐	☐	☐	☐
Fastlege	☐	☐	☐	☐	☐	☐
Kreftsykepleier i kommunen	☐	☐	☐	☐	☐	☐
Kreftsykepleier på sykehuset	☐	☐	☐	☐	☐	☐
BUP (Psykisk helsevern for barn og unge)	☐	☐	☐	☐	☐	☐
Psykisk helsevern for voksne	☐	☐	☐	☐	☐	☐
Ernæringsfysiolog	☐	☐	☐	☐	☐	☐
Pleie/omsorg/rehabiliteringstjeneste i kommunen	☐	☐	☐	☐	☐	☐
Barne- og familietjeneste/PPT-tjeneste	☐	☐	☐	☐	☐	☐
Helsesøster/skolehelsetjeneste	☐	☐	☐	☐	☐	☐
Helsestasjon for ungdom	☐	☐	☐	☐	☐	☐
Rådgivingstjenesten ved universitet/høyskole, samskipnaden	☐	☐	☐	☐	☐	☐
Familierådgiving	☐	☐	☐	☐	☐	☐
Legevakt	☐	☐	☐	☐	☐	☐
Tannlege	☐	☐	☐	☐	☐	☐
NAV Trygd/gamle trygdekontoret	☐	☐	☐	☐	☐	☐
NAV Arbeid/arbeidskontoret	☐	☐	☐	☐	☐	☐
NAV sosial/sosialkontoret	☐	☐	☐	☐	☐	☐
Kreftforeningens tilbud (sosionom, kurs, foredrag etc)	☐	☐	☐	☐	☐	☐
Annet, hvem? (Skriv): ______________________	☐	☐	☐	☐	☐	☐

13. Hvor mye kontakt har du hatt med følgende helse- og velferdstjenester i forbindelse med kreftsykdommen?

Sett et kryss på hver linje	Mye kontakt	Litt kontakt	Har prøvd å oppnå kontakt uten hell	Ikke kontakt	Ikke hatt behov	Husker ikke
Sykehus	☐	☐	☐	☐	☐	☐
Fastlege	☐	☐	☐	☐	☐	☐
Kreftsykepleier i kommunen	☐	☐	☐	☐	☐	☐
Kreftsykepleier på sykehuset	☐	☐	☐	☐	☐	☐
BUP (Psykisk helsevern for barn og unge)	☐	☐	☐	☐	☐	☐
Psykisk helsevern for voksne	☐	☐	☐	☐	☐	☐
Ernæringsfysiolog	☐	☐	☐	☐	☐	☐
Pleie/omsorg/rehabiliteringstjeneste i kommunen	☐	☐	☐	☐	☐	☐
Barne- og familietjeneste/PPT-tjeneste	☐	☐	☐	☐	☐	☐
Helsesøster/skolehelsetjeneste	☐	☐	☐	☐	☐	☐
Helsestasjon for ungdom	☐	☐	☐	☐	☐	☐
Rådgivingstjenesten ved universitet/høyskole, samskipnaden	☐	☐	☐	☐	☐	☐
Familierådgiving	☐	☐	☐	☐	☐	☐
Legevakt	☐	☐	☐	☐	☐	☐
Tannlege	☐	☐	☐	☐	☐	☐
NAV Trygd/gamle trygdekontoret	☐	☐	☐	☐	☐	☐
NAV Arbeid/arbeidskontoret	☐	☐	☐	☐	☐	☐
NAV sosial/sosialkontoret	☐	☐	☐	☐	☐	☐
Kreftforeningens tilbud (sosionom, kurs, foredrag etc)	☐	☐	☐	☐	☐	☐
Annet, hvem? (Skriv): ______________________	☐	☐	☐	☐	☐	☐

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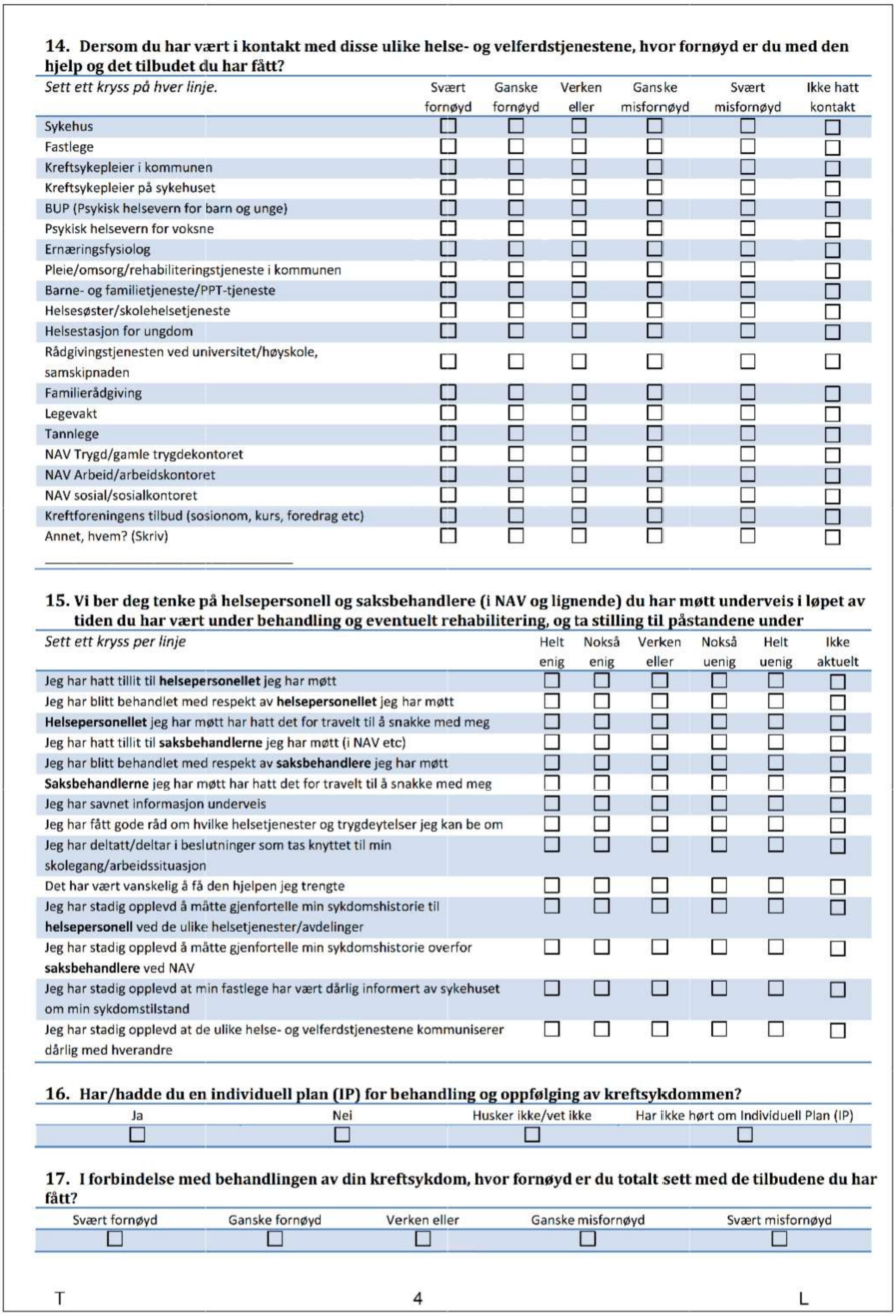


14. Dersom du har vært i kontakt med disse ulike helse- og velferdstjenestene, hvor fornøyd er du med den hjelp og det tilbudet du har fått?

Sett ett kryss på hver linje.	Svært fornøyd	Ganske fornøyd	Verken eller	Ganske misfornøyd	Svært misfornøyd	Ikke hatt kontakt
Sykehus	☐	☐	☐	☐	☐	☐
Fastlege	☐	☐	☐	☐	☐	☐
Kreftsykepleier i kommunen	☐	☐	☐	☐	☐	☐
Kreftsykepleier på sykehuset	☐	☐	☐	☐	☐	☐
BUP (Psykisk helsevern for barn og unge)	☐	☐	☐	☐	☐	☐
Psykisk helsevern for voksne	☐	☐	☐	☐	☐	☐
Ernæringsfysiolog	☐	☐	☐	☐	☐	☐
Pleie/omsorg/rehabiliteringstjeneste i kommunen	☐	☐	☐	☐	☐	☐
Barne- og familietjeneste/PPT-tjeneste	☐	☐	☐	☐	☐	☐
Helsesøster/skolehelsetjeneste	☐	☐	☐	☐	☐	☐
Helsestasjon for ungdom	☐	☐	☐	☐	☐	☐
Rådgivingstjenesten ved universitet/høyskole, samskipnaden	☐	☐	☐	☐	☐	☐
Familierådgiving	☐	☐	☐	☐	☐	☐
Legevakt	☐	☐	☐	☐	☐	☐
Tannlege	☐	☐	☐	☐	☐	☐
NAV Trygd/gamle trygdekontoret	☐	☐	☐	☐	☐	☐
NAV Arbeid/arbeidskontoret	☐	☐	☐	☐	☐	☐
NAV sosial/sosialkontoret	☐	☐	☐	☐	☐	☐
Kreftforeningens tilbud (sosionom, kurs, foredrag etc)	☐	☐	☐	☐	☐	☐
Annet, hvem? (Skriv) ____________________________	☐	☐	☐	☐	☐	☐

15. Vi ber deg tenke på helsepersonell og saksbehandlere (i NAV og lignende) du har møtt underveis i løpet av tiden du har vært under behandling og eventuelt rehabilitering, og ta stilling til påstandene under

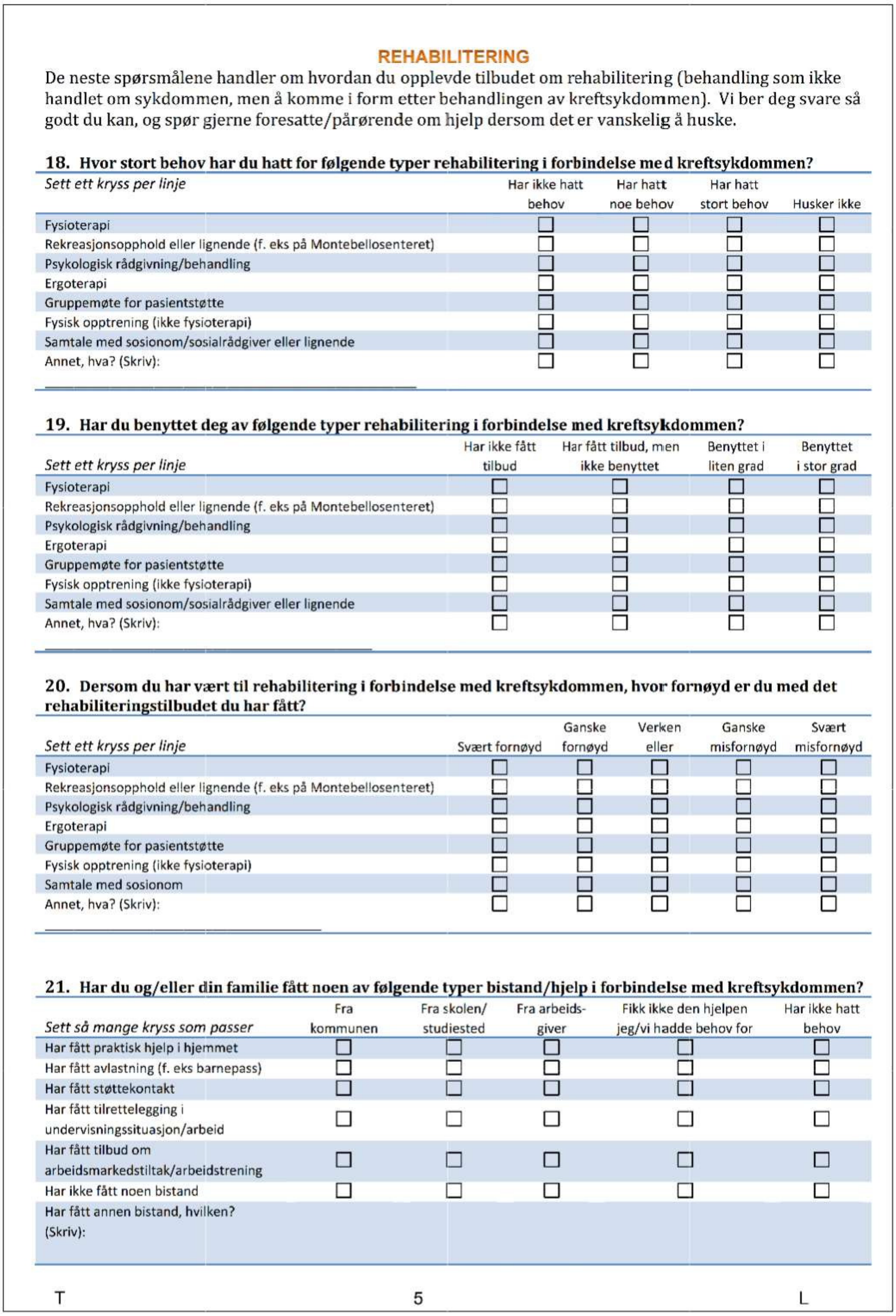
Sett ett kryss per linje	Helt enig	Nokså enig	Verken eller	Nokså uenig	Helt uenig	Ikke aktuelt
Jeg har hatt tillit til **helsepersonellet** jeg har møtt	☐	☐	☐	☐	☐	☐
Jeg har blitt behandlet med respekt av **helsepersonellet** jeg har møtt	☐	☐	☐	☐	☐	☐
Helsepersonellet jeg har møtt har hatt det for travelt til å snakke med meg	☐	☐	☐	☐	☐	☐
Jeg har hatt tillit til **saksbehandlerne** jeg har møtt (i NAV etc)	☐	☐	☐	☐	☐	☐
Jeg har blitt behandlet med respekt av **saksbehandlere** jeg har møtt	☐	☐	☐	☐	☐	☐
Saksbehandlerne jeg har møtt har hatt det for travelt til å snakke med meg	☐	☐	☐	☐	☐	☐
Jeg har savnet informasjon underveis	☐	☐	☐	☐	☐	☐
Jeg har fått gode råd om hvilke helsetjenester og trygdeytelser jeg kan be om	☐	☐	☐	☐	☐	☐
Jeg har deltatt/deltar i beslutninger som tas knyttet til min skolegang/arbeidssituasjon	☐	☐	☐	☐	☐	☐
Det har vært vanskelig å få den hjelpen jeg trengte	☐	☐	☐	☐	☐	☐
Jeg har stadig opplevd å måtte gjenfortelle min sykdomshistorie til **helsepersonell** ved de ulike helsetjenester/avdelinger	☐	☐	☐	☐	☐	☐
Jeg har stadig opplevd å måtte gjenfortelle min sykdomshistorie overfor **saksbehandlere** ved NAV	☐	☐	☐	☐	☐	☐
Jeg har stadig opplevd at min fastlege har vært dårlig informert av sykehuset om min sykdomstilstand	☐	☐	☐	☐	☐	☐
Jeg har stadig opplevd at de ulike helse- og velferdstjenestene kommuniserer dårlig med hverandre	☐	☐	☐	☐	☐	☐

16. Har/hadde du en individuell plan (IP) for behandling og oppfølging av kreftsykdommen?

Ja	Nei	Husker ikke/vet ikke	Har ikke hørt om Individuell Plan (IP)
☐	☐	☐	☐

17. I forbindelse med behandlingen av din kreftsykdom, hvor fornøyd er du totalt sett med de tilbudene du har fått?

Svært fornøyd	Ganske fornøyd	Verken eller	Ganske misfornøyd	Svært misfornøyd
☐	☐	☐	☐	☐



REHABILITERING

De neste spørsmålene handler om hvordan du opplevde tilbudet om rehabilitering (behandling som ikke handlet om sykdommen, men å komme i form etter behandlingen av kreftsykdommen). Vi ber deg svare så godt du kan, og spør gjerne foresatte/pårørende om hjelp dersom det er vanskelig å huske.

18. Hvor stort behov har du hatt for følgende typer rehabilitering i forbindelse med kreftsykdommen?

Sett ett kryss per linje	Har ikke hatt behov	Har hatt noe behov	Har hatt stort behov	Husker ikke
Fysioterapi	☐	☐	☐	☐
Rekreasjonsopphold eller lignende (f. eks på Montebellosenteret)	☐	☐	☐	☐
Psykologisk rådgivning/behandling	☐	☐	☐	☐
Ergoterapi	☐	☐	☐	☐
Gruppemøte for pasientstøtte	☐	☐	☐	☐
Fysisk opptrening (ikke fysioterapi)	☐	☐	☐	☐
Samtale med sosionom/sosialrådgiver eller lignende	☐	☐	☐	☐
Annet, hva? (Skriv): ________________________________	☐	☐	☐	☐

19. Har du benyttet deg av følgende typer rehabilitering i forbindelse med kreftsykdommen?

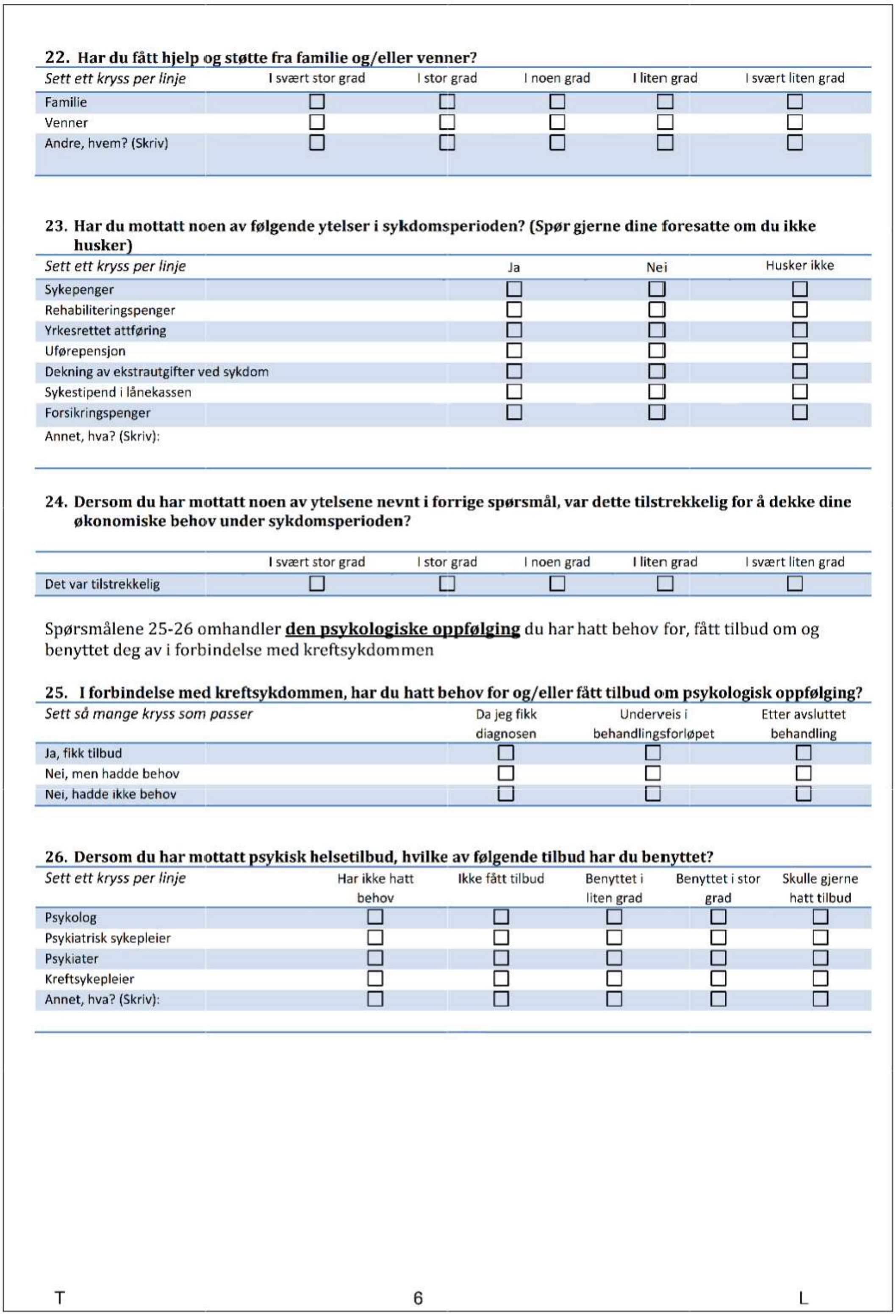
Sett ett kryss per linje	Har ikke fått tilbud	Har fått tilbud, men ikke benyttet	Benyttet i liten grad	Benyttet i stor grad
Fysioterapi	☐	☐	☐	☐
Rekreasjonsopphold eller lignende (f. eks på Montebellosenteret)	☐	☐	☐	☐
Psykologisk rådgivning/behandling	☐	☐	☐	☐
Ergoterapi	☐	☐	☐	☐
Gruppemøte for pasientstøtte	☐	☐	☐	☐
Fysisk opptrening (ikke fysioterapi)	☐	☐	☐	☐
Samtale med sosionom/sosialrådgiver eller lignende	☐	☐	☐	☐
Annet, hva? (Skriv): ____________________________	☐	☐	☐	☐

20. Dersom du har vært til rehabilitering i forbindelse med kreftsykdommen, hvor fornøyd er du med det rehabiliteringstilbudet du har fått?

Sett ett kryss per linje	Svært fornøyd	Ganske fornøyd	Verken eller	Ganske misfornøyd	Svært misfornøyd
Fysioterapi	☐	☐	☐	☐	☐
Rekreasjonsopphold eller lignende (f. eks på Montebellosenteret)	☐	☐	☐	☐	☐
Psykologisk rådgivning/behandling	☐	☐	☐	☐	☐
Ergoterapi	☐	☐	☐	☐	☐
Gruppemøte for pasientstøtte	☐	☐	☐	☐	☐
Fysisk opptrening (ikke fysioterapi)	☐	☐	☐	☐	☐
Samtale med sosionom	☐	☐	☐	☐	☐
Annet, hva? (Skriv): __________________________	☐	☐	☐	☐	☐

21. Har du og/eller din familie fått noen av følgende typer bistand/hjelp i forbindelse med kreftsykdommen?

Sett så mange kryss som passer	Fra kommunen	Fra skolen/ studiested	Fra arbeids-giver	Fikk ikke den hjelpen jeg/vi hadde behov for	Har ikke hatt behov
Har fått praktisk hjelp i hjemmet	☐	☐	☐	☐	☐
Har fått avlastning (f. eks barnepass)	☐	☐	☐	☐	☐
Har fått støttekontakt	☐	☐	☐	☐	☐
Har fått tilrettelegging i undervisningssituasjon/arbeid	☐	☐	☐	☐	☐
Har fått tilbud om arbeidsmarkedstiltak/arbeidstrening	☐	☐	☐	☐	☐
Har ikke fått noen bistand	☐	☐	☐	☐	☐
Har fått annen bistand, hvilken? (Skriv):					



22. Har du fått hjelp og støtte fra familie og/eller venner?

Sett ett kryss per linje	I svært stor grad	I stor grad	I noen grad	I liten grad	I svært liten grad
Familie	☐	☐	☐	☐	☐
Venner	☐	☐	☐	☐	☐
Andre, hvem? (Skriv)	☐	☐	☐	☐	☐

23. Har du mottatt noen av følgende ytelser i sykdomsperioden? (Spør gjerne dine foresatte om du ikke husker)

Sett ett kryss per linje	Ja	Nei	Husker ikke
Sykepenger	☐	☐	☐
Rehabiliteringspenger	☐	☐	☐
Yrkesrettet attføring	☐	☐	☐
Uførepensjon	☐	☐	☐
Dekning av ekstrautgifter ved sykdom	☐	☐	☐
Sykestipend i lånekassen	☐	☐	☐
Forsikringspenger	☐	☐	☐
Annet, hva? (Skriv):			

24. Dersom du har mottatt noen av ytelsene nevnt i forrige spørsmål, var dette tilstrekkelig for å dekke dine økonomiske behov under sykdomsperioden?

	I svært stor grad	I stor grad	I noen grad	I liten grad	I svært liten grad
Det var tilstrekkelig	☐	☐	☐	☐	☐

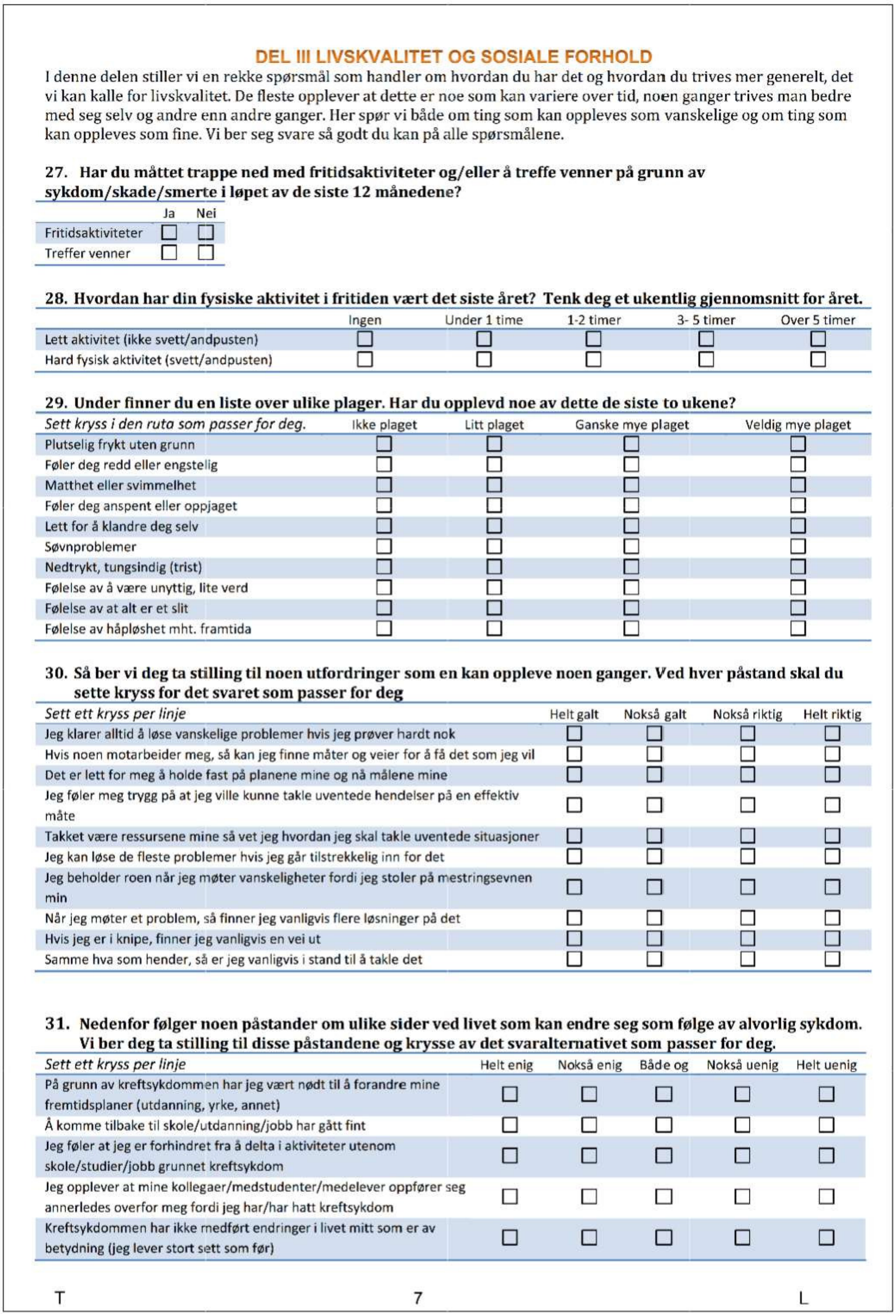
Spørsmålene 25-26 omhandler **den psykologiske oppfølging** du har hatt behov for, fått tilbud om og benyttet deg av i forbindelse med kreftsykdommen

25. I forbindelse med kreftsykdommen, har du hatt behov for og/eller fått tilbud om psykologisk oppfølging?

Sett så mange kryss som passer	Da jeg fikk diagnosen	Underveis i behandlingsforløpet	Etter avsluttet behandling
Ja, fikk tilbud	☐	☐	☐
Nei, men hadde behov	☐	☐	☐
Nei, hadde ikke behov	☐	☐	☐

26. Dersom du har mottatt psykisk helsetilbud, hvilke av følgende tilbud har du benyttet?

Sett ett kryss per linje	Har ikke hatt behov	Ikke fått tilbud	Benyttet i liten grad	Benyttet i stor grad	Skulle gjerne hatt tilbud
Psykolog	☐	☐	☐	☐	☐
Psykiatrisk sykepleier	☐	☐	☐	☐	☐
Psykiater	☐	☐	☐	☐	☐
Kreftsykepleier	☐	☐	☐	☐	☐
Annet, hva? (Skriv):	☐	☐	☐	☐	☐



DEL III LIVSKVALITET OG SOSIALE FORHOLD

I denne delen stiller vi en rekke spørsmål som handler om hvordan du har det og hvordan du trives mer generelt, det vi kan kalle for livskvalitet. De fleste opplever at dette er noe som kan variere over tid, noen ganger trives man bedre med seg selv og andre enn andre ganger. Her spør vi både om ting som kan oppleves som vanskelige og om ting som kan oppleves som fine. Vi ber seg svare så godt du kan på alle spørsmålene.

27. Har du måttet trappe ned med fritidsaktiviteter og/eller å treffe venner på grunn av sykdom/skade/smerte i løpet av de siste 12 månedene?

	Ja	Nei
Fritidsaktiviteter	☐	☐
Treffer venner	☐	☐

28. Hvordan har din fysiske aktivitet i fritiden vært det siste året? Tenk deg et ukentlig gjennomsnitt for året.

	Ingen	Under 1 time	1-2 timer	3- 5 timer	Over 5 timer
Lett aktivitet (ikke svett/andpusten)	☐	☐	☐	☐	☐
Hard fysisk aktivitet (svett/andpusten)	☐	☐	☐	☐	☐

29. Under finner du en liste over ulike plager. Har du opplevd noe av dette de siste to ukene?

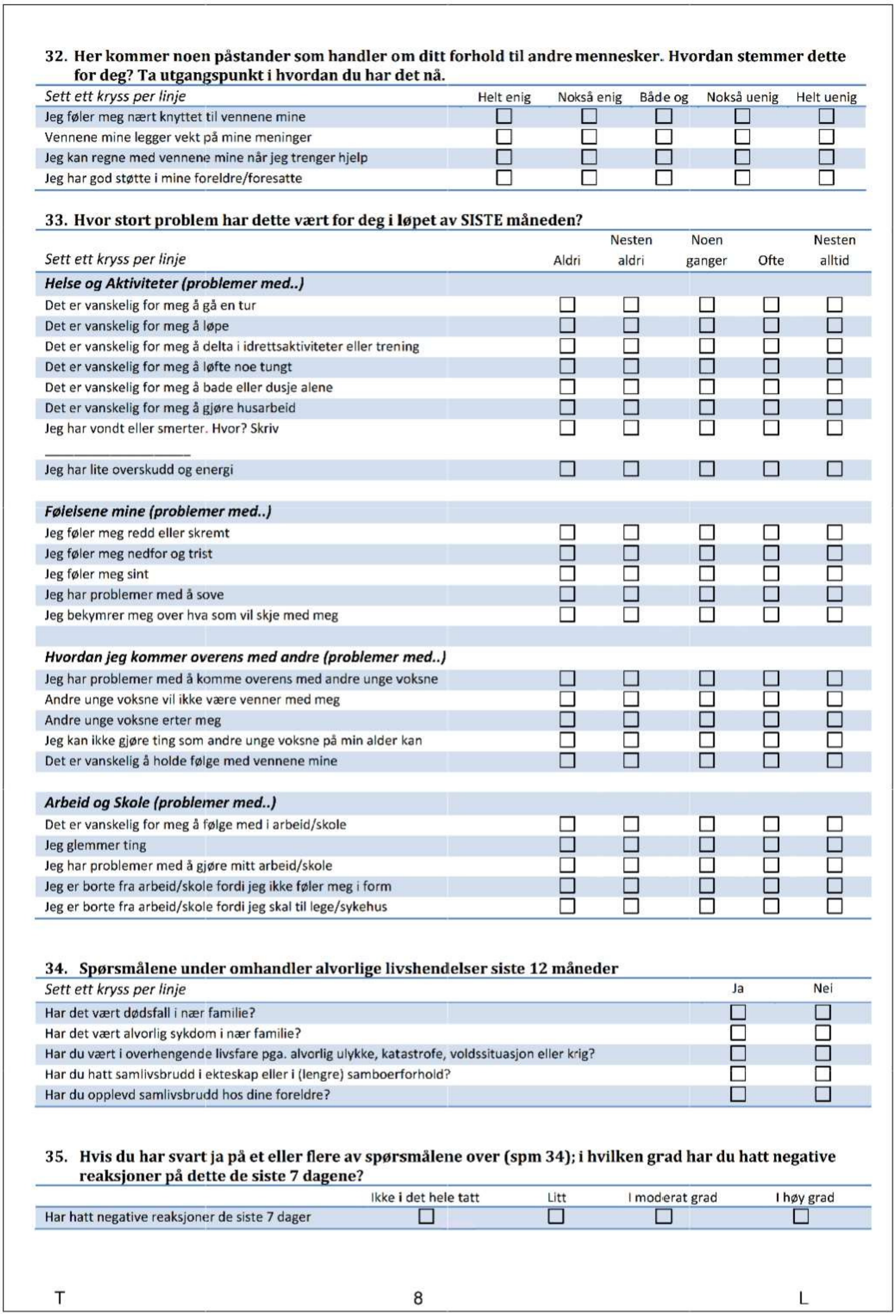
Sett kryss i den ruta som passer for deg.	Ikke plaget	Litt plaget	Ganske mye plaget	Veldig mye plaget
Plutselig frykt uten grunn	☐	☐	☐	☐
Føler deg redd eller engstelig	☐	☐	☐	☐
Matthet eller svimmelhet	☐	☐	☐	☐
Føler deg anspent eller oppjaget	☐	☐	☐	☐
Lett for å klandre deg selv	☐	☐	☐	☐
Søvnproblemer	☐	☐	☐	☐
Nedtrykt, tungsindig (trist)	☐	☐	☐	☐
Følelse av å være unyttig, lite verd	☐	☐	☐	☐
Følelse av at alt er et slit	☐	☐	☐	☐
Følelse av håpløshet mht. framtida	☐	☐	☐	☐

30. Så ber vi deg ta stilling til noen utfordringer som en kan oppleve noen ganger. Ved hver påstand skal du sette kryss for det svaret som passer for deg

Sett ett kryss per linje	Helt galt	Nokså galt	Nokså riktig	Helt riktig
Jeg klarer alltid å løse vanskelige problemer hvis jeg prøver hardt nok	☐	☐	☐	☐
Hvis noen motarbeider meg, så kan jeg finne måter og veier for å få det som jeg vil	☐	☐	☐	☐
Det er lett for meg å holde fast på planene mine og nå målene mine	☐	☐	☐	☐
Jeg føler meg trygg på at jeg ville kunne takle uventede hendelser på en effektiv måte	☐	☐	☐	☐
Takket være ressursene mine så vet jeg hvordan jeg skal takle uventede situasjoner	☐	☐	☐	☐
Jeg kan løse de fleste problemer hvis jeg går tilstrekkelig inn for det	☐	☐	☐	☐
Jeg beholder roen når jeg møter vanskeligheter fordi jeg stoler på mestringsevnen min	☐	☐	☐	☐
Når jeg møter et problem, så finner jeg vanligvis flere løsninger på det	☐	☐	☐	☐
Hvis jeg er i knipe, finner jeg vanligvis en vei ut	☐	☐	☐	☐
Samme hva som hender, så er jeg vanligvis i stand til å takle det	☐	☐	☐	☐

31. Nedenfor følger noen påstander om ulike sider ved livet som kan endre seg som følge av alvorlig sykdom. Vi ber deg ta stilling til disse påstandene og krysse av det svaralternativet som passer for deg.

Sett ett kryss per linje	Helt enig	Nokså enig	Både og	Nokså uenig	Helt uenig
På grunn av kreftsykdommen har jeg vært nødt til å forandre mine fremtidsplaner (utdanning, yrke, annet)	☐	☐	☐	☐	☐
Å komme tilbake til skole/utdanning/jobb har gått fint	☐	☐	☐	☐	☐
Jeg føler at jeg er forhindret fra å delta i aktiviteter utenom skole/studier/jobb grunnet kreftsykdom	☐	☐	☐	☐	☐
Jeg opplever at mine kollegaer/medstudenter/medelever oppfører seg annerledes overfor meg fordi jeg har/har hatt kreftsykdom	☐	☐	☐	☐	☐
Kreftsykdommen har ikke medført endringer i livet mitt som er av betydning (jeg lever stort sett som før)	☐	☐	☐	☐	☐



32. Her kommer noen påstander som handler om ditt forhold til andre mennesker. Hvordan stemmer dette for deg? Ta utgangspunkt i hvordan du har det nå.

Sett ett kryss per linje	Helt enig	Nokså enig	Både og	Nokså uenig	Helt uenig
Jeg føler meg nært knyttet til vennene mine	☐	☐	☐	☐	☐
Vennene mine legger vekt på mine meninger	☐	☐	☐	☐	☐
Jeg kan regne med vennene mine når jeg trenger hjelp	☐	☐	☐	☐	☐
Jeg har god støtte i mine foreldre/foresatte	☐	☐	☐	☐	☐

33. Hvor stort problem har dette vært for deg i løpet av SISTE måneden?

Sett ett kryss per linje	Aldri	Nesten aldri	Noen ganger	Ofte	Nesten alltid
Helse og Aktiviteter (problemer med..)					
Det er vanskelig for meg å gå en tur	☐	☐	☐	☐	☐
Det er vanskelig for meg å løpe	☐	☐	☐	☐	☐
Det er vanskelig for meg å delta i idrettsaktiviteter eller trening	☐	☐	☐	☐	☐
Det er vanskelig for meg å løfte noe tungt	☐	☐	☐	☐	☐
Det er vanskelig for meg å bade eller dusje alene	☐	☐	☐	☐	☐
Det er vanskelig for meg å gjøre husarbeid	☐	☐	☐	☐	☐
Jeg har vondt eller smerter. Hvor? Skriv ____________________	☐	☐	☐	☐	☐
Jeg har lite overskudd og energi	☐	☐	☐	☐	☐
Følelsene mine (problemer med..)					
Jeg føler meg redd eller skremt	☐	☐	☐	☐	☐
Jeg føler meg nedfor og trist	☐	☐	☐	☐	☐
Jeg føler meg sint	☐	☐	☐	☐	☐
Jeg har problemer med å sove	☐	☐	☐	☐	☐
Jeg bekymrer meg over hva som vil skje med meg	☐	☐	☐	☐	☐
Hvordan jeg kommer overens med andre (problemer med..)					
Jeg har problemer med å komme overens med andre unge voksne	☐	☐	☐	☐	☐
Andre unge voksne vil ikke være venner med meg	☐	☐	☐	☐	☐
Andre unge voksne erter meg	☐	☐	☐	☐	☐
Jeg kan ikke gjøre ting som andre unge voksne på min alder kan	☐	☐	☐	☐	☐
Det er vanskelig å holde følge med vennene mine	☐	☐	☐	☐	☐
Arbeid og Skole (problemer med..)					
Det er vanskelig for meg å følge med i arbeid/skole	☐	☐	☐	☐	☐
Jeg glemmer ting	☐	☐	☐	☐	☐
Jeg har problemer med å gjøre mitt arbeid/skole	☐	☐	☐	☐	☐
Jeg er borte fra arbeid/skole fordi jeg ikke føler meg i form	☐	☐	☐	☐	☐
Jeg er borte fra arbeid/skole fordi jeg skal til lege/sykehus	☐	☐	☐	☐	☐

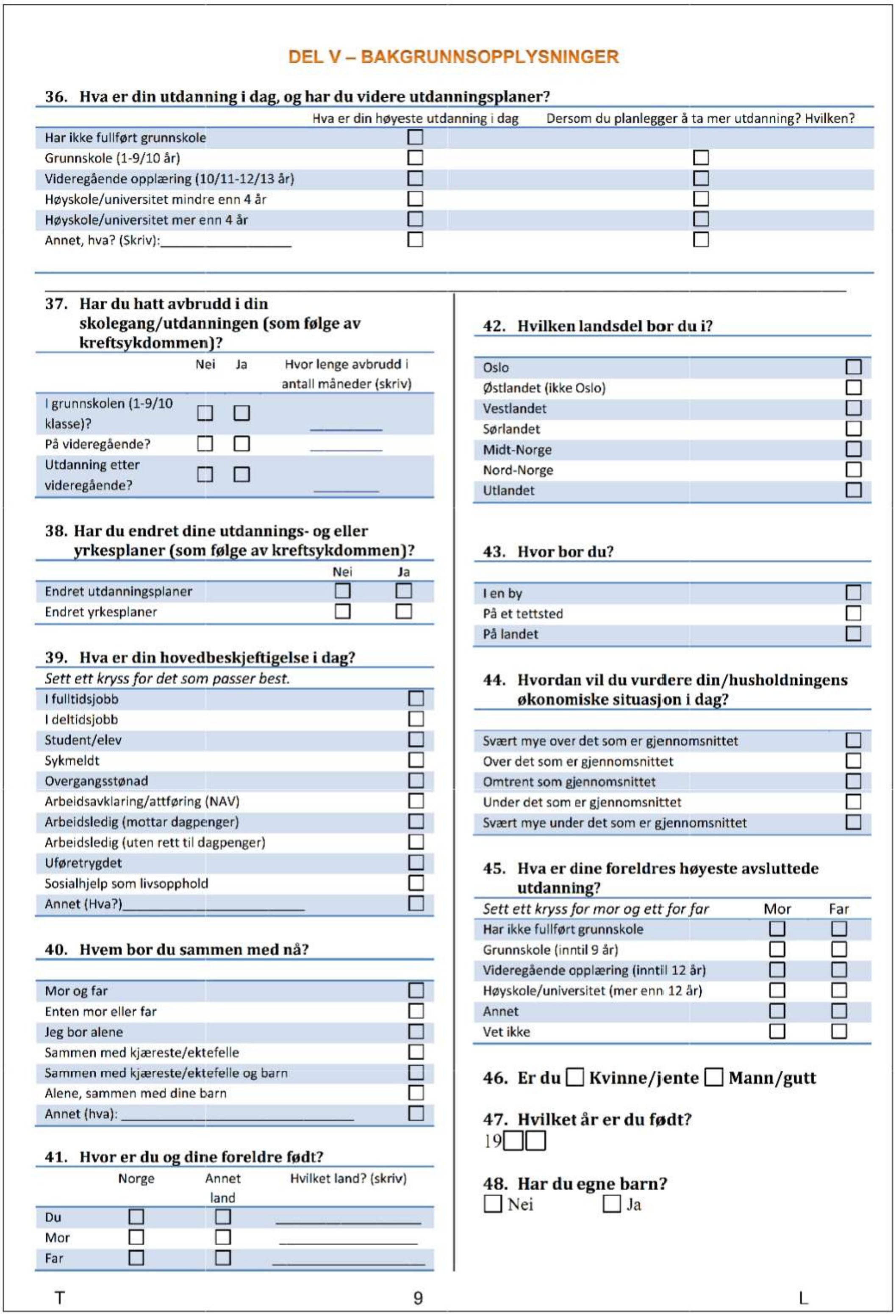
34. Spørsmålene under omhandler alvorlige livshendelser siste 12 måneder

Sett ett kryss per linje	Ja	Nei
Har det vært dødsfall i nær familie?	☐	☐
Har det vært alvorlig sykdom i nær familie?	☐	☐
Har du vært i overhengende livsfare pga. alvorlig ulykke, katastrofe, voldssituasjon eller krig?	☐	☐
Har du hatt samlivsbrudd i ekteskap eller i (lengre) samboerforhold?	☐	☐
Har du opplevd samlivsbrudd hos dine foreldre?	☐	☐

35. Hvis du har svart ja på et eller flere av spørsmålene over (spm 34); i hvilken grad har du hatt negative reaksjoner på dette de siste 7 dagene?

	Ikke i det hele tatt	Litt	I moderat grad	I høy grad
Har hatt negative reaksjoner de siste 7 dager	☐	☐	☐	☐

T 8 L



DEL V – BAKGRUNNSOPPLYSNINGER

36. Hva er din utdanning i dag, og har du videre utdanningsplaner?

	Hva er din høyeste utdanning i dag	Dersom du planlegger å ta mer utdanning? Hvilken?
Har ikke fullført grunnskole	☐	
Grunnskole (1-9/10 år)	☐	☐
Videregående opplæring (10/11-12/13 år)	☐	☐
Høyskole/universitet mindre enn 4 år	☐	☐
Høyskole/universitet mer enn 4 år	☐	☐
Annet, hva? (Skriv):________________	☐	☐

37. Har du hatt avbrudd i din skolegang/utdanningen (som følge av kreftsykdommen)?

	Nei	Ja	Hvor lenge avbrudd i antall måneder (skriv)
I grunnskolen (1-9/10 klasse)?	☐	☐	________
På videregående?	☐	☐	________
Utdanning etter videregående?	☐	☐	________

38. Har du endret dine utdannings- og eller yrkesplaner (som følge av kreftsykdommen)?

	Nei	Ja
Endret utdanningsplaner	☐	☐
Endret yrkesplaner	☐	☐

39. Hva er din hovedbeskjeftigelse i dag?

Sett ett kryss for det som passer best.

I fulltidsjobb	☐
I deltidsjobb	☐
Student/elev	☐
Sykmeldt	☐
Overgangsstønad	☐
Arbeidsavklaring/attføring (NAV)	☐
Arbeidsledig (mottar dagpenger)	☐
Arbeidsledig (uten rett til dagpenger)	☐
Uføretrygdet	☐
Sosialhjelp som livsopphold	☐
Annet (Hva?)____________________	☐

40. Hvem bor du sammen med nå?

Mor og far	☐
Enten mor eller far	☐
Jeg bor alene	☐
Sammen med kjæreste/ektefelle	☐
Sammen med kjæreste/ektefelle og barn	☐
Alene, sammen med dine barn	☐
Annet (hva): ________________________	☐

41. Hvor er du og dine foreldre født?

	Norge	Annet land	Hvilket land? (skriv)
Du	☐	☐	______________
Mor	☐	☐	______________
Far	☐	☐	______________

42. Hvilken landsdel bor du i?

Oslo	☐
Østlandet (ikke Oslo)	☐
Vestlandet	☐
Sørlandet	☐
Midt-Norge	☐
Nord-Norge	☐
Utlandet	☐

43. Hvor bor du?

I en by	☐
På et tettsted	☐
På landet	☐

44. Hvordan vil du vurdere din/husholdningens økonomiske situasjon i dag?

Svært mye over det som er gjennomsnittet	☐
Over det som er gjennomsnittet	☐
Omtrent som gjennomsnittet	☐
Under det som er gjennomsnittet	☐
Svært mye under det som er gjennomsnittet	☐

45. Hva er dine foreldres høyeste avsluttede utdanning?

Sett ett kryss for mor og ett for far	Mor	Far
Har ikke fullført grunnskole	☐	☐
Grunnskole (inntil 9 år)	☐	☐
Videregående opplæring (inntil 12 år)	☐	☐
Høyskole/universitet (mer enn 12 år)	☐	☐
Annet	☐	☐
Vet ikke	☐	☐

46. Er du ☐ Kvinne/jente ☐ Mann/gutt

47. Hvilket år er du født?

19☐☐

48. Har du egne barn?

☐ Nei ☐ Ja

T 9 L

Til slutt ber vi deg tenke tilbake på tiden du har vært syk og tiden etterpå, og notere ned hva du har opplevd som det beste og det verste. Dersom du har forslag til hva som kunne vært bedre ber vi deg skrive ned det også.

49. Hvis du ser på tilbudet du har fått under og etter kreftbehandlingen totalt sett:

a) Hva var du **mest fornøyd** med? (Skriv)

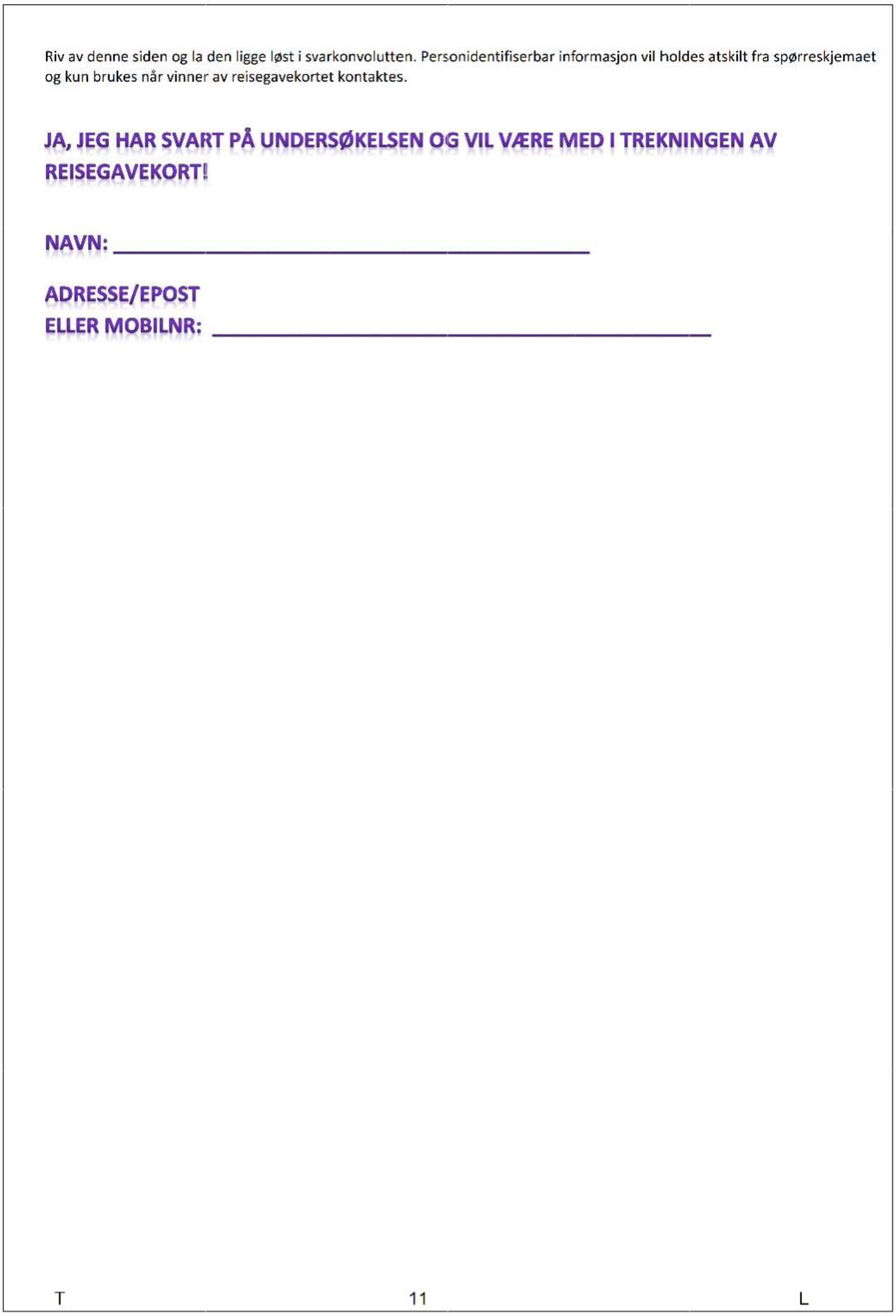
b) Hva var du **minst fornøyd** med? (Skriv)

c) Hva kan **bli bedre?** (Skriv)

50. Her kan du skrive kommentarer til selve undersøkelsen

TUSEN TAKK FOR AT DU BIDRO I DENNE UNDERSØKELSEN!

Dersom du ønsker å delta i trekningen av reisegavekortet på kr 8 000 må du fylle ut kontaktinformasjon på neste side. Dette er nødvendig om vi skal kunne kontakte deg om det er du som vinner.



Riv av denne siden og la den ligge løst i svarkonvolutten. Personidentifiserbar informasjon vil holdes atskilt fra spørreskjemaet og kun brukes når vinner av reisegavekortet kontaktes.

JA, JEG HAR SVART PÅ UNDERSØKELSEN OG VIL VÆRE MED I TREKNINGEN AV REISEGAVEKORT!

NAVN: ______________________________________

ADRESSE/EPOST
ELLER MOBILNR: ____

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