Assessment of diet quality and lifestyle behaviors among cancer survivors at a cancer-related meeting place

A cross-sectional study

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Abstract

Background. Diet, weight and physical activity are regarded as major modifiable risk factors in cancer development. Efforts in preventing cancer are made globally by developing and continually updating guidelines. Cancer survivors are vulnerable to secondary cancers and other diseases and benefit from lifestyle changes post-diagnosis, but compliance to the health recommendations might not be optimal.

Objectives. To examine the proportion of cancer survivors meeting cancer-associated dietary and lifestyle recommendations at Vardesenteret, a cancer-related meeting place, to identify dietary challenges among men and women, and further compare findings of diet quality and lifestyle with a validated method.

Method. A short diet questionnaire (DQ) was distributed to 257 cancer survivors visiting the Vardesenters in Oslo. Eighty-two percent (n=211) returned the questionnaire. Diet quality was assessed by evaluating reported intake against the Norwegian Food-Based Dietary Guidelines (NFBDG) of vegetables, fruit and berries ("5-a-day"), wholegrain and red and processed meat. Lifestyle factors evaluated included body mass index (BMI), smoking, alcohol use and physical activity (PA). Diet quality, in addition to alcohol intake and PA, was compared to the validated NORDIET food frequency questionnaire (FFQ) in a sub-group of the study population.

Results. A total of 193 cancer survivors were included in the study. Mean age of the population was 60 years (SD 12), 64% were women and 73% had university background. Five-a-day, wholegrain, red meat and processed meat recommendations were reported met by 16%, 43%, 98% and 58%, respectively. Fewer men reported meeting the 5-a-day and limited processed meat recommendation compared to women. Forty-six percent were overweight or obese, 6% were current smokers and 8% had higher alcohol intake than recommended. One third met the PA recommendation. Seventy-one of the cancer survivors also completed the NORDIET-FFQ, reporting similar dietary challenges.

Conclusion. Well-educated cancer survivors have dietary challenges requiring further effort and advocacy at Vardesenteret. A red meat intake within recommendation is reported by most survivors, but adherence to the 5-a-day recommendation, especially in men, and the wholegrain recommendation can be improved.

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List of abbreviations

AHEI – Alternative Healthy Eating Index

AICR – American Institute for Cancer Research

aMED – Alternative Mediterranean Score

BMI – Body Mass Index

CAM – Complementary and Alternative Medicine

CPR – Cancer Prevention Recommendations

CRC – Colorectal cancer

CUP – Continuous Update Project

DASH – Dietary Approaches to Stop Hypertension

DQ – Diet Questionnaire

DQI – Diet Quality Index

FFQ – Food Frequency Questionnaire

HEI – Healthy Eating Index

HRQOL – Health Related Quality of Life

IARC – International Agency for Research on Cancer

NCD – Non-communicable Diseases

NFBDG – Norwegian Food Based Dietary Guidelines

PA – Physical Activity

WCRF – World Cancer Research Fund

WHO – World Health Organization

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1   Background

1.1   Cancer and nutrition

Today's research has emphasized the importance of a proper diet for the prevention of different non-communicable diseases (NCDs). World Cancer Research Fund (WCRF) reports that about a third of the most common cancers can be prevented by a healthy diet, healthy weight and regular physical activity (1), while figures from the Norwegian Institute of Public Health indicate cancer to be the most important cause of death in the population under 70 years in Norway (2). The number of cancer survivors is rising due to improved survival and an aging population (3). WCRF defines cancer survivors as "all people who have been diagnosed with cancer, including before, during and after treatment" (4). In absence of nutritional and physical impairments, a healthy diet and lifestyle are both important during and after a cancer diagnosis as cancer survivors are shown to be at increased risk for secondary cancer and other lifestyle diseases (5). Avoidance of excessive ultraviolet radiation to the skin and prevention of long-term infections that can cause cancer are important in cancer prevention, but these are also less modifiable risk factors. Maintaining a healthy weight, healthy diet and physical activity (PA) are considered the major modifiable risk factors after smoking and other tobacco use (6). Over the years, the importance of the diet has moved from only focusing on the effect of single nutrients and dietary components to a more holistic approach (7). As the diet is complex, and food and nutrients are consumed in combination, it is difficult to attribute health outcomes to certain foods or nutrients. The diet is, however, with no doubt an important contributing factor in NCDs.

1.1.1   World Cancer Research Fund (WCRF)

The research on cancer and nutrition is comprehensive. The many years of research have provided a great body of evidence on proposed effects of diet and dietary components on cancer risk. WCRF promotes cancer prevention through diet, weight and PA and is considered the leading, scientific source in this field. The organization constitutes of American Institute for Cancer Research (AICR) and three branches in Netherlands, Hong Kong and the UK who contribute in analyzing global research on cancer prevention and survival. Through the Continuous Update Project (CUP), research from all around the world is collected, systematically reviewed by an independent expert panel and summarized to form the Cancer

Prevention Recommendations (CPR) (**figure 1.1.**). The result of this project is a comprehensive expert report. The third and latest report was published in 2018 and is the basis of the recommendations given today, implying increased or limited intake of different dietary components, being physically active and at a healthy weight (8). Although certain food and nutrients are associated with decreasing or increasing risk of cancer, the CPR provides a package of healthy behaviors relating to diet, PA and weight maintenance. The expert panel emphasizes that the most benefit of the recommendations is gained when treated as an integrated pattern of behaviors. Evidence shows that following a pattern similar to the 2007 CPR reduces the risk of new cancer cases, dying of cancer and dying of all causes (9, 10). In other words, diet quality is important for cancer survivors; they are recommended to follow the CPR to the extent possible and unless otherwise advised by health professionals.

Figure 1.1. The World Cancer Research Fund's Cancer Prevention Recommendations (11)

When reviewing the WCRF/AICR Expert Report, the evidence supporting the core of the CPR is graded. The evidence is graded "strong", either convincing or causal, "limited", either suggestive or no conclusion, or as "substantial effect on risk unlikely". Strong evidence supports a judgement of either convincing or probable causal relationship and justifies making recommendations, the former being more persuasive and more unlikely to change than the latter. Limited evidence can either be limited in numbers, methodological flaws or divergent results. Limited, suggestive evidence is however consistent and suggestive of direction of effect, but too incomplete to permit convincing or probable causal judgement. Exposures judged as "substantial effect on risk unlikely" are supported by strong evidence of an unlikely causal relation to cancer outcome. When forming the recommendations, the expert panel has focused on the evidence judged as "strong" where possible.

In addition to diet quality and dietary risk factors, maintaining a healthy weight constitutes an important part of the CPR. Adult body fatness is reported with strong evidence to increase the risk of 12 cancers (12). International Agency for Research on Cancer (IARC) reported sufficient evidence of preventive association for additional three cancer diagnoses: meningioma, thyroid cancer and multiple myeloma (13). The evidence shows that the more excess weight people have as adults, the higher the risk of cancer; the exception is pre-menopausal breast cancer where the risk is generally lower. However, the latter association is complex and not heavily weighted in regards to the recommendations. Weight gain in adults is also reported to increase the risk of post-menopausal breast cancer. Due to the importance of maintaining a healthy weight, recommendations are made for dietary factors affecting body fatness. Being physically active plays a major role in keeping a healthy weight, but it also affects other metabolic, immunologic and endocrinologic processes in the body that may affect cancer risk. This knowledge points out a crucial part of cancer prevention. Although made specifically for cancer, the CPR also aim to reduce the risk of other NCDs.

1.1.2   European Code against Cancer

The European Code against Cancer, a project coordinated by the IARC, constitutes of experts and scientist from across the European Union with the aim to inform people about cancer preventive actions (14). The 4th European Code introduced "12 ways to reduce your cancer risk", which to a great extent cover the recommendations of WCRF/AIRC. While the latter has developed recommendations for diet, physical activity and weight maintenance only, the Code's recommendations comprise important actions to prevent cancer development (**textbox 1.1**). It is suggested that half of all cancer deaths in Europe could be avoided if the recommendations were followed. The Code's emphasis on a healthy diet is plenty of wholegrain, pulses, vegetables and fruits and limited red and processed meat, salty foods, high-calorie foods and sugary drinks. For the dietary recommendations, the WCRF/AICR Second Expert Report from 2007 has been dominant for the evidence base (15).

Textbox 1.1. The European Code against Cancer's 12 ways to reduce cancer risk.

1.1.3   Norwegian Food-Based Dietary Guidelines (NFBDG)

Many countries develop national dietary guidelines for the purpose of lifestyle-related disease prevention to fit the food culture and intake of the population. There is an overall agreement between these dietary recommendations, both among countries and with international guidelines. The Norwegian Food-Based Dietary Guidelines (NFBDG) contain 12 recommendations based on the 2011 report from the National Nutrition Council which systematically summarizes research on the prevention of chronic diseases (**textbox 1.2**) (16). The recommendations are based on Norwegian staple foods and food culture, but can be incorporated and modified to fit individual preferences and other cultures. The NFBDG correspond with the newly published guidelines for a healthy diet by World Health Organization (WHO) (17). Whereas the European Code's 12 ways are merely cancer-specific actions, the CPR and NFBDG aim to reduce NCDs with diet and PA. Some recommendations

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are made for the purpose of weight maintenance, but in regards to more direct effect on cancer, key dietary principles include increased consumption of wholegrains, vegetables, fruit and berries and limited consumption of red and processed meat. This proposes an approach of diet quality assessment.

The Norwegian Dietary Guidelines

1. Enjoy a varied diet with lots of vegetables, fruit and berries, whole-grain foods and fish, and limited amounts of processed meat, red meat, salt and sugar.
2. Maintain a good balance between the amount of energy you obtain through food and drink and the amount of energy you expend through physical activity.
3. Eat at least five portions of vegetables, fruit and berries every day.
4. Eat wholegrain foods every day.
5. Eat fish two to three times a week. You can also use fish as a spread on bread.
6. Choose lean meat and lean meat products. Limit the amount of processed meat and red meat.
7. Include low-fat dairy foods in your daily diet.
8. Choose edible oils, liquid margarine and soft margarine spreads instead of hard margarines and butter.
9. Choose foods that are low in salt and limit the use of salt when preparing food and at the table.
10. Avoid foods and drinks that are high in sugar.
11. Choose water as a thirst-quencher.
12. Be physically active for at least 30 minutes each day.

Textbox 1.2. The Norwegian Dietary Guidelines.

1.2 The key dietary principles of cancer prevention

The prevention of cancer related to diet involves preventing excessive calorie intake, increasing protective factors and decreasing risk factors. To avoid weight gain, one is recommended to limit "fast foods" and other processed food, as well as to limit consumption of sugar sweetened drinks. The NFBDG also advocate a low intake of sugar-rich foods. Additionally, the guidelines promote a high intake of low-energy, nutritious food, aiding adequate nutrient intake and avoidance of weight gain.

1.2.1 Wholegrains, vegetables and fruit

The WCRF/AICR Expert Report and the European Code recommend making wholegrains, vegetables, fruits and beans a part of usual dietary intake. In general, there is convincing evidence that the more wholegrains and food containing dietary fiber that people consume, the lower the risk of colorectal cancer (CRC) in particular. The evidence concerning non-starchy vegetables and fruits is only judged limited-suggestive in the Third Expert Report.

However, the evidence is consistent in the same direction, showing a probable protective effect against different aerodigestive cancers. Consumption of non-starchy vegetables and fruits is also consistent with dietary patterns associated with lower risk of cancer and other NCDs. Although the evidence is not strong separately, it is judged strong when aggregated and the recommendation is considered important in cancer prevention. The NFBDG contain two food-based recommendations for wholegrains, vegetables and fruit: it is recommended to consume four wholegrain portions equaling 70-90g of wholegrains per day and five portions of vegetables, fruit and berries per day ("5-a-day") to help meet the recommended intake of fiber, vitamins and minerals.

1.2.2   Red and processed meat

The consumption of red meat is recommended to be moderate. Red meat includes all mammalian muscle meat from beef, veal, lamb, pork, horse and goat. As meat is an important source of protein and iron for many individuals, the recommendation is not to exclude it from the diet, but research has reported strong, probable evidence that high intake increases the risk of CRC (18, 19). Strong evidence indicates similar outcome for processed meat. Processed meat is not generally defined, but WCRF refers it to be all meat that has gone through "salting, curing, fermentation, smoking or other processes to enhance flavor or improve preservation" (18). The guidelines recommend the consumption of processed meat to be none or as little as possible. The NFBDG recommend to limit the intake of red meat, including processed red meat, to 500g cooked weight per week.

1.2.3   Dairy products

Strong, probable evidence that dairy products may protect against CRC is presented in the Third Expert report. However, a specific recommendation for cancer prevention has not been made. Studies have suggested dairy products to increase the risk of prostate cancer, and though the strength of the evidence is insufficient to make a recommendation, precaution has been made. The NFBDG recommend using low-fat dairy products, but not for the purpose of cancer prevention; dairy products provide the population with important nutrients as protein, calcium and iodine due to high consumption. As findings associated with cancer are inconsistent, the European Code does not address consumption of dairy products in their guideline.

1.2.4   Alcohol

Although not a dietary factor by definition, the recommendation to limit alcohol consumption is based on strong evidence that alcohol increases the risk of eight cancers, as well as other NCDs. The risk is dependent on the amount and frequency consumed, but increases with all types of alcoholic drinks as ethanol acts as the cancer causing agent (20). A probable positive effect of moderate alcohol consumption (up to two alcoholic drinks per day) on kidney cancer is reported; this finding is, however, far outweighed by the increased risk of other cancers as stated in the recommendations (20). There is not a specific recommendation for alcohol in the NFBDG, but European and Norwegian national guidelines recommend limited alcohol consumption, less than 10g of alcohol (one unit) per day for women and 20g (two units) per day for men (21, 22).

1.3   Diet quality indices and cancer risk

The shift in dietary research from studying single nutrients to overall diet has provided evidence for the importance of diet quality. To assess diet quality, indices have been developed. Throughout the literature, associations between higher scores on diet quality indices (DQIs) and positive health outcomes have been established. Using a DQI, means using a a-priori approach; that is a score which provides a summary of dietary habits according to predefined criteria of what a healthy or unhealthy diet entails (23). These kinds of indices are usually measured as the degree of adherence to a set of national nutritional guidelines or specific dietary patterns based on foods, food groups or nutrients, or in combination. The patterns and indices differ to some extent, but a "healthy" diet is most commonly rich in fruit, vegetables, wholegrains, nuts, legumes, low-fat dairy products, fish and other seafood, and low in red and processed meat, sugary and alcoholic beverages, and table salt (24). *Milajerdi et.al.* reported a significant inverse association between cancer mortality and three DQIs: the Dietary Approaches to Stop Hypertension diet (DASH), the Alternative Healthy Eating Index (AHEI) and the Healthy Eating Index (HEI) (25). Similar findings on the positive effects of a high diet quality have been reported (26, 27).

Although the diet is not clearly defined, the Mediterranean diet has also been drawn out to be protective. WCRF reports a probable decreased risk of weight gain, overweight and obesity following a Mediterranean type dietary pattern (6). Indices, both including and excluding moderate alcohol consumption as part of the dietary score, have been used in

assessing the effect of the diet on disease risk and mortality. Research suggests that a higher adherence to the diet is associated with reduced risk of certain types of cancer (25, 26, 28).

It is postulated that cancer survivors may have a particularly motivation for lifestyle changes. *Fassier et.al.* addressed dietary modifications before and after cancer diagnosis in the NutriNet Santé cohort study; they observed more favorable changes (reduction in alcohol and sweetened drinks consumption) and less favorable changes (reduction of vegetable consumption and many vitamins and minerals), suggesting that "cancer diagnosis is a key period of nutritional changes" (29). *Demark-Wahnefried et.al.* refer to it as "the teachable moment" created by cancer diagnosis and an opportunity to improve long-term health in a vulnerable population (30). Improving lifestyle among cancer patients and survivors is suggested to make a significant difference for life quality and reduction of mortality. *Mercedes et.al.* found a dose-dependent-relationship between change in diet quality over a 12-year period using AHEI, DASH and alternative Mediterranean score (aMED), and total mortality among healthy individuals. A 20-percentile increase in diet quality scores was associated with 8 to 17% decrease in all-cause mortality, while a worsening diet quality over 12 years was associated with an increase in mortality of 6 to 12%. It was, however, no consistency with cancer mortality. Despite examining healthy individuals, these results might suggest a beneficial effect of changing the diet quality among cancer survivors, as they are more prone to secondary diseases.

1.4   Dietary challenges among cancer survivors

WCRF recommends all cancer survivors to follow the CPR to the extent possible and unless otherwise advised by health professionals. While the term survivors comprise all individuals who have been diagnosed with cancer, cancer patients comprise primarily survivors awaiting or receiving treatment (31). Cancer patients are especially vulnerable to weight loss and malnutrition due to metabolic changes and treatment (31). An example is head and neck cancer patients, whom due to the disease and intensive treatment experience impaired oral intake and thereby magnified risk of malnutrition (32). Rapid weight loss is associated with impaired treatment, reduced immune system, more side effects, longer hospital stays and increased expenses (33). If not identified and treated, cancer cachexia, characterized by abnormal metabolism, muscle protein depletion and impaired physical function, can aggravate the disease and increase mortality. Identification of individuals in need of nutritional support is crucial to prevent development of malnutrition or cachexia. In Norwegian hospitals, it is estimated that

every third patient is malnourished or at risk of malnutrition (34). The Norwegian health authorities have therefore recommended implementation of nutritional risk screening in all hospitals on admission and when necessary for early detection of nutritional impairments (35). It is postulated that 50-90% of cancer patients experience weight loss (36), meaning they are especially at risk for developing malnutrition.

Prevention of weight loss is important for all cancer survivors under active treatment independent of BMI, age and diagnose, explaining why following the cancer preventive dietary recommendations is not of priority in any part of the cancer process if nutritional impairments exist. However, the long-term effects of healthy dietary changes must be considered when conditions allow and should be attempted when perceived beneficial for the survivor. Following the CPR or NFBDG, increase the intake of nutritious, low-calorie foods and reduce intake of high-energy, unhealthy foods, promoting a healthy diet and weight maintenance or weight loss if needed. Weight loss is not recommended during treatment due to risk of malnutrition, but as overweight and obesity are important risk factors for cancer, gradual weight loss after treatment, if appropriate, is most probably favorable to improve survival and prevent secondary diseases (37).

The recommendations of WCRF and Norwegian health authorities target individuals capable of and who benefit from dietary changes. While some might criticize the recommendations to be ineffective because of the growing cancer population, the compliance to the recommendations is highly questionable. The latest national dietary survey in Norway (Norkost 3, 2010-2011) reported low adherence to vegetables and fruits, wholegrain and PA recommendations, ranging from 14% for vegetables and 26% for wholegrain (38). Although assumed to be more motivated, studies addressing lifestyle factors in cancer survivors indicate inconsistent compliance to the health recommendations. *Zhang et.al.* found that cancer survivors had a significant lower score on the HEI-2010 index compared to the non-cancer group, whereas survivors were more likely to be current smokers with poorer diet quality than non-smokers (39). Although most cancer survivors report making positive health behavior changes after cancer, the level of change might be limited (40). Internationally, research reports that the majority of survivors refrain from smoking and have low alcohol intake, but adherence to 5-a-day ranges from 14-34%, PA recommendation from 30-47%, while overweight and obesity are present in 54-70% of the survivors (39, 41-44).

1.5   Cancer in Norway

For the past decade, the number of people living with cancer in Norway has increased with 47% (45). However, the annual increase between 2013-2017 has been relatively small. The Cancer Registry of Norway publishes an annual report about cancer incidence, mortality, survival and prevalence. The newest report available is from 2017.

Statistics show that breast cancer most frequently occur in women aging 25-70 years. While testicular cancer is most frequent in men aged 25-49 years, prostate cancer is more common from 50 years and older. For the younger population under 50 years, there is an increasing rate of melanoma in both men and women. The highest survival rates are found among prostate, breast, melanoma and colon cancer survivors. Improved screening and treatment allow more people to live longer and better after a cancer diagnosis; in 2017, it was estimated that over 5% of the population were cancer survivors.

Survivors might live better, but it is also known that more of them live with side-effects from diagnosis and treatment. Research shows that many cancer survivors experience psychosocial distress affecting quality of life, whereas fear of cancer recurrence is highly prevalent (46, 47). As postulated by several, the window of opportunity to promote lifestyle changes after a cancer diagnosis can be essential in the survivors' lives. Lifestyle changes among survivors have been associated with increased health related quality of life (HRQOL). There is convincing evidence that PA affect HRQOL (48, 49). However, *Kassianos et.al.* also reported a suggestive positive association between dietary change and HRQOL, especially for breast, prostate and colon cancer patients (50). The authors concluded with mixed findings and a need for more research, but also with an argument that especially cancer survivors rather than patients under treatment might have the benefit of dietary changes. With the lack of control during diagnosis and treatment, lifestyle factors may present as an opportunity to make self-controlled decisions and thereby increasing HRQOL (51). An effort to improve long-term survival by preventing or delaying cancer recurrence or disease development in survivors will be an important matter for the public health.

1.6 Vardesenteret

Receiving a cancer diagnosis is distressing in many ways, not only for the cancer survivors themselves, but also for the relatives. *Vardesenteret* is a meeting place meant as a recreation ground for both cancer patients, survivors and relatives. It is a collaboration between Norwegian hospitals and the Norwegian Cancer Society (Nor: Kreftforeningen). The first center was established in 2010, but today there is a total of seven centers around Norway. Two of them are located in Oslo at the Radium hospital and Ullevål hospital (Oslo University Hospital). Except being a haven for cancer survivors and relatives, Vardesenteret offers many services, including counselling, legal assistance, diet courses and guidance, leisure activities among others, mostly provided by volunteers. Additionally, Vardesenteret collaborates with the hospitals' patient education program, "Læring- og mestringssenteret" and rehabilitation program, "Kreftrehabiliteringssenteret", that both offer patient centered courses at the Vardesenter's locations. There is also collaboration with Active against Cancer's (Nor: Aktiv mot kreft) established training rooms, Pusterommet. At Ullevål, Pusterommet has joint locations with Vardesenteret.

As a growing and well utilized offer for cancer survivors, the Vardesenters provide help to cope with the disease, as well as promoting life quality and well-being. The centers in Oslo have many visitors; out of the yearly 14 000 visitors, approximately 90% are cancer survivors. Although the number does not consistently reflect various individuals, the centers reach a large group. However, to this date, there has not been conducted any nutrition-related research to study the visitors. The lack of data on lifestyle measures and dietary habits makes it difficult to design specific offers to meet the interest and challenges of the survivors. To improve the services offered, data collection is most necessary. Internal numbers from the centers reveal that 55-60% of the visitors are women, but the number of male visitors have increased the past years. This is partly due to the increased offers for prostate cancer survivors. It has though not been questioned if men and women at the centers differ in regards to dietary challenges. Is there a need for customization in relation to gender beyond cancer diagnosis or establishment of gender-specific offers? Addressing these matters will open up for better understanding and knowledge, also beyond the benefits of the centers. However, Vardesenteret serves as a recreational ground with no requests where survivors and relatives can come as they are, meaning the vision of the center must not be suppressed due to data collection. The least demanding and time-consuming method is therefore required.

1.7   The methods of dietary assessment

Different methods exist to address dietary measures, but the usage is dependent on the research questions, as well as time, setting and financial aspects. The methods can be either objective or subjective, prospective or retrospective. Objective methods include observation and assessment by research staff, while subjective methods are subjects' own rendering of dietary intake. Prospective methods are not dependent on memory as the diet is recorded when consumed, while retrospective methods depend on subjects' memory to recall dietary intake. When assessing diet, subjective methods are mostly used, including prospective methods like diet record and retrospective methods like 24-hour recall, diet history and food frequency questionnaires (FFQ) (52). The different methods are chosen dependent on the aim, either to assess actual intake or usual intake over a specific time-period. In large epidemiological studies, the diet is very often assessed with FFQs to capture usual intake. Using questionnaires, allow for a larger coverage of the group of interest and higher partition rate as it is more cost-effective and less demanding for both researcher and respondent than diet records and 24-hour recalls. However, FFQs are mostly long and extensive and therefore not suitable for all settings. To provide a fair estimate of energy and nutrient intake, the questionnaire must cover all aspects of the diet, resulting in a long questionnaire. For the purpose of Vardesenteret, a quick dietary assessment completed within a few minutes, manageable in course settings and at the centers, is ideal. Hence, a brief questionnaire addressing respondents' intake of the major cancer-related food groups according to national nutritional recommendations is desired.

Quick dietary assessment tools as short questionnaires have been developed and validated for different settings. *Schröder et al.* validated two short diet quality screeners with monthly 24-hour recalls for a year; they reported good ranking of individuals according to the dietary indices used and relatively low gross misclassification into opposite tertile (53). Several studies have reported sufficient agreement of short diet questionnaires and 24-hour recalls, diet records and FFQs (54-57). However, few questionnaires exist in Norwegian on cancer-specific diet quality. To date, there is not any validated, Norwegian diet questionnaires to the best of our knowledge that can be completed within few minutes. An important aspect of using a short diet questionnaire at Vardesenteret is to assess if the focus of the nutrition-related offers corresponds with the dietary challenges of the visitors. Much of the emphasis in the diet-related patient education until now has been on vegetables, fruit and berries, and wholegrain. Still, we do not know if this reflects the current challenges among cancer survivors at the centers. The

NFBDG are the basis of the dietary recommendations given, meaning assessment of diet quality require a questionnaire and a diet score build upon these guidelines. A suitable questionnaire with preferred objectives has not been detected. The risk of designing and using a non-validated questionnaire involves uncertainty of the accuracy of the items and findings, making any justified conclusions impossible. Hence, careful interpretation of results and support of any findings is needed.

1.8   Objectives

Nutrition-related research has never before been conducted at the Vardesenters in Oslo. As the centers offer many services concerning a healthy diet, increasing knowledge about the visitors will not only provide information on who they are, but also help improve the Vardesenter's offers like dietary courses, educational programs, brochures and other patient material. Much effort is directed at promoting important cancer-related dietary recommendations, but actual dietary challenges are unknown.

The aim of the thesis is to collect data on diet and lifestyle of visitors at Vardesenteret. The objectives of the thesis include:

I.   To examine the proportion of cancer survivors meeting cancer-related dietary and lifestyle recommendations. Dietary factors for the diet quality assessment include vegetables, fruit & berries, wholegrain, red meat and processed meat. Lifestyle factors include body mass index (BMI), smoking, alcohol consumption and PA.

II.   To compare gender-specific differences in relation to diet and lifestyle.

III.   To compare the developed questionnaire with a validated method on diet quality and lifestyle.

2   Material and methods

2.1   Study population

Adult cancer survivors visiting Vardesenteret at the Radium hospital and Ullevål hospital at different occasions between September and December 2018 were recruited to the study. Men and women with all cancer diagnoses were asked to participate, both cancer survivors before, during and after treatment. All survivors who agreed to participate were firstly screened by the student or the project leader using Nutritional Risk Screening (NRS-2002) (**Appendix 1**). NRS-2002 is the recommended screening tool in Norwegian hospitals and combines indicators of malnutrition (BMI, weight loss and food intake) and severity of disease, whereas a score of ≥ 3 points indicate nutritional risk. Survivors at nutritional risk were excluded as they often need or have received dietary advices beyond the general cancer preventive recommendations. After the screening, the participants received a consent form (**Appendix 2**) and the questionnaire (**Appendix 3)** to fill out on their own, but student or project leader were available for questions at all times. Survivors who commonly visited the center got the opportunity to return the questionnaire at another occasion if they were unable to fill out while present. At Ullevål hospital, Pusterommet is joint with Vardesenteret, meaning Pusterom users were more easily recruited. However, at the Radium hospital, Pusterommet is in a separate building, meaning only users who visited the center afterwards were reached.

Cancer survivors were also recruited from courses at the center's facilities, including dietary courses, "Læring og mestring" courses and "Kreftrehabilitering" courses. Course attendees were screened with NRS-2002 before receiving the questionnaire where possible. Participants from courses lasting more than one day were able to bring the questionnaire home and return it at the next course day. Where time was limited, screening was done afterwards with reported height and weight, weight loss the past three months and food intake the last week. Survivors who filled out the short diet questionnaire (DQ) or returned to the center from mid-October to December 2018 were also asked to fill out a validated, short FFQ, the NORDIET-FFQ. Participants returning to the center, especially course attendees, could bring the FFQ home, but mostly they filled it out when given.

2.2   Background data

Participants self-reported height and weight, year of birth, education level, cancer type and treatment, as well as ailments and comorbidities. BMI was calculated by $\frac{weight\ (kg)}{height\ (m)^2}$ and grouped according to cut-off values suggested by Norwegian Directorate of Health (58). Age-adjusted BMI was applied for the population ≥70 years; for the population <70 years and ≥70 years, respectively, underweight was defined by BMI <20 and <22 kg/m^2, normal weight between 20-24.9 and 22-26.9 kg/m^2, overweight between 25-29.9 or 27-29.9 kg/m^2 and obesity if ≥30 kg/m^2. Where birth year was not reported, cut-offs for the population under 70 years were used.

Participants were registered with on-going cancer treatment if they had replied "yes" to currently receiving either chemotherapy, radiation, anti-/hormone treatment, operation and/or immunotherapy. Participants had ailments/comorbidities if they replied "yes" to one or more ailment or disease: cardiac disease, high blood pressure, chronic lung disease, diabetes, kidney- or liver disease, irritable bowel, bowel disease, stoma, food allergy, celiac disease or lactose intolerance, reduced gluten or lactose tolerance, or fatigue.

2.3   The short DQ

A self-administered short diet questionnaire (DQ) was developed particularly for cancer survivors visiting Vardesenteret. The short DQ assesses the intake of vegetables, fruit and berries, juice, wholegrain and red and processed meat the past month. BMI, smoking, alcohol intake and PA are included as lifestyle measures. The questionnaire is intended to easily assess the healthiness of the diet and lifestyle according to national guidelines. Food groups were chosen based on the present knowledge of secondary cancer preventive recommendations, aiming for the shortest questionnaire possible. Items used in the questionnaire were composed and derived from other questionnaires, modified to fit the purpose of the item and to address the proportion of participants not meeting dietary recommendations. Items regarding wholegrain, smoking and PA were modified from the Nord-Trøndelag Health Study (HUNT) questionnaires, while items regarding alcohol, vegetables and fruit & berries were modified from the Swedish board of health and social welfare, Socialstyrelsen's questionnaire on lifestyle habits (59). Due to red and processed meat's relevance for cancer and lack of validated items, items were composed based on the NORDIET-FFQ. Other diet factors like fish, sugar-sweetened drinks, sweets and desserts, and oil/margarine/butter were included in the

questionnaire, but omitted due to non-specific cancer relevance. The aim was to develop a short diet questionnaire that could be filled out within a few minutes; a non-time-consuming tool that can also be used in courses. By collecting such data about the patient group, the questionnaire will be an aid in improving Vardesenteret's offers, especially to improve and customize nutrition courses, but also provide helpful information about dietary challenges when facing cancer survivors.

The short DQ assesses frequency of consumption per day or week. Portion sizes are specified for vegetables, fruit & berries and alcohol. One portion of vegetables, fruit or berries is specified as a handful while alcohol is measured in units, all illustrated in the questionnaire. As data on Vardesenteret's visitors is scarce, a comprehensive questionnaire was developed to provide a cluster of new data to the centers. It was designed to assess the use of complementary and alternative medicine (CAM), perceived barriers against a healthy diet and user experience. The items were included, but are not addressed in current thesis.

2.4 Measured variables

Smoking. Participants who responded "yes, daily" or "yes, occasionally" to smoking were registered as current smokers, whereas former smokers and never-smokers were registered as non-smokers.

Alcohol consumption. Based on the response to the number of alcohol units consumed per week, participants either had a low or high intake. The recommendation limits the alcohol intake to one unit per day for women and two per day for men. Women who responded having 6-10 units per week (approximately ≥1 unit per day) were registered with a high intake. Men had a high intake if the number of units per week exceeded 14 (>2 units per day).

Table 2.1 shows how PA and the dietary factors were scored in the short DQ.

PA. The PA recommendation for cancer survivors is the same as the general population: at least 150 min of moderate-intensity PA or 75 min high-intensity PA per week (21). Moderate intensity is defined as activities that give higher heart rate than normal like fast walking, household chores and cycling, while high intensity includes activities that require more effort like running, fast swimming and team sports. The recommendation was updated in 2014 and replaced the recommendation of at least 30 minute daily PA from the NFBDG. Participants met

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or did not meet the PA recommendation based on their responses to frequency and intensity of PA; low intensity was defined as "without sweating or losing breath", moderate intensity as "sweating and breathless" and high intensity as "to near exhaustion".

5-a-day. A recommendation of five portions of 100g vegetables and fruit & berries per day is given in the NFBDG. The highest reportable consumption of both vegetables and fruit & berries in the short DQ were three portions per day, yielding the maximum score. Participants consuming a glass of juice per day or more could score an additionally portion if they did not meet the maximum score for fruit & berries, meaning a consumption of two portions per day or less. Although the recommendation is 50-50 vegetables and fruit & berries, five portions or more could be achieved if the participants consumed two or three portions of vegetables and correspondingly portions of fruit & berries, including a glass of juice.

Wholegrain. The food-based recommendation for wholegrain contribute to the consumption of recommended dietary fiber of 25-35g per day in addition to 5-a-day. Consumption is rated by four items in the short DQ. The NFBDG recommend an intake of 70-90g of wholegrain per day; in food amount, this equal either 1) four slices of wholegrain bread, 2) two slices of bread and one portion of oatmeal, 3) one portion of oatmeal and one portion of wholegrain pasta or rice, or a similar combination. One wholegrain equivalent is defined as two slices of bread, one portion of oatmeal or one portion of wholegrain pasta/rice. This equals 50% of the recommendation if consumed every day, meaning the recommendation is met when participants consume at least two wholegrain equivalents per day. They could only score for bread if they checked for wholegrain bread. Less frequent intake of wholegrain pasta and rice than every day are estimated as intake per day based on average consumption per week.

Red and processed meat. WCRF and Norwegian guidelines recommend a weekly intake of maximum 500g of cooked red meat, equivalent to three portions a day, including processed red meat. Overall intake of processed meat should be limited if any. The recommendation for red meat was met if the participant reported having red meat for dinner or warm lunch three times per week or less, assuming each time equals one portion. As there is no quantified recommendation for processed meat, intake of one portion per week or less was accepted as meeting the recommendation, similar to *Berstad et.al* (60). Processed meat spread was excluded.

Table 2.1. Scoring of PA and dietary factors based on the items in the short DQ.

		Items	Response categories	Measured score
PA		How often do you do physical activity for 30 minutes or more per day?	Almost every day	1 if moderate or high intensity
			2-3 times per week	1 if high intensity
			Once per week or rarer	0
			Never	0
		How intense PA do you do on average?	Easy, without sweating or losing breath	Low intensity
			Sweating and breathless	Moderate intensity
			To near exhaustion	High intensity
			Maximum score	1
5-a-day	Vegetables	How many portions of vegetables (except potatos/sweet potatos) do you eat in total during a day?	Three portions or more	3
			Two portions	2
			One portion	1
			Some portions per week or less	0.5
	Fruit & berries	How many portions of fruits or berries do you eat in total during a day?	Three portions or more	3
			Two portions	2
If < 3 portions fruit & berries:			One portion	1
			Some portions per week or less	0.5
	Juice	How often do you drink juice (not nectar)?	Twice per day or more	1
			Once per day	1
			Some times per week	0
			Once a week or less	0
		Consumption of 5-a-day	Portions of vegetables + portions of fruit & berries, including a glass of juice	
			Maximum score:	5
Wholegrain		If you eat bread/crisp bread, which type do you usually eat?	White/semi-coarse bread (<50% wholegrain)	-
			Wholegrain bread (>50% wholegrain)	+
If checking for wholegrain bread:		How many slices of wholegrain bread/crisp bread do you eat?	Four slices per day or more	2
			Three slices per day	1.5
			Two slices per day	1
			One slice per day or less	0.5
		How often do you oatmeal?	Every day	1
			4-6 times per week	$1 \times \frac{5}{7} = 0.7$
			1-3 times per week	$1 \times \frac{2}{7} = 0.3$
			Less than once per week	0.00
		How often do you eat wholegrain pasta or rice?	Every day	1
			4-6 times per week	$1 \times \frac{5}{7} = 0.7$
			1-3 times per week	$1 \times \frac{2}{7} = 0.3$
			Less than once per week	0.00
			Maximum score:	2
Red and processed meat		How often do you eat red meat for dinner or warm lunch?	4 times per week or more	0
			2-3 times per week	1
			Once per week	1
			Less than once per week	1
			Maximum score	1
		How often do you eat processed meat like sausage, hamburger, meatballs, bacon and lunch cake for dinner or warm lunch?	Five times per week or more	0
			Four times per week	0
			2-3 times per week	0
			Once per week or less	1
			Maximum score	1

PA: physical activity

2.5 The NORDIET-FFQ

The NORDIET-FFQ is a semi-quantitative FFQ developed and validated at Department of Nutrition, Faculty of Medicine at University of Oslo (61). The 63-item long FFQ covers frequency and amount of food items consumed over the previous 1-2 months. The dietary intake is assessed in grams per day. The FFQ was designed to measure compliance to the NFBDG and is on average completed within 15 minutes.

The food groups covered by the FFQ are chosen to correspond with the NFBDG and include fruit, berries, nuts, vegetables, cereals, beverages, cakes, sweet candy, breads and spreads, oils, margarine and butter, dairy products, fish, meat, rice, pasta, and dietary supplements. The FFQ also includes two items on PA concerning frequency (times per week) and duration (in minutes each time) of moderate intensity PA and high intensity PA per week. Questionnaires were checked by the student in case of incomplete answers before scanning. Scanning and transforming from image files into data files was performed using Cardiff Teleform 2006 Software (6.0) (Datascan, Oslo, Norway). Missing values were handled as described by Henriksen et.al (62).

The NORDIET-FFQ was validated with a 7-day weighed food record and assessed by means of ability to estimate intake, strength of association between methods (Spearman's rank order correlation), bias and presence of outliers (Bland-Altman plots), as well as ability to detect individuals not complying to the NFBDG. The FFQ showed good ability to estimate intake related to NFBDG on group level for the intake of fruit, vegetables, nuts, fish, dairy products, unprocessed meat, red meat, processed meat, beverages and sugar- and fat-rich foods. It was able to detect individuals with insufficient compliance to cancer-related dietary recommendations like fruit, vegetables, wholegrains, processed meat and alcoholic beverages.

2.6 Handling of sensitive data

Sensitive data was obtained from the consent form to be able to compare participants' short DQ and NORDIET-FFQ. All handling of the participants' data and statistical work were therefore performed on the TSD (Tjeneste for Sensitive Data) facilities, owned by the University of Oslo, operated and developed by the TSD service group at the University of Oslo, IT-Department (USIT).

2.7   Statistical analyses

Statistical analyses were performed using IBM SPSS software for Windows, version 25. Participants' characteristics and reported diet and lifestyle measures are presented with descriptive statistics; categorical data in frequencies and percentages and continuous data (all normally distributed) with mean and standard deviation (SD). For continuous data, comparisons between groups were completed with Independent-Samples T-test. Comparisons between groups of categorical data were completed with Chi-Square or Fisher's Exact test. Where the assumptions were not met, Linear-by-Linear Association test was used. Statistical significance level was set to 0.05, presented as two-sided p-values.

Sensitivity and specificity were calculated to assess the short DQ's ability to detect participants not meeting the recommendations relative to the NORDIET-FFQ. Sensitivity was defined as the percentage of participants not meeting the recommendations in the short DQ and FFQ, divided by participants not meeting the recommendations in the FFQ only. Specificity was defined as the percentage of participants meeting the recommendation in the short DQ and FFQ, divided by participants meeting the recommendation in the FFQ only.

Potential misclassification of categorized intake assessed by the short DQ compared to NORDIET-FFQ was examined by the proportion of participants classified in same, adjacent or extreme opposite category for alcohol intake, PA and the dietary factors vegetables, fruit & berries, fruit & berries including juice, 5-a-day, wholegrain, red meat and processed meat. Gross misclassification is the proportion classified in the extreme opposite category. **Table 2.2** shows conversions made from the NORDIET-FFQ. The FFQ assesses alcohol by intake of beer, wine and liquor separately. As one unit in the FFQ does not correspond with the units illustrated in the short DQ, conversions were made from grams per day to units to calculate total alcoholic units consumed per week. PA was compared by the proportion of participants meeting recommendation and not based on the short DQ and the FFQ. As the short DQ only examines one intensity of PA while the FFQ examines both moderate and high intensity PA, misclassification could not be checked. Misclassification was however calculated for frequency of PA for 30 minutes or more, using estimated total PA (including both moderate and high intensity PA) in minutes per day from the NORDIET-FFQ. As the ordering in the short DQ do not cover the range of total PA in minutes per day, all participants who reported PA more than 2x per week (= 9 min total PA/day) but less than every day (= <30 min total PA/day), were categorized as "2-3x per week".

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Table 2.2. Conversions made from the NORDIET-FFQ to match the grouping variables in the short DQ.

	sDQ	NORDIET-FFQ
	Grouping variable	**Conversion from minutes**
PA	*Meeting the recommendation*	
	Yes	≥150 min moderate or ≥75 high intensity PA per week
	No	<150 min moderate or <75 high intensity PA per week
	Times per week	*Total PA in minutes per day*
	Never	0
	≤1	$< \frac{60}{7} = 9$
	2-3	9-29
	Almost every day	≥30
		Conversion from grams per day
Alcohol intake	*Total number of units*	
	1 unit beer	330
	1 unit wine	125
	1 unit liquor	40
Vegetables	*Number of portions*	*1 portion = 100 g*
	<1	<100
	1	100-199
	2	200-299
	≥3	≥300
Fruit & berries	*Number of portions*	*1 portion = 100 g*
	<1	<100
	1	100-199
	2	200-299
	≥3	≥300
5-a-day	*Number of portions*	*1 portion = 100 g*
	1-<2	100-199
	2-<3	200-299
	3-<4	300-399
	4-<5	400-499
	≥5	>500
Wholegrain	*Equivalents*	*1 equivalent = 35 g*
	<1	<35
	1 - <2	35-69
	≥2	>70
Red meat	*Times per week*	*1 time = 150 g*
	<1	<150
	1	150
	2-3	151-500
	≥4	>500
Processed meat	*Times per week*	*1 time = 150 g*
	≤1	≤150
	2-3	150-500
	4	501-649
	≥5	≥650

sDQ: short diet questionnaire; NORDIET-FFQ: NORDIET food frequency questionnaire; PA: physical activity

Vegetables, fruit & berries and 5-a-day were ranked according to reported portions in the short DQ and estimated portions from grams per day in the NORDIET-FFQ, counting 100 grams as one portion. Wholegrain was adapted from grams to equivalents, counting minimum 70 grams wholegrain as two equivalents. One portion of red and processed meat is defined as 150 grams in the FFQ, providing the basis for the conversion. Total consumption of red meat and processed meat in the FFQ include meat spread. As the short DQ only questions use of red and processed meat for dinner and warm lunch, conversion from grams to portions in the FFQ included 1) red meat: unprocessed red meat and processed red meat and 2) processed meat: processed red meat and processed white meat. The degree of agreement for the ordered data was evaluated by quadratic weighted kappa (κ) coefficient with cut-off values suggested by Landis and Koch (**table 2.3**).

Table 2.3. Interpretation of strength of agreement by kappa from Landis and Koch, adapted from (63).

Kappa, κ	Interpretation
<0	Poor
0.0-0.20	Slight
0.21-0.40	Fair
0.41-0.60	Moderate
0.61-0.80	Substantial
0.81-1.0	Almost perfect

3 Results

3.1 Study population

In total, 211 cancer survivors agreed to participate in the study (82% participation rate). Participants with incomplete questionnaires and screened to be at nutritional risk were excluded (**figure 3.1**). Forty-eight percent of the participants were recruited from the centers, while the remaining were recruited from courses. Participant characteristics are presented in **table 3.1**. The study included men and women between 25 and 83 years, either diagnosed or previously diagnosed with cancer. Women represented 64% of the participants. The mean age was 60 years and only 4% were younger than 40 years (data not shown). The study population was well-educated with 73% reported having university background. Ten different cancer diagnoses were registered; breast and prostate cancer accounted for the largest patient groups (41% and 21%, respectively).
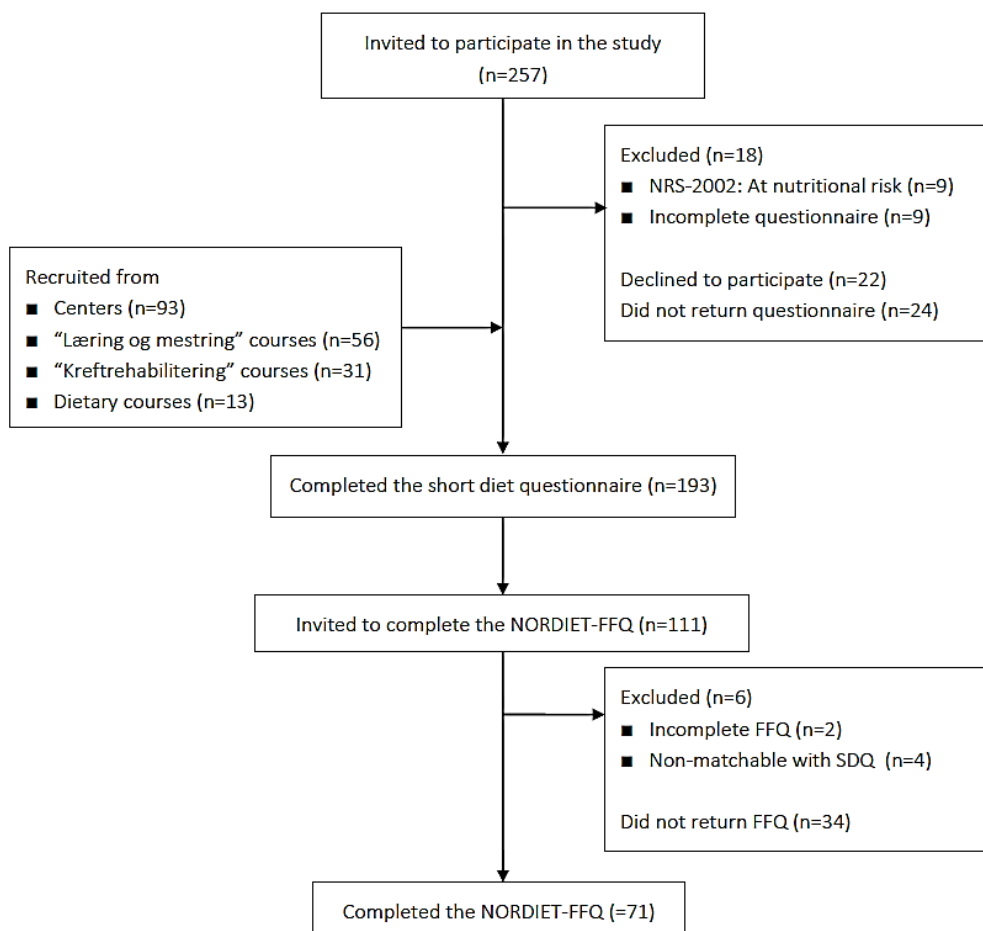
Figure 3.1. Flow chart of participant recruiting.

Table 3.1. Self-reported participant characteristics of the short DQ respondents.

		Number of participants, n (%)
No. of participants		**193**
Gender (n=193)	Male	70 (36.3)
	Female	123 (63.7)
Age (years), mean (SD) (n=192)		60 (12.4)
Age-adjusted BMI (kg/m^2) (n=191)	Underweight	10 (5.2)
	Normal weight	94 (49.2)
	Overweight	56 (29.3)
	Obese	31(16.2)
Marital status (n=190)	Live alone	52 (27.4)
	Married/cohabitant	138 (73.3)
Education (n=191)	Primary school	11 (5.8)
	High school	40 (20.9)
	University	140 (73.3)
Cancer diagnosis (n=179)	Breast cancer	73 (40.8)
	Prostate cancer	38 (21.2)
	Gynecological cancer	16 (8.9)
	Head and neck cancer	14 (7.8)
	Brain cancer	12 (6.7)
	Other[a]	26 (14.5)
Ongoing cancer treatment (n=192)	Yes	126 (65.6)
	No	66 (34.3)
Ailments/comorbidities (n=192)	Yes	120 (62.5)
	No	72 (37.5)
Smoking (n=192)	Current smokers	12 (6.3)
	Non-smokers	180 (93.8)

SD: Standard deviation; BMI: Body mass index.

[a]Other diagnoses reported: colon cancer (n=8), lung cancer (n=7), blood cancer (n=5), sarcoma (n=4) and neuroendocrine tumors (n=2)

3.2 Lifestyle: obesity, smoking, alcohol consumption and PA

Mean BMI was 25.5 kg/m^2 (SD 4.0). Forty-six percent of the participants were overweight or obese. Few were current smokers, but 44% reported being former smokers (data not shown). Reported alcohol consumption was relatively low; 83% of the participants consumed 1 to 5 units per week or less (**figure 3.2.a**). Gender-specific classification of alcohol intake indicates low intake among 92% of the participants (**figure 3.2.b**). Almost daily PA of 30 minutes or more was reported by 63% of the participants (**figure 3.3.a**). Weekly PA of ≥150 min moderate intensity or ≥75 min high intensity was met by 36% of the participants (**figure 3.3.b**).
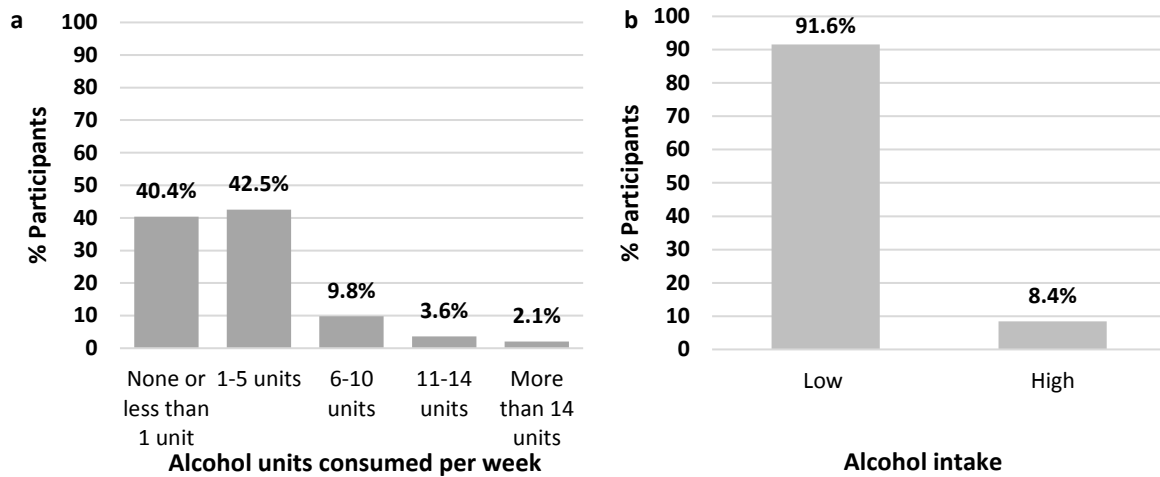
Figure 3.2. a. Reported intake of alcholic units per week and **b.** proportion of participants with low and high intake according to the gender-specific recommendation for alcohol (n=190).
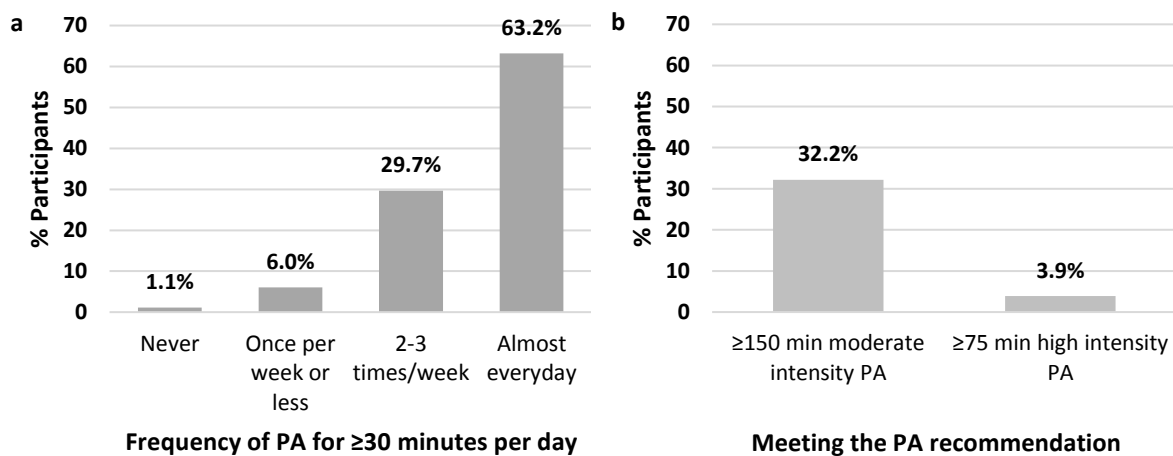
Figure 3.3. a. Reported frequency of PA for ≥30 minutes per day (n=182) and **b.** proportion of participants meeting PA recommendation based on frequency of PA ≥30 minutes per day and reported average intensity (n=180).

3.3   Diet quality as compared to the NFBDG

Vegetables, fruit and berries. Thirty-seven percent of the participants reported consuming two portions of vegetables per day, but only 8% consumed three portions or more (**figure 3.4**). The majority reported a daily consumption of one or two portions of fruit or berries. When juice was included, the percentage of participants having three portions of fruit & berries per day increased from 12% to 26%. Five-a-day was reported met by 16% of the participants (**figure 3.5**).
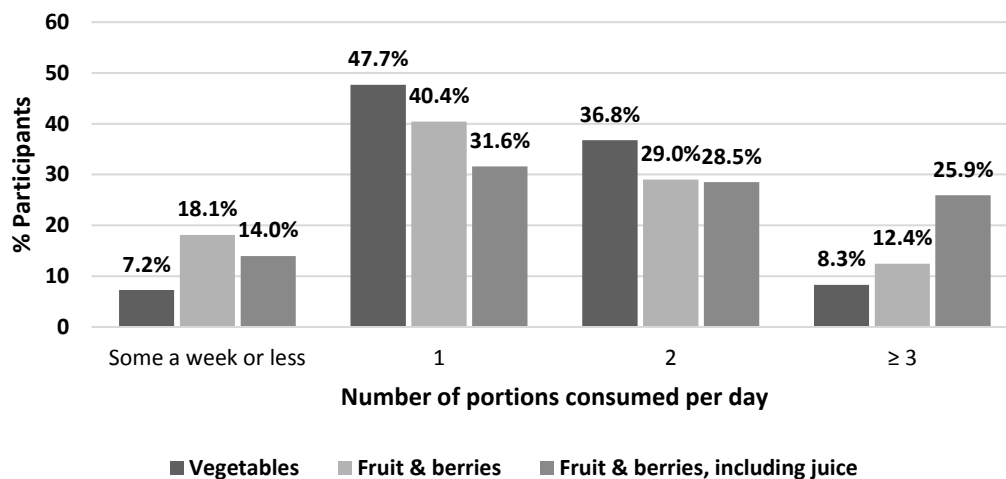
Figure 3.4. Number of portions reported consumed per week of vegetables, fruit & berries and fruit & berries including a glass of juice (n=193).
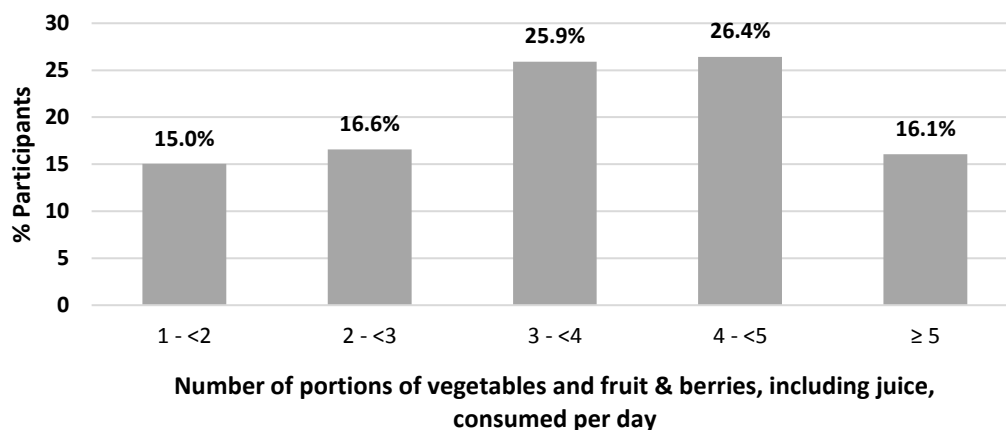
Figure 3.5. Number of vegetables, fruit and berries, including juice, portions reported consumed per day in total (n=193). Maximum countable portions of either vegetables or fruit and berries are three. Juice can only equal one portion of fruit & berries if the intake is <3.
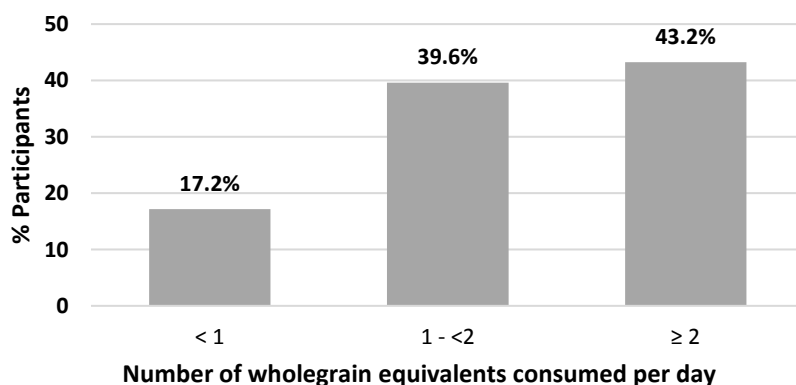
Figure 3.6. Number of wholegrain equivalents reported consumed per day (n=192). One wholegrain equivalent equals two slices of wholegrain bread, one portion of oatmeal or one portion of wholegrain pasta or rice. Two equivalents or more cover the recommendation of at least 70-90g of wholegrain per day.

Wholegrain. A consumption of two wholegrain equivalents was reported by 43% of the participants (**figure 3.6**). Almost one third covered the recommendation with the consumption of wholegrain bread (data not shown).

Red and processed meat. Close to 98% reported an intake of red meat three times per week or less, meaning meeting the recommendation if assuming intake of a portion each time (**figure 3.7.a**). Fifty-eight percent of the participants reported consuming processed meat once per week or less (**figure 3.7.b**).

a   **b**
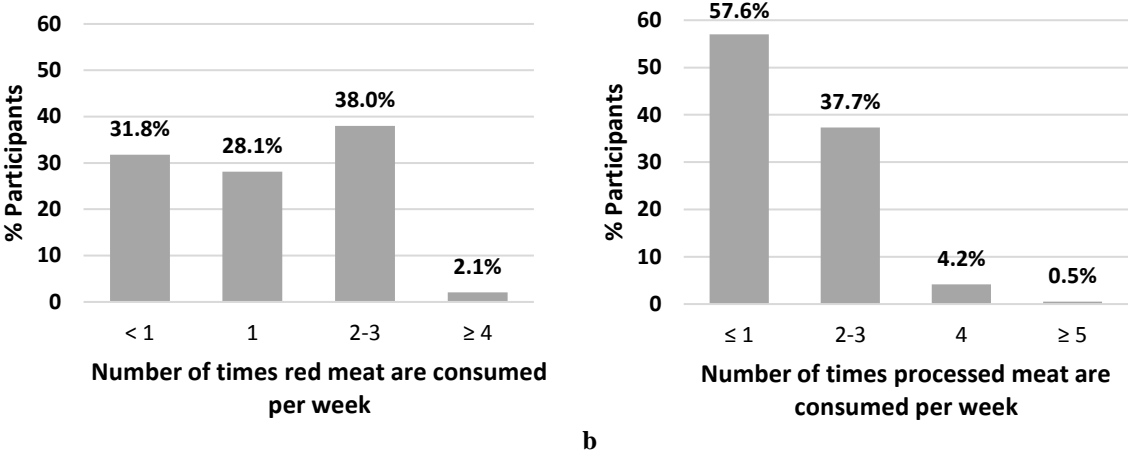
Figure 3.7. Number of times **a.** red meat (n=192) and **b.** processed meat (n=191) were reported consumed per week.

3.4 Comparison of men and women

Table 3.2 shows participant characteristics stratified by gender. Men were significantly older (mean difference: 8.9 years, p <0.001). Significantly more women lived alone compared to men (p=0.046). The most common cancer diagnoses among women were breast (64%), gynecological (14%) and head and neck cancer (6.1%). Among men, prostate (59%), brain (14%) and head and neck cancer (11%) were mostly reported. Although few reported being current smokers, 11 out of 12 were women.

Table 3.2. Self-reported participant characteristics of the short DQ respondents, stratified by gender.

		Total n (%)		
		Men	**Women**	**p-value**
No. of participants		70	123	
Age (years), mean (SD) (n=192)		65.3 (12.2)	56.4 (11.5)	**<0.001**
Age-adjusted BMI (kg/m²) (n=191)	Underweight	3 (4.3)	12 (9.9)	0.36
	Normal weight	31 (44.3)	59 (48.8)	
	Overweight	22 (31.4)	33 (27.3)	
	Obese	14 (20.0)	17 (14.0)	
Marital status (n=190)	Live alone	13 (18.8)	39 (32.2)	**0.046**
	Married/cohabitant	56 (81.2)	82 (67.8)	
Education (n=191)	Primary school	2 (2.9)	9 (7.4)	0.081
	High school	20 (28.6)	20 (16.5)	
	University	48 (68.6)	92 (76.0)	
Ongoing cancer treatment (n=192)	Yes	51 (73.9)	75 (61.0)	0.070
	No	18 (26.1)	48 (39.0)	
Ailments/comorbidities (n=192)	Yes	44 (63.8)	76 (61.8)	0.79
	No	25 (36.2)	47 (38.2)	
Smoking (n=192)	Current smokers	1 (1.4)	11 (8.9)	0.059
	Non-smokers	68 (98.6)	112 (91.1)	

SD: standard deviation; BMI: body mass index.

3.4.1 Reported alcohol intake, PA and dietary consumption

Significant differences between men and women were detected for the consumption of vegetables, 5-a-day and processed meat when dichotomizing intake to high and low according to the dietary recommendations (**table 3.3**). Men reported consuming fewer portions of vegetables per day compared to women; women were five times more likely to consume two portions or more per day (OR=5.2, p<0.001). Similarly, more women had higher consumption of vegetables, fruit and berries than men (OR=2.8, p=0.001), also significant when assessing the proportion of men and women meeting the recommended 5-a-day (OR=3.5, p=0.011) (data not shown). More men reported consuming processed meat more than once per week (OR=2.9, p=0.001).

Table 3.3. Reported alcohol intake, PA and dietary consumption among men and women of the short DQ respondents.

		Men n (%)	Women* n (%)	Dichotomized categories	Men n (%)	Women n (%)	p-value	OR	95% CI
Alcohol intake	Low	65 (94.2)	109 (90.1)				0.33	0.56	0.17-1.81
	High	4 (5.8)	12 (9.9)						
PA of ≥150 min moderate intensity or ≥75 min high intensity per week (n=180)	Yes	39 (32.8)	19 (30.2)				0.72	1.13	0.58-2.17
	No	80 (67.2)	44 (69.8)						
Vegetables, portions per day (n=193)	<1	4 (3.3)	10 (14.3)	<2	55 (78.6)	51 (41.5)	**<0.001**	5.18	2.64-10.20
	1	47 (38.2)	45 (64.3)						
	2	59 (48.0)	12 (17.1)	≥2*	15 (21.4)	72 (58.5)			
	≥3	13 (10.6)	3 (4.3)						
Fruit & berries, including juice, portions per day (n=193)	<1	14 (11.4)	13 (18.6)	<2	15 (26.3)	35 (32.1)	0.44	0.76	0.19-1.54
	1	34 (27.6)	27 (38.6)						
	2	40 (32.5)	15 (21.4)	≥2*	42 (73.7)	74 (67.9)			
	≥3	35 (28.5)	15 (21.4)						
5-a-day, portions per day (n=193)	1 - <2	13 (10.6)	16 (22.9)				**0.001**	2.81	1.49-5.32
	2 - <3	13 (10.6)	19 (27.1)	<4	51 (72.9)	60 (48.8)			
	3 - <4	34 (27.6)	16 (22.9)						
	4 - <5	37 (30.1)	14 (20.0)	≥4*	19 (27.1)	63 (51.2)			
	≥ 5	26 (21.1)	5 (7.1)						
Wholegrain, equivalents per day (n=192)	<1	20 (16.4)	13 (18.6)	<2	38 (54.3)	71 (58.2)	0.60	0.85	0.47-1.54
	1 - <2	51 (41.8)	25 (35.7)						
	≥2	51 (41.8)	32 (45.7)	≥2*	32 (45.7)	51 (41.8)			
Red meat, times per week (n=192)	<1	40 (32.8)	21 (30.0)				1.00	0.58	0.06-5.65
	1	37 (30.3)	17 (24.3)	≤3*	69 (98.6)	119 (97.5)			
	2-3	42 (34.4)	31 (44.3)						
	≤4	3 (2.5)	1 (1.4)	>3	1 (1.4)	3 (2.5)			
Processed meat, times per week (n=191)	≤1	81 (66.9)	29 (41.4)	≤1*	29 (41.4)	81 (66.9)	**0.001**	2.86	1.56-5.26
	2-3	35 (28.9)	37 (52.9)						
	4	5 (4.1)	3 (4.3)	>1	41 (58.6)	40 (33.1)			
	≥5	0	1 (1.4)						

PA: Physical Activity; OR: Odds ratio; CI: Confidence interval.

*Reference group

3.5 Comparison of the short DQ and NORDIET-FFQ

3.5.1 Sub-group population

A total of 77 FFQs was collected. However, six did not meet inclusion criteria and were excluded (**figure 3.1**). Sub-group characteristics of only short DQ respondents and short DQ/NORDIET-FFQ respondents are presented in **table 3.4**. Distribution of cancer diagnoses was significant different as 84% in the sub-group had either breast or prostate cancer, the former equaling 54% (p<0.001).

3.5.2 Reported alcohol intake, PA and dietary consumption

Figure 3.8 shows the proportion of participants meeting the PA and dietary recommendations based on the short DQ and the NORDIET-FFQ. Both the short DQ and FFQ report a high rate of alcoholic intake within the gender-specific recommendations. Accounting for intensity of PA, the FFQ finds that 70% meet the recommendation of PA of ≥150 min moderate intensity or ≥75 min high intensity per week while the short DQ reports a rate of 33%. Comparing the proportion of participants reporting doing daily PA of ≥30 min in the short DQ with the estimated total PA of ≥30 min per day in the FFQ, the short DQ finds a higher rate of daily PA (70% vs. 57%) (data not shown). The short DQ reports half the amount of participants meeting 5-a-day compared to the FFQ. More participants are found to consume three portions or more of vegetables and fruit & berries in the FFQ, but the same proportion is found for fruit & berries when including juice (data not shown). The short DQ reports a lower proportion of participants meeting the wholegrain recommendation compared to the NORDIET-FFQ. Comparing the proportion of participants meeting the red meat recommendation of maximum 500g per week, the short DQ reports that 97% meet the recommendation while the FFQ reports a rate of 70%. The recommendation includes unprocessed red meat, processed red meat and red meat spread. However, the short DQ only examines consumption of red meat served as dinner or warm lunch. When excluding red meat spread, the FFQ finds that 89% of the participants are reported meeting the red meat recommendation of three portions or less per week (data not shown). For processed meat, the short DQ finds twice as many participants meeting the recommendation compared to the FFQ, both excluding processed meat spread.

Table 3.4. Self-reported participant characteristics, stratified by only short DQ (sDQ) respondents and sDQ/NORDIET-FFQ respondents.

		Number of participants, n (%)		
		sDQ	sDQ/ NORDIET-FFQ	p-value
No. of participants		122	71	
Gender (n=193)	Male	43 (35.2)	27 (38.4)	0.70
	Female	79 (64.8)	44 (61.6)	
Age (years), mean (SD) (n=192)		60 (13.3)	60 (10.9)	0.91
Age-adjusted BMI, kg/m² (n=191)	Underweight	7 (5.8)	8 (11.3)	0.38
	Normal weight	60 (50.0)	30 (42.3)	
	Overweight	32 (26.7)	23 (32.4)	
	Obese	21 (17.5)	10 (14.1)	
Marital status (n=190)	Live alone	30 (25.2)	22 (31.0)	0.39
	Married/cohabitant	89 (74.8)	49 (69.0)	
Education (n=191)	Primary school	10 (8.3)	1 (1.4)	0.089
	High school	27 (22.5)	13 (18.3)	
	University	83 (69.2)	57 (80.3)	
Cancer diagnosis (n=179)	Breast cancer	36 (32.4)	37 (54.4)	**<0.001**
	Prostate cancer	18 (16.2)	20 (29.4)	
	Other[a]	57 (51.4)	11 (16.2)	
Ongoing cancer treatment (n=192)	Yes	77 (63.1)	49 (70.0)	0.33
	No	45 (36.9)	21 (30.0)	
Ailments/comorbidities (n=192)	Yes	77 (63.1)	43 (61.4)	0.82
	No	45 (36.9)	27 (38.6)	
Smoking (n=192)	Current smokers	8 (6.6)	4 (5.6)	0.79
	Non-smokers	113 (93.4)	67 (94.4)	

sDQ: short diet questionnaire; NORDIET-FFQ: NORDIET food frequency questionnaire; BMI: body mass index.

[a] Other diagnoses reported: blood cancer, colon cancer, gynecological cancer, lung cancer, brain cancer, head and neck cancer.
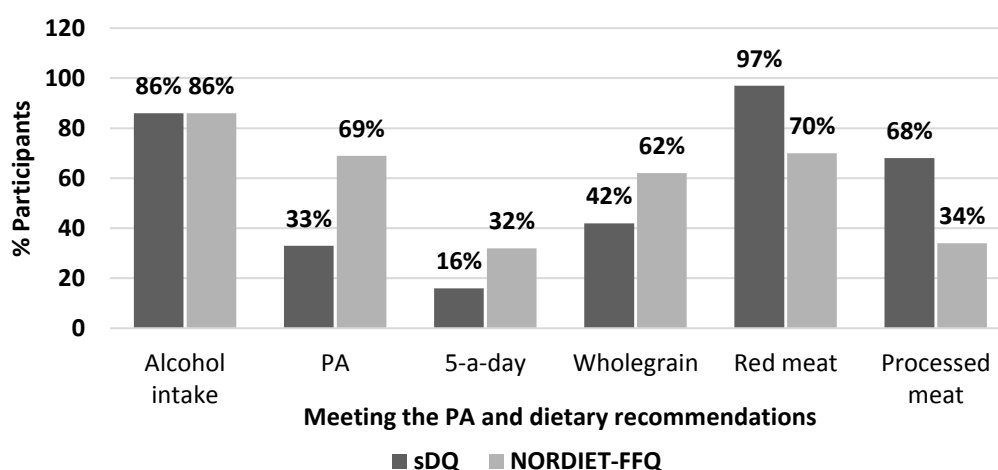
Figure 3.8. Proportion of participants meeting the PA and dietary recommendations according to the NFBDG based on the short DQ (sDQ) and NORDIET-FFQ (n=71).

3.5.3 Sensitivity and specificity

The short DQ reported high sensitivity and ability to detect individuals not meeting the PA, 5-a-day and wholegrain recommendations (75-97%) relative to the NORDIET-FFQ. Sensitivity was low for alcohol intake and red and processed meat, but the short DQ showed good ability to detect individuals meeting the recommendations (specificity 88-98%) (**table 3.5**).

Table 3.5. Sensitivity and specificity of the short DQ to detect participants not meeting and meeting the NFBDG compared to the NORDIET-FFQ.

Health recommendations derived from the NFBDG	Sensitivity (%)	Specificity (%)
Maximum one alcoholic unit per day for women and two units per day for men*	50.0	91.7
PA of ≥150 min moderate intensity or ≥75 min high intensity per week*	75.0	35.4
Minimum 5 portions of vegetables, fruit and berries per day (including juice)	96.6	37.5
Minimum 70-90g wholegrain per day	88.9	62.2
Maximum 500g (3 portions) of red meat per week	4.8	98.0
Limit intake of processed meat (≤1 portion per week)	42.6	87.5

NFBDG: Norwegian food-based dietary guidelines; PA: Physical activity.

*Not specifically derived from the NFBDG, but specified national guidelines on diet, nutrition and PA (21).

3.5.4 Calculation of misclassification

The proportion of participants classified in the same, adjacent or opposite category was calculated for alcohol intake, PA and all dietary factors according to defined categories. **Table 3.6** shows the proportion of misclassification within alcohol intake and PA. For the lifestyle factors, the majority is placed in the same category for alcohol, but the misclassification is high for the proportion meeting PA recommendation. The gross misclassification is however zero for frequency of total PA. The weighted kappa was poor for the PA recommendation, but moderate for both alcohol intake and total PA.

Table 3.6. Agreement between the short DQ and NORDIET-FFQ in classifying participants within defined categories for alcohol intake and PA.

	Categories	Same (%)	Adjacent (%)	Opposite (%)	Weighted Kappa	95% CI	p-value
Alcohol intake	Low (n=60)	91.7	-	8.3	0.42	0.12-0.72	<0.001
	High (n=10)	50.0	-	50.0			
	Total (n=70)	**85.7**	-	**14.3**			
PA of ≥150 min moderate intensity or ≥75 min high intensity per week	Yes (n=23)	73.9	-	26.1	0.08	-0.09-0.26	0.370
	No (n=47)	66.0	-	34.0			
	Total (n=70)	**47.1**	-	**52.9**			
Total PA (times per week)	Never (n=1)	100.0	0	0	0.45	0.15-0.74	<0.001
	≤1 (n=1)	0	100.0	0			
	2-3 (n=19)	63.2	36.8	0			
	Almost every day (n=49)	67.3	24.5	0			
	Total (n=70)	**64.8**	**28.2**	**0**			

CI: Confidence interval; PA: Physical activity

For the dietary factors, the proportion of participants classified within the same category ranged from 30% to 69%, lowest for fruit & berries and highest for processed meat (**table 3.7**). The proportion of adjacent misclassification ranged from 25% for processed meat and 61% for fruit & berries. Calculation of adjacent misclassification was not relevant for wholegrain. Gross misclassification was relatively low for the dietary factors, ranging from 4% for vegetables to 7% for 5-a-day. Weighted kappa showed fair to moderate agreement for the dietary factors, lowest for red meat (0.27, p=0.007) and highest for wholegrain (0.53, p<0.001).

Table 3.7. Agreement between the short DQ and NORDIET-FFQ in classifying participants within defined categories for the dietary factors.

	Categories	Same (%)	Adjacent (%)	Opposite (%)	Weighted Kappa	95% CI	p-value
Vegetables (portions per day)	<1 (n=4)	50.0	50.0	0	0.43	0.21-0.65	<0.001
	1 (n=35)	54.3	45.7	0			
	2 (n=27)	37.0	51.9	11.1			
	≥3 (n=5)	80.0	0	0			
	Total (n=71)	**49.3**	**45.0**	**4.2**			
Fruit & berries (portions per day)	<1 (n=13)	30.8	53.8	7.7	0.35	0.16-0.54	0.003
	1 (n=28)	46.4	46.4	7.1			
	2 (n=24)	8.3	87.5	4.2			
	≥3 (n=6)	33.3	33.3	0			
	Total (n=71)	**29.5**	**60.6**	**5.6**			
Fruit & berries, including juice (portions per day)	<1 (n=10)	20.0	50.0	10.0	0.40	0.20-0.59	0.001
	1 (n=24)	54.2	33.3	12.5			
	2 (n=21)	14.3	85.2	0			
	≥3 (n=16)	50.0	37.5	0			
	Total (n=71)	**36.6**	**52.2**	**5.6**			
5-a-day (portions per day)	1-<2 (n=11)	9.1	45.5	27.3	0.43	0.22-0.64	<0.001
	2-<3 (n=14)	15.8	64.3	4.8			
	3-<4 (n=17)	31.8	52.9	5.9			
	4-<5 (n=18)	27.8	66.7	0.0			
	≥5 (n=11)	81.8	0.0	0.0			
	Total (n=71)	**35.2**	**42.3**	**7.0**			
Wholegrain (equivalents per day)	<1 (n=14)	42.8	-	28.6	0.53	0.34-0.72	<0.001
	1-<2 (n=27)	48.1	-	-			
	≥2 (n=30)	90.0	-	0.0			
	Total (n=71)	**64.8**	**-**	**5.6**			
Red meat (times per week)	<1 (n=24)	33.3	33.3	4.2	0.27	0.05-0.49	0.020
	1 (n=25)	36.0	64.0	0			
	2-3 (n=20)	65.0	20.0	15.0			
	≥4 (n=2)	0	100.0	0.0			
	Total (n=71)	**42.3**	**49.3**	**5.6**			
Processed meat (times per week)	≤1 (n=48)	83.3	14.6	2.1	0.37	0.15-0.59	0.001
	2-3 (n=20)	40.0	50.0	10.0			
	4 (n=3)	33.3	33.3	33.3			
	≥5 (n=0)	0	0	0			
	Total (n=71)	**69.0**	**25.4**	**5.6**			

Adjacent category was not calculated for wholegrain. CI: Confidence interval; PA: Physical activity.

4 Discussion

The project conducted in this master thesis has collected data on diet quality and lifestyle behaviors among cancer survivors visiting Vardesenteret, a haven for cancer survivors and relatives, during September to December 2018. No nutrition-related research has been conducted before and data on the visitors is in general scarce. The aim of the project has been to collect nutrition- and lifestyle-related data and identify dietary challenges among the center's visitors to improve and customize nutrition courses and offers. A questionnaire was designed with emphasis on diet quality assessment and lifestyle behaviors. To support any findings, the developed questionnaire was compared to a validated FFQ on diet, alcohol intake and PA, for cancer survivors in a sub-group of the study population.

4.1 Discussion of methods

4.1.1 Development of the short diet questionnaire

The items and food groups in the short DQ were chosen based on the present knowledge of cancer-associated dietary factors. As the questionnaire was aimed to be as short as possible, only food groups most relevant for cancer were selected. The dietary items were mostly derived and modified from HUNT- and Socialstyrelsen's questionnaires. Dietary questions from HUNT have not been validated, but dietary measures from Socialstyrelsen have been validated with good correlation to dietary intake from food records (64). The PA questionnaire from HUNT (HUNT-PAQ) has disclosed sufficient reliability and validity (65, 66). However, extracting items from one setting to another, leaves unknown validity and reliability. Moreover, translation of items from a language to another might give interpretation problems. The similarity between Norwegian and Swedish might though suppress this issue.

Certain challenges are associated with modifying items and developing a questionnaire. The wording and the structure of the items are essential to create an effective tool with least possible misunderstandings. Introducing focus groups or conducting interviews can help consider layout and content, but due to the scope of the project, this was not carried out. The questionnaire was however pre-tested on a few individuals to examine the reasonableness of the questions and time-use. Nothing in particular was noted by these subjects regarding the wording of the questions.

Using closed questions provide easier coding procedures, but leave no room for additional information. Estimating intake from defined portion sizes might make it difficult to give correct data, resulting in under- or overreporting of consumption. Excluding portion sizes or including self-reported portion sizes can both be challenging when scoring (67). "A handful" is commonly used to describe one portion as part of 5-a-day and provide a simpler estimate for the respondent than grams or deciliters. However, as the short DQ examines total portions throughout a day, estimating total intake might be difficult. Vegetables and fruits consumed as snack in between meals or in combined dishes can easily be forgotten, suggesting a possible weakness when using 1-item assessment of dietary intake. Similar issues might arise for meat, especially when a portion size is not defined, causing underreporting of meat intake.

4.1.2 Selection and recruitment of cancer survivors

Data was collected from all the centers' facilities, including courses and training at Pusterommet. All adult cancer survivors visiting Vardesenteret were recruited to the study. However, survivors at nutritional risk were excluded as they most likely have nutritional impairments affecting usual food intake. As the prevention of weight loss is prioritized under treatment, initiating awareness of healthy and unhealthy foods might provide more concern in an already distressing time. Survivors might receive nutritional support suppressing usual oral intake. The intention of the questionnaire was to capture dietary challenges among survivors who benefit from following dietary recommendations. The possibility of selection bias must be noted. The study participants might differ from other survivors visiting the Vardesenters, i.e. in age, having a healthier lifestyle or being less affected by treatment. Moreover, many survivors were recruited from courses. It is postulated that course attendees have higher education, explaining a possible consequent healthier lifestyle. Course attendees agreeing to participate might also represent the more healthy part of the group.

As breast cancer is the cancer specific course most commonly arranged and one of the most common cancers, many breast cancer survivors were recruited. We deliberately did not recruit survivors from during-treatment head-and-neck cancer courses, as dietary challenges due to treatment are common. This can explain the low number of participants screened to be at nutritional risk. The recruitment from courses was affected by the sometimes modest time to present, explain and screen during course days, resulting in a low participation rate. However, the courses lasting over several days provided the opportunity to bring the questionnaire home.

Although possibly more subjects recruited, it was also to a lesser extent possible to guide the respondents. When collecting the questionnaires, there was rarely time to control for missing answers. Participants recruited at the centers and in connection with Pusterommet mostly completed the questionnaire when given, meaning misunderstandings and missing were easier to capture straight away. Due to the circumstances, one can assume uneven guidance of the course attendees and other participants. However, there were rarely any questions regarding the questionnaire. On the contrary, social desirability bias can also affect reported intake, whereas participants underreport unhealthy foods and overreport healthy foods. Course attendees may have been less exposed as they completed the questionnaire in the absence of the student, project leader and other participants.

4.1.3 Dietary assessment methods

Both dietary assessment methods used in current thesis are retrospective and memory-dependent, calling for potential systematic bias. Using another questionnaire as a reference include the same weaknesses as the short DQ. Both questionnaires consist of closed items and are prone to recall bias. Prospective methods like 24-hour recall or weighed diet record are open, not memory-dependent methods that can partly confine this problem. Although validation of short screeners with longer FFQs has been commonly used (57, 67), an overestimate of the relative validity of the test method might be present as the methods contain correlated errors. However, due to the time limit, the emphasis of using a reference method in this project was to support any findings, thus a comparison was accepted.

The NORDIET-FFQ, developed and validated for CRC survivors at Department of Nutrition, University of Oslo, is designed to assess compliance to NFBDG. The FFQ comprises important cancer-associated dietary risk factors, essential in present study. As identification of dietary challenges is the important matter of the short DQ, total energy and nutrient intake often collected by longer FFQs, 24-hour recalls and diet records was not important. Moreover, prospective methods are time-consuming and demanding for both researcher and responder, difficult to carry out based on the time frame and implementation capacity at Vardesenteret. The NORDIET-FFQ is not designed to estimate total energy and nutrient intake. Validation of the FFQ against 7-day weighed food record (WR) showed good ability to assess compliance to the NFBDG for vegetables, fruit and berries, fish, meat, high-fat dairy products, beverages and energy-dense foods on group level (62). However, the FFQ was not able to estimate intake for

wholegrain products, red meat and processed meat, which are three of four dietary recommendations assessed in the short DQ. For wholegrain products, the FFQ tended to over-report, especially with higher intakes. Differences in estimation of red and processed meat between methods were only non-significant for women. Additionally, correlation between methods of vegetable intake estimation was poor. In spite of this, the FFQ was able to identify men and women not fulfilling the dietary recommendation of 70-90g wholegrain (sensitivity 67% and 100%, respectively). Red meat had fair correlation coefficient (Spearman's ρ=0.45) between methods and individuals meeting the recommendation was sufficiently detected (specificity 80%). Individuals not meeting the processed meat recommendation were sufficiently detected (sensitivity 82%). Although vegetables had poor correlation, vegetables, fruit and berries in total showed fair correlation and high sensitivity (84-87%), meaning the FFQ was able to detect subjects not fulfilling the recommendation. Overall, good ability to assess non-compliance to cancer-associated dietary risk factors according to the NFBDG, was reported.

Timing and sequence of administration of the questionnaires most likely prevented any learning effects as the test-method was given prior to the reference-method (68). Moreover, both the FFQ and short DQ covered dietary intake the past month and were administered in a relatively short time period, causing few differences in recording. Yet, the possibility of suddenly dietary changes due to the effects of treatment and disease must be noted. As many subjects in the study had ongoing treatment, their oral intake can differ from usual, causing potential information bias.

4.1.4 Statistical analyses for the comparison of questionnaires

Frequently used strategies to measure agreement between dietary assessment methods include Pearson's/Spearman's different correlation coefficients, Cohen's (unweighted) or Fleiss' (weighted) Kappa coefficient, Bland-Altman plots and ranking misclassification. Whereas correlation coefficients measure strength of a linear association between methods of continuous data, Kappa coefficients measure agreement of categorical data, taking in the possibility of agreement occurring by chance (69). Unweighted Kappa assesses agreement between dichotomized variables, while weighted Kappa allows weighing of ordered variables. Bland-Altman plots have shown to be an effective method to assess agreement between methods as it can detect bias, outliers and range of agreement. However, the plots are made to illustrate

agreement of quantitative, continuous data, while the short DQ mainly provides ordered data. In identifying dietary challenges necessary for action on group level, the important matter is whether a challenge is actually present. Calculating the degree of misclassification can illustrate the proportion of participants classified as having a dietary challenge, but in reality do not, or reverse, so called gross misclassification. The misclassification into adjacent category is not as critical as it does not provide substantial information of a dietary challenge being present and can be considered as partial agreement. Thus, the weighted Kappa is constructive in comparing the agreement of the methods. The weighted Kappa can be assessed with either linear or quadratic set of weights. Whereas the linear set assesses wrongful classification with the same penalty, the quadratic set assesses wrongful classification worse with increasing categories. As gross misclassification is judged more serious, quadratic weights were chosen in the analyses. It is worth noting that the magnitude of the weighted kappa is influenced by the number of categories and by the prevalence and bias effect (70). For a dichotomized variable, the prevalence effect is present when the proportion of agreement on the positive classification differs from that of the negative classification, while the bias effect is influenced by the extent to which the methods disagree on the proportion of positive or negative cases. The effect is more difficult to evaluate when the variables have more than two categories (71) and is not examined in current thesis.

4.1.5 Data handling and missing values

All handling of data was conducted by the student. The coding of the short DQ was done manually for each participant. Manual management is susceptible to mistyping. Coding was however controlled by the student after collecting all questionnaires. There were some missing values in the data set, most prevalent for PA (7% missing), leading to a smaller n in the analyses. The higher missing rate on PA is due to a printing error, excluding the items on PA in the questionnaires of the ten first participants. These questionnaires were still included as the dietary questions were answered.

4.2 Discussion of results

4.2.1 Study population

Of the 193 participants, 64% were women. This corresponds well with internal numbers at the centers reporting up to 60% female visitors. The most common cancer diagnoses reported reflect well the courses recruited, but also the most common cancer diagnoses in Norway: breast and prostate cancer. The offers for these patient groups at Vardesenteret are many and well-established. Breast cancer occurs in younger individuals than prostate cancer and can explain the lower mean age among women compared to men. Although few subjects are below 40 years, statistics show cancer incidence in the age group 25 to 49 years more often occur in women than men (45).

Over 70% of the participants had higher education on university level. This is twice the percentage of higher education on population level in Norway (72). A possible explanation is the proportion of participants recruited from courses; course attendees might characterize a group of higher socio-economic status (SES) including higher education. Additionally, as breast cancer survivors account for the largest group, breast cancer tends to affect higher educated women more than lower (73).

The questionnaire also addressed cancer treatment and comorbidities. Cancer treatment and comorbidities affect cancer survivors' lifestyle and daily function. Common ailments reported due to treatment include nausea, loss of appetite, altered smell and taste, fatigue, gastrointestinal and physical ailments (13), explaining why malnutrition is prevalent among cancer survivors. Moreover, survivors can have comorbidities affecting treatment, but also lifestyle behaviors. A common feedback from participants and a known challenge in cancer survivors is the treatment-related dietary changes. Although not discussed in the thesis, no significant difference between survivors receiving treatment and not, or with reported ailments or comorbidities and not, were observed for alcohol intake, PA and the dietary factors. However, the participants were asked if they were currently receiving any treatment, but not to specify which treatment(s) they were receiving, meaning the subjects could not be distinguished to examine whether some treatments affect a healthy diet more than others. In addition, time since diagnosis and treatment can also affect the degree of lifestyle changes (74), but that was not sufficiently detected by the questionnaire. As for the effect of ailments and comorbidities, the participants reported diseases and ailments they have or have had, not efficiently assessing

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which ailments or diseases currently prevalent. The number of subjects with different ailments/comorbidities was also too low to perform any constructive comparisons.

4.2.2 Assessment of lifestyle measures

Overweight and obesity. Forty-six percent of the participants were overweight or obese. The prevalence of overweight and obesity has risen substantially in Norway; the European Health Report 2018 reported a prevalence of 58% overweight or obese Norwegian citizens over 18 years (75). Overweight and obesity have been associated with level of education, proposing lower prevalence among those with higher education than lower (76). As the weight and height are self-reported, it might be under- or overreported based on memory, previous normal height and weight or desired weight, affecting the reported prevalence of overweight and obesity in the study population. Although reported a lower prevalence than in the general population, overweight and obesity pose as an important risk factor of cancer recurrence, increased mortality and other diseases, still making promotion of a healthy weight in cancer survivors essential (77). Survivors vulnerable to weight gain due to treatment, in example breast cancer survivors, might need special attention (78).

Smoking. Only 6% of the study population were current smokers, 11 out of 12 were women. The larger proportion of women in the study population might have caused the observed difference, but higher prevalence of continued smoking among female cancer survivors has been reported (79). Smoking prevalence among study subjects is half the percentage of daily smokers in the general Norwegian population (80). Previous studies among cancer survivors have reported higher prevalence of current smokers, ranging between 9-18% (43, 81, 82). However, the prevalence of daily smokers in Norway has decreased steadily the past four decades (83), proposing a potential difference in general smoking prevalence compared to other countries and studies. *Gjerset et.al.* explored the lifestyle of 576 cancer survivors attending an inpatient educational program in Norway; they reported a prevalence of 12% current smokers (84). Smoking status has been associated with SES, suggesting higher prevalence among those with lower education below college (79, 82). The high proportion of participants with university background might explain the few current smokers.

Alcohol. The reported alcohol consumption was low; only 8% reported consuming more than recommended for their gender. The response categories assessing alcohol consumption did however not have a clear cut-off according to the recommendation for women, meaning women who in reality consumed six or seven units per day were categorized with high intake, but had a consumption within the recommendation. *Kanera et.al.* reported that 75% of the survivors in their study population met the same alcohol recommendation used in current thesis (43). As there is no universally accepted alcohol recommendation for cancer survivors, different recommendations and cut-off values have been used in assessing alcohol intake. Overall, it is reported better compliance to alcohol recommendation than other health behaviors (44, 85), but the difference between cancer survivors and individuals without cancer might be minimal (74, 86). Moreover, there is no threshold where consumption of alcohol does not increase risk of at least some cancers (20), explaining why cancer survivors at best should not drink alcohol.

PA. Thirty-six percent of the participants met the PA recommendation of weekly ≥150 min moderate-intensity or ≥75 min high-intensity PA, corresponding well with national numbers in Norway reporting compliance among one third of the adult population (87). This finding is consistent with similar studies in cancer survivors (42-44). *Gjerset et.al.* reported that 45% of the participants were meeting the PA recommendation, 47% women and 41% men. Non-significant in both studies, fewer men met the recommendation. Older age have in previous studies been associated with poorer compliance among cancer survivors and might explain the result in current study as 55% of the participants are 60 years or older (88, 89). Although PA is reported beneficial in many aspects of cancer survivors, research indicates that survivors might find it difficult to increase PA level (90), calling for further development of customized low-threshold offers like Pusterommet. It should also be noted that visitors of the Vardesenters are potentially more physical active than other survivors as Pusterommet is coordinated with the centers.

4.2.3 Assessment of diet quality

Vegetables, fruit and berries. Daily consumption of 2-3 portions vegetables and fruit & berries, including juice, were reported by 45% and 54% of the participants, respectively, but only 16% reported meeting the recommendation of 5-a-day. Higher consumption of fruit and berries compared to vegetables has also been reported in the general population; 15% of men and 13% of women consumed at least 250g vegetables, while 34% men and 41% women

consumed at least 250g fruit and berries (38). Norkost 3 also reported adherence to five-a-day in 22% men and 25% women. In other words, the consumption of 5-a-day is generally low in the Norwegian population. There is reason to believe that the vegetable intake in the population is slightly higher today than reported in Norkost as the vegetable consumption in Norway has increased with approximately 11% the past decade (91). Although it is probably still too low, it shows a positive trend. The short DQ was not able to detect the recommendation of half-half vegetables, fruit and berries, but aimed to assess achievement of 5-a-day. As the study was conducted during the fall- and wintertime, seasonal variation might have influenced the intake.

In current population of cancer survivors, significant differences were observed between men and women; women were 5 times more likely to consume ≥2 portions of vegetables per day and 3 times more likely to consume ≥4 portions of vegetables, fruit & berries per day. The significance was also present when assessing the proportion of participants meeting 5-a-day (21% of women and 7% of men). Similar finding was reported by *Gjerset et.al*, suggesting a need for increased attention in men. However, low compliance to 5-a-day is commonly reported both in the general population and cancer survivors (44, 92, 93), urging a need for further advocacy as it constitutes an important part of cancer prevention. A diet rich in vegetables and fruits will ensure less room for unhealthy foods, especially in prevention of weight gain and obesity.

Wholegrain. A wholegrain consumption according to the recommendation was met by 43% of the participants. Compared to the general population, Norkost 3 reported that 26% were meeting the recommendation, meaning a seemingly better adherence in cancer survivors. The NFBDG recommend women to consume at least 70g wholegrain and men at least 90g. As food-based scores were calculated, the short DQ could not separate men and women meeting the gender-specific recommendation. No significant difference was observed between men and women in current study population, though more men met the recommendation. The chosen foods to estimate wholegrain intake might not have covered all the products important for the participants' wholegrain consumption, underestimating the proportion meeting the recommendation. Consumption of breakfast cereals and wholegrain porridges besides oatmeal were not assessed. Thus, a broader formulation of the item assessing these kinds of wholegrain products might reveal a higher proportion of participants meeting the recommendation than reported in current thesis. No studies found have assessed wholegrain consumption in cancer survivors, but *Coups et.al*. reported an intake of ≥25g fiber in only 12% of cancer survivors and

individuals without cancer. However, cereals are highly consumed in Norway and the consumption is assumingly higher among Norwegian cancer survivors than American cancer survivors (94). Still, more than half the survivors in current study population failed to meet the recommendation. Post-diagnostic increase in dietary fiber and wholegrain intake is associated with decreased risk of CRC-specific and all-cause mortality (95), supporting current and further emphasis in health promotion.

Red and processed meat. Results from the short DQ show that nearly all cancer survivors meet the red meat recommendation, making it the best-met recommendation in the study population, both among men and women. However, the red meat recommendation includes all red meat, including processed red meat and red meat spread like ham, roast beef and salami. The short DQ only assesses intake of red meat for dinner or warm lunch, meaning a possible underestimation of total red meat intake. As the short DQ does not separate red and white processed meat, a better estimation of total intake is not possible. Still, the main source of consumption is addressed and may be the target of dietary advices. In the general population, 45% of men and 67% of women consume less than the maximum recommended intake and is correspondingly the best complied dietary recommendation. Although there is no quantitative recommendation of processed meat, seemingly fewer survivors manage to limit processed meat intake to once per week or less. When comparing gender, men report a more frequent consumption of processed meat. The short DQ does not cover the consumption of processed meat spread, meaning the consumption is underreported if the subjects have a high intake of spreads like liver paste, cured ham and sausages. It is important to note that the short DQ asks about number of times red and processed meat are consumed per week, assuming one time equals one portion. However, it is not given that every subject consumes one portion, meaning the cut-offs might classify the subjects incorrectly. The high proportion of cancer survivors meeting the recommendations might still be real as studies suggest feasible reduction in red and processed meat consumption in cancer survivors (96, 97). Poor to moderate compliance to red meat recommendation has been reported in childhood cancer survivors (93, 98), while compliance among 75% was reported in breast cancer survivors (99).

4.2.4 Comparison of the short DQ and NORDIET-FFQ

Study population. The subjects responding to both the short DQ and the NORDIET-FFQ were significantly different to those responding to only the short DQ in cancer diagnose distribution. The sDQ/NORDIET-FFQ respondents were 84% breast and prostate cancer survivors, the former accounting for the largest part (54%). This is mainly due to the recruitment of subjects from courses and their possibility to answer both questionnaires.

Alcohol intake. Both the NORDIET-FFQ and the short DQ report a large proportion of participants to have a moderate alcohol consumption within recommendation (86% in both questionnaires). Ten individuals were misclassified in the short DQ compared to the FFQ. Estimating total intake, as in the short DQ, might make it easier to underreport intake as the response categories vary by 3-5 units. However, as the FFQ questions intake of beer, wine and liquor separately, the total alcohol intake might be overestimated as one type of alcohol might replace another when consumed during a week. Still, the cut-offs were less precise in the short DQ as the response categories did not have a clear cut-off for women.

PA. The NORDIET-FFQ reports that 69% of the comparable participants are meeting the PA recommendation, while the short DQ only reports 33% meeting the recommendation. Almost half of the participants are wrongly classified. When comparing the frequency of $\geq$30 min PA per week from the short DQ with total PA per day from the NORDIET-FFQ, better agreement is observed. Sixty-seven percent of the participants reporting being physical active almost every day were placed in the same category in both questionnaires. However, the questionnaires differ in that the short DQ examines low, moderate or high intensity PA, while the NORDIET-FFQ reports both moderate and high intensity activities. The PA recommendation does not count low intensity PA, meaning the recommendation cannot be met if low-intensity is registered in the short DQ. This could explain why more participants is classified as doing PA almost every day by the short DQ, while more participants meet the recommendation in the FFQ. The ranking misclassification of daily total PA shows no gross misclassification, suggesting the short DQ's ability to detect frequency of PA, but not intensity. The short DQ is not able to detect subjects meeting the recommendation by doing PA longer and fewer times per week. *Henriksen et.al.* reported that the HUNT-PAQ underreports all intensities of PA, but shows better ability to detect individuals not fulfilling the recommendation than the NORDIET-FFQ (66). The short DQ did however not include the item on average time spent on PA from the HUNT-PAQ as "$\geq$30 min" was specified in the item, describing the inability to detect participants doing PA

longer each time and meeting the recommendation. The NORDIET-FFQ allows respondents to report both moderate and high intensity PA, whereas the HUNT-PAQ only permits report of one intensity and thus potentially underestimating PA behavior in cancer survivors.

Vegetables, fruit and berries. More participants consume ≥3 portions of vegetables and fruit & berries in the FFQ than the short DQ. Only half the proportion of participants reported to consume 5-a-day in the FFQ was reported in the short DQ. The majority of subjects are though placed in the same or adjacent category, showing moderate agreement with weighted kappa, except for fruit & berries. The rate of gross misclassification is relatively low; highest rate is observed for 5-a-day. A 2-item fruit and vegetable screener similar to the short DQ was reported to underestimate vegetable intake, overestimate fruit intake and overall underestimate total fruit and vegetable intake compared to 24h recalls (100), indicating a possible underreport of the proportion of participants meeting 5-a-day in current thesis. Poor to moderate agreement of vegetable intake between short diet questionnaires and reference methods has been reported in other studies (101-103), but as it comprises an important part of healthy eating, inclusion of the item is important anyhow. The FFQ was found to underreport vegetables with increasing intake, but showed good ability to measure intake combined with fruit and berries and according to the recommendation. The short DQ shows good ability to detect individuals not meeting the recommendation of 5-a-day compared to the NORDIET-FFQ.

Wholegrain. The NORDIET-FFQ reports a higher proportion of survivors meeting the wholegrain recommendation than the short DQ (62% vs. 42%). The wholegrain intake in the short DQ is based on the food-based recommendations of wholegrain bread, pasta/rice and oats, probably underreporting the actual intake as it is unable to cover other products. The short DQ classified 65% of the participants in the same category as the FFQ and had low gross misclassification, presenting the highest weighted kappa among the dietary factors. The NORDIET-FFQ is found to overreport wholegrain intake with increasing intake, making a comparison biased as the two questionnaires used in current thesis have similar errors. *England et.al* validated their brief diet questionnaire with 4-day diet record; in assessing intake of high fiber bread and cereal, they reported a weighted kappa of 0.36 and 0.35, respectively (103). The moderate agreement observed in current study may therefore be overestimated. The NORDIET-FFQ is however able to detect individuals not meeting the recommendation, supporting the short DQ's high sensitivity. It is possible that the proportion of participants meeting the recommendation is somewhat closer to the reported proportion in the short DQ.

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Red and processed meat. Both questionnaires report a high proportion of cancer survivors meeting the red meat recommendation, but the short DQ seems to underreport total red meat intake. Thus, the difference in the proportion meeting recommendation is most likely due to the NORDIET-FFQ's assessment of total red meat intake, including processed red meat and red meat spread. Both the short DQ and FFQ accept one portion of processed meat per week as meeting the recommendation, but the short DQ overestimates the proportion of participants meeting the recommendation relative to the FFQ. Processed meat includes both red and white processed meat, possibly causing an underestimation in the short DQ as it is not specified. The assumption of one time equals one portion is seemingly applicable as the median reported portion each time of consumption in the FFQ was one portion (150g). Although the majority is placed in the same or adjacent category, only a fair agreement is reported between methods for red meat and moderate agreement for processed meat. That can be owed to the prevalence and bias effect mentioned earlier. The FFQ has shown good ability to identify individuals following the red meat recommendation and those not meeting the processed meat recommendation. Similar specificity was reported for red meat in the short DQ, posing a potential interpretation problem as the reported proportion meeting the recommendation is overestimated by both questionnaires. With that in mind, the short DQ can suggest the level of red meat consumption and target dietary advices. Moreover, the reported limited red meat intake can reflect cancer survivors' understanding of the negative effects of a high red meat intake on cancer.

4.2.5   Feasibility at Vardesenteret

The overall impression and feedback from the participants indicate that the short DQ is applicable in the settings of the Vardesenters. The short DQ was not perceived particularly demanding by the participants. It is alone completed in 3-5 minutes when including the non-specific cancer-related dietary items. Removing these items will make the questionnaire even shorter or provide room for other relevant items without lengthening the questionnaire. However, several participants have pointed out the lack of a response variable of never for several dietary factors. Short dietary screeners like the short DQ are narrow and limited to the fact that they are restricted in the ability to cover all specters of usual intake. However, as that is not the purpose of current dietary assessment at the Vardesenters, a dietary screener has been a suitable tool. In regards to the use of the validated NORDIET-FFQ at the centers, the employees at the Oslo Vardesenters perceived the FFQ to be too demanding to be handed out to the visitors, both routinely and in course settings with limited time available.

4.3   Strengths and limitations of current study

As the diet is dynamic, there are no completely accurate measurement tools of dietary intake. The diet can change rapidly, especially during the cancer process, causing a difference in reported dietary intake.

The study conducted in current thesis has reached a relatively large group of survivors at the Vardesenters in Oslo. Findings from the novel short DQ have been compared to a validated method, the NORDIET-FFQ. However, subjective, retrospective methods rely on the subjects' memory and validation of the NORDIET-FFQ has reported weaknesses. Still, addressing the limitations, provide knowledge of necessary considerations in interpretation of the results. A concern of the diet quality assessment is that the short DQ reports participants to meet recommendations when they in reality are in the extreme opposite category, meaning existing dietary challenges are not detected at all. There was no gross misclassification of participants reported to meet the recommendation in the short DQ compared to the NORDIET-FFQ. Moreover, assessing the data collected from both questionnaires, dietary challenges among the cancer survivors are indeed present in some degree. Significant differences among men and women in consumption of vegetables and processed meat were also reported in the NORDIET-FFQ (data not shown). Although the difference in consumption of ≥ 4 portions vegetables, fruit and berries among men and women was only borderline significant in the FFQ (p=0.082), the combined findings support the possible need for gender-specific customization.

5 Conclusion and future perspectives

The current thesis suggests that cancer survivors visiting the Vardesenters in Oslo can improve their diet and lifestyle. Low smoking rate and alcohol use is reported, but overweight and obesity are present in almost half the survivors. The majority report doing some PA, but far from all participants are meeting the recommendation. A red meat intake within recommendation is reported by most survivors, but few report consuming 5-a-day, less men than women. The consumption of wholegrain among survivors can also be improved. Processed meat consumption might need more attention, especially in men as they more frequently report consuming processed meat more than once per week compared to women. These findings support the emphasis currently put in the offers at Vardesenteret and advocate further effort to improve diet quality and customize nutrition-related offers and courses, in particular among men.

Current thesis is the first nutrition-related project conducted at the Vardesenters in Oslo, providing data on the status quo among cancer survivors visiting the centers. Much emphasis is put on the importance of diet without knowledge on the group of interest. Based on the results, further effort should be made in promoting increased consumption of vegetables, fruit and berries. Similar to the existing dietary course at Vardesenteret, a shorter and specific diet course on how to increase fruit and vegetable intake in the diet can raise awareness and increase knowledge. Prostate cancer survivors have their own dietary courses, but establishing a low threshold course for men only, perhaps held by a male, might increase learning and involvement among men. Low threshold offers like existing inspiration days about food, short talks about important dietary factors and questions-and-answers sessions in the centers' peak visiting hours, ideally combined with training sessions at Pusterommet, can be an easy way to reach survivors and raise awareness.

Further assessment can provide better understanding of cancer survivors' challenges and needs, also when addressing other health behaviors. The questionnaire developed has yielded data on CAM-use and barriers of a healthy diet that were not addressed in current thesis. Use of natural and herbal medicine has been reported in 1 of 4 Norwegian cancer survivors (104). Dietary supplements and other CAM agents can potentially interact with cancer treatment, yet the use in cancer survivors is reported enhanced post-diagnosis (105, 106). Low consumption of vegetables and fruits as reported in the thesis, can perhaps lead to a high use of supplements

among survivors as an attempt to compensate for the lack of healthy food intake. Additionally, in helping survivors with sustaining healthy lifestyle changes, it is suggested that emphasis must be put on stress and coping models (51). Detecting barriers to follow health recommendations might provide important knowledge and bring better understanding to the circumstances of cancer survivors. Targeting the two major cancer groups at the centers, breast and prostate cancer, can yield important lifestyle-related data to improve offers, but also beyond the centers. The project conducted positively views the possibility of doing more research at the centers within appropriate surroundings.

The short diet quality questionnaire developed at the Vardesenters in Oslo can serve as a helpful and quick dietary assessment tool in cancer survivors. The briefness of the questionnaire might fit to address important dietary challenges in time-limited settings to target dietary advices. However, the short DQ has in this project been used on group level among well-educated individuals. Improving and validating the questionnaire based on the weaknesses reported in current thesis, can contribute in creating a valid tool, also for use on individual level, educational diversity and in clinical settings. As survivors are prone to dietary changes due to treatment and ailments, reliability measures are needed to correctly address dietary challenges. Further evaluation of use is thus necessary. As healthy dietary changes are associated with decreased mortality in cancer survivors, evaluating the questionnaire's ability to measure change should be valuable both for use within and beyond the centers.

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Appendices

Appendix 1. Nutritional Risk Screening (NRS-2002)

Appendix 2. Consent form

Appendix 3. Complete questionnaire used in the thesis, including the short diet questionnaire

Appendix 4. Approval by the data protection officials at Oslo University Hospital (OUS)

Appendix 5. Response from the Regional Ethics Committee

Innledende inklusjon/eksklusjon utført av klinisk ernæringsfysiolog/klinisk ernæringsfysiologstudent:

Hvor høy er du? _____   **Hvor mye veier du? _____**

NRS2002:

Er BMI < 20,5?	☐ Ja	☐ Nei
Har du tapt vekt i løpet av de 3 siste månedene?	☐ Ja	☐ Nei
Har du hatt redusert næringsinntak i den siste uken?	☐ Ja	☐ Nei

Ernæringsstatus		**Sykdomsgrad**	
Normal ernæringsstatus	☐	Fraværende	☐
Vekttap> 5 % i løpet av 3 måneder eller matinntak 50-75 % av normalt behov i siste uke (score =1)	☐	Mild (kreftsykdom) (score = 1)	☐
Vekttap> 5 % i løpet av 2 måneder eller BMI 18.5-20.5 + nedsatt almenn-tilstand eller matinntak 25-50 % av normalt behov i siste uke (score =2)	☐	Moderat (score = 2)	☐
Vekttap> 5 % i løpet av 1 måned (>15 % siste 3 måneder) eller BMI<18.5 + nedsatt almenntilstand eller matinntak 0-25 % av normalt behov siste uke (score = 3)	☐	Alvorlig (score = 3)	☐

Er du 70 år eller mer (score = 1)   ☐ Ja   ☐ Nei

Hvis du scorer tre eller mer på skjemaet over betyr det at du er i fare for eller er underernært. I så fall er det andre kostråd som gjelder for deg og derfor ikke hensiktsmessig for deg å fortsette utfyllingen av skjemaet.

Oslo
universitetssykehus

KARTLEGGING AV KOSTKVALITET OG BRUK AV KOSTTILSKUDD HOS

KREFTPASIENTER

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å evaluere et spørreskjema for sunt kosthold, samt kartlegge kosthold, kostkvalitet og kosttilskudd hos pasienter/tidligere kreftpasienter ved Vardesenteret/Pusterommet. Hensikten er å utvikle et best mulig kostholdstilbud tilpasset pasienter ved Vardesenteret.

HVA INNEBÆRER PROSJEKTET?

Deltakelse i studien innebærer at du fyller ut vedlagte spørreskjema ved hjelp fra klinisk ernæringsfysiolog/klinisk ernæringsfysiologstudent. Spørreskjemaet tar ca. 15 minutter å fylle ut. Spørreskjemaet inneholder blant annet spørsmål om ditt kosthold, kosttilskudd, sivil status, høyde og vekt, sykdom, behandling av sykdom, fysisk aktivitet, røyk og alkohol, bruk av Vardesenteret, barrierer for å følge kostrådene, årsaker til å bruke kosttilskudd og behov for oppføling. Informasjonen fra spørreskjemaet vil bli brukt til å bedre forstå hvilke kostholdsrelaterte behov de som benytter seg av Vardesenteret/Pusterommet har og bedre tilpasse tilbudene på Vardesenteret i forhold til dette.

Noen deltagere vil i tillegg bli spurt om å være med på å sammenlikne det korte spørreskjemaet for sunt kosthold med et litt lenger kostholdsskjema. Dette siste skjemaet tar ca. 15 minutter å fylle ut. Du kan være med i resten av spørreskjemaundersøkelsen selv om du ikke ønsker å fylle ut det litt lenger skjemaet.

MULIGE FORDELER OG ULEMPER

Fordelen for deg med å delta i denne studien er at du vil få en oversikt over kostholdet ditt. Har du generelle spørsmål rundt kosthold, hva som er sunt å spise for kreftpasienter, hvilke kosttilskudd som er lurt å ta etc. kan du få mulighet til å stille dem til klinisk ernæringsfysiolog/klinisk ernæringsfysiologstudent i etterkant av deltakelse i studien.

En eventuell ulempe med å delta i studien er at det tar noe tid å svare på spørreskjemaet. Hvis du takker ja til å svare på det lengre kostholdsskjemaet, vil det ta ytterligere mer tid.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. 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 prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder Susanne Weedon-Fekjær, telefon: 90682118, e-post: minwee@ous-hf.no

Kartlegging av kostkvalitet og bruk av kosttilskudd hos kreftpasienter/tidligere kreftpasienter

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 gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Denne kodelisten vil bli oppbevart i lukket skuff ved Oslo Universitetssykehus (OUS) og makulert innen august 2019.

Prosjektet er et samarbeid mellom OUS og Universitetet i Oslo. Avidentifiserte opplysninger vil bli utlevert til Universitetet i Oslo. Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte.

FORSIKRING

Ved deltakelse gjelder pasientskadeloven (lov om erstatning ved pasientskade).

OPPFØLGINGSPROSJEKT

Dersom det på et senere tidspunkt vil bli aktuelt med et oppfølgingsprosjekt av denne undersøkelsen vil du bli kontaktet igjen.

GODKJENNING

Prosjektet er godkjent av Personvernombudet (saksnummer 18/16825)

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato   Deltakers signatur

Deltakers navn med trykte bokstaver

Fylles ut av prosjektleder/masterstudent

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato   Signatur

Rolle i prosjektet

Instruksjoner for utfylling av spørreskjema

Vi ber deg om å svare på dette spørreskjema så godt du kan ved å krysse av for det svaret som passer best for deg. Mange av spørsmålene har ikke «riktige» eller «gale» svar, så vi ber deg krysse av for det alternativet som passer best for deg og din situasjon. Ta utgangspunkt i den siste måneden når du svarer på spørsmål om kosthold og fysisk aktivitet.

Dato for utfylling: ☐☐ ☐☐   2018
　　　　　　　　　　Dag　　Måned

BAKGRUNNSOPPLYSNINGER

Navn:

Kjønn:　　　　☐ Kvinne　☐ Mann

Fødselsår:　☐☐☐☐

Hva er din nåværende sivilstatus?
☐ Bor alene ☐ Gift/samboende

Har du barn?　　　☐ Ja　☐ Nei

Hvor mange hjemmeboende barn har du? _____

Hva er din høyeste fullførte utdanning?
☐ Grunnskolen 7-10 år
☐ Artium, videregående skole
☐ Universitet/høyskole (mindre enn 4 år)
☐ Universitet/høyskole (4 år eller mer)

I hvilken grad synes du pris er viktig for om du kjøper matvarer som frukt, grønnsaker, grovbrød, mat merket med nøkkelhull m.m.?
☐ I veldig stor grad
☐ I stor grad
☐ I noen grad
☐ Ikke i det hele tatt

KROPP OG VEKT

Er du fornøyd med vekten din?
☐ Ja　　　☐ Nei, for lett　　☐ Nei, for tung

Har du prøvd å slanke deg de siste par årene?
☐ Ja　　　☐ Nei

RØYKING OG ALKOHOL

Hvor mange enheter alkohol drikker du per uke?

En enhet tilsvarer:

Et lite glass vin (1,25 dl)　Et veldig lite glass brennevin (0,4 dl)　En flaske pils (3,3 dl)

☐ Ingen (eller mindre enn 1 glass/uke)
☐ 1–5 enheter per uke
☐ 6–10 enheter per uke
☐ 11–14 enheter per uke
☐ Flere enn 14 enheter per uke

Hvor ofte drikker du 5 glass eller mer av øl, vin eller brennevin ved samme anledning?
☐ Sjeldent　　☐ Ukentlig
☐ Månedlig　　☐ Daglig

Røyker du i dag?
☐ Nei, jeg har aldri røykt
☐ Ja, røyker av og til (fest/ferie, ikke daglig)
☐ Nei, jeg har sluttet å røyke
☐ Ja, røyker daglig

KOSTHOLD

(Ta utgangspunkt i hva du har spist <u>den siste måneden</u> når du svarer på spørsmålene under)

Hvor mange porsjoner grønnsaker (utenom potet/søtpotet) spiser du sammenlagt i løpet av en dag (inkl. ferske, frosne, varmebehandlet, hermetisk)? *Én porsjon tilsvarer en håndfull.*
- [ ] Tre porsjoner per dag eller fler
- [ ] To porsjoner per dag
- [ ] En porsjon per dag
- [ ] Noen porsjoner i uken eller færre

Hvor mange porsjoner frukt og/eller bær spiser du sammenlagt i løpet av en dag? (inkl. ferske, frosne, varmebehandlet, hermetisk)? *Én porsjon tilsvarer en håndfull.*
- [ ] Tre porsjoner per dag eller fler
- [ ] To porsjoner per dag
- [ ] En porsjon per dag
- [ ] Noen porsjoner i uken eller færre

Hvor ofte drikker du juice (ikke nektar)?
- [ ] To ganger per dag eller oftere
- [ ] En gang per dag
- [ ] Noen ganger i uken
- [ ] En gang i uken eller mindre

Hvor mange glass sukkerholdig brus, saft og/eller nektar/iste drikker du sammenlagt i løpet av en dag (<u>ikke</u> lettbrus og lettsaft)?
Sammenlign med glasset som er avbildet.
- [ ] To glass per dag eller fler
- [ ] Et glass per dag
- [ ] Noen glass i uken
- [ ] Et glass i uken eller færre

= 2 dl

Hvor ofte spiser du kaker, sjokolade, godteri eller snacks?
- [ ] To ganger per dag eller oftere
- [ ] En gang per dag
- [ ] Noen ganger i uken
- [ ] En gang i uken eller mindre

Hvor ofte spiser du fisk eller skalldyr (som hovedrett, i salat eller som pålegg)?
- [ ] Tre ganger i uken eller mer
- [ ] To ganger i uken
- [ ] En gang i uken
- [ ] Noen ganger i måneden eller mindre

Hvor ofte spiser du bearbeidede kjøttprodukter som pølse, hamburger, kjøttboller, bacon og lunsjkake til middag/varm lunsj? Ikke inkluder pålegg.
- [ ] Fem ganger i uken eller mer
- [ ] Fire ganger i uken
- [ ] To til tre ganger i uken
- [ ] En gang i uken eller mindre

Hvor ofte spiser du rødt kjøtt til middag/varm lunsj (inkl. svin, storfe, lam, geit, biff, kotelett)?
- [ ] Fire ganger i uken eller mer
- [ ] To til tre ganger i uken
- [ ] En gang i uken
- [ ] Mindre enn en gang i uken

Hvis du spiser brød/knekkebrød, hva spiser du mest av i løpet av uken?
- [ ] Fint/halvgrovt brød (<50% sammalt mel)
- [ ] Grovt brød (50% eller mer sammalt mel)

0 - 50%   51 - 100%

Hvor mye grovt brød/knekkebrød spiser du?
- [ ] Fire skiver eller mer per dag
- [ ] Tre skiver per dag
- [ ] To skiver per dag
- [ ] En skive eller mindre per dag

Hvor ofte spiser du havregrøt?

☐   Hver dag
☐   4-6 ganger i uken
☐   1-3 ganger i uken
☐   Mindre enn 1 gang i uken

Hvor ofte spiser du fullkornspasta eller fullkornsris?

☐   Nesten hver dag
☐   4-6 porsjoner i uken
☐   1-3 porsjoner i uken
☐   Mindre enn 1 porsjon i uken

Hvilken type smør/margarin bruker du oftest på brødskiven?

☐   Bruker ikke
☐   Smør/margarin som er hardt fra kjøleskapet (meierismør, Bremykt, Melange, kokosfett o.l.)
☐   Margarin som er mykt fra kjøleskapet (Vita, Soft Flora, Brelett o.l.)

Hvilken type smør/margarin/olje bruker du oftest til matlaging?

☐   Bruker ikke
☐   Smør/margarin som er hardt fra kjøleskapet (meierismør, Bremykt, Melange, kokosfett o.l.)
☐   Margarin som er mykt fra kjøleskapet (Vita, Soft Flora, Brelett o.l.)
☐   Flytende margarin og oljer (flytende Melange, raps, soya, olivenolje o.l.)

Salter du vanligvis maten på tallerkenen?

☐ Ja   ☐ Nei

Følger du en spesifikk diett eller unngår matvarer på grunn av kreftsykdom?

☐ Ja   ☐ Nei

Hvis JA, spesifiser gjerne hva/hvilken.

_____
_____
_____

SYKDOM, INKLUDERT KREFTBEHANDLING

Hva slags kreftsykdom er du til behandling for/ble du sist behandlet for?

_____

Når fikk du diagnostisert denne kreftsykdommen?

Måned ☐☐   Årstall ☐☐

Har du hatt andre krefttyper tidligere? *Spesifiser gjerne type og årstall for diagnose.*

_____
_____
_____

Hva slags kreftbehandling har du fått/får du?

	Ja	Nei	Vet ikke
Cellegift	☐	☐	☐
Strålebehandling	☐	☐	☐
Kreftbehandling med hormoner/anti-hormoner	☐	☐	☐
Operasjon	☐	☐	☐
Høydosebehandling med stamcellestøtte/benmargs-transplantasjon	☐	☐	☐
Immunoterapi	☐	☐	☐
Annen behandling	☐	☐	

→ *Hvis JA*, hvilken type annen behandling har du fått? _____

Får du noen av de nevnte behandlingene nå?

☐ Ja   ☐ Nei

Hvis NEI, når ble siste behandlingen avsluttet?

Måned ☐☐   Årstall ☐☐

Har du eller har du hatt noen av disse sykdommene/plagene?

	Ja	Nei
Hjertesykdom (f. eks hjerteinfarkt, hjertesvikt, hjertekrampe (angina pectoris)	☐	☐
Høyt blodtrykk	☐	☐
Kronisk lungesykdom (f. eks astma, kronisk bronkitt eller kols)	☐	☐
Diabetes (sukkersyke)	☐	☐
Nyresykdom/leversykdom	☐	☐
Irritabel tarm (oppblåsthet, diare/forstoppelse i plagsomme mengder)	☐	☐
Tarmsykdom (f. eks Crohns sykdom, ulcerøs kolitt)	☐	☐
Stomi	☐	☐
Matvareallergi (spesifiser)	☐	☐
Cøliaki, laktoseintoleranse	☐	☐
Tåler ikke gluten/laktose	☐	☐
Fatigue (utmattelse)	☐	☐

FYSISK AKTIVITET

Med fysisk aktivitet mener vi at du f.eks. går tur, går på ski, svømmer eller driver trening/idrett.

Hvor ofte er du fysisk aktiv i 30 min eller mer per dag? *Slå sammen all fysisk aktivitet i løpet av dagen som varer i minst 10 min.*
☐ Omtrent hver dag
☐ 2-3 ganger i uken
☐ En gang i uken eller sjeldnere
☐ Aldri

Hvor hard fysisk aktivitet gjør du vanligvis i gjennomsnitt?
☐ Tar det rolig uten å bli andpusten eller svett
☐ Tar det så hardt at jeg blir andpusten og svett
☐ Tar meg nesten helt ut

KOSTTILSKUDD OG ALTERNATIV BEHANDLING

Hvor opptatt er du av å ta kosttilskudd nå i forhold til før du fikk kreft?
☐ Like opptatt   ☐ Mindre opptatt   ☐ Mer opptatt

Tar du noe kosttilskudd?
☐ Ja   ☐ Nei

Hvis JA, hva tar du?

☐ Tran, trankapsler/fiskeoljekapsler, omega-3
☐ Vitamin/mineral tilskudd (spesifiser gjerne type)

_____
_____

☐ Helsekosttilskudd (spesifiser gjerne type)

_____
_____

☐ Andre urtemedisiner/super food (spesifiser gjerne type)

_____
_____

Hvis JA, har du nevnt det for legen din?
☐ Ja   ☐ Nei

Har du i løpet av de siste 12 månedene besøkt en alternativ terapeut (homeopat, akupunktør, zoneterapeut, urtemedisiner, healer etc.)?
☐ Ja   ☐ Nei

Hvis JA, spesifiser gjerne hva slags terapeut.

_____
_____

Har du i løpet av de siste 12 månedene brukt meditasjon, yoga, qi gong, thai chi, kunstterapi eller andre avslapningsmetoder som egenbehandling?
☐ Ja   ☐ Nei

Hvis JA på bruk av urtemedisin/superfood/helsekosttilskudd: hva er årsaken til at du bruker det?

Du kan sette flere kryss.

Manglende effekt av behandling i det vanlige helsevesenet ☐

For å unngå bivirkninger av medisinsk behandling ☐

For å supplere/støtte medisinsk behandling ☐

For at alle muligheter skal være prøvd ☐

For å forebygge sykdom/tilbakefall ☐

Har tro på alternativ behandling ☐

Tidligere erfaring med alternativ behandling ☐

Etter anbefaling fra helsepersonell ☐

Etter anbefaling fra andre (familie/venner etc) ☐

Annen grunn ☐

Har du fått effekt av behandlingen? ☐ Ja ☐ Nei ☐ Vet ikke

→ *Hvis JA*, hvilken effekt har du fått av behandlingen?

_____

_____

BARRIERER/MOTIVASJON FOR SUNT KOSTHOLD

Hvor opptatt er du av å spise sunt nå i forhold til før du fikk kreft?

☐ Like opptatt   ☐ Mindre opptatt   ☐ Mer opptatt

Under er det listet opp noen eksempler på årsaker/faktorer som <u>stopper eller begrenser</u> en i å spise sunt. Oppgi i hvilken grad disse påstandene er sanne eller usanne for deg.

	Sant	Tildels sant	Usant
Mangler interesse for sunt kosthold	☐	☐	☐
Mangler motivasjon for å lage sunn mat	☐	☐	☐
Usikker på hva som er sunt å spise	☐	☐	☐
Mangler støtte fra andre	☐	☐	☐
De/den jeg bor sammen med liker ikke sunn mat	☐	☐	☐
Tar for lang tid å lage sunn mat	☐	☐	☐
Sunn mat er for dyrt	☐	☐	☐
Vanskelig å få tak i sunn mat	☐	☐	☐
Mangler gode oppskrifter	☐	☐	☐
Sliten og trett (fatigue)	☐	☐	☐
Bor alene og mangler noen å spise sammen med	☐	☐	☐
Liker ikke smaken	☐	☐	☐
Har andre helseproblemer som ikke er relatert til tidligere/eksisterende kreftsykdom (ryggproblemer, hodepine, vonde bein/føtter, angst etc.)	☐	☐	☐

VARDESENTERET

Hvor mange ganger har du vært på Varde-senteret?
- [ ] Første gang
- [ ] 2-4 ganger
- [ ] 5-10 ganger
- [ ] Mer enn 10 ganger

I hvilken grad har besøket/besøkene på Varde-senteret vært nyttig?

Ikke nyttig   *Svært nyttig*

0	1	2	3	4	5	6	7	8	9	10
[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]

Har du gått på/går du på noe kurs på Vardesenteret?
- [ ] Ja
- [ ] Nei

Hvis ja, hvilket/hvilke kurs:

_____

_____

I hvilken grad har kursene vært nyttige for deg?

Ikke nyttig   *Svært nyttig*

0	1	2	3	4	5	6	7	8	9	10
[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]

Er det tilbud du savner på Vardesenteret?
- [ ] Ja
- [ ] Nei

Hvis ja, hvilket/hvilke tilbud:

_____

_____

_____

_____

_____

Har du trent på/trener du på Pusterommet?
- [ ] Ja
- [ ] Nei

BEHOV FOR OPPFØLGING

Hadde du hatt behov for/ønske om veiledning/ oppfølging vedrørende <u>ditt kosthold</u>?
- [ ] Ja
- [ ] Nei

Hvis JA, vil du ha denne veiledningen/ oppfølgingen i form av (du kan sette flere kryss):

- [ ] Individuell veiledning/oppfølging på Vardesenteret
- [ ] Forelesninger på Vardesenteret
- [ ] Praktisk matlaging på Vardesenteret
- [ ] Hjemmebasert f.eks. via telefon, skype, video, treningsapp, video e.l.)
- [ ] Råd og tips på Vardesenterets nettsider
- [ ] Oppskrifter på Vardesenterets nettsider
- [ ] Trykte oppskrifter
- [ ] Trykte brosjyrer med informasjon/tips om kosthold ved kreft

- [ ] Annet: _____

_____

PERSONVERNOMBUDETS TILRÅDING

Oslo universitetssykehus HF

Postadresse:
Postboks 4950 Nydalen
0424 Oslo

Sentralbord:
02770

Til:	Mina Susanne Weedon-Fekjær

Kopi:

Org.nr:
NO 993 467 049 MVA

www.oslo-universitetssykehus.no

Fra:	Personvernombudet ved Oslo universitetssykehus
Saksbehandler:	Annika Mortensen
Dato:	22.08.2018
Offentlighet:	Ikke unntatt offentlighet
Sak:	Personvernombudets tilråding til behandling av personopplysninger
Saksnummer:	18/16825

Personvernombudets tilråding til behandling av personopplysninger for:

«Registration of food quality and the use of nutritional supplements in cancer patients»

Formål: Hovedformålet med prosjektet er å utvikle og validere et kort og lettfattelig spørreskjema for å identifisere i hvilken grad kreftpasienter følger anbefalinger for sunt kosthold.

Tidsrom: 22.08.18 – 31.12.19

Vi viser til innsendt melding om behandling av personopplysninger.

Med hjemmel i forordning (EU) nr. 2016/679 (generell personvernforordning) artikkel 37, er det oppnevnt personvernombud ved Oslo Universitetssykehus (OUS).

Den behandlingsansvarlige skal sikre at personvernombudet på riktig måte og i rett tid involveres i alle spørsmål som gjelder vern av personopplysninger, jf. artikkel 38. Artikkel 30 pålegger OUS å føre oversikt over hvilke behandlinger av personopplysninger virksomheten har. Behandling av personopplysninger meldes derfor til sykehusets personvernombud.

Før det foretas behandling av helseopplysninger, skal den behandlingsansvarlige rådføre seg med personvernombudet, jf. personopplysningsloven § 10. Ved rådføringen skal det vurderes om behandlingen vil oppfylle kravene i personvernforordningen og øvrige bestemmelser fastsatt i eller med hjemmel i loven her. Rådføringsplikten gjelder likevel ikke dersom det er utført en vurdering av personvernkonsekvenser etter personvernforordningen artikkel 35.

Databehandlingen tilfredsstiller forutsetningene for melding etter forordning (EU) nr. 2016/679 (generell personvernforordning) artikkel 30.

Personvernombudet tilrår at databehandlingen gjennomføres under forutsetning av følgende:

1. Oslo universitetssykehus HF ved adm. dir. er behandlingsansvarlig virksomhet.
2. Avdelingsleder eller klinikkleder ved OUS har godkjent databehandlingen.
3. Databehandlingen skjer i samsvar med og innenfor det formål som er oppgitt i meldingen.
4. Data lagres som oppgitt i meldingen og i samsvar med sykehusets retningslinjer.
5. Oppslag i journal med formål å identifisere potensielle deltagere til studien gjøres av ansatte ved sykehuset som har selvstendig lovlig grunnlag for oppslaget. Se http://ehandboken.ous-hf.no/.
6. Studien er frivillig og samtykkebasert. Det innmeldte samtykke skal benyttes.
7. Eventuelle fremtidige endringer som berører formålet, utvalget inkluderte eller databehandlingen må forevises personvernombudet før de tas i bruk.
8. Den behandlingsansvarlige har rådført seg med personvernombudet, jf. personopplysningsloven § 10.
9. Kryssliste som kobler avidentifiserte data med personopplysninger lagres som angitt i meldingen og i samsvar med sykehusets retningslinjer.
10. Publisering i tidsskrift forutsettes å skje uten at deltagerne kan gjenkjennes, hverken direkte eller indirekte.
11. Eventuelle krav fra tidsskrift om at grunnlagsdataene utleveres, skal behandles som en utlevering av helse- og personopplysninger, jf. sykehusets eHåndbok og dokumentet «Utlevering av personopplysninger», dokumentID 15408. Se http://ehandboken.ous-hf.no/. Denne tilråding dekker ikke slik utlevering.
12. Data slettes eller anonymiseres ved prosjektslutt 31.12.19 ved at krysslisten slettes og eventuelle andre identifikasjonsmuligheter i databasen fjernes. Når formålet med registeret er oppfylt sendes melding om bekreftet sletting til personvernombudet.

Prosjektet er registrert i sykehusets offentlig tilgjengelig database over forsknings- og kvalitetsstudier.

Med hilsen

Annika Mortensen
Personvernrådgiver

Oslo universitetssykehus HF
Stab fag, pasientsikkerhet og samhandling
Avdeling for informasjonssikkerhet og personvern

E-post: personvern@oslo-universitetssykehus.no
Web: www.oslo-universitetssykehus.no/personvern

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:		Vår dato:	Vår referanse:
REK sør-øst	Tor Even Marthinsen	22845521		27.06.2018	2018/1101/REK sør-øst C
				Deres dato:	Deres referanse:
				07.05.2018	

Vår referanse må oppgis ved alle henvendelser

Mina Susanne Weedon-Fekjær
Oslo Universitetssykehus

2018/1101 Kartlegging av kostkvalitet og bruk av kosttilskudd hos kreftpasienter

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 07.06.2018. Vurderingen er gjort med hjemmel i helseforskningsloven § 10.

Forskningsansvarlig: Oslo universitetssykehus HF
Prosjektleder: Mina Susanne Weedon-Fekjær

Prosjektomtale (original):
Hovedformålet med prosjektet er å utvikle og validere et kort og lettfattelig spørreskjema for å identifisere i hvilken grad kreftpasienter følger anbefalinger for sunt kosthold. Skjemaet vil bli bruke for å kartlegge kostkvalitet hos pasienter ved Vardesenteret (et ressurssenter for kreftpasienter ved Oslo Universitetssykehus). Pasientene vil også bli spurt om bruk av kosttilskudd og behov for tilbud for å kunne følge kostrådene. Kunnskapen fra spørreskjemaene vil være grunnlag for videre utvikling av tilbud til kreftpasienter ved Vardesenteret slik at tilbudene blir best mulig utviklet i henhold til pasientenes behov.

Vurdering
Komiteen viser til søknadens del **4.1 Fordeler**, hvor det angis: *Fordel med studien er at det utvikles og valideres et spørreskjema som raskt og effektivt kan fange opp behov for kostholdsintervensjon mhp sunt kosthold for kreftpasienter. Dette vil kunne brukes både i klinisk praksis og i forskningsstudier på kreftpasienter der sunt kosthold ikke er hovedfokuset.*

Studien vil danne et kunnskapsgrunnlag om ernæringsbehovet til kreftpasienter ved Vardesenteret/Pusterommet som vil bidra til å kunne utvikle ernæringstilbud og informasjon til kreftpasienter som er bedre tilpasset pasientgruppen enn det som er tilfelle i dag.

Helseforskningslovens gjelder for medisinsk og helsefaglig forskning, forstått som virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom, jf. helseforskningslovens § 4.

Komiteen er ikke i tvil om at spørreskjemaet – når det er validert og tatt i bruk – vil kunne fungere som et godt kartleggende verktøy. Formålet med selve prosjektet, slik det er beskrevet her, er dog ikke å skaffe til veie ny kunnskap om helse eller sykdom *per se*, snarere å undersøke egnetheten til skjemaet.

Prosjektet faller dermed ikke inn under bestemmelsene i helseforskningsloven.

Vedtak
Prosjektet omfattes ikke av helseforskningslovens virkeområde, jf. helseforskningslovens § 2. Prosjektet er

ikke fremleggelsespliktig, jf. helseforskningslovens § 4 annet ledd.

Komiteens avgjørelse var enstemmig.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. Forvaltningslovens § 28 flg. Eventuell klage sendes til REK Sør-Øst. Klagefristen er tre uker fra mottak av dette brevet.

Med vennlig hilsen

Britt Ingjerd Nesheim
professor dr. med.
leder REK sør-øst C

Tor Even Marthinsen
seniorrådgiver

Kopi til: gunsae@rr-research.no